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FALL 1998

Insurance Coverage for Fluency Treatment Targeted

by Eugene B. Cooper

Representatives of the Stuttering Foundation of America (SFA) and the American Speech-Language-Hearing Association's (ASHA) Division for Fluency and Fluency Disorders met recently to begin coordinating efforts to increase the number of health insurance providers covering the treatment of stuttering. There being many complex factors behind the failure of most insurance companies to cover stuttering treatment, no single effort can resolve the problems. The SFA/ASHA representatives agreed to begin addressing the issue by developing an informational brochure that would assist those who stutter in seeking and in obtaining coverage for the assessment and treatment of stuttering.

A first draft of such a brochure was completed at a two-day conference sponsored jointly by the SFA and ASHA. The brochure is currently undergoing revisions prior to its release. The brochure begins with very brief statements regarding the nature and etiology of stuttering. Such statements, reflecting the current thinking regarding stuttering, may assist clients and parents of clients in communicating with insurance companies regarding the disorder. The bulk of the brochure's content is a listing of detailed suggestions for those filing a claim for third reimbursement and directions on obtaining assistance in doing so. Following field testing of the brochure's usefulness, the brochure may be ready for general distribution within six months.

Participants in the meeting agreed that long-term efforts to alter existing universal health care and diagnostic codes that, for example, erroneously categorize stuttering as a mental disorder, must continue to receive top-priority attention. In the meantime, the participant's concluded, immediate efforts to better educate both the public and insurance companies with respect to stutter-

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Rileys Presented With Prestigious Malcolm Fraser Award Special Interest Division Site of Award

MEMPHIS—The husband and wife team of Glyndon and Jeanna Riley of Laguna Beach, California, were presented the prestigious Malcolm Fraser Award for their lifetime of service to those who stutter. The award was presented at the American Speech-Language-Hearing Association Division for Fluency and Fluency Disorders' Fifth Annual Leadership Conference in Marco Island, Florida, April 29, 1998.

The Rileys are most widely known for their work in developing instruments to assess the nature and severity of stuttering and in predicting which disfluent children are more at risk for continuing to stutter. Two of their clinical instruments, the Stuttering Severity Instrument and the Stuttering Prediction Instrument, are the most widely used assessment instruments in the field. In addition, the Rileys have become known for the excellence of their clinical programming for those who stutter and for stimulating the development of innovative stuttering therapy procedures.



Dr. Glyndon Riley and Dr. Jeanna Riley receiving Malcolm Fraser Award.

Glyndon Riley is Professor Emeritus of the California State University, Fullerton, a practicing clinician, and currently serving as Director for the Center for Children

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Ann Landers Article Gives SFA Web Site and Toll-free Number!

A letter from a young Russian woman who stutters in Ann Landers' syndicated column recently prompted hundreds and hundreds of telephone calls and letters to the Stuttering Foundation of America.

Ann Landers published SFA's Web site and toll-free telephone number and address when responding to this letter in her column on June 17th of this year.

The column was published in most



U.S. newspapers, reaching an estimated 90,000,000 readers according to sources in Ms. Landers' office.

The SFA, warned in advance of Landers' column, had three telephone

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Specialists Workshop Celebrates 12th Year

The Memphis-based Stuttering Foundation of America and Northwestern University hosted their annual instructional workshop for speech-language pathologists specializing in stuttering from July 13 through July 24, 1998.

Each year, 20 speech pathologists from around the world with a special interest in stuttering are accepted to participate in the workshop. Under the leadership of Dr. Hugo Gregory, the workshop is organized to focus on therapeutic skills and techniques for intervention with children and adults.

This year's workshop participants come from the United States, Canada, Argentina, Norway, Brazil, Norway, and the Sultanate of Oman.

"We're gaining new perspectives and are excited to return home with them," added Inger Jordell of Norway, Luz Rivera Guzman of San Juan, Puerto Rico, and Jamil Babli of the Sultanate of Oman. Added Lucia Maria Barbosa of Sao Paulo, Brazil, "I've learned a tremendous amount during these two weeks."



SFA's Jane Fraser, Anila Punnoose, Workshop Director Hugo Gregory



Kristin Walton, Anila Punnoose, Lucia Barbosa during work session



Joe Donaher, Joan Kazer, Alex Johnson, Monica de Brito Pereira Viana, Carla Bernier, Inger Jordell, John McManus.

"It was phenomenal," remarked Dr. Alex Johnson of the Henry Ford Hospital in Detroit. "I learned a lot, met a lot of great people, and refreshed my enthusiasm for working in stuttering."

