

# STUTTERING 2003 FOUNDATION

A Nonprofit Organization

1-800-992-9392

www.stutteringhelp.org

Since 1947... Helping Those Who Stutter

- Media Awards Mark 12 Years
- Speech by Alan Rabinowitz Highlights Philadelphia Conference
- SFA Conducts Survey on Use of Electronic Devices

## Scientists Find Evidence for Gene That Predisposes Individuals to Stuttering

By Dennis Drayna, Ph.D.

In a study published in the *American Journal of Medical Genetics*, scientists at the National Institutes of Health have found evidence that a gene can predispose individuals to stuttering.



Dennis Drayna, Ph.D., of the NIH, is the senior author of a study that found evidence that a gene can predispose individuals to stuttering.

The research enrolled over one thousand families in which more than one person stuttered, and from this group, 70 families were chosen for additional scrutiny. In a series of laboratory experiments, researchers examined genetic markers located along the length of each of the human chromosomes, and found a group of markers on

chromosome 18 that tended to be inherited along with stuttering in these families. This co-inheritance indicates that stuttering in these family clusters is caused by a gene that resides on this chromosome.

"At this time, it's not clear how wide the impact of this gene is," said Dr. Dennis Drayna, the senior author of the study. "We know that many different genes are likely to be involved in inherited cases of stuttering. It's clear that this gene on chromosome 18 is involved in some cases, but we don't yet know whether it's involved in a large majority of cases.

"The good news is that we've shown this type of genetic study is actually

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## Ed Conture Receives Prestigious Malcolm Fraser Award of Excellence

As recognition of his creative and extraordinary contributions to the field of stuttering, Edward G. Conture, Ph.D., was named the recipient of the Malcolm Fraser Award for Excellence.

"His record of contribution to our field and the people we are so intent on helping indicate a scope of ability and accomplishment that is astonishing," said Walter Manning, Ph.D., associate professor and dean at The University of Memphis. "He has a long history of inspiring students and colleagues with his energy, enthusiasm, and excellence. His insight and style are refreshing and contagious."

Vivian Sisskin, M.S., led this year's selection committee. The award was presented at the Division 4 Leadership Conference in St. Louis on April 25, 2003.

"As evident throughout his long and distinguished teaching career, Ed Conture has a wonderful ability to nurture growth in others," said Jane Fraser, president, The Stuttering Foundation.



Dr. Edward G. Conture receives the 2003 Malcolm Fraser Award from Jane Fraser, SFA president.

"Edward Conture exemplifies the person who should receive the Malcolm Fraser Award," echoed Glyndon Riley, Ph.D. "The clinical focus and high quality

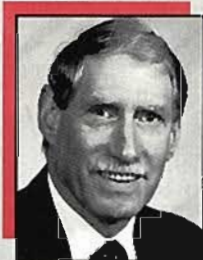
of his career seem to be exactly what the award was designed to honor."

Professor and Director, Graduate Studies, Department of Hearing and Speech Sciences at Vanderbilt University, Conture, is the author of over 100 journal articles, books, book chapters, monographs and videos dealing with stuttering, especially in early childhood. An ASHA Fellow and recipient of several awards for his clinical/scholarly contributions (e.g. 2000, Pioneering Contributions, International Fluency Association), from 1993-1997 he was the Margaret O. Slocum Professor of Education, Syracuse University and from 1994-95, the Visiting Researcher at the University of Nijmegen, The Netherlands.

"I'm truly thankful to receive the 2003 Malcolm Fraser Award for it connects me

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## Two New Members Welcomed to SFA Board



Robert M. Kurtz, Jr.

The Stuttering Foundation announces with pleasure the appointments of Robert M. Kurtz, Jr. and Alan Rabinowitz, Ph.D., to the Board of Directors.

Both men know personally the struggles and challenges faced by those who stutter.

Kurtz is Chairman and CEO of Kurtz Bros. He and his wife, Marilyn, reside in Clearfield, Penn.

"I hope to do whatever I can to fur-

ther the agenda and aims of the Foundation," Kurtz said in accepting the position. "It is a real honor, and I deeply appreciate the opportunity to serve."

Kurtz is an entrepreneur, award-winning amateur photographer, father, and grandfather. Prior to joining the family business, Rob graduated from the Mercersburg Academy (where



Alan Rabinowitz, Ph.D.

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## School Clinicians Gain Therapy Techniques at Two-Day Conference

School-based clinicians at the Stuttering Foundation's annual conference, *Stuttering Therapy: Practical Ideas for the School Clinician* were moved and motivated by professionals in the field and by special guest speaker Alan Rabinowitz, Ph.D., who spoke about his own struggles growing up with stuttering. (see full text of speech, this page.)

The conference brought together about 105 people from such settings as schools, university clinics and private practice to improve their skills at evaluating and treating children who stutter, according to conference organizer Dr. Lisa Scott Trautman.

Presenters Vivian Sisskin, Patricia Zebrowski, Charles Healey, Barry Guitar, Kristin Chmela, and Peter Ramig offered practical strategies for therapy, counseling parents, working with adolescents, measuring progress, and dealing effectively with emotions and attitudes.

