Outreach to Republic of China — Taiwan Update

Three videotapes produced by the Stuttering Foundation, Stuttering and Your Child: A Videotape for Parents, Therapy in Action: The School-Age Child Who Stutters and Do You Stutter: Straight Talk for Teens, as well as the book, Stuttering and Your Child: Questions and Answers, will be seen on educational television throughout Taiwan.

“We have distributed these tapes and your book, Stuttering and Your Child: Questions and Answers, free of charge to all the primary schools, kindergartens, normal schools, universities, teaching hospitals, libraries, and families of children who stutter throughout Taiwan,” writes Chung-Yao Liu of Harvest Entertainment, Ltd. in Taipei, Taiwan.

“A department of the Postal Administration is helping to promote this project for public welfare,” he adds.

“We are thrilled to learn about the tremendous outreach to schools and libraries in this country with a population of over 22,000,000. This represents a real milestone for us,” noted SFA president Jane Fraser.

“On behalf of all the young people of my country, we thank the Foundation for sharing these materials so generously. We know they will impact many lives,” adds Chung-Yao Liu.

Stuttering Didn’t Keep Her Grounded

Annie Glenn Chairs National Stuttering Awareness Week, May 10–16

by Jim Sparlock

When John Glenn returned to space last year, most people may not have known that there is another family member who also has The Right Stuff.

Annie Glenn, wife of the former Senator and the first American to orbit the earth, has confronted fear and overcome adversity every bit as tough as the NASA hero. Annie Glenn has learned to come to grips with a significant stuttering problem — and changed her life in the process.

Imagine her anxiety on February 20, 1962, when she waited for her husband to return safely from his space flight. Mrs. Glenn also knew that hundreds of reporters would want her to speak publicly afterward. Humbled and embarrassed by her incapacity to speak without a significant struggle, she chose to let her children answer questions from the media. Trying to get out the words smoothly and fluently before the cameras was impossible.

Yet the story does not end here. Annie Glenn was not going to be conquered by her speech disability or be less than a full partner in her husband’s future public service career. She attended an intensive three week program for stuttering. Slowly, painfully, she learned to speak in a new way. Hesitations, blocks, repetitions of sounds — none of those magically disappeared. But, through perseverance and sheer determination, Annie Glenn learned to talk with more ease and self-confidence. Over the years, her problem finally stopped being a problem.

For her remarkable achievements, the nonprofit Stuttering Foundation of America is pleased to announce that Mrs. Annie Glenn will be the 1999 Honorary Chair of National Stuttering Awareness Week, May 10-16.

“Congress authorized this annual awareness week because it knows that Continued on page 4

SFA Targets 9,400 Public Libraries

The Stuttering Foundation offered all four of its videotapes — Stuttering and Your Child, Do You Stutter: Straight Talk for Teens, Therapy in Action: The School-Age Child Who Stutters, and If You Stutter: Advice for Adults — free of charge to all main public libraries across the country in March and April.

To keep the Memphis office from being inundated with an overwhelming number of requests all at once, letters to libraries were sent out in groups of 2,500 for four weeks. The response has been outstanding, and SFA now has a database giving the location of the more than 3,000 libraries which have some or all of its tapes on their shelves.

Comments from libraries have been overwhelmingly favorable.

“Many individuals in our communities will benefit from having these materials available to check out and use in their homes,” said Elaine S. Plotkin of the Harris County Public Library in Houston, Texas.

“We are happy to help you reach the many children, teens, and adults in the Continued on page 7
The NIH Study on Genetics of Stuttering

by Dr. Dennis Drayna, Ph.D.

The Stuttering Family Research Project at the National Institutes of Health reports another year of steady progress. Focused on inherited factors that can contribute to stuttering, the NIH study is examining members of the same family who stutter in an effort to locate the genes that may be causing stuttering in these cases.

Finding these genes and understanding what they do in people who stutter and in those who are normally fluent holds the promise of revealing some of the underlying causes of stuttering. From this, researchers hope to be able to develop better therapies for stuttering.

So far more than 550 families have contacted the project and over half of these families have the right qualifications to participate. Some 350 participants have donated cheek swab samples for DNA, and almost 300 of these have also completed their speech sample. This represents the largest collection of stuttering family materials in the world today.

Within the past few months, this family collection has reached the size big enough to reveal a major gene, if one exists, at work in stuttering.