Added Joe Donaher of Philadelphia, "SFA's commitment to the field is inspirational."

Kristin Walton of Salt Lake City noted, "I have many ideas and new motivation and knowledge as a result of the workshop at Northwestern. It was an experience I will never forget!"

This unique workshop has gained international recognition for its excellence in the post-graduate study of stuttering.

For more information about this intensive workshop which will take place July 12 through 23, 1999, write: Dr. Hugo H. Gregory, Speech and Language Pathology Department, Northwestern University, 2299 Campus Drive North, Evanston, IL 60208-3570,



Lisa Scott, Grace Privette, Rosa Lopez, and Karina Couselo Rios discuss charts.



Joe Donaher, John McManus and Alex Johnson with map showing where workshopers live around the world.



Jamil Babli and Dr. Hugo Gregory hold map showing workshop attendees around the world.



Jollity prevails at farewell dinner festivities.

or call the Stuttering Foundation at 1-800-992-9392. Fellowships for the workshop are provided by the Stuttering Foundation. □



Front row: June Campbell, Diane Hill, Hugo, Jane Fraser, Carolyn Gregory. Middle row: Andrea Gingras, Anne Boever, Joan Kazer, John McManus, Anila Punnoose, Joe Donaher, Karina Couselo Rios, Inger Jordell, Carla Bernier, Luz Rivera Guzman, Rosa Irene Lopez, Lucrezia Tomes, Jamil Babli, Monica de Brito Pereira Viana. Back row: Grace Privette, Alex Johnson, Andrea Lynch, Lucia Maria Barbosa, Lisa Scott, Kristin Walton.

Stuttering Foundation Announces 1998 Award Winners in Journalism

The Stuttering Foundation of America announced today its 1998 Awards for Excellence in news reporting. Each winning entry has successfully enhanced public understanding of this complex speech disorder.

"We continue to be impressed by the increased and informed attention that journalists now are giving to the causes and treatment of stuttering," said Jane Fraser, president of the 50-year-old non-profit foundation. "The entries this past year from print and electronic journalists clearly indicate that news media professionals increasingly are sensitive to a speech disorder that affects the lives of millions of Americans."

Nine distinguished journalists are honored this year for their outstanding contributions. They are:

■ **Mary Powers** for "Speech Is Golden" in the Memphis, Tennessee, *Commercial Appeal*. First place winner in the large print publication category, this incisive



Mary Powers

article chronicles the painful experience of a local professor during his youth and the hard work it takes to achieve greater fluency. Accurately describing "the only handicap people still laugh at," Ms. Powers provides valuable information to those who stutter through the story of an admirable role model.

■ **Bob Condor** for "A War of Words" in *The Chicago Tribune*. Tied for second place in the large print publication category, he discusses the lack of a single "cure" for stuttering and provides a positive role model in the experiences of ABC news correspondent John Stossel.



Bob Condor

■ **Alma E. Hill** for "Excellent Tips to Parents" in *The Atlanta Constitution*. Also tied for second place for the large print publication category, she gives parents important tips of things they can do to help a child who is stuttering as well as accurate facts about the disorder.

■ **Charles Runnells** for "Freedom of Speech" in the Petersburg, Virginia, *Progress-Index*. First place winner in the small print publication category, this well-researched piece discusses aspects of stuttering often overlooked, including the tendency by many Americans to stereotype

persons who stutter as less intelligent (not true) or to place a stutterer in a difficult speaking situation without asking for permission.

■ **Maryann G. Eidemiller**, "Twisted Tongues" in the Greensburg, Pennsylvania, *Tribune-Review*. Second place



Maryann G. Eidemiller

winner in the small print category, her companion stories underscore the importance of therapy, practice and courage on the part of young people who seek to overcome stuttering. The neurological origins of this disorder are cogently reviewed by the writer.

■ **Diane Rodecker** for a series of columns including "Internet Offers Information, Aid to Stutterers" in *The Orange County Register*. Winner in the syndicated columnist category, she continues to offer solid advice and information on locally based therapy. Ms. Rodecker also is one of the first to recognize the growing popularity of the Stuttering Foundation's web site: www.stuttersfa.org.



Diane Rodecker

■ **Kathy Brandt** for "Helping Children who Stutter," gives parents accurate information on stuttering, debunks the many myths surrounding the disorder, and gives parents tips on how to help their child and where to find help.



