



# THE STUTTERING FOUNDATION

A Nonprofit Organization

WINTER 2006

Since 1947... Helping Those Who Stutter

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## A look at genetic and neurological correlates of stuttering

By Lisa Scott, Ph.D.

The Florida State University

In November, four of the leading scientists in stuttering presented their latest research at the American Speech-Language-Hearing Association convention in San Diego. Participating in a session entitled, "Genetic and Neurological Correlates of Stuttering," were Drs. Dennis Drayna, NIDCD, Christine Weber-Fox, Purdue University, Ann Foundas, Tulane University, and Gerald Maguire, University of California-Irvine. In a session coordinated by Dr. Christy Ludlow, NIDCD, four presenters focused their discussions on state-of-the-art research in the understanding of genetic and neurological factors that contribute to stuttering. Three of the four researchers, Drs. Drayna, Weber-Fox, and Foundas, have previously contributed articles on their research to past issues of this newsletter.



Drayna



Weber-Fox



Foundas



Maguire

### Genetics and Stuttering

Dr. Drayna described the current knowledge of the role of genetics in stuttering. He provided an overview of how genetics are studied, including the use of twin and adoption

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## Redesigned Web site easier to use

Information about stuttering is just a mouse click away.

The Stuttering Foundation has redesigned its Web site, [www.stutteringhelp.org](http://www.stutteringhelp.org), so the public and speech clinicians can more easily find the information they need.

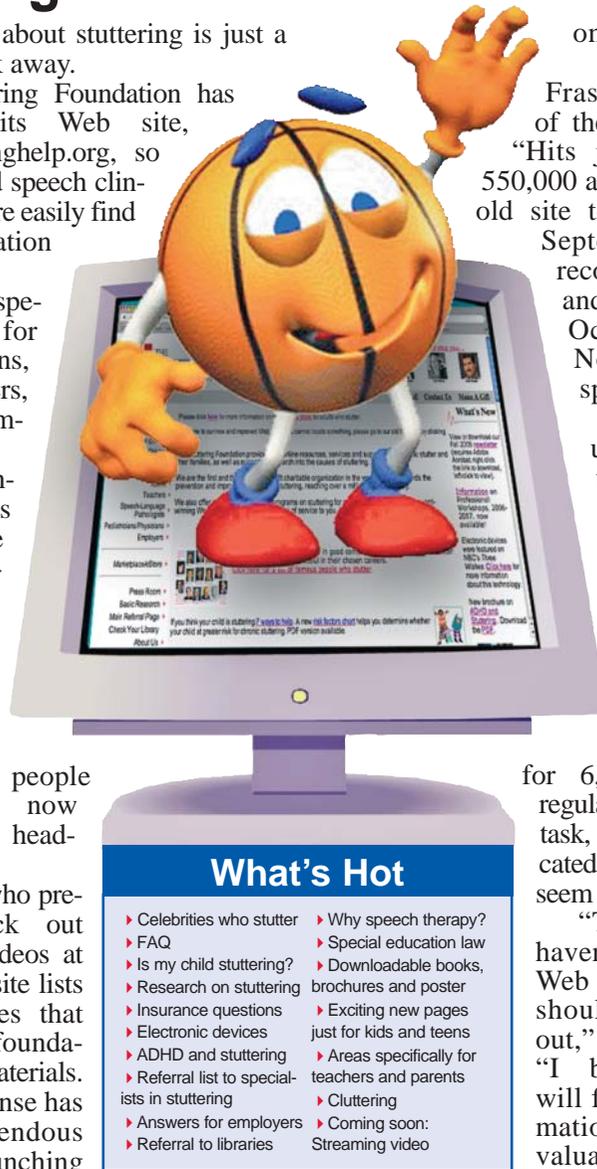
There are special pages for children, teens, adults, teachers, SLPs and employers.

All the foundation's brochures are available online and several books are too.

Favorites like the extensive list of famous people who stutter now highlight the headline banner.

For those who prefer to check out books and videos at libraries, the site lists 6,500 libraries that shelve the foundation's latest materials.

"The response has been tremendous since the launching



on July 4th," says Jane Fraser, president of the Foundation. "Hits jumped from 550,000 a month on the old site to 850,000 in September to a record 1,250,000 and 1,300,000 in October and November respectively."

The Web site uses the latest technology to quickly upload information and keep the Web site up-to-date. Loading precise addresses and information

for 6,500 libraries regularly is no small task, but our dedicated staff makes it seem easy.

"Those who haven't been to the Web site recently should check it out," Fraser said. "I believe they will find the information timely and valuable." □

## Annenberg Foundation grant helps SFA reach children

An unprecedented grant from the Annenberg Foundation is making *Stuttering: For Kids, By Kids* available free of charge to every public library in the country. By year-end, more than 6,500 libraries will have the new DVD whose animated star, Swish, is doing a jump shot above.

The 12-minute DVD is getting



lots of press these days — from daily and weekly newspapers and leading magazines like *Woman's Day* to the *ASHA Leader* and *Advance* for SLPs.

"All those interested in helping

kids learn more about stuttering will want to see this tape," says speech-language pathologist Bill Murphy of Purdue University. "The children featured are a perfect example of how to openly and honestly handle stuttering. This is an important tool for families and teachers of kids who stutter too."

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## On the air on NBC

NBC stations around the nation aired a health segment about stuttering during their local newscasts in early December.

The broadcast featured speech-language pathologist Dr. Tricia Zebrowski of the University of Iowa working with a 7-year-old boy who stutters.

WIS TV in Columbia, S.C., told viewers, "There's no miracle cure for stuttering and it's best to evaluate a problem early." The station then listed the Stuttering Foundation as a resource for parents.

In addition, WIS TV linked to the Foundation's Web site from their home page and posted the story and a video clip online for Internet users. Viewers could even e-mail the news segment and story to others who may need this valuable information. □



## Annenberg

*Continued from front page*

Children on the DVD share their views on dealing with teasing, how to teach others about stuttering, and what helps them manage their stuttering.

