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SPRING-SUMMER 1998

Return of a Bestseller!

by Stephen B. Hood, Ph.D.

In 1972, the Stuttering Foundation of America published a remarkable book entitled *To the Stutterer*. Chapters were contributed by 23 people who stutter, all well-known professionals in the field of stuttering.



Dr. Hood

Each of the contributors had personally experienced a significant problem with stuttering; each of them had worked to successfully manage their stuttering; and each had the self-confi-

dence to make a contribution to their fellow "brothers and sisters of the tangled tongue."

The original book was reprinted seven times and was translated into many foreign languages, including German, Spanish and French.

Now, some twenty-five years later, a new edition has just rolled off the press, Advice to Those Who Stutter.

It includes some of the original chapters with four of the original contributors, Drs. Joseph Agnello, Richard



Boehmler, Hugo Gregory, and J. David Williams, writing new chapters and two, Dr. Gerald Moses and Dr. Fred Murray, making only minimal changes in their original chapters.

All ten of the new contributors have stories to tell, and you will live vicariously through the experiences of these specialists in the field of stuttering. Dorvan Breitenfeldt, David Daly, Walter Manning, Larry Molt, Bill Murphy, Lois Nelson, Robert Quesal, Peter Ramig, Gary Rentschler, and Kenneth St. Louis—all reflect upon their own personal histories with stuttering and share the things which have helped them and others they work with

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Stuttering Didn't Silence His Song Mel Tillis Spokesman for National Stuttering

Awareness Week

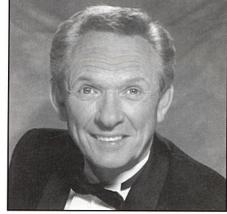
by Jean Gruss

Early in his career, country music superstar Mel Tillis stuttered so severely that he couldn't even thank the audience at the end of a performance. But ever since his role as the curtain-puller for a first-grade play, Tillis wouldn't let stuttering keep him from the stage.

"I found out early on that I could sing without stuttering," Tillis said. His first-grade teacher realized that too. She encouraged young Mel to sing in front of the class at his elementary school in Plant City, Florida.

"Understanding what dramatically reduces stuttering during singing may eventually help us understand stuttering better," explains Barry Guitar, Ph.D., a noted speech-language pathologist at the University of Vermont. Adds Peter Ramig, Ph.D., of the University of Colorado, "In singing, we use our vocal chords, lips, and tongue differently than when we talk. Also, there is no time pressure in singing. We know the song by heart, and words are connected in a rhythmic pattern. Likewise, there is evidence that the brain functions differently for singing than for talking."

Singing in front of the class was Mel's first step toward legendary fame as a recording artist, performer and songwriter. Today, Tillis is spokesman



Mel Tillis

for the nonprofit Stuttering Foundation of America and is Honorary Chairman of National Stuttering Awareness Week, May 11–18, 1998.

"Mel Tillis is living proof that people who stutter can be highly successful," said Jane Fraser, president of the Stuttering Foundation.

-Tillis joins a host of other famous people who stuttered, like Winston Churchill, singer Carly Simon, actor James Earl Jones and journalist John Stossel. The Stuttering Foundation estimates that stuttering affects more than 3 million Americans.

But like so many artists, success came only after hard work and long hours on the road. Tillis played music wherever he

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SFA Book Reaches China

Stuttering and Your Child: Questions and Answers
Translated into Chinese

by Paul Malott, Ph.D.

During the winter of 1996, I was a visiting professor at the Chinese Academy of Science in Beijing, Peoples Republic of China. One of the classes that I taught was a linguistics class to master's level students. Each student was to complete a project related to any aspect of speech communication.

I had suggested to the class that a

translation of an American text concerning speech disorders would be an acceptable project. Such a project would fulfill the class requirement

class requirement as well as serve a useful function to the general community of China.