Kathy Brandt

■ **Barbara F. Backer** for "Is My Child Stuttering?" in *Lowcountry Parent*. Second-place winner in the magazine category, this contribution to the South Carolina-based regional magazine provides specific and balanced advice to parents about detection and professional treatment of children



Barbara F. Backer

who may stutter. It succinctly summarizes "things that help" and "things that hinder" in helping a child who is coping with this speech disorder.


■ **Bruce Beggs** for his profile of country music legend Mel Tillis in *Grit*. Tied for the second place award in the magazine category, this piece reminds readers that Mel Tillis had to learn how to cope with his stuttering disorder and endure ridicule on the way to recording more than 60 albums. While he still wishes he could speak without stuttering, Tillis confronts each situation with good humor.



Bruce Beggs

■ **Karen Hill**, news reporter for Cable News Network and recipient of a first place electronic media award. Ms. Hill's revealing and sensitive news story discussed the professional and personal challenges of the speech disorder with ABC's John Stossel.

Each of the Stuttering Foundation of America's 1998 first place winners received a cash award of \$250. The Stuttering Foundation is a nonprofit organization that has worked toward the prevention and improved treatment of stuttering since 1947. For more information, call the toll-free Hotline on Stuttering, 1-800-992-9392 or contact SFA's web site at www.stutterSFA.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.

Ann Landers

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lines to handle the inquiries in the days following the column's publication.

SFA President Jane Fraser credited SFA employees in Memphis with turning around inquiries and orders within two days despite the volume. Leslie Harrell, Tracy Grever, Pat Hamm, Anne Edwards, Sally Archer, and Roberta Brugge worked long hours and continue to help SFA's operations run smoothly.

The Landers' column is still generating calls and letters more than three months after its publication.

—Jean Gruss □

Newport Beach Conference Draws Record Crowd

by Judy Montgomery, Ph.D.

Sunny southern California was the location for the annual SFA conference for school clinicians, *Stuttering Therapy: Practical Ideas for the School Clinician*, June 5 and 6, 1998, in Newport Beach, California!

Co-sponsored by the Stuttering Foundation of America, the California Speech-Language-Hearing Association (CASHA), and Chapman University in Orange, California, the conference began with comments from co-ordinator Dr. Judy Montgomery and CASHA President Dr. Barbara Moore-Brown. SFA President Jane Fraser narrated an interesting slide presentation of the historical figures in the field of stuttering and the history of the Foundation itself.

A record attendance of one hundred and thirty professionals from schools and related settings in five states heard state-of-the-art intervention strategies to assist children who stutter.

Participants were particularly pleased with the practical aspects of the conference information such as grouping strategies, counseling ideas, effective scheduling, measuring progress in more functional ways, and using multiple therapy approaches for maximum effectiveness.

Many participants commented on the format of this unique conference, presentations followed by discussion groups led by professionals skilled in

therapy techniques, and applauded it as a great learning strategy for busy clinicians.

Barry Guitar, Peter Ramig, Charles Healey, Bill Murphy, Kristin Chmela, Nina Reardon provided informative sessions on both days. Discussions after each presentation were coached by well-known clinicians in the field—Richard Forcucci, Pearl Gordon,



Registration staff, smiling and efficient!



Discussion group led by June Campbell

Barbara Moore-Brown, Ellen Bennett, Patricia Zebrowski, June Campbell and Nina Reardon.

Conference coordinator Judy Montgomery, with able assistance from Keisha Henderson, both from Chapman University, were pleased to read post-conference evaluations such as: "exceptional conference," "probably the best presentations on stuttering I have ever heard," "very professional and yet fun—how did you do it?" Remarked one attendee from northern California, "These two days have changed the way I deliver services to children." Another remarked, "What a wonderful gift of knowledge and strategies for the school-based clinician!" □



Attendees continue discussions during luncheons.



Participants applaud presentations

Bob Love, Keynote Speaker for Convention



Chicago Bulls' legend Bob Love autographs SFA posters at Council for Exceptional Children Convention in Minneapolis, April, 1998. Love was the Keynote Speaker for the convention which brings together thousands of teachers and directors of special education programs across the country.



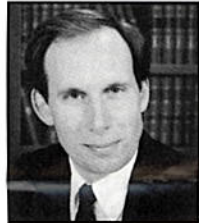
Conference organizers, speakers, and discussion group leaders. Back row: Patricia Zebrowski, Ellen Bennett, Bill Murphy, Nina Reardon, June Campbell, Barry Guitar, Peter Ramig, Charles Healey, Rich Forcucci, Pearl Gordon. Front row: Kristin Chmela, Judy Montgomery, Jane Fraser, Barbara Moore-Brown.