Speech-language pathologists who specialize in the treatment of fluency disorders spent more than a year developing the script for this film.

The concept of Swish was thoroughly researched by a computer graphics design team at Purdue University for optimum appeal and memory attention for children in grades 2-6. Once created, the bouncy, genderless cartoon character with a kid's voice and vocabulary was extensively field-tested in speech clinics at Purdue and The Florida State University.

Judging from the letters that continue to pour in, libraries around the country are very excited and grateful for this donation.

"On behalf of the Board of Trustees, staff and patrons, I want to thank you for the material your organization has provided for our collection," writes the director at the Aracnum, Ohio, library.

The library director in Chatham, Ill., echoed that sentiment, "This resource is a welcome addition to our collection." □



# Stuttering and the basal ganglia

By Per Alm, Ph.D.  
University of Alberta

*Editor's note: Per Alm has a Ph.D. in neuropsychology and has been working with research on stuttering in Sweden but is currently teaching at the University of Alberta, Edmonton. We asked Per if he could write something about his research and his view on stuttering and the brain.*

The variability of stuttering is often striking to the listener and mysterious for the person who stutters.

Based on personal experiences I have felt that the lack of real knowledge about the underlying mechanisms of stuttering is a problem in many ways. It makes it more difficult to treat, it leaves the field open to unfounded speculations, and it makes it difficult for persons who stutter to reach self-understanding. For this reason, I changed my vocation from engineering to research on the nature of stuttering, about 10 years ago.

When I began my Ph.D. studies, it was not easy to know what to do to advance the understanding of stuttering. So many ingenious efforts had already been made. Comparing this research to a puzzle, it felt important to try to make sense of the scattered pieces. Therefore I worked both with experimental studies and theoretical overviews of previous research findings.

In this article I will focus on the main theoretical work, regarding the possible relation between stuttering and the basal ganglia, brain structures involved in automatization (Alm, 2004). This work led to the proposal of the dual premotor systems model of stuttering (Alm, 2005). The idea that stuttering is related to the basal ganglia is not new. The first account came from the German physician Sahli, based on studies of epidemic encephalitis around 1920. Among later examples can be mentioned Caruso (1991) and Molt (1999).

Conditions where stuttering tends to be absent provide important clues about the underlying dysfunction. One such condition is the "rhythm effect": persons who stutter usually become fluent when speaking to the pace of a metronome. They seem unable to stutter when following the beats. This distinction, to have a problem performing a motor sequence on your own, but being

able to do it when receiving external "timing cues," is characteristic of dysfunction of the basal ganglia motor circuits (including related structures, such as the supplementary motor area (SMA)). Normally, the basal ganglia seem to provide "go-signals" for the segments in a motor sequence, e.g. the syllables in speech.

Without sufficiently strong go-signals the speech cannot be started or will be disrupted. The rhythm effect appears to be a key feature of stuttering, providing a strong indication that stuttering is related to some type of disturbance of the basal ganglia motor circuits.

There are several other indications for the important role of the basal ganglia in stuttering, for example: (1) Lesions that cause "acquired stuttering" often affect the basal ganglia (Ludlow et al., 1987). (2) The drugs that have shown the clearest effect on stuttering, to make it better or worse, affect the dopamine system. Dopamine is a key transmitter that regulates the function of the basal ganglia. (3) Basal ganglia motor disorders characteristically worsen during stress and "nervous tension," and improve under relaxed conditions.

In the review on stuttering and the basal ganglia (Alm, 2004), it was also argued that the typical pattern of onset of stuttering around age 2.5 to 3, with a large percentage of early recoveries, may be related to a natural phase of the development of the basal ganglia. Specifically, it has been shown that children in general have a peak in the number of dopamine receptors type D2 in the basal ganglia at this time. There are theoretical arguments for how a large number of D2 receptors may increase the risk for stuttering. Furthermore, the drugs that have shown the best documented effect on stuttering act by blocking these D2 receptors.

The number of D2 receptors has also been reported to show correlation with cognitive performance, which is in accord with the observation that children with early onset of stuttering often display precocious language development (Watkins, Yairi, & Ambrose, 1999).

In the thesis, On the causal mechanisms of stuttering (Alm, 2005), the basal ganglia model was developed further, based on the theoretical work on the human motor system proposed by Goldberg (1985, 1991) and others.

Goldberg argued that the human brain has two parallel premotor systems, i.e. systems involved in planning and execution of movements, including speech.



Per Alm, Ph.D.

## The phones keep ringing

### Annie's Mailbox reaches millions, even in South Korea

The Memphis staff is hearing ringing in their sleep after a wave of calls flooded the Stuttering Foundation's switchboard following mentions in two syndicated columns.

One mother wrote, "My son sometimes can't say anything and then will say the same word over and over. Please help!"

"Since I read the column, I feel like there is hope for my daughter," said a father in Ohio.

On Oct. 22, Int'l. Stuttering Awareness Day, *Annie's Mailbox* listed SFA as a source of help and information on stuttering and included SFA's Web site address and toll-free phone number. The column's authors, Marcy Sugar and Kathy Mitchell, said, "We are happy to help out. Thanks for all the good work you do."

Their syndicated column is read by nearly 90 million people. Newspapers as far away as Seoul, South Korea, carried the story, which resulted in many requests for help.

Earlier this summer, Dr. Robert Wallace, who writes *Tween 12 & 20*, mentioned the Foundation twice in two separate columns that reach nearly 5 million readers.

On Aug. 18, he described *Stuttering: Straight Talk for Teachers* as an important resource and listed the SFA Web site.

On Sept. 17, a single New Orleans mother without Internet access wrote Dr. Wallace seeking help for her young son. He followed up by listing eight tips from SFA right in his column. □



Marcy Sugar



Kathy Mitchell



Robert Wallace

## The age factor in stuttering

Ehud Yairi, Ph.D.  
University of Illinois

Age is among the strongest risk factors for stuttering with several important implications. Although the disorder begins within a wide age-range, current robust evidence indicates that, for a very large proportion of cases, it erupts during the preschool period. Data obtained at the University of Illinois Stuttering Research Program revealed that for 65% of the child participants, stuttering onset occurred prior to age 3; the figure rose to 85% by 3 1/2 years of age (Yairi & Ambrose, 2005).