New ideas were shared for incorporating teachers into the therapy process, leading inservices, and writing meaningful goals and objectives for the classroom setting. Then it was time to prac-



Workshop attendees with small group leader Ann McKeehan, right, at the luncheon with guest speaker wildlife conservationist Alan Rabinowitz, Ph.D.

Below: Group leader Elise Kaufman, right, listens to a conference participant at lunch. Right: conference leaders and SFA staff with clinicians who presented sessions, a "fabulous panel of talented, personable, insightful presenters," according to one conference participant.



"As a result, I will definitely modify my assessment and treatment strategies. I intend to carve out more time for my students who stutter." —Conference participant

"This conference is one of the top five conferences I've attended within the past 10 years," said yet another. "Thank you for this wonderful learning opportunity."

The next two-day conference will be held June 10 and 11, 2004. For information contact the SFA at 1-800-992-9392 or info@stutteringhelp.org. □

tice, as small group leaders Barbara Moore-Brown, Joe Donaher, Susan Cochran, Susan Dietrich, Elise Kaufman, and Ann McKeehan guided participants through speech modification skills.

The conference earned uniformly good grades from attendees.

"Wow! I wish I could remember to use these strategies with kids all the time," wrote one participant.

"I loved the idea of guided practice," wrote another. "I would strongly recommend continuing this method of learning."

"Thank you so much for a great two days," enthused a third. "I feel that I gained more here than I have in my graduate class."

## Moving Speech by Alan Rabinowitz Highlights Conference



*Editor's Note: following is the speech given by Alan Rabinowitz at the SFA's two-day school's conference in Philadelphia on June 6, 2003.*

I'm very happy to be here today, although it was difficult for me to decide to come. I've spent days thinking about what I would say to you, what I could offer. I know that all of you have your own experiences and stories. So all that I can really offer to all of you here today is a completely honest piece of my own life, for whatever it is worth.

For the past 25 years of my life, I have lived in and explored some of the most remote places on earth. I have lived for days in caves chasing bats, I have captured and tracked bears, jaguars, leopards, tigers, and rhinos. I have discovered new animal

species such as the second smallest, most genetically primitive deer in the world in northern Burma, and then its closely related primitive counterpart in the cloud forests of the Annamite Mtns. between Laos and Vietnam. I have documented lost cultures such as the Taron, the world's only Mongoloid pygmies in the eastern Himalayas. I have been called the Indiana Jones of wildlife by the New York Times and given lectures and talks all over the world, to thousands of people. Yet not a year has passed, not a country traveled in, when I have not at some point felt again the little stuttering, insecure boy inside who'd come home from school and hide in a special corner of his closet. That boy is never far from the surface.

Stuttering has been a gift. I can say that now. But it has been a gift realized only after years of pain and suffering that I also believe no young person should have to go through.

I've been stuttering for as long as I can remember, and as a youth my blocks were so severe that my body would twist and spasm in trying to get a word out. So at some point in my early years, I just stopped talking. The world outside my closet was viewed as the enemy.

When I was in grade school in the New York City public school system, I was removed from my classroom each day and placed in a special class for disturbed children. The other children called this the retarded



Rabinowitz's speech drew both laughter and tears from therapists.

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# Media Awards Celebrate 12 Years

## Quality reporting raises awareness about stuttering

The Stuttering Foundation is pleased to announce the winners of the 2003 Media Awards for Excellence. Now in their 12th year, the media awards recognize quality news reporting in print and electronic media. Each winner has significantly enhanced public understanding of this complex speech disorder.

"Journalists have given unprecedented attention to the causes and treatment of stuttering over the past year," said Jane Fraser, president of the nonprofit Foundation. "The entries from print, radio and electronic media have shown an increased sensitivity to a speech disorder that affects millions of people."

Seven distinguished journalists are honored this year for their contributions.



Kat Carney

In the **National Television** category, *CNN Health Anchorwoman Kat Carney* is the winner for her interview with *Buffy the Vampire Slayer* star Nick Brendon. The segment shared information about stuttering and sources of help with viewers. Throughout June, the story ran on in-flight television on Continental Airlines, and in July aired nationally in physicians' offices on *AccentHealth*, a network of health programming.



Frank Field, M.D.

In the **Local Television** category, *Frank Field, M.D., of WWOR-TV UPN9*, is the winner. In a three-minute segment educating teachers and parents, Dr. Field interviewed speech-language pathologist Phillip Schneider on the difficulties children who stutter face in the classroom and where to find help.

The first place winner in the **Magazine** category is *Rebecca Murphy of Metro Augusta Parent* magazine. Her piece, *Stuttering:*



Rebecca Murphy, Maggie, 3, Porter, 6 months.

*Handling an Elusive Disorder* is an excellent explanatory article with answers to many questions people have about stuttering and speech therapy for children, with solid advice for parents and teachers.



Robin Immerman

**Writer Robin Immerman** with *Parents* magazine wins second place for her work on *When Stuttering Is Serious*. In an excellent example of tight news writing,

Robin conveyed the most important facts about stuttering and provided readers with a way to get help.



Philip Potempa

First place in the **Newspapers** category goes to **Philip Potempa** of *The Times* (Munster, Ind.). In *Speaking To It*, Potempa puts very human faces on the problem of stuttering with interviews of famous people who stutter.

He brings home the message that stuttering doesn't prevent anyone from achieving great things.

