



THE STUTTERING FOUNDATION®

A Nonprofit Organization

SUMMER 2006

Since 1947... Helping Those Who Stutter

Google™ Grant awarded to SFA

The Stuttering Foundation's Web site, www.stutteringhelp.org, has received more than five million hits since it was re-designed last fall. And those numbers are sure to increase thanks to *Google™ Grants*.

The SFA Web site had 1,606,472 hits in March alone.

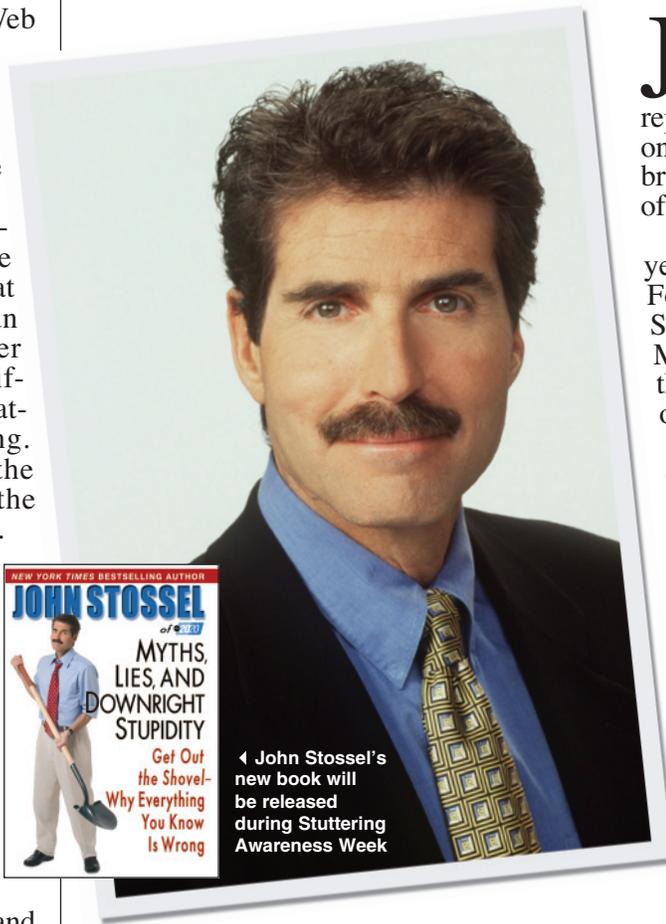
The online search engine selected the Foundation to receive free Web ads that appear when an Internet user searches for specific key words related to stuttering. The ads link the Web user to the Foundation's site.

In announcing the grant, *Google™* wrote, "After careful review of all the applications we received, we chose your group based on the strength of your application. We're excited to be able to help you reach your target audience with public service messages."

The Stuttering Foundation was chosen because of its "strong mission to help the world in the area of education and global public health."

Since it was launched in 1997, the Web site has been an essential tool in helping the Foundation fulfill its mission of providing resources and educating the public about stuttering. □

20/20's Stossel leads campaign Stuttering Awareness Week May 8-14



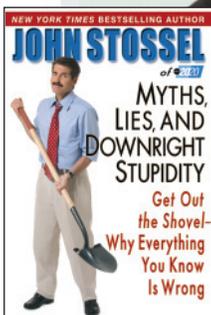
John Stossel, co-anchor of *20/20*, is one of the most recognized and articulate reporters today. However, he once considered giving up his broadcasting career because of his stuttering.

Stossel didn't quit, and this year he joins the Stuttering Foundation in recognizing Stuttering Awareness Week, May 8 - 14, and celebrating the Foundation's 59th year of helping those who stutter.

"Fear of stuttering can easily become worse than the stuttering itself," observed Stossel. "The idea that I'm on television and making speeches is still a shock to me sometimes."

During Stuttering Awareness Week, the Emmy Award-winning reporter and SFA will work to educate Americans about this little understood speech disorder

Continued on page 4



John Stossel's new book will be released during Stuttering Awareness Week

Did You Know?

- ▶ National Stuttering Awareness Week was passed by a Joint Resolution of Congress in May 1988.
- ▶ Over three million Americans stutter.
- ▶ Stuttering affects three to four times as

- many males as females.
- ▶ People who stutter are as intelligent and well-adjusted as non-stutterers.
- ▶ People who stutter often have excellent communication skills. John Stossel is a great example.

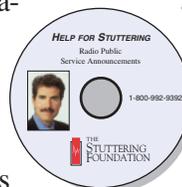
Index

- ▶ Tiger Woods speaks out on stuttering 3
- ▶ Genetics studies in Pakistan . . . 5
- ▶ Public service ads hit a home run 5
- ▶ Genetics of stuttering 2
- ▶ Survey on stuttering in the workplace 6
- ▶ State conventions are hot 7
- ▶ Kids respond. 8

PSAs hit the airwaves nationwide

Stuttering Awareness Week started early this year when radio stations around the country began running 15- and 30-second public service announcements narrated by John Stossel.

The PSAs were distributed to 2,618 radio stations across the country in time for Stuttering Awareness Week, which begins May 8.



Mary J. Atkins, promotions, PSA and community calendar coordinator with Clear Channel radio stations in Bozeman, Mont., said, "Your press kit looked so good! I have already sent them to production to be added into our rotation," she said.

You can hear the the radio PSA at www.stutteringhelp.org. □

Genetics of stuttering: New developments

By Ehud Yairi, Ph.D.
University of Illinois

For a long period, information on the familiarity of stuttering was primarily based on data concerning the percent of people who stutter having relatives with histories of stuttering. This figure has varied from 20% to 74%. Although it is apparent that stuttering runs in families, this fact, in-and-by itself, is insufficient to conclude genetic underlining. After all, a good number of tendencies, e.g., religious and political affiliations, also run in families.