Leaving room for some sampling errors, children past age 4 face a relatively low risk for stuttering. From clinical considerations, these statistics call for greater emphasis on preparing clinicians for working with early childhood stuttering.

Age brings out other factors. The fact that the critical age for stuttering onset parallels the age span when significant rapid developments occur in the anatomy of the speech system, as well as in complex language and articulatory skills, invites speculations that interferences in these maturation



Ehud Yairi, Ph.D.

processes contribute to stuttering; hence the possibility of relations among stuttering, language, and articulation. Although our own data (Watkins, Yairi, & Ambrose, 1999), and those of our colleagues from Germany (Rommel et. al., 1999), show that the language skills of children who stutter, as a group, meet or exceed norms, we suspect that there are differences in the ways in which they process language. One research priority consequent to information about age at onset is experimental manipulation of similarities and/or differences in language processing and production between children who stutter near the onset of the disorder and normally fluent children, particularly in terms of the nature of linguistic knowledge and the time course of knowledge activation. Varied responses to semantic and phonological distracters, slower reaction time, and/or alternative activation paths may reveal differences in language processing. One of the intriguing questions is: does age at stuttering onset – prior to, or after, a certain point in language development – underlie distinct subtypes of the disorder? Currently, scientists in several laboratories are pursuing such issues.

Brain imaging studies of children should also enhance understanding of this issue. Our team members, Chang, Erickson, and

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## Outreach to pediatricians

By June Campbell, M.A.

Physicians once again flocked to the SFA Exhibit Booth at the American Academy of Pediatrics Annual Conference and Exhibition in Washington, D.C., this October. It was noted that the demographics of physicians stopping by to discuss cases and materials was broadening: whether young into their careers or well-seasoned, physicians came not only from many major U.S. metropolitan and rural areas such as Fly Creek, N.Y., and Homer Glen, Ill., but also from Sydney, Australia, Athens, Greece, Lima, Peru, Trinidad, West Indies, and many locations in Mexico.

Requests for Spanish edition books and brochures was at an all-time high as were the DVD formatted films. Kudos to SFA for reaching out to the medical field which can most help with early intervention! □



Before



During

June and Allen Campbell discuss *Stuttering: For Kids, By Kids* with a pediatrician.

# Iowa workshop brings together clinicians from around the world

The Stuttering Foundation and the University of Iowa held the second Workshop for Specialists in Stuttering in Iowa City this past summer, under the leadership of Patricia Zebrowski, Ph.D., and Toni Cilek, M.A.

The event hosted 20 clinicians from 10 states and eight foreign countries.

Guest lecturers during the two week course included Edward G. Conture, Ph.D., of Vanderbilt University and Peter Ramig, Ph.D., of University of Colorado-Boulder. The first workshop at Iowa was offered in 2003, and the third will be offered in the summer of 2007.

“The second workshop met our expectations – and then some,” said Patricia Zebrowski. “I hope we continue our track record of receiving applicants from all over the world – this year we had specialists from the United States as well as from Russia, Italy, Turkey, Thailand, Japan, Taiwan and New Zealand.

This course gives me the opportunity to talk about how research and clinical practice complement each other, and to hear from specialists in the field about how this relationship functions in the real world of therapy.

The international flavor provides an excellent opportunity to discuss diverse practices and experiences with people who stutter, and these discussions help all of us who work with this population.”

The response from those attending this year’s workshop has been outstanding.

“Attending the Iowa workshop made me feel like I was part of an ‘All-Star’ stuttering team wrestling with this complicated disorder,” said Peter Reitzes of Brooklyn, N.Y.

“What a fantastic workshop here at Iowa,” said Cheryl Arismendi of Pomona, Calif. “I have learned so much and had a wonderful time meeting others



The Class of 2005 gathers for pictures during Stuttering Therapy: Workshop for Specialists, sponsored by the Stuttering Foundation and the University of Iowa, Iowa City. Front row (from left): Jeanjai Jeeraumporn, Jennifer Tseng, Jennifer Peacock, Calista Keck, Ashley Jackson, Jane Fraser, Erol Belgin, and Nao Yasuda. Second row: Amie King, Suzanne Sylvester, Patricia Zebrowski, Michelle Jones, Toni Cilek, and Joe Fulcher. Third row: Margaret Schmidt, Maria Gurrister, Yulia Filatova, Cheryl Arismendi, and Mavis Kulak Kayikci. Back row: Nina Conrad, Peter Ramig, Massimiliano Marchiori, Peter Reitzes, Michelle Snead, and Kathleen Scaler Scott.



▲ Ashley Jackson, Peter Reitzes, and Toni Cilek take time for a picture during the workshop.

◀ Jennier Peacock (from left), Massimiliano Marchiori, Calista Keck, Peter Reitzes, and Ashley Jackson visit the Field of Dreams.

who are also wanting to help those who stutter. I appreciate your generosity in making workshops like this one come to life. I will have an opportunity to meet with my colleagues in the school district to share the workshop information.”

Kathy Scaler Scott of Flemington, N.J., said, “This program is an amazing method for pro-

viding training to speech-language pathologists throughout the world. It provides many speech-pathologists who could never otherwise afford it the opportunity to be well trained in the field of fluency.”

Information on upcoming workshops can be found on the Stuttering Foundation’s Web site, [www.stutteringhelp.org](http://www.stutteringhelp.org). □

# “I’m not hiding anymore”

By Rob Bloom

I stutter. I always have. In fact, I can remember being three years old and trying very hard to push out the word “d-d-daddy.”

When it became apparent that I was not going to “grow out of it,” I decided I would do whatever it took to keep my shameful stuttering a secret from the world. And thus began a life of substituting words, avoiding sounds, and quite frankly, living in fear.

I hid my stuttering throughout college, often taking drastic means to do so — from claiming to have laryngitis to giving a fake name when meeting new people. Sure, I was successful in lying to the world...but the truth was catching up with me: in the form of a stomach ulcer.