The Stuttering Family Research Project— A Progress Report

by Dennis T. Drayna, Ph.D.

The Stuttering Family Research Project at the National Institutes of Health (NIH) is continuing to make progress in its efforts to identify genes which may cause stuttering.

Because genetic factors are likely to be only one of the causes of stuttering, the project needs to study a large number of families in its research. "In the past year, we have had contact from over 275 families—a wonderful response," said Dr. Dennis Drayna who works in the National Institute on Deafness and Other Communication Disorders.



Dennis T. Drayna, Ph.D.

Over one hundred of these families have qualified for the study, and from these, almost 150 individuals have been enrolled in the past twelve months. "We still have a long way to go to reach our goal of 400 families," notes Dr. Drayna, "but the help in finding families that we have received from SFA has been invaluable."

A significant boost to the research project has been the participation of Jimmy Kilshaw of Baton Rouge, Louisiana. Jimmy, who has stuttered since childhood, has been doing telephone follow-up on all the families who have contacted the study. He not only welcomes new individuals into the project but also help contact the various other members of each family, encourages their participation, and makes certain the study procedures are followed.

One of the recent areas of intensive work has been clinical evaluations of all family members by a speech-language pathologist. The results of the first one hundred clinical evaluations have been encouraging as the occurrence of clinically confirmed stuttering closely parallels the occurrence as reported by the family members themselves. This correlation suggests that the right kind of families are coming forward to participate.

A second area of activity has been in the laboratory developing new methods to evaluate DNA samples

from participating family members. Traditionally genetic studies have required a blood sample as a source of DNA but obtaining blood can be unpleasant for the subjects and difficult to organize in such a large study.

As an alternative, the NIH project has used a method of obtaining DNA from the inside of the cheek taken by rubbing cotton swabs in the mouth. This source of DNA has been carefully evaluated for the needs of this project; and a new method has been developed to treat the DNA which makes it equivalent to the DNA obtained from blood. "Because it removes a lot of barriers to participating in our research, we are excited about this new method of sample collection," added Dr. Drayna.

The NIH Stuttering Family Research Project is still seeking additional families for enrollment. Requirements are that there should be more than one living person in the family who stutters and that participants must be age eight or older. The study seeks both individuals who stutter and those who do not, depending on each family. All information provided is kept strictly confidential. If you are interested in participating, please contact us at this address:

Stuttering Family Research Project
7831 Woodmont Avenue, Suite 394
Bethesda, MD 20814-9408
Telephone: 1-888-239-1703
1-301-402-4930
e-mail: stutter@nhgri.nih.gov □

Insurance Coverage

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ing, such as the brochure described above, need to be continued and expanded.

Attending the SFA/ASHA conference were Jane Fraser, president of the Stuttering Foundation of America; Harriet Klontz, ASHA's Private Health Plans Unit; Michelle Ferketic, Division Liaison with the ASHA National Office; and the following Division for Fluency and Fluency Disorders affiliates: Eugene B. Cooper, David A. Daly, Catherine O. Montgomery, Jeanna Riley, and Jennifer B. Watson.

SFA Reports Phenomenal Outreach

The Stuttering Foundation of America reached over 23 million newspaper and magazine readers across the country in July.

SFA news releases reached large and small audiences through newspapers like the *Chicago Sun-Times*, with a daily circula-

Is there help for stutterers?

By Peter H. Gott, M.D.

DR. GOTT

PETER GOTT, M.D.

DEAR DR. GOTT: Why do people stutter? What can I do to overcome this embarrassing affliction?

DEAR READER: Stuttering is defined as a disorder affecting the fluency of speech, in which the individual has difficulty in getting his or her message across. It is not a sign of intelligence or lack of confidence. It is a disorder of the speech mechanism, involving the vocal tract, the brain, and the hearing apparatus.

The disorder is found in all cultures and languages. It is four times more frequent in males than in females. It is usually first noticed in early childhood, but may be first noticed in late childhood or early adulthood. It is a chronic condition, but it may improve with treatment. The most common cause of stuttering is a hereditary factor. It is a complex disorder, involving the vocal tract, the brain, and the hearing apparatus.

Most cases of stuttering are hereditary. It is a complex disorder, involving the vocal tract, the brain, and the hearing apparatus. It is a chronic condition, but it may improve with treatment. The most common cause of stuttering is a hereditary factor.