As research methods improved, family pedigrees (trees) were analyzed in detail to study the occurrence of stuttering in different classes of relatives: mothers, fathers, sisters, and brothers, taking into account family size, something that was overlooked in the past. Obviously, a family of 12 with one member who stutters presents a very different picture than a family of 4 with one who stutters. Using sophisticated computer programs (e.g., segregation analysis), investigators evaluated the transmission of stuttering by matching the disorder's familial distribution against several possible genetic models. They were successful in showing that a few alternative models provided a good fit. Professor Kenneth Kidd of Yale University and his team made an enormous contribution in this respect, e.g., Kidd, et al. (1978) and Cox, et al. (1984). (For a more comprehensive review, see Yairi, et al., 1996).

Approximately 13 years ago, Ambrose, et al. (1993) at the University of Illinois were the first to report statistically significant evidence for a Mendelian single major locus model (SML) which assumes that there is one, or several major genes responsible for stuttering. Viswanath et al., also supported this finding. If correct, then chances for identifying genes underlying stutter-



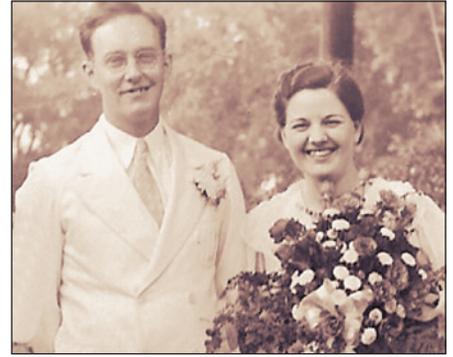
Ehud Yairi, Ph.D.

ing are brighten. The Illinois group later concluded that a mixed model, incorporating SML, polygenic components (many other genes), as well as environmental factors, had the best fit (Ambrose, et al. 1997). Furthermore, they showed that not only does the initial expression of stuttering have strong genetic components but also its future developmental course. That is, children who stutter and have a familial history of chronic stuttering would tend to follow that same pattern. And vice versa, children who stutter but have a familial history of naturally recovered stuttering, would tend to follow that pattern. Another significant contribution was made by twin studies that consistently demonstrated considerably higher concordance levels of stuttering in identical than in non-identical twin pairs (e.g., Howie, 1981; Felsenfeld, et al., 2000).

The accumulated findings justified a move from behavioral and statistical genetics into biological genetics. Typically, the first phase in such research is linkage analysis aimed at identifying the general location of possible genes using DNA extracted from samples of body tissues. Then, forms of known marker genes are identified on every chromosome (or just chromosomes of interest). When a marker gene form is co-inherited with stuttering (linkage), the indication is that the gene contributing to stuttering is on the same chromosome as the marker gene; in fact, very close to it.



At the beginning of the current millennium, Nancy Cox (2000) reported the results of the first complete standard genome-wide screen of DNA markers for analysis of stuttering for members of the Hutterite population in North Dakota. In this ground-breaking study, areas in chromosomes 1, 3, 5, 9, 13, and 15 had evidence for linkage of stuttering. Since then, four additional promising genome-wide linkage studies have identified several chromosomal regions that appear to be associated with stuttering. Shugart et al. (2004) reported a modest signal for a



Charles and Katy Van Riper on their wedding day.

Speech pioneer remembered

Catherine Jane Hull Van Riper is her full name, but most remember her simply as Katy.

Jane Fraser, president of the Stuttering Foundation spoke about her on Nov. 20 during a forum on early pioneers in the field of speech at the ASHA convention in San Diego, Calif.

While many know Katy's husband, the late Dr. Charles Van Riper, was a pioneer in the field of stuttering, less is known publicly about Katy, who was also a pioneer in her own right.

"She was the first woman to graduate in the field of speech pathology at the University of Iowa," Fraser said.

While Katy was the valedictorian of her high school class and graduated from the University of Iowa, she was turned down for a job on her first interview. "You are too young," she was told.

She later found work at a new speech clinic started by Bryng Bryngelson at the University of Minnesota.

"To be on faculty of a major university with only a B.A. degree was unheard of at the time. Especially for a woman," wrote her husband in a biography years later.

Katy taught many of Dr. Bryngelson's classes, helped him with his research, and edited his professional articles.

"It was the perfect job for me, with new challenges every day," she later wrote. Her salary was \$1,200 a year.

Katy died in 1984 after a long battle with cancer.

"Many of you will remember her for the warmth and caring she gave to all whom she touched" her husband wrote after her passing. □

Continued on page 6

100 years young!

After 100 years, Edward Rondthaler has his routine down. He writes a weekly column for his local newspaper, walks each morning, does his own errands, and regularly helps others — including the Stuttering Foundation. In fact, other than the Foundation’s founder Malcolm Fraser, Rondthaler was the first major contributor to the organization.

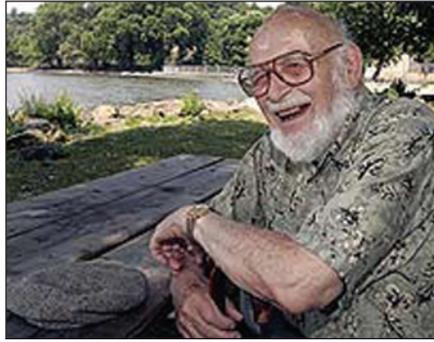
Staying busy keeps Rondthaler in great shape.

“Being 100 feels like being a year older than 99,” he says. “200 is pretty old, but 100 is not.”

On Nov. 23, 1981, Rondthaler included a \$1,000 contribution with a letter he wrote to the then Speech Foundation of America.

His letter said, “It is with this enormous pleasure that I send you this check for a thousand dollars. Two weeks ago I received your book *Self-Therapy for the Stutterer* and have read it with amazement. Every word in it rings true. And I speak from a lifetime of experience ... Today at 76, the severity is much, much less, and for half of my life stammering has been more of an inconvenience than a handicap. What excites me is that at least someone has gotten to the root of the trouble and can write about it in an understanding, lucid way.”