After graduation, I took a job writing for an advertising agency where I continued to portray the role of a fluent speaker on the outside. But despite professional success and recognition, I could barely look at myself in the mirror. When the economy slumped and my job was eliminated, I had the opportunity to do a little soul-searching. It was then that I had a startling realization: I needed to stop hiding.

I forced myself to face my fears directly. One way I did this was to do the very thing that scared me more than anything else: stuttering. I walked into situations and intentionally stuttered. Although agonizingly difficult at first, I slowly began to desensitize myself to the behavior. In addition, I joined Toastmasters where I willingly stood before a group of people and spoke. Did I stutter? Of course. But I also proved to myself that I was much more than the behavior of stuttering and even came to realize that I actually enjoy public speaking.

In opening up about stuttering, I’ve discovered the stigma and fears that I’ve based my life around die a little bit more with each passing day. I’ve also accepted the fact that, yes, I do stutter. I now know that if I stutter, my arms aren’t going to fall off and my head isn’t going to spin around. I’m just going to...well...stutter. And while this may always be the case, I now realize that there are much more important things to focus on.

Rob Bloom is a humor writer who has stuttered his entire life. In addition to his humor column, Rob has written for the Cartoon Network, Travel Channel, and National Public Radio. You can read some of Rob’s work at his Web site, [www.robloom.com](http://www.robloom.com). □



Rob Bloom

# All-new DVD series for 1.0 CEUs

Do you ever remember a name, but not recognize a face? Well, that’s what may happen when you see one of SFA’s newest productions.

The *Child Who Stutters: Practical Ideas for the School Clinician Series* has the same title as a former production, but you won’t recognize it because everything about it is new.

The six-DVD series, which offers speech-language pathologists 1.0 CEUs, has been totally redone.

Six fluency specialists went before the camera this past year to remake this popular series.

Barry Guitar, Ph.D., of the University of Vermont describes stuttering modification and fluency shaping and demonstrates both concepts.

Peter Ramig, Ph.D., of the University of Colorado-Boulder gives general information on stuttering, outlines basic principles, offers case studies, and suggests ways to determine

whether treatment is recommended for young children.

E. Charles Healey, Ph.D., of the University of Nebraska-Lincoln addresses the conceptual framework of CALMS as a model for planning stuttering assessment and treatment.

Kristin A. Chmela, M.A., of Northwestern University discusses counseling, listening and valuing, creating communicative space, taking timed risks, and documenting your goals.

Bill Murphy, M.A., of Purdue University discusses the emotions of school-age children, the stuttering triangle, essential tools, conspiracy of easy fluency, and keys to progress.

Patricia Zebrowski, Ph.D., of the University of Iowa offers help to understand adolescence and discusses motor training, mental training, and emotions.

For more information on this DVD series, visit [www.stutteringhelp.org](http://www.stutteringhelp.org) or call 1-800-992-9392.



Guitar

Ramig

Chmela

Healey

Murphy

Zebrowski

# SFA materials travel the world helping people

Stuttering knows no boundaries. It is a disorder that affects people everywhere.

Just this year alone, SFA material has been translated into several different languages — most recently, Lithuanian, Japanese, and Hebrew.

The Stuttering Problem Club of Lithuania translated two books, *Stuttering: An Integration of Contemporary Therapies* and *Counseling Those Who Stutter* into a single publication.

Benny Ravid of the Israeli Stuttering Association translated *Do You Stutter: A Guide for Teens* into Hebrew.

“It is the first publication for

young people who stutter in Hebrew in the last 35 years or more,” says Benny, chair of ISA.

The DVDs, *Stuttering and Your Child: Help for Families*, *Stuttering: Straight Talk for Teachers*, and *Stuttering: For Kids By Kids*, have been converted to Japanese this year.

“It’s our really great honor to produce and publish such excellent programs as your titles in Japanese versions,” writes Kazunari Katsumasa, CEO of the Institute of Medical Education. □



# Boston workshopers leave with enthusiasm

By Diane Fillion Parris, M.S.

Twenty speech-language pathologists representing nine states in the U.S., Turkey, Thailand, and Lebanon, attended the New England Workshop at Boston University from June 22 – 26, 2005.

Instruction and practical experiences in the diagnosis and treatment of children and adolescents who stutter were lead by Edward Conture, Ph.D., Vanderbilt University, Susan Dietrich, Ph.D., Harvard Medical School, Sheryl Gottwald, Ph.D., University of New Hampshire, and Diane Parris, M.S., Boston University.

During the five-day workshop, participants received instruction in differential diagnosis of fluency disorders, interpretation of diagnostic findings, treatment techniques for motor speech behaviors as well as desensitization and counseling strategies, and approaches to working with parents and teachers.

Guided practical training with local preschoolers, school-age children, and young teens left participants with enthusiasm and confidence in their new skills.

"All of my students who stutter are greatly benefiting from all of my new



Front (front): Laura Halley, Vanessa Sheets Paddock, Jane Fraser, Elise Goodman, Debra Robinson, Ponjit Jithavech, and Susan Dietrich. Second row: Sheryl Gottwald, Burcu Ardaman, Nancy Swartz, Dollen Tabri, Amanda Taylor, Tara Turken, Helen Selle, Rose Marie Pietrzyk, Susan Carnavale, and Laura Delaney. Back row: Joe Fulcher, Diane Parris, Paul Quin, Christine LaFleur, Joe Wohlgemuth, Karen Dohn, Terry Colyar. Not pictured are Jo Ellen Ryan and guest speaker Ed Conture.

knowledge," says Joseph J. Wohlgemuth of New Jersey.

"The intense format of the workshop combined with the practice with children helped transition the theory into practice," states Paul Quin.

Dollen Tabri of Beirut, Lebanon,

writes, "I learned new therapy techniques in a wonderful, professional environment, techniques I have already put successfully in use with more than one patient. The joint efforts led by the Stuttering Foundation of America are making a great difference in many people's lives." □

## Stuttering

*Continued from front page*

studies and studies of families in Africa.