**Polly Drew**, of the *Milwaukee Journal Sentinel*, is the second-place winner with *Stuttering Difficult to Talk About*. The columnist describes her own challenges with stuttering, while offering hope and advice to others.



Polly Drew

The **Radio** award goes to **Bobbi Conner**, host of NPR's *The Parent's Journal*. In an informative segment, Conner discusses the challenges faced by school-age children who stutter in class and gives listeners a toll-free number and web-site where they can readily find help. □



Bobbi Conner



### New PSA Released

## Nick's Message of Help to TV Viewers

*Buffy the Vampire Slayer* may have ended, but actor Nick Brendon's role as honorary chairman for SFA's National Stuttering Awareness Week is enjoying a huge "afterlife."

Of course, you'll still be able to see Nick in the role of Xander Harris on reruns, but Nick is also appearing in a new, creative public service announcement that he and his wife, Tressa di Figlia, produced for The Stuttering Foundation.

The PSAs are being sent to selected television stations across the country as funds permit, and are already airing in several major market areas. You can also view the PSA on Nick's web site, NickBrendon.com.

Brendon has used his web site to help promote and support the mission of the SFA in other ways as well. Since 2001 when Nick first became a spokesperson for the SFA, visitors to his site have donated over \$5,000.

"I was so inspired by Nick that I decided to donate a SFA poster and some pamphlets to my local library," wrote Lexie Aldridge with her donation. "I now see kids looking at the SFA poster with excitement... I know those kids have hope and can get help."

"Helping the SFA has been a very significant outcome of Nick's role on *Buffy*," notes the web site. Through these new PSAs and the Nicholas Appreciation Project, the actor is expanding his role with the Foundation with the goal of raising an additional \$5,000 in contributions to the SFA to help others who stutter.

Thanks to all who support the Nicholas Appreciation Project, Nick, Tressa and Nick's wonderful webmaster, Jacqui Day! □



## "Worst Storm in Century" Devastates Memphis, Closes Foundation Office

A windstorm that struck Memphis on Tuesday, July 22 dealt a devastating blow to the entire Shelby County area of Tennessee.

Seven people lost their lives as the result of the worst storm to hit Memphis in 100 years. According to official reports, more than 1000 homes sustained damage and more than 338,000 residences and businesses lost power. Virtually every neighborhood was impacted by the hurricane force winds.

Unlike the widespread power outage that swept the Northeast U.S. and Canada in August, electricity in Memphis was slow to be restored. Two weeks after the storm, thousands were still without power.

The Stuttering Foundation's Office was without electricity for eight days, making it impossible for the staff to continue work. Instead, staff members, who checked the east Memphis office daily, loaded their car trunks with what work could be done at home, and forged ahead as best they could.

"It was an eye-opener to see the tremendous amount of work the Memphis staff handles each day, both



Crews with the Memphis Traffic Engineering Department were putting in 16-hour days trying to get traffic lights up and working again following a storm that hit the city on July 22.

in terms of information packets sent out and in orders placed," said Kathy Davis. As office coordinator in SFA's Georgia office, it fell to Davis to handle most of the helpline phone calls and fulfill requests for information during the power outage in Memphis. "With no air conditioning and no light in Memphis, they were really struggling to move ahead at all odds."

"It looked like a war zone here," said Memphis office manager Patty Hamm. "Huge trees are still down all over the city, but at least we're back at work and catching up. Thanks to everyone for their patience while we fill orders and information requests as quickly as possible." □

www.stutteringhelp.org

Newly updated resource/referral lists as well as lists of all libraries which shelve Stuttering Foundation books and videotapes can now be found on-line. The libraries now number over 6,000. Also of interest is Dr. Alan Rabinowitz's keynote address at the SFA's two-day conference. Practical Ideas for the School Clinician. Parents, teens, and adults who stutter are all finding help on our web site at [www.stutteringhelp.org](http://www.stutteringhelp.org). Here are some of their comments.

■ I've been dealing with a stuttering problem off and on. I'm tired of feeling so self-conscious. I'm seeking whatever information you can provide about the causes and more importantly, the various treatment options and resources available to those who stutter. I appreciate all your hard work in trying to raise peoples' awareness of this rather lonely problem.

■ "I am from India, a student 23 years old and I stutter. Please let me know about stammering therapy."

Check both Foundation web sites for many downloadable, free versions of our brochures, books and other resources: for English, [www.stutteringhelp.org](http://www.stutteringhelp.org) or [www.tartamudez.org](http://www.tartamudez.org) for resources in Spanish.

■ "I am a 23-year-old male who has been stuttering for 15+ years. I would like to learn techniques and methods to improve my speech in the long run."

■ "My boyfriend stutters; he's 17 years old and has been doing so since the fourth grade. Is there anything I can do to help him?"

■ "My child is 5 and entering kindergarten in the fall. I am looking for information on how to choose a speech pathologist and what to expect from that treatment. How to make sure I have a good therapist for my child."

■ "I have stuttered as long as I can remember. Stuttering has kept me from doing a lot of things in my life and being able to say what I feel in certain situations. I have a two-year-old daughter and I have noticed she is stuttering and does it from time to time. I would like some information on how to help me know if she will stutter because I do." □

## Classic Starbuck Videos Newly Released

In 1974, Dr. Harold Starbuck made a series of videotapes demonstrating stuttering modification therapy techniques with a group of teenagers and adults to be distributed by The Stuttering Foundation, at that time known as the Speech Foundation of America.