He continues, “When I was a boy, there were many young stammerers. There seem to be fewer now, and for a long time I had been wondering why. It’s been a long time since I’ve seen the little ads that Bogue and others used to have in almost every



At 100 years old, Edward Rondthaler continues to support causes important to him such as the Stuttering Foundation.

magazine. Clearly, speech correction has at last risen above quackery, and I’m sure that your foundation has had much to do with that...”

Rondthaler says he gives to the SFA because “it completely changed my life for the good.”

In fact, he says he’s always recommending that others who stutter contact the SFA.

“I have recommended it to so many people. I’m so happy to support it in any way I can,” Rondthaler says. “I even give out copies of Malcolm’s book.”

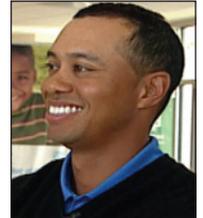
In 1970, Rondthaler co-founded the International Typeface Corporation — an international leader in typeface design and marketing. ITC collaborates with world-class designers to provide a library of over 1,650 classic typefaces and innovative new designs.

In 1975, he was awarded the TDC Medal, the award from the Type Directors Club presented to those “who have made significant contributions to the life, art, and craft of typography.” □

Tiger wins at golf — and stuttering

Top-ranked golfer Tiger Woods tells CBS’s 60 Minutes that it takes hard work and a competitive spirit to overcome childhood stuttering.

“The words got lost, you know, somewhere between the brain and the mouth. And it was very difficult, but I fought through it. I went to a school to try and get over that, and I just would work my tail off,” Woods told the news program in April.



Woods

“The parallels between speech performance and sports performance are striking,” said Jane Fraser, president of the Stuttering Foundation, “and Tiger Woods is the latest example of how the many hours of practice and hard work to win in sports are no different from those long hours spent in therapy for stuttering.”

NBA Hall of Famer and sports commentator Bill Walton dealt with stuttering just like he did basketball. “I thought about the fundamentals of the game and how to start with the basics like the ability to mechanically duplicate moves on a basketball court. And then I just applied that to speaking.”

Chicago Bulls’ legend Bob Love notes that “countless hours of work taught me to manage moments of difficult speech.”

In a recent interview, Denver Nuggets’ star Kenyon Martin said of his stuttering, “How I got through it was just by working hard at it.”

U.S. Open golf champion Ken Venturi adds, “I have had to work through the years to overcome stuttering and to speak more easily and fluently.” Venturi compares moving smoothly through speech to moving gracefully through a golf stroke.

“Tiger Woods is the perfect role model for all school-age children who struggle with this complex disorder,” said Fraser. The Foundation offers free resources at www.stutteringhelp.org where Tiger joins a long list of celebrities who stutter. □

Annual Audit of Foundation

The annual audit of the Stuttering Foundation financial reports for 2005 was recently completed by the accounting firm of Cannon and Company, Certified Public Accountants, Memphis, Tenn. Following is a recap of funds and expenditures for the year.

Funds expended for:

Creation, production, printing and distribution of educational materials	\$554,564	46.3%
Public information and education	312,247	26.1%
Educational symposia for professionals and research	201,355	16.8%
Maintain Web site and toll-free stuttering information hotline	76,086	6.4%
Total for Program Services:	\$1,144,251	95.6%
Other expenditures:			
Administration and general	45,524	3.8%
Fund-raising expense	7,627	0.6%
Total Expenditures:	\$1,197,402	100%

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

The 3.8% of expenditures for administration and general expenses and the 6/10 of 1% for fund raising are very low, and since we are fortunate to have an endowment which more than covers our overhead expenses, donors can be assured that their gifts will go directly to support our program services.

Stossel

Continued from front page

that affects more than three million people in the United States.

Stossel has also chosen Stuttering

A w a r e n e s s
Week to release his newest book **Myths, Lies and Downright Stupidity: Get Out the Shovel** —

Why Everything You Know Is Wrong.

Stossel's childhood and the early part of his career were fraught with the difficulties of stuttering. "I remember terror in the classroom," Stossel said. "In my early days as a reporter, I did regular live 30-second segments with the anchor of the news program; I woke up every morning in fear of that. The fear stayed with me all day long."

He considered quitting but, fortunately, sought speech therapy first. "Once I began to see the results of treatment, I was like a cork out of a bottle," he said. "I started talking all the time, celebrating and testing

my newly found fluency."

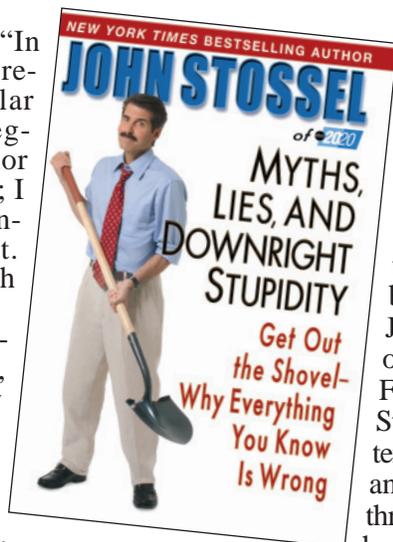
Stossel is aware of the need for continued practice. "Immediately after going through intensive treatment, I remember having the attitude

that I'd never have a stuttering problem again, and then the crushing disappointment when I did," he notes. "I had to constantly remind myself to keep practicing." Many adults who stutter must remember to practice speech therapy techniques in order to stay on top of their fluency.

"We are thrilled to have as our spokesperson someone who has brought important issues and news-breaking topics to the nation's attention through his broadcast voice," said Jane Fraser, president of the Stuttering Foundation. "Mr. Stossel did not let stuttering silence his story, and we hope that through his success and hard work, others will find encouragement to deal with theirs." □



John on the set at 20/20.



John Stossel's new book will be released during Stuttering Awareness Week.



June Campbell answers questions at the SFA booth in March during the National Association of Pediatric Nurse Practitioner's Annual Conference in Washington, D.C.