The evidence for genetic factors in stuttering is overwhelming, with genetic factors playing a role in at least half of all cases. Although stuttering does cluster in families, severity does not. In other words, if you have a family member who stutters, you are more likely to stutter. However, if you have a family member who stutters severely, his or her severity does not put you at additional risk for stuttering nor does it relate to the severity of your own stuttering.

Another interesting finding is that the male-to-female ratio in familial cases of stuttering is approximately 1.5:1. This means that in families who appear to have some genetic transmission of stuttering, for every 1.5 cases of males who stutter, there is a case of a female who stutters. This figure is considerably different from past reports of male-to-female ratios for stuttering, which have previously been described as 4 or 5 males for every 1 female. This suggests that genetic transmission of stuttering affects females almost as frequently as males, and that the male-to-female ratio is much higher, probably 7 or 8 males for every 1 female, for individuals with no family history of stuttering.

Despite this genetic evidence, however, Dr. Drayna cautioned that most human medical problems are a combination of genes and "something else," such as environment or learning. Also, geneticists who study stuttering are almost certain that there are many genes that contribute to stuttering rather than one particular gene having most responsibility. For example, there are over 100 genes that cause deafness.

## Language Processing and Stuttering

Dr. Christine Weber-Fox discussed the neurological evidence for how individuals who stutter process linguistic information. Her purpose in pursuing this line of research is to investigate whether individuals who stutter exhibit atypical brain functions when they are processing linguistic information, such as deciding whether a sentence contains a grammatical error or whether two words rhyme. Her work is based on the theory that moments of stuttering, or breakdowns in speech motor control,

are related to difficulty processing elements of language such as grammar, retrieving specific words, or processing small units of speech such as individual speech sounds or syllables. She stated that current thinking in this area of research is that there are bidirectional influences between language and motor processing. That is, the complexity of the sentence or timing demands in recalling a specific word seem to influence the individual's ability to generate the necessary sequence of muscle movements to say the sentence, and vice versa.

Dr. Weber-Fox discussed a series of studies she and colleagues at Purdue University have conducted that have led to their conclusion that stuttering is not based solely on an individual's ability to execute a sequence of muscle movements in the mouth, larynx, and

respiratory systems but is also determined by language processing.

She uses a research technique called event-related potentials to illustrate how the brain processes information. A series of electrodes are placed on a person's head and the electrical energy that is emitted while the individual completes a task is measured by the electrodes. The researcher then examines the print-outs of the electrical waves to determine in what areas of the brain, and how quickly, the brain processes a given signal.

Her findings for adults who stutter show differences in their ability to accurately judge grammatical information such as verb-agreement violations. This reduced ability was also characterized by differences in the degree and patterns of electrical energy in the brain. Additionally, in a study where individuals had to process different types of words or phrases (e.g., I didn't know what time it was so I looked at my rain), those who stuttered showed a delay in processing that was not seen in individuals who did not stutter.

Because the brain is plastic or changeable over time with experiences, it is difficult to determine if these differences exist at the onset of stuttering and thus could be partially responsible for the problem. Alternatively, because of plasticity, it might be that living with stuttering over time may contribute to the differences being noted in adults as the brain attempts to compensate for stuttering. Therefore, Dr. Weber-Fox's current research is focusing on making similar types of measurements in children who stutter to determine whether the differences noted for adults are present in younger individuals. □

**Editor's note:** This entire article, including Drs. Maguire's and Foundas' research, can be found at [www.stutteringhelp.org](http://www.stutteringhelp.org) under *What's New*.

This article was greatly abridged because of space limitations.

# An almost famous singer

While the SFA's Web site list of Famous People Who Stutter includes many high-profile names, we like to think that every person who stutters is unique in their own right.

One person who stutters who unfortunately never became famous was Rory Storm.

Born Alan Caldwell in Liverpool in 1942, he took the name Rory Storm when he formed his own rock

band, Rory Storm & the Hurricanes. Rory stuttered badly but was totally fluent when singing, as is the case for many people. All accounts of Rory describe his speech problem as being severe.

Rory Storm & the Hurricanes was the most popular band in Liverpool and — at one point — even had more fans than their friends The Beatles. Rory's blonde hair and blue eyed good looks made him quite popular with young women in Liverpool.

Rory would indirectly make history when he advised his drummer, Ritchie Starkey, to change his name because it did not sound artistic. Not wanting to change his name, the drummer finally did when Rory suggested he take the name "Ringo" because of the drummer's penchant for wearing rings.

Ironically, Rory Storm & the Hurricanes played in the same club in Hamburg with the Beatles for a year. Ringo Starr had to fill in many times for original Beatle drummer Pete Best and it always went well.

When the Beatles canned Best just prior to recording their first record in 1962, Ringo was the unanimous choice to replace the popular Best.

Rory was sorry to lose Ringo but wished him well. Unfortunately for Rory, he and the Hurricanes would never see any glory days. With Beatlemania in England, other groups out of Liverpool, such as Gerry & the Pacemakers, achieved some success. However, Rory and his band fell on hard times and were

constantly passed over for a recording contract.

Rory had to deal almost on a daily basis with the Beatles' success because his sister Iris was Paul McCartney's girlfriend for awhile, both before and after the Beatles' success. She was Paul's last Liverpool girlfriend, and even after their break-up, Paul kept in touch regularly with Rory's mother, Violet Caldwell. In fact, when Paul

wrote *Yesterday*, the first person he called was Violet Caldwell to sing it to her over the phone.

It was difficult for a talented person like Rory to be passed over during the Liverpool craze in rock history. He found it most difficult to adjust to a life in which he had to speak rather than sing.

Another hardship would come later. While known on the club scene throughout England, his trademark moves on stage coupled with his blonde hair and good looks were legendary. It is widely believed that an upstart singer Rod Stewart, who saw Rory perform many times in the early days, "stole" the singer's trademark persona and found success of his own with well-choreographed moves on stage and flaunting his blonde hair.