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初你的孩子

SFA in Prime Time

The Stuttering Foundation's new public-service announcements for television feature children in a playground setting. They were aired by an evergrowing number of stations and networks across the country in 1997 and the first four months of 1998, thereby increasing the public's awareness of stuttering and giving them a nonprofit source of help.

ABC Television Network and ABC Stations

For the first time, the ABC Television Network is airing the Foundation's 30 second PSA nation-



wide. Many airings have been during prime time, usually during "Good Morning America." Calls have come in from viewers in all 50 states from the West Coast all the way to the U.S. Virgin Islands.

NBC Network and Affiliates

We were included in the national rotation of public-service announcements at NBC again in 1997 and 1998.



On March 17th, 1998, NBC aired our PSA every 15 minutes for five hours, resulting in thousands of calls to our toll-free number not only on that day, but for weeks afterwards. Usually a PSA is aired once and that generates many calls; the nonstop airing by NBC was an unexpected surprise.

CBS Keeps SFA in Rotation

Support from CBS, Inc. was outstanding all during 1997 and again in 1998. We have heard from hundreds of CBS viewers in the following cities in response to the regular airing of our PSA: Burlington, Vermont; Boston, Massachusetts; Jacksonville, Florida; Florence, South Carolina; Macon, Georgia; El Paso, Texas, and many more.

Fox Broadcasting Company Supports SFA

Our PSA is also in the national rotation of PSA's at Fox Broadcasting Company. We have heard from Fox viewers in the following cities: Wilmington, North Carolina; Cleveland, Ohio; Houston, Texas; Rochester, New York; Chicago, Illinois; Washington, D.C.; and Flint, Michigan.

America's Health Network

This exciting new network has not only aired our PSA, but also did a



two hour series on stuttering with pediatrician Dr. Alix Casler and speech-language pathologist June Campbell, which is still airing. We have received hundreds of calls in response to both.

■ Kaleidoscope

This is America's Disability Channel, and it too has been airing our public service announcement quite regularly. This channel has also aired our new videotape for teenagers, *Do You Stutter: Straight Talk for Teens*, in its entirety on many occasions during the past 18 months.

SFA Financial Report for 1997

The annual audit of SFA financial reports for 1997 was recently completed by Ernst & Young, Certified Public Accountants. Following is a recap of funds and expenditures for the year.

The 3.81% of expenditures for administration and general expenses

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

Funds expended for:		
Creation, production and distribution of		
educational materials	\$485,936	50.66%
Public information and education	224,176	23.37%
Educational symposia and research	126,886	13.23%
Stuttering Information Hotline	79,837	8.32%
Total for Program Services	\$916,835	95.58%
Other expenditures:		
Administration and general	\$ 36,573	3.81%
Fund-raising expense	5,715	61%
Total Expenditures	\$959,123	100.00%

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.

SFA Co-Sponsors Conference on **Insurance Coverage**

One of the biggest problems encountered by people who stutter and parents of children who stutter seeking the services of a speech-language pathologist is to obtain financial assistance through their health insurance plans.

It appears that many people are informed that their healthcare plans do not cover the treatment of stuttering disorders or that because stuttering is presently miscoded as being a mental disorder—which it most definitely is NOT—its treatment is not included in the healthcare plan.

Changing the medical code is an obvious way to extend third party reimbursement. Members of the American Speech-Language-Hearing Association's Division for Fluency and Fluency Disorders and Governmental Relations and Public Policy are actively involved in seeking a resolution to that problem. The Stuttering Foundation is also working in this direction.

However, because the process for bringing about changes in the code can take as many as five to seven years, other avenues of help are needed now. By the conclusion of this conference, we hope to have put together a packet of information summarizing methods and procedures for seeking insurance coverage or third-party reimbursements for stuttering therapy services. This packet should be of help to both the public and the professional.

The conference, co-sponsored by the Stuttering Foundation and ASHA's Special Interest Division for Fluency and Fluency Disorders, will take place at the headquarters of the American Speech-Language-Hearing Association in Rockville, Maryland. The participants will include Dr. Eugene B. Cooper, Catherine Otto Montgomery, Dr. Jeanna Riley, Dr. David Daly, Harriet Klontz of ASHA, Joe Fulcher and Jane Fraser of SFA, Dr. Jennifer Watson.