Pediatric nurses on the front line

Pediatric nurse practitioners are frequently the first medical professionals with whom parents interact regarding the well-being of their children.

These dedicated professionals proved they are perfect resources to support parents with questions about stuttering as illustrated by their interactions with June and Allen Campbell at the National Association of Pediatric Nurse Practitioner's Annual Conference in Washington, D.C. in late March.

Nurse practitioners from around the country flocked to the Stuttering Foundation Exhibit Booth to obtain literature, ask questions and discuss specific cases.

A frequent topic of discussion was educating parents regarding how to best interact with disfluent preschoolers.

Nurses were thrilled to learn about the expanded Web site and DVD formatted films as well as available pamphlets and books in English and Spanish.

The nurse practitioners represented diverse work settings including private practices, clinics, schools, and a variety of hospital departments including acute care, oncology, neurology, and extended care. □

Wedding gifts that help children

Some supporters are helping the Foundation by saying "I do."

Thanks to the I Do Foundation, the SFA has received donations from brides and grooms across the country.

The SFA uses these funds for its many projects, including helping children who stutter.

The I Do Foundation allows couples to request that guests donate to

the charity of their choice. Fortunately, the Stuttering Foundation figures among those lucky enough to be chosen.

I Do Foundation

Bringing Charitable Giving to Weddings.

The organization also partners with stores and honeymoon destinations that contribute a portion to charity.

To participate or for more information, contact SFA at 1-800-992-9392 or visit www.stutteringhelp.org. □

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

THE STUTTERING FOUNDATION

New light on genetic factors

By Dennis Drayna, Ph.D.
NIDCD

Studies in Pakistan over the past few years have added new impetus to research on genetic factors in stuttering. Research at the National Institutes of Health has recently identified a specific location for a gene that seems to be an important contributor to stuttering in this population. Scientists have found that this gene resides on chromosome 12, which provides a start to identifying the gene itself. These results were recently published in the *American Journal of Human Genetics*, a leading scientific journal.



Dennis Drayna, Ph.D.

Like elsewhere in the world, stuttering in Pakistan appears to come from both genetic and non-genetic causes. Although stuttering does not seem to occur at a higher rate in the Pakistani population overall, it often occurs in large family clusters. This may be due to traditional marriage patterns that have existed in Pakistan for many generations, in which marriage between cousins is considered highly desirable.

“We are fortunate to have wonderful cooperation from the many Pakistani families involved in this study,” said Dr. Dennis

Drayna, a leader of the NIH study. “While we have not yet identified this gene on chromosome 12, we know where to look, and we’re optimistic that we’ll see rapid progress in the coming year,” said Dr. Drayna.

The work was carried out at the National Institute on Deafness and Other Communication Disorders, in collaboration with scientists at the University of Chicago and the Centre of Excellence in Molecular Biology at the University of the Punjab, in Lahore, Pakistan.

Finding a gene alteration that causes stuttering is of great interest, as it may help shed light on the underlying causes involved. Of particular interest will be what the gene codes for, and how it acts, both in stutterers and in normally fluent individuals.

“Even finding one gene is unlikely to be the whole story,” cautioned Dr. Drayna, who emphasized that it’s likely there will be other genes, as well as non-genetic factors involved in stuttering. “But we’d be delighted to have one gene to study to get us started on understanding the bigger picture.” he said.

Reference:

Riaz, N., Steinberg S., Ahmad, J., Pluzhnikov, A., Raizuddin, S., Cox, N., and D. Drayna. Genomewide significant linkage to stuttering on chromosome 12. *American Journal of Human Genetics*. 76:647-651 (2005) □

PSAs hit a home run

The Stuttering Foundation’s public service ads (PSAs) are scoring big this year thanks to the many national publications that provide space.

For the first time, *ESPN* ran PSAs and it was a double play! The magazine ran two ads in the April 10th edition. One was a full-page PSA and the other was an ad featuring NBA All Star and Hall of Famer Bill Walton.



Full-page PSA used by ESPN.

The Foundation makes several versions of PSAs available to magazines and newspapers.

Among those featured in PSAs are 20/20 co-anchor John Stossel, conservationist Alan Rabinowitz, Winston Churchill, *Buffy the Vampire Slayer* star Nick Brendon, legendary basketball star Bob Love, Annie Glenn, and country music star Mel Tillis. The Nick Brendon ad is also produced in Spanish.

In addition to *ESPN* magazine, PSAs so far this year have appeared in *Time*, *Forbes*, *Redbook*, *Seventeen*, *Golf Digest*, *Prevention*, *Town & Country*, *Porthole*, *Black Enterprise*, *House Beautiful*, *American Medical News*, *JAMA*, *Georgia Trend*, *Parents*, *Penthouse*, *Northshore*, *Alabama*

Living, and others — which have a combined circulation of more than 12 million readers.

Next time you pick up a magazine, be on the lookout. □



Early stuttering treatment crucial

Dr. Tricia Zebrowski of the University of Iowa was featured on TV stations around the country discussing the importance of early intervention for children who stutter.

Since the segment first ran in December, many more stations have aired the report, including the CBS station in Green Bay, Wis., the NBC station in Omaha, Neb., and the ABC station in Creve Coeur, Ill.

The report tells viewers, “There’s no miracle cure for stuttering. It’s best to evaluate a problem early.”

The segment features Zebrowski working with a 7-year-old boy who



stutters.

Many stations airing the segment include a link to the Foundation’s Web site, www.stutteringhelp.org. And some include a way for viewers to e-mail the article to others. □

Stuttering may make a difference at work

A newly released survey by Professor Marshall Rice of the Schulich School of Business at York University, Toronto, found 51 percent of respondents — all of whom stutter — believe they would have a better job if they didn't stutter.

Sixty-eight percent of those surveyed agreed with the statement: "I believe my capabilities, at times, have been misjudged by my supervisors because of my stuttering."