Rory successfully treated his speech problem and became a fluent disc jockey for several years. However, tragedy would follow. In 1972, shortly after the death of his father and down on his luck, Rory took an overdose of pills and whiskey to end his life. His distraught mother died hours later of a heart attack.

True followers of the Liverpool club scene prior to 1962 know that Rory Storm was just as talented as any of the acts that found fame in the "British invasion." Success was all around Rory Storm for many years, but life dealt him an unfortunate hand. While he did not achieve fame and fortune, his unique accomplishments put him on our radar screen as a famous person who stutters. □



Photo from [www.beatlesource.com](http://www.beatlesource.com)

Rory Storm & the Hurricanes



Next time you peruse a magazine at the doctor's office, don't be surprised if you see a public service ad for the Stuttering Foundation. Oprah's *O Magazine*, *Redbook*, *Forbes*, *Good Housekeeping*, *Better Homes and Gardens*, *Ladies Home Journal*, *Cosmo*, *Cosmogirl*, and *Newsweek* are just a few of the major magazines who have donated space this year. Major specialized publications supporting the foundation include *Physicians Practice*, *School Nurse News*, and *Discovery*, which is distributed aboard Princess Cruise ships. □



SFA material received special attention at the Rensselaer (Ind.) Public Library.

## A special bookshelf

The Rensselaer (Ind.) Public Library did more than just place books and material on stuttering on a shelf. Glenda Brown made a special display complete with posters of famous people who stutter, videos and other resources.

The material on the display was also available to check out.

The display was so good that the local newspaper did an entire article on it and SFA supporter, Leon "Jigger" Sirois.

The Stuttering Foundation is able to make resources available free of charge to public libraries nationwide because of donations from people like Sirois of Williamsburg, Va.

If your local library doesn't have SFA material, please encourage them to contact the Foundation at 1-800-992-9392. □

# ASHA 2005

While temperatures for much of the country began to drop for winter, it was a different story in warm San Diego, Calif., which hosted the 2005 convention for the American Speech-Language-Hearing Association in mid-November.

The Foundation booth was wildly busy with a number of items proving to be very popular, including *Stuttering: For Kids, By Kids* and the new DVD series.

Many volunteers staffed the booth. A special thanks to Peter Ramig, Joe Donaher, Charlie Healey, Peter Reitzes, Tony Buhr, Vianne Bjornberg, Liz Edwards, Steffi Schopick, Judy Kuster, Nancy Ribbler, Glenn Weybright, Maria Gurrister, Brenda Malepeai, John Ellis, Ryan Pollard, Tom Gurrister, Darrell Dodge, Lorrie Scott, Julie Anderson, Mark Pellowski, Kathleen Chase, Jennifer Watson, Linda Louko, and Susan Hamilton. □



SFA anchor Carol Ecke gets ready for the big rush.



E. Charles Healey (left) and Joe Donaher speak with a customer.



Peter Reitzes answers a question.



▲ Susan Hamilton and Marlene Taylor donated \$500 to the Stuttering Foundation from money they raised by selling jewelry at the Cookie Lee booth.

◀ SFA materials draw a crowd.

## Age factor

*Continued from page 3*

Ambrose (2005) successfully obtained high resolution structural MRI data from stuttering and control children ages 8-13. Initial results indicate significant group differences in white and grey matter volume in brain areas involved in integrating sensory and motor aspects of speech. Testing younger children closer to onset should advance our knowledge.

Evidence is also accumulating that age at onset may bear a relation to genetic factors, in particular, it appears there may be a trend for persistent stuttering to have a slightly later onset than recovered stuttering (Yairi & Ambrose, 2005). As the Illinois team continues to uncover possible interactions among different genetic loci (Cox, et al., 2005), the age factor should become more clear.

Age is also a risk factor in regard to children's awareness of disfluent speech. The belief that preschoolers who stutter lack in such awareness played a major role in theories and developmental models of the disorder. For many years, clinicians' assumption that awareness would trigger strong emotions (e.g., anxiety) in children was the main

reason for shunning direct speech therapy for preschoolers. Whereas some three-year olds are either clearly, or appear to be, aware of stuttering, available experimental data show a very large increase in awareness between ages 4 and 5, including normally fluent children (Ambrose & Yairi, 1994; Ezrati, Platzky, & Yairi, 2001). This information would seem to justify direct intervention techniques as well as provide clues for the timing of intervention and should be considered in counseling of parents and teachers about reactions of normally fluent children to their stuttering peers.

Finally, important information about persistent stuttering may be uncovered by studying upper age groups — people who have stuttered for many years into advanced ages. Perhaps they exhibit more pronounced characteristics that reveal differences not easily identifiable in the typical child or young adult who stutters. Indeed, our team's members are currently pursuing structural brain imaging studies of aged people who stutter.

All of the above serve to highlight the role of age in the onset and development of stuttering, in subtype differentiation, and in treatment strategies. Knowledge is

accumulating at a rapid pace but much remains to be learned.

### References

- Ambrose, N., & Yairi, E. (1994). The development of awareness of stuttering in preschool children. *Journal of Fluency Disorders*, 19, 229-245.
- Chang, S., Erickson, K., & Ambrose, N. (2005). Regional white and grey matter volumetric growth differences in children with persistent versus recovered stuttering: An MRI (VBM) study. Presented at the annual meeting of the Society for Neuroscience, 2005, Washington, D.C. Program No. 565.5. 2005 Abstract Viewer/Itinerary Planner. Online
- Cox, N., Roe, C., Suresh, R., Cook, E., Lundstrom, C., Garsten, M., Ezrati, R. Ambrose, N., & Yairi, E. (2005). Chromosomal signals for genes underlying stuttering. Presented at the Oxford Disfluency Conference, Oxford University, Oxford, United Kingdom.
- Ezrati, R., Platzky, R., & Yairi, E. (2001). The young child's awareness of stuttering-like disfluency. *Journal of Speech, Language, and Hearing Research*, 44, 368-380.
- Rommel, D., Hage, A., Kallehne, P., & Johannsen, H. (1999). Developmental, maintenance, and recovery of childhood stuttering: Prospective longitudinal data 3 years after first contact. In K. Baker, L. Rustin, & K. Baker (Eds.), *Proceedings of the fifth Oxford disfluency conference* (pp.168-182). Chappell Gardner, UK: Windsor, Berkshire.
- Watkins, R., Yairi, E., & Ambrose, N.G. (1999). Early childhood stuttering III: Initial status of expressive language abilities. *Journal of Speech, Language, and Hearing Research*, 42, 1125-1135.
- Yairi, E. & Ambrose, N. (2005). Early childhood stuttering. Austin: Pro-Ed, Inc. □



# Dear SFA: Reader Response

Send letters to SFA, P.O. Box 11749, Memphis, TN 38111-0749 or email [info@stutteringhelp.org](mailto:info@stutteringhelp.org).