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 taxdeductible, subject to limitations under the Code.

Tillis Inspires Others

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Tillis with daughter, Pam Tillis, 1994 Country Music Awards Female Vocalist of the Year.

went, even putting together a band in the Air Force to entertain the troops.

Mel never spoke on stage until long after he moved to Nashville and became an established songwriter and guitar player. Things changed after he joined Minnie Pearl's band.

Minnie noticed that despite his stutter, Mel had a great sense of humor and joked with other band members when they were off the stage.

"Minnie Pearl was the one who convinced me to talk on stage," Tillis recalled. "She told me, 'If you want to be a singer, you have to learn to talk on stage." I told her, "Miss Minnie, I just can't. They'll laugh." She replied, "Let 'em laugh. Goodness gracious, laughs are hard to get, and I'm sure they'll be laughing with you and not against you, Melvin."

"Minnie was right. That first step was an important one. I started to talk and joke some—a beginning. It took a long time before I made much progress, but it did happen over the years. It came real slowly. Still, just the idea that I could dare to talk in front of crowds of people was great."

Tillis, who never had formal therapy, said his sense of humor carried him through some of the tough times.

"Laugh through it, if you can," Tillis advises people who stutter. "Don't let it mess up your life."

Tillis said he jokes about his own stutter in performances today, but he said he is careful never to poke fun at others who stutter. "It can be too painful," he recalled.

Ironically, the stage is now where Tillis feels most comfortable with his speech.

"When I'm on stage, I feel like I'm the king. This is my world," Tillis said.

While Mel can joke about his stutter today, he couldn't laugh it off in his younger days. That was especially

true in school, when other kids teased him about the way he talked.

His advice to kids who stutter today: get help from a speech-language pathologist.

"When I was a child, we didn't have that," Tillis said.

Readers looking for help with stuttering can obtain a list of speech-language pathologists who specialize in stuttering from the Stuttering Foundation. For more information and a copy of the National Stuttering Awareness Week brochure featuring Mel Tillis and 12 other famous people who stutter, call 800-992-9392 or visit their Web site at www.stutterSFA.org.

Coming Soon— Videotape for **Adults Who Stutter**

A week-long conference took place March 1-7, 1998, to work on the production of a new videotape focused on adults who stutter.

Dr. Barry Guitar of the University of Vermont chaired the conference. Other participants included Dr. Hugo Gregory, Dr. Peter Ramig, Carroll Guitar, and Jane Fraser of SFA.

The new videotape will be approximately 45 minutes long and will feature:

- self therapy tips on ways to help oneself,
- concrete ideas of ways to deal with fears often surrounding stuttering,
- how to work on changing attitudes about stuttering,
- · outstanding footage of therapy in action with many adults who stutter.

The videotape should be available later in the year, so watch this Newsletter for more news on its availability.

To Someone Who Stutters, It's Easier Done Than Said.

For information, write or call toll-free:



1-800-992-9392

www.stutterSFA.org · stutterSFA@aol.com

SFA Book Reaches China

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The profession of speech pathology does not exist in China. With a population of 1.2 billion people, even conservative estimates of the prevalence of stuttering in China represents a sizable group of individuals who are not being helped by any professional group.

Wang Kai, a student in the class, eagerly accepted this topic as his class project. I just happened to have brought a copy of *Stuttering and Your Child: Questions and Answers** to China. He translated one chapter at a time, after which we reviewed his work for its relationship to the original text. I then wrote an introduction to the Chinese version of the booklet. The project was finished in less than a month.

Our biggest task was yet to come, finding a publisher. The dean of the Foreign Language Training Program assured me that a publisher, with whom he was associated, would be happy to accept this project. Several months passed, and we had not yet received a positive response from the Shanghai publisher. The academic term was over, and I had to return to the U.S.