"The results point to the need to further educate employers about stuttering," Dr. Rice said. "Clearly, some employers do not understand stuttering and make incorrect assumptions about the abilities of their employees who stutter. This misunderstanding results in reduced employment and promotion opportunities."



Rice

The Foundation offers an updated brochure, *Stuttering: Answers for Employers* to help dispel these incorrect assumptions.

The survey of 566 people who stutter from 37 countries also found 42 percent felt a job interview was "cut short." Fourteen percent said an employer told them directly that they would not be hired for a position because of their stuttering. Sixty-one percent agreed with the statement, "I feel I have to be 'better' than fluent speakers in order to have the same opportunities for employment."

Forty-four percent indicated they were currently a member of a stuttering support group. Fifty-nine percent said they have been a member of a support group at one time.

The largest number of responses came from the United States, Britain, Canada, Australia and India. □



Frances Cook, Barry Guitar, Jane Fraser (front row), Carroll Guitar, Peter Ramig, Lisa Scott and Patricia Zebrowski are creating a new DVD called *Stuttering: A Demonstration of Basic Techniques and Clinical Skills*.

It will be a comprehensive first course in stuttering therapy including fluency shaping and stuttering modification techniques. Starting with the basics — how we talk, how we stutter — clinicians will then be taught techniques, such as soft starts, changing rate, in block corrections or pull-outs, and more. The DVD will be accompanied by a learner's manual and will be available for ASHA CEUs.

Genetics

Continued from page two

stuttering locus on chromosome 18 and Riaz et al. (2005), using Pakistani families, found a strong linkage signal on chromosome 12. An NIH team under the leadership of Dr. Drayna studied stuttering in a large Cameroon family and reported a modest evidence for linkage on chromosome 1 (Levis, et al., (2004).

The largest and most recent study on linkage mapping was conducted by the Illinois International Genetics of Stuttering Project under the leadership of Professor Nancy Cox, University of Chicago, using blood samples from families in the USA, Sweden, and Israel. Our team identified moderate evidence for linkage for the broad category of "ever-stuttered" (including both persistent and recovered stuttering) on chromosome 9 whereas for persistent stuttering only it was on chromosome 15. The strongest signal for males only appeared on chromosome 7 and for females only on chromosome 21.

Also very interesting, further analyses revealed two possible genetic routs to stuttering. First, there was a significant increase in the evidence for linkage on chromosome 12 for families who had high linkage signal

on chromosome 7. The region on Chromosome 12 is very close to that reported signal by Riaz and colleagues for the Pakistani families. Second, a region on chromosome 2 showed a significant increased linkage signal for families who had high linkage signal chromosome 9 or negative signal on chromosome 7. Incidentally, the region on chromosome 2 has been implicated in recent studies of autism. We have speculated that such gene interactions may provide better insight into stuttering sub-types.

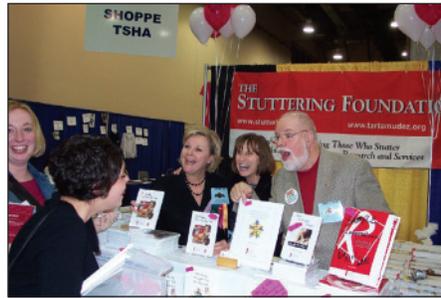
Although it is too early to speculate on what genes might be involved, it appears that the genes in the different chromosomes are similar, having some evolutionary homology. This might be consistent with the possibility that related genes affect susceptibility to stuttering. In summary, we have advanced from simplistic casual observations that stuttering runs in families, arriving now at a point where we are within arm's reach of identifying the specific gene, or genes, underlying stuttering. One has to keep in mind, however, that appreciable portions of the available evidence have consistently assigned significant roles to non-shared environmental factors.

References

- Ambrose, N.G., Yairi, E., & Cox, N. (1993). Genetic aspects of early childhood stuttering. *Journal of Speech and Hearing Research*, 36, 701-706.
- Ambrose, N.G., Cox, N.J., & Yairi, E. (1997). The genetic basis of persistence and recovery in stuttering. *Journal of Speech, Language, and Hearing Research*, 40, 567-580.
- Cox, N., Kramer, P., & Kidd, K. (1984). Segregation analyses of stuttering. *Genetic Epidemiology*, 1, 245-253.
- Cox, N. (2000). Genetics of stuttering: Insights and recent advances. Presented at the annual national convention of the American Speech-Language-Hearing Association. Washington, D.C.
- Felsenfeld, S., Kirk, K.M., Zhu, G., Statham, D.J., Neale, M.C. & Martin, N.G. (2000). A study of the genetic and environmental etiology of stuttering in a selected twin sample. *Behavioral Genetics*, 30, 359-366.
- Howie, P. M. (1981). Concordance for stuttering in monozygotic and dizygotic twin pairs. *Journal of Speech and Hearing Research*, 24, 317-21.
- Kidd, K.K., Kidd, J.R., & Records, M. (1978). The possible causes of the sex ratio in stuttering and its implications. *Journal of Fluency Disorders*, 3, 13-23.
- Levis, B., Ricci, D., Lukong, J., & Drayna, D. (2004). Genetic linkage studies in a large West African kindred. *American Journal of Human Genetics*, 75, S2026.
- Riaz, N., Steinberg, S., Ahmad, J., Pluzhnikov, A., Riazuddin, S., & Cox, N.J., et al. (2005). Genomewide significant linkage to stuttering on chromosome 12. *American Journal of Human Genetics*, 76, 647-651.
- Shugart, Y.Y., Mundorff, J., Kilshaw, J., Doheny K., Doan, B., Wanyee, J., et al. (2004). Results of a genome-wide linkage scan for stuttering. *American Journal of Medical Genetics A*, 124, 133-5.
- Suresh, R., Roe, C., Pluzhnikov, A., Wittke-Thompson, J., C-Y Ng, M., Cook, E., Lundstrom, C., Garsten, M., Ezrati, R., Yairi, E., Ambrose, N., & Cox, N. (2006). New Complexities in the Genetics of Stuttering: Significant Sex-specific Linkage Signals. *American Journal of Human Genetics*.
- Viswanath, N., Lee, H., & Chakraborty, R. (2004). Evidence for a major gene influence on persistent developmental stuttering. *Journal of Human Biology*, 76, 401-12.
- Yairi, E., Ambrose, N. & Cox, N. (1996). Genetics of stuttering: a critical review. *Journal of Speech and Hearing Research*, 39, 771-84. □



Carol Ecke shows a new workbook to CSHA President Tricia Chambers during the California convention.