## Video gets four stars

Dear SFA:

*Stuttering: For Kids, By Kids* is about stuttering. What I liked about the movie was that the children in the video say that they are not shy to talk. Another thing I liked about it was that the children stutter and they just kept on talking. For example, when they spoke they just let their stuttering out and did not care about their stuttering.

During speech class, I watched this video with four of my friends. My friend Katie said, "I learned that stuttering is not a big deal because everyone has problems." Jennifer said, "I learned that some people can help themselves with stuttering." Martha said, "What I learned was that you should tell your friends if you stutter." Susan said, "What I learned is that stuttering is not funny." My speech teacher said, "I am so glad that Melissa shared her stuttering and this video with her friends."

Melissa  
Fifth grade  
New York

## I do what I want to do

Dear SFA:

My name is John. I am 11 years old. I am a 5th grader in Chicago. I like to read and hang out with friends. I have been stuttering since kindergarten. At first when I stuttered I couldn't get every word that I said out of my mouth. But then when I got older I tend to repeat words two or three times and then I am fluent. My dad also stutters but not that much. My little brother also stutters.

I notice that when I am not paying attention to how I talk, I don't stutter. I never stutter when I sing or when I'm in a play. I don't let stuttering stop me from doing anything I want to do. When I am stuttering I don't like it when people interrupt me.

I don't care that I stutter. Stuttering actually helps me meet new people because either some of my friends introduce me to their friends or they make sure that I am in a group project, and I meet new kids there.

My speech therapist told me about your Web site and your newsletter. I

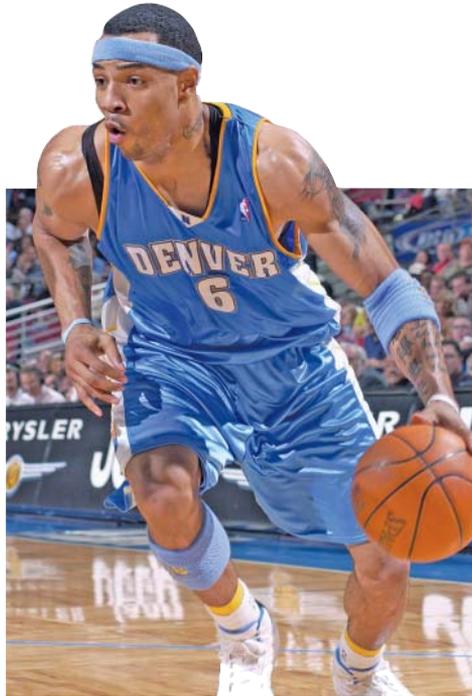


Photo by Fernando Medina/NBAE via Getty Images. Copyright 2004 NBAE. Used with permission.

Since our summer newsletter, we have heard from many people who have been inspired by Denver Nuggets basketball sensation Kenyon Martin. He is now included on our *16 Famous People Who Stutter* poster.

am surprised that so many famous people stutter. I like reading the letters.

John  
Chicago

## Web site a great help

Dear SFA:

I thank you for your Web site. My mother has stuttered all of her life. And she has always been embarrassed to talk to people due to her stuttering. I also use to stutter when I was younger. I still do, when I am nervous. My son, brother and many of my uncles and aunts still stutter. I was so surprised to see how many people has stuttered. Because of your Web site, my mother is not as ashamed of her stuttering.

I cannot thank you enough for allowing so many people to see that they were not alone. If you can help others as you did my mother and myself, than you are doing something great. Keep up the good work. God bless you all for reaching out to people like me and my family. Thank you.

Francis  
Boston

## School scares me

Hi:

I am very happy I found your Web site. Stuttering is a real problem for me and I think it is going to limit the opportunities I have in life. I am only 13. I always get nervous in school and sometimes I can't ask important questions because I can't say it quickly. If I didn't stutter, I would look forward to school and I would be an actress and sing! But I can't and I am scared when I go to school because you don't know if you are going to have to read something out loud. If you have any ideas for helping me, please e-mail! Thank you for your support and I appreciate every bit of it!!

Sarah  
Atlanta

*Editor: Help has gone out to Sarah.*

## Workplace survey

Marshall Rice, Ph.D. of York University in Toronto, Canada, is conducting a survey on the impact of stuttering at work. To enable him to better understand the issues and challenges that people who stutter face on the job. The research may help identify policies that will help to prevent discrimination against people who stutter. Please complete the confidential survey online at: [www.survey-city.com/survey/stutter/pws.html](http://www.survey-city.com/survey/stutter/pws.html). If you have questions, contact Dr. Marshall Rice at [mrice@schulich.yorku.ca](mailto:mrice@schulich.yorku.ca) or at 416-736-2100, Ext. 58241.

## Online journal

Peter Reitzes and Gregory Snyder will launch an online journal, *The Journal of Stuttering Therapy, Advocacy, and Research*, to be ready in February, [www.JournalofStuttering.com](http://www.JournalofStuttering.com). To submit papers, e-mail Gregory Snyder, at [OleMiss@GregorySnyder.com](mailto:OleMiss@GregorySnyder.com).