"The quality of the recording is clearly somewhat primitive," said Jane Fraser of SFA, "but the step-by-step analysis of the stuttering modification procedures has never been replicated in the intervening years."

Barry Guitar, Ph.D., of the University of Vermont plans to include information about the tapes' availability in the new edition of his textbook, *Stuttering: An Integrated Approach to Its Nature and Treatment*.



Dr. Harold Starbuck. In background are Drs. Dean Williams and David Prins.

In a recent interview, Guitar noted. "Despite the scratchy audio track and grainy visual quality of the tapes, you will learn a great deal from Dr. Starbuck's lucid teaching style."

Starbuck's demonstrations of each step of therapy using several individuals who stutter will make it possible for you to develop your own version of stuttering modification therapy from start to finish," added Guitar.

Tapes include #1 *Identification and Analysis*; #2 *The Process of Post-Block Correction*; #3 *The Process of In-Block Correction and Pre-Block Correction*; #4 *Predetermined Speech, Dismissal and Transfer*; and #5 *Motivation*.

The complete 5-videotape series (product #0221) is available for \$20. □



## Award

*Continued from page 1*  
to Malcolm Fraser and his organizational legacy, the Stuttering Foundation of America, an organization that reaches out and touches countless lives each day, in a myriad of consequential ways," said Conture. "Malcolm Fraser was a man of uncommon common sense, an individual who continually worked on issues bigger than himself and who clearly understood the difference between being consequential and famous, so it is truly an honor to receive an award named after him."

Conture holds degrees from Emerson, Northwestern and the University of Iowa. He began his academic career in 1971 at Syracuse University, where he was subsequently promoted to full professor. His text, *Stuttering, Its Nature, Diagnosis and Treatment*, is considered one of the most thought-provoking texts in the field.

A popular presenter at conferences throughout Australia, North America and Europe, Conture has also served as editorial consultant to numerous professional

journals, and is sought-after by national news services for his expertise.

He has served on national and international associations, including ASHA, NIH and IFA. For the past two years, he has served on the Specialty Board on Fluency Disorders, where he has undertaken the

"I'm thankful to receive the Award for it connects me to Malcolm Fraser and the SFA, an organization that touches countless lives."

—Edward G. Conture, Ph.D.

formidable task of developing the exam for determining specialty recognition. He also continues to take an active role in the clinic, both in treatment and in supervision of graduate students. Presently, Ed is pursuing a federally-funded program studying the syntactic, semantic, and phonological as well as emotional reactivity and regulation abilities and behaviors of children

who stutter, when not pursuing interests in herbs, soccer and windsurfing.

"This is a man who has devoted his professional life to producing knowledge about stuttering, improving the quality of clinical care, and attracting new students to devote their careers to fluency disorders," noted Anthony Caruso, Ph.D., emeritus professor of Kent State University.

"Perhaps, to paraphrase the immortal bard, Clint Eastwood, who said upon receiving such an award, 'This award is supposed to go to a mature, accomplished teacher, scholar, clinician. Thus I want to thank the awards committee for making a major exception in my case,'" said Conture with signature wit. "Seriously though, I'd like to thank my mother for teaching me to revere the spoken and written word, and my father for teaching me how to use both. Furthermore, to my many colleagues, friends, and former/present students, I'd like to thank them for teaching me that few things worth accomplishing can be accomplished alone." □

## Booth Brisk at ASHA Schools Conference

Although attendance was down at the 2003 ASHA Schools Conference, business at the SFA booth was brisk. The conference, held July 11-13 in Anaheim, Calif., drew fewer people than in 2002, but SFA's sales topped last year's.



Nina Reardon, left, and Liz Brown helped in the SFA booth in Anaheim.

"Since we make our books and videos available at below cost, I always find the word 'sales' a bit of a misnomer in regard to SFA materials," noted

Deborah Squires, who staffed the booth at the conference. "It's such a pleasure to hear school-based clinicians say they appreciate the affordability and quality of our materials.

"This was especially critical this year, with major budget cuts in many school districts. More than a few of the speech-language pathologists paid their own way to the conference and knew they would not be reimbursed for resources they purchased."

Thanks to SLPs Judith Kuster, Nina Reardon, and Liz Brown for their help! Kuster and Reardon also led sessions at the conference. □

## SFA On the Airwaves

National Public Radio's Linda Wertheimer interviewed Stuttering Foundation president Jane Fraser for a segment on *Weekend Edition*. Fraser was also interviewed by the British Broadcasting Corporation's Gerry Jackson for *Outlook*, which aired live in London on August 13.

The topic of both interviews was research done in 1939 on stuttering and orphans. Conducted by Wendell Johnson, the title of the research was *An Experimental Study of Evaluative Labeling on Speech Fluency*, and its aim was to see if labeling someone a stutterer would induce them to stutter—which of course it did not.

The study continues to claim media attention, fired up by a recent Associated Press wire story by Todd Dvorak which linked to the Stuttering Foundation web site, [www.stutteringhelp.org](http://www.stutteringhelp.org). The web site had over 8,000 hits the morning of August 6 when the wire story was featured on Yahoo News, reported SFA webmaster John Bell.