Jennifer Watson, Carol Ecke and Russ Hicks smile about the great materials during the 2006 Texas convention!



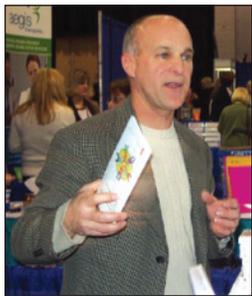
Tricia Krauss-Lehrman, Carol Ecke and Sheila Patterson in Texas.



Kristin Chmela and Mary Mantilla give helpful tips in Illinois.



The Stuttering Foundation booth was the first booth you saw as you walked in the door in Texas 2006.



Tom Chmela keeps things moving!

Carol Ecke makes an impact wherever she goes

Nationwide tour is HOT

If you've been to a state convention recently, chances are you've probably visited the Stuttering Foundation's booth and consulted with Carol Ecke, a Board Recognized Specialist in Fluency Disorders.

Ecke travels from coast to coast to work the SFA booth several times each year — reaching more than 27,500 people.

Ecke, a speech-language pathologist herself, is able to answer questions, suggest specific publications, and offer advice.

After each convention, she provides feedback about products and comments from attendees. These suggestions are then used to update materials and inspire new directions.

"I really enjoy traveling to the states and meeting the therapists who have

not had the opportunity to actually look through the materials and see the DVDs. They are totally thrilled when they examine the materials," Ecke says.

"I also view my role as a teaching opportunity for each individual I meet," Ecke explains.

"Carol is our eyes and ears in the field," says Jane Fraser, president of the Foundation. "Ideas for new books, videos, brochures and other products often come from the feedback we receive at these conventions."

Recently, she has been in San Diego, Fullerton and San Francisco, Calif.; Rosemont, Ill.; Bellingham, Wash.; Great Falls, Mont.; Atlantic City, N.J.; New Orleans, La.; Indianapolis, Ind.; Kansas City, Kan.; Louisville, Ky.; Myrtle Beach, S.C.; Columbus, Ohio; and Austin and Grapevine, Texas. □



TCU students' smiles bring SLPs to the booth.



Judy Martin and Carol Ecke greet SLPs in Myrtle Beach.



Volunteer SLP Lonnie Harris helps out in Louisville.



Judy Martin got to meet some of her on-line students at the SFA booth.



This table in Ohio is set for SLPs.



Carol Ecke tries a new angle in Louisville!



Dear SFA: Reader Response

Send letters to SFA, P.O. Box 11749, Memphis, TN 38111-0749 or email info@stutteringhelp.org.

Teachers check out DVD

Dear SFA:

Thank you for sending our school the free DVD and handbook about stuttering in response to our request. Our teachers are already checking them out of the library to learn how to help their individual students more effectively.

Sue Cusey

Library Technician

Breeze Hill Elementary School

Vista, Calif.

Speech is getting easier

Dear SFA:

I'm a 7-year-old who stutters. I enjoy video games, swimming and acting. Sometimes stuttering bothers me and sometimes it doesn't. When it bothers me, I get mad and walk out of the room to catch a breath. I see a speech therapist who helps me talk easier. I like working with her. Thanks for reading my story.

Noah, 7

Charleston, S.C.

Overcoming teasing

Hello:

My name is James and this is my story. When I was about 7 years old, I got picked on about my stuttering. Sometimes I used to cry when I got picked on. Then when I was 9, I started to get over people picking on me. Then when I was 10, which is now, I am a master at ignoring people who make fun of me.

James, 10

Kannapolis, N.C.

'I wish people understood'

Dear SFA:

My name is Martina and I'm 12 years old. A lot of people in my class tease me about my stuttering. When I ask someone a question, I get very nervous before I ask them because I'm afraid I'm going to stutter. A cashier looked at me like I was crazy. I wish it would just go away, and I wish people understood my problem. When people make fun of me, I just cry.

Martina, 12

New York City

No one is perfect

Hello:

I am 11 years old. My stuttering needs just a little bit of improvement. I am fine with my stuttering. I understand that I'm not perfect and no one else is either.

Prince, 11

Boston

Films such as *Stuttering and Your Child: Help for Parents* are now available free as streaming video online at www.stutteringhelp.org.



Nurses send thanks

Dear SFA:

The New York State Association of School Nurses would like to thank you for your literature, brochures, and samples your organization generously donated for the New York State School Nurse Orientation. This information was given to new school nurses throughout the state. Thank you again in helping school nurses add to their resource information to share with students, staff and parents.

Barbara Weingart, RN, NCSN

Westfield Central School

Westfield, N.Y.

Speaking can be hard

Hi:

I'm Nick. Usually people just want to know if stuttering is hard for me. Some people even tease me about it. I hate it when people tease me. When I'm mad about stuttering, I go up to my room and talk to my stuffed animals.

Nick

New York City

Stuttering is 'part of me'

Hi:

I'm Paul. I don't like stuttering because whenever I stutter, people tease me by saying, "da, da, da, da" or

"slow down." I usually stutter when I'm excited, interrupted, or trying to say something fast. I usually talk fast. Some kids laugh at my stuttering and my sister thinks my stuttering is cute. By my stuttering teacher says it's OK to stutter, and it's part of me and now I'm used to it.