Several months later, I received a message indicating that the Shanghai publisher was not interested in printing a book about stuttering.

I taught over 90 graduate students at the Chinese Academy of Science. Within the next year, four of my former students from China had moved to the U.S. to study, including Wang Kai. The search for a publisher continued.

Mr. Wang's grandfather had been in the publishing business in southern China before he retired. His grandfather indicated that he would help us find a publisher. Several weeks passed and we received a note that the Hubei Provincial Publishing House expressed an interest in our project. The first task was to get approval from the government to determine if the book was worthy of publishing. After another delay of many months, the publisher indicated that the publishing committee of the government gave the publisher the approval to publish Stuttering and Your Child: Questions and Answers.

In China, the cost of printing is not the responsibility of the publisher, but the author. Wang Kai had taught English to many individuals in southern China. One of his former students agreed to pay the printing costs of the project.

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Another Record Year for Public Service Ads in Magazines

This year's National Stuttering Awareness Week got off to a wonderful start with generous public service ads featuring country music star Mel Tillis placed by *Business Week, Family Circle, U.S. News & World Report,* and *Forbes.*

Business Week donated public service ad space for three weeks in a row which resulted in hundreds of calls from their readers. U.S. News & World Report gave SFA a generous full page PSA generating even more calls.

American Medical Association publications, *The American Medical News*,

Archives of Internal Medicine, and the Journal of the American Medical Association (JAMA) also featured new PSA's as did McGraw-Hill Healthcare publications, The Physician and Sportsmedicine and Postgraduate Medicine.

The excellent support of so many magazines brought the total of donated space to a record \$1,112,000 over the past twelve months! The Stuttering Foundation extends its heartfelt thanks to the 420 magazines which have been so very generous to us this year, some of whose names are listed here:

TIME Newsweek GOLF Business Week People Weekly Money Forbes Family Circle Woman's Day Sports Illustrated Journal of Accountancy Black Enterprise Essence Prevention U.S. News & World Report Seventeen New York Magazine The New Yorker United Airlines Hemispheres Medical Economics Money Maker's Monthly

The Carlson Voyageur

Kansas City Business Journal TN Small Business Review Utne Reader Penthouse Los Angeles Magazine Science and Children Mid-Atlantic Country Orange County Living America West Airlines Infectious Diseases in Children American Pharmacy Easyriders Memphis Magazine Twin Cities Business Monthly Communications Briefings Annals of Internal Medicine Journal of the American Medical Association

Medical Association Archives of Internal Medicine Minneapolis-St.Paul South Florida Parenting The Atlantic Monthly The Science Teacher

Northwest Airlines World Traveler Instructor In Pittsburgh Physical Therapy Archives of General Psychiatry Kansas City Business Journal Resident & Staff Physician Surgical Rounds Resident & Staff Physician Contemporary Surgery Christian Parenting Today Cincinnati Magazine Long Term Care Journal St. Louis Business Journal Salt Lake City Magazine Business & Health Young Children Northwest Baby & Child Golf Digest ...and many, many more.

SFA Book Reaches China

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Many months passed before we received notification that the presses had rolled and our translation was finished. Wang Kai and I had discussed the problems of distribution. Like the cost of printing, the cost of distribution is not the responsibility of the publisher.

We had decided that we were not interested in selling the book, but wanted to distribute Stuttering and Your Child: Questions and Answers at no cost to individuals who need it. One method of getting the information to those who needed it was to place the booklet in public libraries. This too was not a cost-free project. However, copies of Stuttering and Your Child: Questions and Answers have now been sent to libraries in southern China.

There are still quite a few copies of the booklet left. What should we do with these? Again, Wang Kai's family helped with this question. His grandmother had to go to the hospital for surgery. While she was there she asked hospital employees to look at the book her grandson had translated.