"In the 60 intervening years since the study, no researcher has demonstrated that labeling someone a stutterer or criticizing speech alone results in stuttering," Fraser said. "Recent studies indicate that genetics,



Tom Patton, news director at WJCT, the National Public Radio station in Jacksonville, Fla., runs a sound check before Jane Fraser's interview with Linda Wertheimer for NPR's *Weekend Edition*.

neurophysiology, child development, and family dynamics all play a role."

The positive outcome of so much media attention is that more people seek out the many resources available to those who stutter and their families, and are often referred to the Foundation's toll-free helpline, 1-800-992-9392, and its web sites, [www.stutteringhelp.org](http://www.stutteringhelp.org) and [www.tartamudez.org](http://www.tartamudez.org).

Fraser was also a guest August 19 on The Larry Meiller Show on Wisconsin Public Radio. The 45-minute live segment focused on how classroom teachers can recognize and help children who stutter at school. To listen, go to [www.wpr.org](http://www.wpr.org) and click on the Larry Meiller Show archives. □





## SFA Board Welcomes New Members

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he serves on the Board of Regents) and the University of Redlands, attended the Pennsylvania State University, and served in the U.S. Army. He is a past president of the National School Supply and Equipment Association.

Author and explorer Alan Rabinowitz is the director of the Science and Exploration Program at the Wildlife Conservation Society, based at the Bronx Zoo in New York City.

Rabinowitz served this past year as a spokesperson for the Foundation, appearing in public service advertisements and speaking recently in Philadelphia at the SFA's conference for school-based speech-language pathologists (*see story page 2*).

"I do not, as a policy, accept board positions because of my time con-



The SFA Board of Directors met in Memphis in March. Pictured at the meeting are, from left, back row: George Cooley, Jean Gruss, Joe Fulcher, Donald Lineback and Joseph Walker; front row: Katherine Klyce, President Jane Fraser and staff member Deborah Squires.

straints. However, this request falls into a different category. My wife and I both agree that this is a very important part of my life that I should be more engaged in," said Rabinowitz in accepting the board position. "I am very happy to be a board member and take part in all the incredibly important initiatives that you [the Foundation] are engaged in." □

## Pilot Study on Sleep Apnea and Stuttering

The Neurobiology Department at University of California Los Angeles, is conducting a pilot study to determine the correlation between stuttering and obstructive sleep apnea (OSA).

"During a recent OSA study, we realized a possible relationship between adult onset OSA and childhood stuttering," said Claire Valderama of Harper Lab at UCLA. "Approximately 40 percent of our subjects experienced a speech impediment, primarily stuttering, when they were younger."

The link between speech impediments and OSA may be related to a head injury, which would result in a change in regions within the brain that control speech and respiration.

"If such a relationship exists, childhood stuttering may be a predictor of adult onset OSA," Valderama noted.

A questionnaire, along with a required consent form, is posted online at <http://aunix.neurobio.ucla.edu> for those who wish to participate in the study. Both the questionnaire and consent form may be completed and submitted electronically. □

## SFA Conducts Survey on Satisfaction with Electronic Devices

*By Lisa Scott Trautman, Ph.D.*

Over the past year, increased media attention has focused on auditory feedback devices for the treatment of stuttering. Dramatic testimonials by the inventors and users of these devices were given on nationally televised programs including *Oprah* and *Good Morning America*.

Perhaps due to this media exposure, hundreds of people have contacted the Stuttering Foundation during the past year, seeking information on auditory feedback devices. In response, we prepared a packet of materials providing descriptions of seven devices as well as providing contact information for consumers interested in learning more about a particular product. This packet was sent to anyone who requested more information on devices, either through our toll-free number or via the web site.

Also included was a cover letter from the Foundation emphasizing that the SFA does not endorse any one

therapy process or device. Instead, our goal is to inform consumers about available treatment options and help them make informed decisions.

The letter noted that "no single method has proven to work for everyone despite reports of 'cures' through new treatments, drugs or devices."

Recently, the Foundation decided to

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"I would like to thank the SFA for existing and trying to help stutterers. I will stay in touch and become active in my pursuit to beat the problem."

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—Survey Respondent

follow up on the requests for information by sending out a ten-item survey. To date, this questionnaire has been sent to more than 800 people. The response rate is approximately 13.5 percent, however we continue to receive responses.

Respondent's answers are being analyzed carefully for trends that may reveal why people either chose to purchase a device or declined to do so. Of those responding so far, only about 14 percent have purchased such a device. Preliminary findings suggest that for those who had not purchased a device, expense/lack of insurance coverage was one factor. The respondents who had acquired a device have all owned it less than a year, with over half owning it for less than three months.

We are continuing to analyze the information. A more complete report of the findings of the survey will be forthcoming in the SFA newsletter and released nationally to the media.

If you would like to participate in this survey, please contact the Foundation at 1-800-992-9392 or email [info@stutteringhelp.org](mailto:info@stutteringhelp.org). The Stuttering Foundation web site has more information on the many types of electronic devices available. □



## Scientists Find Gene

*Continued from page 1*

possible for stuttering. These types of studies can lead to the ultimate identification of the variant gene itself, which would be a great advance in our understanding of the causes of stuttering. On a more general level, it adds yet another piece of evidence that inherited factors can be important in stuttering."