Paul

New York City

Seeking help from others

Dear SFA:

In your summer 2005 newsletter, I read the letter that was sent in by a 15-year-old in Atlanta. I was touched by his letter and could really understand where he was coming from. I am 21 years old and have been stuttering my entire life. It's been an uphill battle, but it was nice knowing that I wasn't the only person in the world facing this challenge, even when in my hardest moments I felt alone. I wish I had thought to go to your Web site sooner. High school and college have been another challenge. I live in a rural area, and many of my professors hadn't encountered someone with a speech impediment and would ask me what I would like to do when the time came for me to give an oral presentation. I was torn between receiving special treatment and participating like the rest of the my class. I taught myself different ways to work around my speech, but I'd always wished there was a way for people who stutter to share their experiences and help each other out. So that's why I decided to write. Maybe there could be some kind of way for everyone to communicate and share their experience, whether it's on what to do when someone teases you, talking on the phone, or how to give an oral presentation or what to do on a job interview. I know that you may already have resources for this, but I felt it was something that could help others.

Kathleen

E-mail

Editor's note: The SFA provides many resources, including the brochures Using the Telephone: A

Continued on page 9

Letters

Continued from page 8

Guide for Those Who Stutter, Stuttering: Answers for Employers, which address interviewing, and Notes to the Teacher, which discusses teasing and speaking in class. These brochures are available to download for free at www.stutteringhelp.org or order by calling 1-800-992-9392.



Send us more!

Hi:

I work for the Thief River Falls Public Library in Thief River Falls, Minn. I received one of your DVDs titled, *Stuttering: For Kids, By Kids*. I would like to get three more copies for other branches.

Heidi

Thief River Falls, Minn.

Student from Afghanistan

Hello:

My name is Fahima and I am a girl from Afghanistan. I live in California and I am 11 years old. I have problems with speech. I don't like my stuttering because it makes me feel embarrassed. I go to a speech therapist. It's fun to go to speech because maybe it will help me talk better, and I play games with my speech therapist. My teacher noticed my stuttering in class when I stuttered on the letter "T". I always stutter on letters like "T," "S," and "D." I mostly sutter at home because I don't control it. Anyway, my family is used to my stuttering. I can control my stuttering only when I take a deep breath before I start to talk, and maybe there are some other ways I can control it. I hate my stuttering. I am not the only one who stutters in my family. My brother (17) and my sister (16) stutter too. Their stuttering is even worse than mine because they don't know how to control it. Sometimes my stuttering gets so bad I can't control it. I feel very embarrassed at that time.

Fahima

El Cajon, CA



Book is just what the doctor ordered

The Child Who Stutters: To the Pediatrician is reaching new audiences worldwide.

This 16-page publication is new in its 3rd edition, updated recently by Dr. Barry Guitar.

Adriana DiGrande, a speech-language pathologist in the Boston area, shares, "Whenever I write up an evaluation on a preschooler, I always send along a copy of *The Child Who Stutters: To The*



DiGrande

Pediatrician with my report in the hope that I will educate their pediatrician about early childhood stuttering."

She continues, "I really do believe the publication and feedback from parents have changed the practices of many pediatricians regarding early childhood disfluency."

The book also includes a convenient referral checklist and can be ordered by calling 1-800-992-9392. Or download it at www.stutteringhelp.org. Just click on the "Pediatricians/Physicians" tab on the left. □

Celebrity Corner

Cuban author frequently wrote about stuttering

In June 1998, the English-speaking world was introduced for the first time to Cuban writer Calvert Casey, who had died in 1969 at the age of 45. Well known in the world of Latin American literature, 1998 marked the first time that his complete works were translated into English and published in one volume entitled *Calvert Casey: The Collected Stories*.



Casey

Upon its publication, the following was written in *Publishers Weekly*: "This volume is a fine overdue introduction to one of Communist Cuba's most sophisticated writers."

Calvert Casey was born in Baltimore in 1924 to an Irish-American father and a Cuban mother, moving to Cuba as a small child.

His childhood was described by a friend as being "isolated from other children because of his violent stutter."

Other accounts attest that the severity of his stuttering continued into adulthood. Friends and critics alike credit his stuttering for his developing characters in his writing that are uprooted, disenchanting and alienated.

In the *New York Times* book review, James Polk wrote, "Casey writes from the shadows with certainty and fluent assurance of one who knows them well."

His most famous short story is *The Homecoming*, which is about a person who severely stuttered who enthusiastically returns to his beloved Cuba during

the onset of the Castro regime only to find himself a target of attacks by government agents. Another quirky story is *The Execution* in which a man is sentenced to death for a crime he did not commit and never refutes the charges.

Casey was in exile during the last part of the Batista regime, where he lived in New York and wrote magazine articles. Returning to Cuba when Fidel Castro took power, he was prominent among the intelligentsia surrounding Castro and wrote for several government publications.

However, he became totally disenchanting with the political situation in Cuba and went into exile in Rome, where he wrote his famous novella "Notes of a Simulator".

In 1969, struggling with personal issues as well as his severe stuttering, Casey took his own life; on his desk he left open a Henry James book with an underlined passage which read: "He was a man too fragile to live in this world."

While Calvert Casey only wrote one novella and sixteen short stories in his career, he is well known in Latin American literary circles; ironically, he remains ignored by the Cuban literary establishment.

He frequently mentioned stuttering in his writing as he struggled with it every day of his life.

With the publication of his works in English it is hopeful his writing will receive the same recognition in the English-speaking world that it has received in Latin America. □

▶ The Stuttering Foundation two-day conference for speech-language pathologists working with school-age children who stutter, *Practical Ideas for the School Clinician*, will be held on June 9 and 10, 2006, in the Chicago area. For an application form, call the Stuttering Foundation at 1-800-992-9392 or check www.stutteringhelp.org.

▶ The Stuttering Foundation Five Day Workshop, *Diagnosis and Treatment of Children who Stutter: Practical Strategies*, will be held at Children's Hospital of Philadelphia June 21-25, 2006. Workshop leaders are Joseph Donaher, M.A., Lisa Scott, Ph.D., and Kristin Chmela, M.A.