One person to whom she showed the book was a physician who also happened to teach at a medical college in southern China. The physician believed that the information in Stuttering and Your Child: Questions and Answers was information that the physician should have. He expressed an interest in incorporating it into medical school curriculum. It appears that we have yet another outlet!

As we continue to search for other avenues of distribution for this Chinese translation, we are excited that this "small" project has had such a big impact!

Return of a Bestseller!

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deal with stuttering effectively.

This exciting new book is available from SFA for only two dollars to help cover postage and handling. Ask for publication number 9, *Advice for Those Who Stutter* and mail to SFA, P.O. Box 11749, Memphis, TN 38111-0749.

visit us at

www.stutterSFA.org

The Stuttering Family Research Project—A Progress Report

by Dennis T. Drayna, Ph.D.

The Stuttering Foundation of America is currently working with the Stuttering Family Research Project at the National Institutes of Health (NIH). This exciting research project seeks to identify the genetic or inherited factors that predispose individuals to stuttering.

Many types of evidence suggest that inherited factors can influence stuttering, and recent advances in human genetics hold the promise of identify-

ing the specific genes involved. Study of these genes in both individuals who stutter and in normally fluent individuals will help us to better understand the causes of this disorder.

The first phase of the NIH research involves tracing the oc-

currences of stuttering within families that have several members who stutter. To do this, the research project is in the process of identifying qualified families and getting family members signed up to participate.

The SFA has retained Mr. James (Jimmy) Kilshaw of Baton Rouge, Louisiana, as a new member of the research team. Jimmy is dedicated to the task of making telephone contact with the hundreds of individuals in

qualifying families, that is to say, families where more than one member of the family stutters, and encouraging them to follow through on their participation.

As a person who has stuttered throughout his life, Jimmy has recently retired from a prominent career in city government and public service in Louisiana. "We are very fortunate to have Mr. Kilshaw involved in our

project, Dr. Drayna. "He has the time and the wonderful 'people skills' that our project needs right now. As an individual who stutters, he can talk to others who stutter with a true understanding of the problem. The efforts of

Mr. Kilshaw are already making our research go a lot faster."

Mr. Kilshaw formally came on board the project at a series of meetings at the NIH in Bethesda in January of this year. The meetings included Jimmy Kilshaw, Dr. Drayna, Jane Fraser of SFA, and Dr. James Battey, the recently-appointed Director of the National Institute on Deafness and Other Communication Disorders.



Left to right: Dr. Dennis Drayna, Dr. James Battey, Jane Fraser, James Kilshaw.

South Africa Welcomes World Congress

by Robbie Cameron

The forthcoming 5th World Congress for People Who Stutter will be held at the Johannesburg College of Education, Johannesburg, South Africa, on July 6–9, 1998. The Speakeasy Stuttering Association of South Africa has been instrumental in winning the bid to bring this congress to South Africa.

The Congress theme is "Let's Keep Talking," and stutterers and professionals from over twenty countries worldwide will be in attendance.

The three primary conference objectives are:

· to serve as a forum to share informa-

- tion and technology on the latest developments in the stuttering world;
- to serve as a networking opportunity for people who stutter to meet with their peers;
- to serve as an outreach opportunity for Speakeasy to enable people from disadvantaged communities to access information and treatment for their stuttering.

For more information on this exciting conference, contact Robbie Cameron at e-mail: robbie.cameron @pixie.co.za or P.O. Box 3390, Parklands 2121, South Africa.