The study indicates that stuttering in the family clusters tested is caused by a gene that resides on chromosome 18.

An additional aspect of the study suggests a second gene, located on chromosome 13, may also have some role in genetic causes of stuttering. This is of interest due to previous reports that implicated a gene on chromosome 13 in stuttering in another group of subjects. In a disorder

such as stuttering, which is likely to have a mixture of genetic and non-genetic causes, such independent findings provide important confirmation of the role of these genes in this disorder. The identification of one specific gene could provide greater understanding of the structures and functions in the body that are involved in speech production, and how those functions go awry in stuttering. This understanding, in turn, can lead to improved therapies and treatments for stuttering.

"This understanding, in turn, can lead to improved therapies and treatments for stuttering."

—Dr. Dennis Drayna

The work was a collaboration of two main groups, the National Institute on Deafness and Other Communication Disorders at the National Institutes of Health, in Bethesda, MD, and the Center for Inherited Disease Research at Johns Hopkins University in Baltimore, MD. Additional assistance in finding and enrolling families was provided by the Stuttering Foundation of America. "Most important of all, we couldn't have done this research without the help and cooperation from our stuttering family members," said Dr. Drayna. □



## News Shorts

### A Stutterer's Story Now Available in Italian

■ *A Stutterer's Story*, by Fred Murray, Ph.D.,

is now available in Italian. The book, a personal history of Dr. Murray's struggle with stuttering, includes valuable information on treatment and advice on managing stuttering. The Italian version is published by Red Edizioni and translated by Daniele Orla for the Associazione Italiana per la Balbuzie e la Comunicazione. The English original is available through The Stuttering Foundation (Book No. 0061). □

### Three NSSLHA Chapters Make Gifts to Stuttering Foundation

■ Thank you to the National Student Speech, Language, and Hearing Association chapters at the University of Cincinnati, Texas A & M University at Kingsville, and the University of Arkansas. All three sent donations to help support our programs.

"As future SLPS, we have learned that stuttering is a disorder that affects the person who stutters and the family in so many ways. We need to do whatever we can through research to help them, and hopefully, one day, find a cure," wrote NSSLHA members at Texas A & M. "This is a worthwhile charity pertaining to our field of study," noted the Arkansas chapter. □

### PowerR Game Is Back

■ Play outside the box! The PowerR Game, a popular board game for ages 12 and older, is being re-released by the Stuttering Foundation. The game was developed by Gordon Blood, Ph.D. to help older children, teens and adults deal with their feelings and emotions regarding stuttering. The PowerR Game (No. 0250) will be available this fall. □



### Radio Show Highlights Straight Talk for Teachers

■ Tom Block, a reporter for the Florida State University *Headlines*, a local NPR radio segment, interviewed Dr. Lisa Scott Trautman regarding the videotape, *Stuttering: Straight Talk for Teachers*. Trautman, who produced the tape in collaboration with Carroll Guitar, M.L.S., is an assistant professor at FSU. The interview includes general information on stuttering as well as audio clips from the video. It may be found by going to [www.fsu.edu](http://www.fsu.edu) then clicking on *FSU Headlines* (bottom of the page), Archives, and the month of June in the calendar.



*Stuttering: Straight Talk for Teachers* has become one of the SFA's most popular resources for school-based clinicians and classroom teachers, with more than 4000 purchased since October. □



### Library Outreach

■ The Stuttering Foundation recently contacted more than 7000 public libraries, offering—free of charge—to send them copies of the latest SFA books and videotapes. Currently, more than 6000 public libraries shelve SFA publications, making these resources available to the public for free.

A complete list of libraries is online at our web site. If your library *does not* stock SFA materials, please have them contact us. If your library *does* stock SFA materials but is not included in our list, please let us know directly so that we may add them. We may be reached by phone at 1-800-992-9392 or by email at [info@stutteringhelp.org](mailto:info@stutteringhelp.org). □

### AccentHealth

■ Delivered in physician offices nationwide, *AccentHealth* is a television network with programming produced by CNN. An interview with actor Nick Brendon on stuttering ran throughout July, prompting lots of traffic on our web. The network reaches 19 million viewers each month. □



## Rabinowitz Speech

*Continued from page 2*

class. Sometimes I would make myself physically sick so that I wouldn't have to go to these classes. At other times, I wanted to go to these classes, feeling more at home there than anywhere else.

The greatest of all terrors was to be told that I had to speak in front of the class. I could usually plan some diversion to get out of such activities but one day I was taken by surprise. Without thinking, I dropped a pencil on the floor, bent under the desk, then stabbed the pencil through my hand so that I had to be taken to the hospital. Now I wouldn't have to read in front of the class. The pain in my hand was nothing compared to the anticipated pain of pity and ridicule.

Yet the event that haunts me most in my life happened when I was about 15 years old. I was at the store picking up groceries that my mother had bought and left there earlier in the day. But when my turn in line came I could not say my last name. One person waiting in line told another that I was probably retarded, and should not have been let out of the house alone. So I exaggerated my blocks and took on the role of a retarded child in order to give the people some reason for my behavior. It was easier to be what people thought me to be, than to be who I knew I was. This was a turning point in my young life, for I swore that I would never deny myself again, and that I would strive not to be just like other people but to be far better than everyone else. This became a driving force in my life that continues to this day.