▶ The Stuttering Foundation two-week Workshop for Specialists will be held at the University of Iowa, Iowa City, Iowa, during

June and July, 2007, directed by Patricia Zebrowski, Ph.D. and Toni Cilek, M.A. Guest speakers to be announced. This unique workshop brings together speech-language pathologists from all over the world.

▶ The 9th Annual Convention of Friends will be held July 20-23, 2006, in Philadelphia, PA, at the Embassy Suites Philadelphia Airport Hotel. For information and registration, visit www.friendswhostutter.org or call 866-866-8335.

▶ The International Fluency Association will hold the 5th World Congress on Fluency Disorder in Dublin, Ireland, July 25-28, 2006. Trinity College is the setting for this exciting international meeting. For more information, visit www.theifa.org.

▶ The NSA Annual Convention will be held June 28-July 2, 2006, in Long Beach, CA, at the Westin Long Beach Hotel. For more information and registration, call 800-937-8888.

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

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

▶ For those interested in joining Toastmasters International as a way to improve fluency, communication or public speaking skills, their address is: Toastmasters International, Inc., Attention: Membership Department, P.O. Box 9052, Mission Viejo, CA 92690, Telephone: (714) 858-8255; Fax: (714) 858-1207.

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

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

▶ For those wanting to obtain a copy of *Stuttering and Your Child: Questions and Answers* in Hindi, write to: Dr. Sajiv Adlakha, Adlakha Speech and Hearing Clinic, A67 Dayanand Colony, Lajpat Nagar - 4, New Dehli-110024, India, or e-mail: 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: An Integrated Approach to Its Nature and Treatment*, Third Edition by Barry Guitar. 2006. Available from Lippincott, Williams & Wilkins, 800-638-3030, www.LWW.com

▶ *Stuttering Recovery Personal and Empirical Perspectives* by Dale F. Williams. 2006.

Available from Lawrence Erlbaum Associates, Mahwah, NJ, www.erlbaum.com

▶ *Speech Therapy for the Severe Older Adolescent and Adult Stutterer: A Program for Change* by George Helliesen. 2006. Available from Apollo Press, Newport News, VA, 800-683-9713, www.apollopress.com.

▶ *The Child and Adolescent Stuttering Treatment and Activity Resource Guide* by Peter Ramig and Darrell Dodge. 2005. Available from Thomson Delmar Learning, Clifton Park, NY.

▶ *Early Childhood Stuttering: For Clinicians by Clinicians* by Ehud Yairi and Noline Grinager Ambrose. 2005. Available from ProEd, Austin, TX and amazon.com.

▶ *Begaïement: Intervention preventive precoce chez le jeune enfant* by Anne Marie Simon et al. 2005. Available from the Association Parole Begaïement, www.begaïement.org

▶ *Teach Me How To Say It Right, Helping Your Child With Articulation Problems* by Dorothy P. Dougherty, M.A. 2005. Published by New Harbinger's Publications, Oakland, CA. Available at www.newharbinger.com.

▶ *Troy's Amazing Universe*, by S. Kennedy Tosten. 2002. Published by Brite Press. Order from www.TroysAmazingUniverse.com or amazon.com. A story about a seven year old who stutters.

▶ *The Strong Silent Type*, by C. Kelly Robinson. A gripping novel about a young NFL star coming to grips with his stuttering. Available from New American Library, New York, and www.amazon.com.

▶ *Experiencias para compatir entre padres e hijos* by Karina Couseto Rios, Maria Marta Gebara and Mariela Ginhson. Order from equipfono_gcg@yahoo.com.

▶ *Stuttering Therapy: Rationale and Procedures* by Hugo H. Gregory, June H. Campbell, Diane G. Hill, and Carolyn B. Gregory. Available from Allyn and Bacon, Boston, MA; www.ablongman.com. 2003.

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

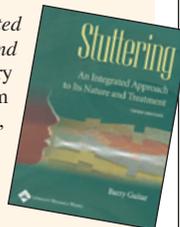
▶ *Forty Years After Therapy: One Man's Story* by George Helliesen, M.A. Available from Apollo Press, Inc., 1-800-683-9713 or www.apollopress.com.

▶ *Understanding Stuttering* by Nathan Lavid. 2003. University Press of Mississippi, Jackson, MS. Order from bookstores or amazon.com.

▶ *Programmed Stuttering Therapy for Children and Adults* by Bruce Ryan, Ph.D. Available through publisher Charles C. Thomas or online at www.amazon.com

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

▶ *Ben Has Something To Say* by Laurie Lears, il-



lustrations 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 49885, for \$13.95 plus \$2 postage and handling, call toll-free 1-866-942-7898; or from the Stuttering Foundation at 800-992-9392.

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

▶ *Stuttering: Its Nature, Diagnosis, and Treatment* by Edward G. Conture, Ph.D., published by Allyn & Bacon, Needham Heights, MA. (781) 433-8410.

▶ *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, 800-551-2959.

▶ *Clinical Decision Making in 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.

▶ *Straight Talk on Stuttering, Information, Encouragement, and Counsel for Stutterers, Caregivers, and Speech-Language Clinicians*, 2nd edition by Lloyd M. Hulit, Ph.D. The publisher is Charles C. Thomas, Springfield, Illinois.

▶ *Le begaïement, option guerison* by Francois Le Huche, M.D., Albin Michel, Paris, France, 1998. Order from Albin Michel, 22, rue Huyghens, 75014 Paris. □

NSSIHA donations

Our thanks to The Florida State University and University of Nebraska at Kearney chapters of the National Student Speech-Language-Hearing Association for their recent gifts to SFA. These generous gifts help children who stutter. □



THE
STUTTERING
FOUNDATION®

A Nonprofit Organization
Since 1947 — Helping Those Who Stutter

3100 Walnut Grove Road, Suite 603
P.O. Box 11749 • Memphis, TN 38111-0749

1-800-992-9392 • 1-800-967-7700

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