## NSSLHA chapters donate

Thanks to The Florida State University and the Eastern Washington University chapters of the National Student Speech-Language-Hearing Association, which recently donated to the SFA. Their generous gifts will help children who stutter. □

## Brain

Continued from page 2

(However, he did not discuss stuttering.) According to this model, both systems have the ability to provide go-signals for movements, but under somewhat different conditions. The lateral system, consisting of the lateral premotor cortex and the cerebellum, is active when the movement is controlled in relation to the sensory input — like when speaking to the pace of a metronome or reading in unison. Similarly, the lateral system is dominant when speech is controlled by auditory or somatosensory feedback.

In contrast, the medial system, consisting of the basal ganglia and the SMA, operates based on automatized programs without external feedback. This system is dominant during spontaneous speech, especially if the speech is propositional, i.e. that it conveys thoughts or emotions.

The lateral system is also assumed to be active when a movement is executed with increased attention and conscious control, while the medial system dominates for automatic responses. This is claimed to be the reason why it is difficult to get a natural smile when asked by a photographer — voluntary and spontaneous smiles are created by two different systems in the brain. This distinction suggests that the lateral system is in charge when speaking in a way that is not automatic, like imitating an accent or playing a role.

This dual premotor systems model of stuttering provides a novel explanation for most of the well-known fluency inducing conditions in stuttering. Stuttering is related to a disturbance of the medial system, but when the control is shifted from the medial to the lateral system the problem is bypassed. As mentioned above, this could

pertain to the metronome effect, unison reading, imitation of an accent, and role play. Furthermore, there are research data supporting that it is the lateral system that is dominant for go-signals during singing and rhythmic speech, conditions know to improve fluency.



An interesting question is how the effect of altered auditory feedback on stuttering can be explained, for example frequency altered feedback (FAF). There are now several brain imaging studies showing specific activation of the lateral premotor system when listening to speech sounds. Moreover, recent brain imaging data (Watkins, Davis, & Howell, 2005) have shown increased activation of the auditory cortex during speech with FAF. These findings point to increased control from the lateral system during altered feedback, so that difficulties with the medial system may be bypassed. This hypothesis is supported by reports that some speech difficulties in Parkinson's disease, which is a basal ganglia disorder, may be improved by either delayed or frequency altered auditory feedback.

An important aspect of the dual premotor model is that it emphasizes that the basal ganglia system is part of a larger medial system, including the complete loop from the cortex through the basal ganglia and the thalamus, and back to the cortex (the SMA). For example, as suggested in Alm (2004), the production of go-signals from the basal

ganglia may be disturbed because of deficient input from the primary motor cortex. In this way the basal ganglia model is compatible with the recent reports of structural anomalies of the cortex and the white matter, e.g. in the sensorimotor region for the speech organs (Foundas et al., 2001; Sommer et al., 2002; Jancke et al., 2004; Watkins et al., 2005). A more detailed account of this dual premotor model of stuttering is currently under way.

A pdf-file of the thesis can be downloaded from <http://theses.lub.lu.se/postgrad/> (However, the online version does not yet include all the research papers, because of copyright questions. For missing papers contact Per.Alm@psychology.lu.se. Printed copies of the complete thesis can be ordered from the Swedish Stuttering Association, kansliet@stamning.se, maybe about \$20 including postage.)

## References

- Alm, PA (2004). Stuttering and the basal ganglia circuits: a critical review of possible relations. *Journal of Communication Disorders*, 37, 325-69.
- Alm, PA (2005). On the causal mechanisms of stuttering. Doctoral thesis. Dept. of Clinical Neuroscience, Lund University, Sweden.
- Caruso, AJ (1991). Neuromotor processes underlying stuttering. In Peters et al. *Speech motor control and stuttering* (101-16).
- Foundas, AL et al. (2001). Anomalous anatomy of speech-language areas ... *Neurology*, 57, 207-15.
- Goldberg, G (1985). Supplementary motor area ... *Behavioral Brain Sci*, 8, 567-616.
- Goldberg, G (1991). Microgenetic theory and the dual premotor systems hypothesis. In Hanlon *Cognitive microgenesis* (32-52).
- Jancke, L et al. (2004). Morphological brain differences ... *BMC Neurology*, 4.
- Ludlow, CL et al. (1987). Site of penetrating brain lesions ... *Ann Neurol*, 22, 60-6.
- Molt LF (1999). The basal ganglia's possible role in stuttering. *Proc. 2nd Internat. Stuttering Awareness Day, Internet*.
- Sommer, M et al. (2002). Disconnection of speech-relevant brain areas ... *Lancet*, 360, 380-3.
- Watkins, K, Davis, M, & Howell, P (2005). Brain activity during altered auditory feedback. Paper at the Oxford Dysfluency Conference 2005, Oxford.
- Watkins, RV, Yairi, E, & Ambrose, NG (1999). Early childhood stuttering III. *J Speech Lang Hear Res*, 42, 1125-35. □

## Workshops

**Stuttering Therapy: Practical Ideas  
for the School Clinician  
June 9-10, 2006 — Chicago**

With Kristin Chmela, M.A., E. Charles Healey, Ph.D.,  
Bill Murphy, M.A., Peter Ramig, Ph.D.,  
Lisa A. Scott, Ph.D., and Patricia Zebrowski, Ph.D.

**The Mid-Atlantic Workshop: Treating  
Children and Adolescents Who Stutter  
Co-sponsored by the Children's  
Hospital of Philadelphia  
June 21-25, 2006**

With Joseph Donaher, M.A., Kristin Chmela, M.A.,  
and Lisa A. Scott, Ph.D.

Applications are available online  
at [www.stutteringhelp.org](http://www.stutteringhelp.org)  
or call 1-800-992-9392



**Newsbriefs and Books, usually found  
on this page, are at *What's New*,  
[www.stutteringhelp.org](http://www.stutteringhelp.org)**



**Our best wishes for a happy new year!**

The SFA staff: (Front row, L to R) Lisa Scott, Jane Fraser and Susie Hall; (Back row, L to R) Joan Warner, Roberta Brugge, Pat Hamm, Lisa Hinton and Anne Edwards. Not pictured are John Bell, Carol Ecke, Don Edwards, Joe Fulcher, Patty Reed and Scot Squires.

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