When events such as these happened, I'd come home and go down to the gym my father built in the basement where I'd lift weights till my body burned with exhaustion or I'd punch the punching bag until my hands bled. I'd punch the faces of the people I met that day whom I felt had looked at me with pity or scorn. Those basement sessions turned into a lifelong passion for exercise that still helps me greatly in my work and life. After every day of school, whether it was a good day or not, I'd come home and retreat to my sanctuary, a special corner of the closet in my room. Here I would talk to my pets—hamsters, turtles, garter snakes—about the days events. I needed the darkness and the solitude. This eventually turned into a life-long bond with animals that set me on my career path.

In my career, in my life, one of the most common questions I am asked is how I came to love animals so much. People expect many kinds of answers but never what I give them. Animals were the only things I

could talk to fluently as a child. Animals listened and let me pour my heart out. At some point in my youth I clearly remember realizing that animals were like me, even the most powerful ones I'd read about or seen on television—they had no voice, they were often misunderstood, and they wanted nothing more than to live their life as best they could apart from the world of people.

As I grew into my teens, I got used to my stuttering and, like many stutterers, became very proficient at all the tricks to avoid situations I didn't want to deal with. My parents never knew quite what to do with me. At first they thought I was too smart, or too excitable, but that everything would be okay. We never talked about stuttering, for they felt that to discuss it would give me more pain. Yet the silence was a much greater pain. All I wanted them to do was to sit and cry with me sometimes. To show me that they understood how hard it was.

When they finally faced the fact that everything was not okay with me we tried drugs, hypnotherapy, and a host of speech specialists who basically told me that I had to accept who I was, stuttering and all, and move on. The therapists were good people, trying to do good things. They made me realize that some people cared. The problem was that they just didn't know what to do. They seemed more frustrated than I was sometimes. They wanted me to accept my stuttering without any alternative.

But that is the one thing I would never do. I never accepted my stuttering and I refused to accept myself as a stutterer. I saw no reason why I shouldn't and couldn't be a fluent speaker despite no one seeming to encourage me towards that end. There seemed to be little literature on the subject at the time and there were no computers, no internet, no way to find out whether there were others out there like me. So I lived in two worlds—the world of people where I stuttered, and my closeted world with animals where I did not. Finally one day my mother heard another woman talking in a bank and we learned of Hal Starbuck's clinic in Geneseo, NY. I was 18 years old, in college, never had a date with a girl, never went to a school dance, and never knew what it was like to speak a complete sentence fluently. Then my life turned around.

Starbuck's clinic made me face the fact

that I was a stutterer, and made me stop being concerned about why I stutter and blaming it on other people. That in itself was a rude awakening. But the difference between him and others was that he then offered to me the tools to be a completely fluent stutterer. Tools to control the flow of air and the contact of the tongue against the upper palate. Tools that were by no means easy to master but were within reach of anyone who wanted them badly enough. I was no longer helpless and floundering. I could be in control if I wanted to be. With constant practice, the tools I was taught became second nature.

It was only then that stuttering started to become a gift, although I still didn't realize it at the time. Through my life of stuttering I had developed a level of compassion, caring, understanding, truth and strength that I doubt I would have had otherwise. And now I could let it surface to guide my behavior and interaction with others. This would continue throughout my life but I only began to see and understand it years afterwards. The important thing at the time was that I was now in control. I had the tools to speak fluently. I could let my two separate worlds start to merge and I could let other parts of me surface.

But learning to speak fluently, while feeling wonderful, didn't heal the scar tissue that had accrued from all those years of suffering. I still wanted little to do with humans at this point and I still had a long way to go to figure out who I was as a person and where my place was in the world. And frankly, once I could speak fluently, I realized that those with so-called normal

speech seemed to have little to say that was of any interest to me. I left everything I knew behind as soon as I could. I ran as fast and as far as I could—combining a need I felt to pay back the debt I owed to animals with the desire to test myself, physically and mentally, to be lost in the wild, the dark closets of the world, among people whose language I couldn't speak and whose lives were so hard that they had no time to dwell on their own or others' misfortunes. I had to purge the feelings of shame, fear, and inadequacy that so controlled my life for so long.

I spent years living in the field with animals doing research, establishing new pro-

*Continued on page 9*



Presenter Patricia Zebrowski, Ph.D., and Alan at the SFA conference in Philadelphia.



## Therapists Can Enhance Effectiveness in Counseling and Earn .6 ASHA CEUs

Many speech-language pathologists are taking an increasing interest in the important part counseling plays in stuttering treatment, with a corresponding interest in improving their skills.

A new videotape and book offer from The Stuttering Foundation focuses on teaching counseling techniques to help persons of all ages who stutter and parents of children who stutter. The set includes the new book *Effective Counseling in Stuttering Therapy*, the recent video *Counseling: Listening To and Talking With Parents of Children Who Stutter*, and the CEU study materials. Successful completion of the test is worth .6 ASHA CEUs or 6 contact hours (Intermediate Level, Professional Area.)