Most cases of stuttering are hereditary. It is a complex disorder, involving the vocal tract, the brain, and the hearing apparatus. It is a chronic condition, but it may improve with treatment. The most common cause of stuttering is a hereditary factor.

Parent education is key. Parents are advised to avoid criticizing their children and to be gentle in their speech. Using the program in speech therapy, using the program in speech therapy, using the program in speech therapy, using the program in speech therapy.

tion of nearly 500,000, and the Cheektowaga Bee of Williamsville, N.Y., with a weekly circulation of 1,496.

"As a result of the widespread publicity, the SFA received a record number of requests for information in July," said SFA President Jane Fraser.

The SFA news releases ran in 172 daily newspapers, 32 weekly newspapers and many magazines. Some of the releases ran on consecutive days or weeks in the same publication, according to Burrelle's Monthly Clipping Report. The above figures include readers of *National Geographic*, *TIME*, and *People Weekly* which donated space to the Foundation in July.

Three nationally syndicated columnists helped boost awareness of stuttering and the Foundation's resources: Ann Landers, Dr. Paul Donohue, and Dr. Peter Gott. All three gave readers the Foundation's toll-free number to call for more information and help.

Besides the columns, newspapers wrote about the SFA's new Web page (www.stutterSFA.com) and the new videotape, *Therapy in Action: The School-age Child Who Stutters*, telling readers about local libraries which have it available for patrons. □

Malcolm Fraser Award

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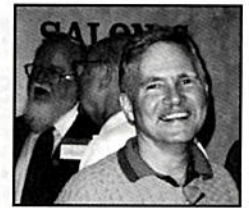
Who Stutter. Jeanna Riley has worked as a school speech pathologist, clinical psychologist, and for many years has directed the Riley Speech and Language Institute.

Both are Fellows of the American Speech-Language-Hearing Association, members of the International Fluency Association, and active in the Special Interest Division for Fluency and Fluency Disorders. They continue to be actively involved in research and clinical activities and even now are involved in creating new stuttering assessment instruments for clinical use.

The Malcolm Fraser Award was created by SFA as a way to annually recognize an individual who has achieved professional excellence in the field of



Conference attendees at SFA reception following Malcolm Fraser Award ceremony.



stuttering. It is presented annually to an individual selected by the American Speech-Language-Hearing Association's Special Interest Division on Fluency and Fluency Disorders.

It is named for the late founder of the Foundation, Malcolm Fraser, who overcame his own speech difficulties to spend a lifetime helping countless others throughout the world. The Foundation, inspired by Fraser's vision and support, distributes over 800,000 books, brochures, and videotapes on stuttering worldwide each year. □

In Memoriam Helen S. Ainsworth 1912-1998

Helen Ainsworth, wife of longtime SFA contributor Dr. Stanley Ainsworth, died at home at the age of 86. She was a talented writer, poet, and artist in her own right as well as being an outstanding painter.

Her creativeness showed up in many ways, so that her home—whatever the circumstances—was always a place of beauty. Her sensitivity to the needs of others enriched the lives of all who knew her. She found a special place in the hearts of many people through the years.

Albert T. Murphy 1924-1998

Dr. Albert T. Murphy, nationally recognized psychologist and expert in speech disorders, made important contributions to the literature on stuttering and edited several SFA publications.

In 1952 he was named Director of the Boston University Speech and Hearing Clinics. He wrote scores of publications on stuttering, voice disorders, hearing impairment, and the counseling of families of handicapped children.

A veteran of World War II, he earned five Distinguished Flying Crosses and seventeen Air Medals during 144 combat missions as a dive-bomber pilot in the Marine Air Corps.

Both of these remarkable people will be missed, not only by their families, but by the many people whose lives they touched.

NEWS BRIEFS

■ 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 12 through July 23, 1999. For application and information about traineeships write to: Hugo H. Gregory, Ph.D., Professor Emeritus, Northwestern University, c/o Stuttering Foundation of America, P.O. Box 11749, Memphis, TN 38111-0749 or telephone SFA at 1-800-992-9392 or Fax 901-452-3931. 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, next summer. Dates to be announced in Winter Newsletter.

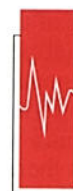
■ The SFA Southeastern Workshop, "Diagnosis and Treatment of Children Who Stutter: Practical Strategies," directed by Dr. Susan Dietrich, will be held at University of North Carolina-Greensboro, in Greensboro, North Carolina, next summer. Dates to be announced in Winter Newsletter.

■ 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 Machida-shi, 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) □



**STUTTERING
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