- The annual "Stuttering Therapy: Workshop for Specialists" co-sponsored by the Stuttering Foundation and Northwestern University will be held at Northwestern University in Evanston, Illinois, July 13-24, 1998. For more information about the workshop, contact the Stuttering Foundation at 1-800-992-9392, or Dr. Hugo Gregory, Stuttering Programs, Northwestern University, 2299 Campus Drive North, Evanston, IL 60208. This unique workshop brings together speech-language pathologists from all over the world.
- The Stuttering Foundation of America New England Workshop, "Diagnosis and Treatment of Children Who Stutter: Practical Strategies," directed by Dr. Sheryl Gottwald, will be held at Boston University, Boston, Massachusetts, July 28th through August 2nd, 1998. For application and information about traineeships, call 1-800-992-9392.
- The SFA Southeastern Workshop, "Diagnosis and Treatment of Children Who Stutter: Practical Strategies," directed by Dr. Susan Dietrich, will be held at University of North Carolina-Greensboro, in Greensboro, North Carolina, June 10th through June 14, 1998. For more information about the 1999 schedule, call SFA at 1-800-992-9392.
- For more information on the Speak Easy Symposium XVII, to be held at the Montvale Holiday Inn in Montvale, New Jersey, July 24-26, 1998, call Bob or Antionette Gathman at (201) 262-0895.
- For more information on the National Stuttering Project annual convention in Atlanta, Georgia, June 24-27, 1998, call 1-800-364-1677.
- For information about the Speak Easy Canadian conference in Saint John, New Brunswick, on August 13-16, 1998, call (506) 696-6799 or e-mail:speakez@nbnet.nb.ca.
- For more information on the 5th World Congress of People Who

- Stutter, call (+27+11)+786-6660 or e-mail:fvh@iafrica.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 looking to obtain a copy of Self-Therapy for the Stutterer in Japanese, write to Dr. Shokichi Nakajima, 2-21-1 Ogawa Machidashi, Tokyo 194, Japan, telephone/fax: 0427 (96) 5092.
- For those looking to obtain a copy of Self-Therapy for the Stutterer in French, write to the Association des Begues du Canada, 7801 Rue Ste. Claire, Montreal, Quebec, Canada, H1L 1V8. Please enclose \$15.00 Canadian to cover printing, postage, and handling costs.
- Dr. Anne Foundas is looking for adults who stutter in the greater New Orleans area interested in participating in a project to study neuroanatomical models of stuttering. If you are interested in participating or have any questions or comments, contact Dr. Anne Foundas at the following address: Department of Neurology, Tulane University School of Medicine, 1430 Tulane Avenue, New Orleans, LA 70112-2699. Phone: (504) 595-5605 (Voice Mail and evenings, ask for Cassie Browning), (504) 588-5734 (Days, ask for Laura Cardin)

New Books on Stuttering Available from Bookstores:

- Stuttering: An Integrated Approach to Its Nature and Treatment by Barry Guitar, Ph.D., Williams & Wilkins, Baltimore, MD.
- Stuttering Intervention: A Collaborative Journey to Fluency Freedom by David Allen Shapiro, published by Pro-Ed, Austin, Texas.
- Clinical Decision Making in the Diagnosis and Treatment of Fluency Disorders by Walter H. Manning,

- Ph.D., published by Delmar Publishers, Albany, New York.
- 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.
- Special Children, Challenged Parents, by Robert A. Naseef, Ph.D., published by Carol Publishing Group, Secaucus, New Jersey.
- Straight Talk on Stuttering, Information, Encouragement, and Counsel for Stutterers, Caregivers, and Speech-Language Clinicians by Lloyd M. Hulit, Ph.D. The publisher is Charles C. Thomas, Springfield, Illinois.
- Stuttering: A Life Bound Up in Words by Marty Jezer. Published by Basic Books, 1997. This book may also be purchased through the NSP, 1-800-364-1677.
- Stuttering and Science by William H. Perkins, Ph.D. It is published by Singular Publishing Group, Inc., in San Diego, California.
- *Elements of Stuttering* by Courtney Stromsta, Ph.D. Available from Atsmore Publishing Company, P.O. Box 533, Oshtemo, MI 49077. Please send \$19.50 plus \$3.00 handling charge.
- Stuttering: A Search for A Cause and a Cure by Oliver Bloodstein, Ph.D.. It is published by Allyn & Bacon, Needham, MA.
- Does My Child Have a Speech Problem? by Katherine L. Martin. Chicago Review Press, Inc., Chicago, IL.



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