Therapists can enhance their clinical effectiveness by considering the classic goals and processes described by leading authorities in *Effective Counseling in*



### *Stuttering Therapy.*

The book reflects new research and thinking on the positive effects of counseling as a component of stuttering therapy. Chapters by leading authorities cover counseling parents, school-age children, teenagers, and adults in group settings.

Time-tested chapters by Charles Van Riper, Joseph Sheehan, Hugo Gregory, Dean Williams and Eugene Cooper from an earlier book, *Counseling Those Who Stutter*, are reprinted here.

Helping parents recognize and cope with their feelings about their child's stuttering is critical to success in therapy. Released last year, *Counseling: Listening To and Talking With Parents of Children Who Stutter* features clinicians demonstrating and discussing strategies for counseling parents in all stages of the treatment process.

This CEU offer may be ordered as a set for \$35.00, or components may be purchased separately. □

## Life's Work Goes On

After a career of helping others, Harriet Simpson Steele has colleagues who are making her retirement work for others as well as for Harriet.

The speech-language pathologist retired in March, but her dedication to improving the lives of those who stutter is living on through donations made in her honor to The Stuttering Foundation.

"Harriet is a dedicated professional who worked with adults who stutter," wrote Debra Church, a colleague with Speech Consultants in Camp Hill, Penn.

Steele encouraged participation in the Toastmasters Club, and organized a "local study group of speech pathologists who met monthly for 18 years to further their growth and knowledge of adult neurogenic speech disorders, including her special interest, stuttering," Church said.

Thanks, Harriet, for a commitment that speaks so eloquently that others feel compelled to pick up the refrain!

Those who donated in her honor were: ■ Patricia Acker-Bailey, Kathleen Bashista, Kim Beard, Debra Church, Elaine Fleegal, Judith Giovannitti, Anne Gilbertson, Dianne Hollinger, Margaret Kloske, Joanne Krzywicki, Jeanne Morrow, Laurie Sabol, Heide Stearns, and Michelle Williams. □

## Rabinowitz Speech

*Continued from page 8*

tected areas, and writing scientific papers and popular books of my experiences. My standing and reputation in my field grew, but that meant little to me. People tried to make me something that I was not — a hero, an altruist. Yet I saw nothing of that in myself. I was a little stuttering boy, now a man, who simply ran to the farthest reaches of the earth to be with animals and try to feel whole. I just wanted to feel whole.

Over the years I did reach that goal and in fact it became harder and harder for me to run away and isolate myself as the wild world and the wildlife I had come to love so much was being lost around me, despite my own and others efforts. Tigers killed for their penises, rhinos for their horns, gorillas for their paws, elephants for their skins. There seemed no way for these magnificent creatures to convey their pain and suffering to the human species that was wiping them out. I felt more than ever that I had to be their voice, and I would live my life trying to give them a home where no one bothered them — give them their own little space in the closet. That was the driving force behind my decision to engage the world of humans again.

Coming here today is another chapter in my life. This is special. While clearly a very emotional event for me, this is something I've wanted to do for a long time. I don't want other young people to go through what I went through, there is no need for it. The speech community has clearly gone through radical changes since I was a boy and stutterers have many places to now turn for help. But on the other hand the general public's response to and understanding of stutterers and stuttering is not what it should be. And I have also been surprised to learn that many speech clinicians and therapists still say the

same things to young people that they said to me as a child. Some still feel uncomfortable with stutterers and others get frustrated when they don't get the kind of response they want or expect from a stutterer. I am here to tell you today that every stutterer can be a fluent

speaker. And that there is a set of tools for every stutterer and for the parents of stutterers to deal with stuttering, if they choose.

I will always believe that stuttering is a special little gift granted to certain people in this world, a little key that opens up parts of the human psyche that would not have been opened otherwise. I also think that people



Alan autographs copies of his most recent book, *Beyond the Last Village* (Island Press).

who know stutterers or work with stutterers can come away a better person themselves for it, if they open their mind and heart to what they are experiencing. But nice words and thoughts do not negate the handicap that stuttering can create in

young and old alike. But that handicap can be fixed. Maybe not quickly. Maybe not easily. But the key is not giving up—for both the clinician and the stutterer. No one should have to suffer through life because they were granted the gift of stuttering. □



## NEWS BRIEFS

■ The Stuttering Foundation two-day conference for speech-language pathologists working with school-age children who stutters, *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 you will be able to download it directly by October at [www.stutteringhelp.org](http://www.stutteringhelp.org).

■ 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.

■ 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 Dr. Lisa Scott Trautman and Kristin Chmela, M.A., will be held at Florida State University, June 23 - 27, 2004.

■ The 6th annual International Stuttering Online Conference opens October 1 and climaxes on October 22, 2003. The theme of the online conference is International Stuttering Awareness Day is really every day. The 2003 Conference can be found at the Stuttering Home Page at <http://www.stutteringhomepage.com>.

■ 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:

■ *Stuttering Therapy: Rationale and Procedures* (2003) 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).

■ *Les bégaiements: Histoire, psychologie, évaluation, variétés, traitements*, (2001) 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 Popolare 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](http://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 Stories by 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, 800-992-9392.

■ *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](http://www.graywolfpress.org) or call 612-641-0077. □



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For Combined Federal Campaign donors, please note that our code number for the 2001-2002 CFC campaign is

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We are proud that over 95 cents of every dollar goes directly into helping those who stutter.



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