According to Dr. Dennis Drayna, director of the NIH study, there is no guarantee that one gene plays a dominant role in stuttering. “It’s certainly possible that there is no one major gene at work here, but we believe it’s essential to look at this early stage. If such a gene exists, we’d like to find out about it as soon as possible,” added Drayna.

The initial laboratory studies to do this have already started. In the meantime, more families are urgently needed for this research.

Families identified through the Stuttering Foundation make up the largest part of the families enrolled in the study to date. Through the appeal in the SFA newsletter in the spring of 1997, more than 300 families heard the call and responded generously with their time and effort.

The NIH study would like to make a renewed appeal for families who would like to participate in this research. If you think you and your family might be qualified and have not already volunteered in the past, please take a minute to fill out and mail in the reply form enclosed in this issue of the Newsletter. Progress in this research depends on families willing to volunteer. Every family counts!

About our study

The NIH Family Research Project on Stuttering is investigating genetic factors in stuttering. While inheritance cannot explain all the aspects of stuttering, genetic studies hold the promise of understanding some of the causes of this disorder. Recent advances in the field of human genetics allow scientists to identify the genes that cause any disorder which shows inheritance in families. The identification of these “stuttering genes” will allow us to understand what they are and how they work, both in normally fluent people and people who stutter.

In our study, we need to find people from families with more than one person who stutters. We first ask people to fill out a questionnaire to tell us about their family and the occurrence of stuttering in it. If the family qualifies based on this questionnaire, we invite the members of the family to participate. We need as many people as possible in each family to participate. Participation involves a brief interview, usually recorded on videotape, and donation of a sample of cells, which are obtained by brushing the inside of your cheek with cotton swabs. This is done by mail and normally, no travel is required. Each individual who completes the two parts of the process will receive $20 for their time and inconvenience.

Volunteers Needed

Is there more than one individual who stutters in your family?

Would you be willing to answer a questionnaire about stuttering in your family?

A new research project involves a study of the role of inheritance in stuttering. Our project is attempting to find families that have pairs of individuals who stutter beyond childhood. The long term goal of this study is to examine genetic influences on stuttering. Participation involves answering a brief questionnaire about stuttering and your family tree. If qualified, participants will be asked to donate a cheek swab sample and a recorded speech sample. There is no cost to participate, and all information is kept confidential.

To reply, please use the enclosed postage-paid self-mailer or contact us at:
Dr. Dennis Drayna
NIDCD/National Institutes of Health
7831 Woodmont Ave., Suite 394
Bethesda, MD 20814
or call: Toll Free 1-800-934-8441

SFA launched its Web site, http://www.stutterSFA.org, over a year ago. It continues to draw more and more browsers. Concerned parents, teens, and adults who stutter around the world are finding help and making comments on the information they find there.

Wrote Gian Ryan, “Just a note to say thanks for all the information on your website which was easy to maneuver. My five year old son stutters and we homeschool and I did not know where to turn for information. Thank you so much for providing it. You were an answer to a prayer tonight.”

Instant information and ease of use draw comments such as “Thank you for being there for me and others like me,” “your website provided me with some hopeful and encouraging information as I previously thought that there was no hope for those who stutter,” and “I am very glad to have found this supportive place.”

The newest brochures on stuttering and on Down’s Syndrome can now be found at www.stutterSFA.org, and the referral/resource lists have been updated recently. New illustrations will now be found for several of the frequently visited brochures such as If You Think Your Child Is Stuttering. Credit card donations may also be made to SFA via the Web.
Exciting New Series of Videotapes for Speech-Language Pathologists

A new series of videotapes, Practical Ideas for the School Clinician, are now available from the Stuttering Foundation. They feature five speech-language pathologists, all specialists in stuttering, filmed during live presentations at the annual SFA June conference entitled Practical Ideas for the School Clinician.

The five specialists include Kristin Chmela, Nina Reardon, Bill Murphy, Peter Ramig, and Barry Guitar. The tapes focus on different topics:

1) The School-Age Child Who Stutters: Working Effectively With Attitudes and Emotions, a 37-minute videotape featuring speech-language pathologist Kristin Chmela, M.A., in collaboration with Nina Reardon, M.S.

2) The School-Age Child Who Stutters: Dealing Effectively With Guilt and Shame, a 35-minute videotape featuring speech-language pathologist Bill Murphy, M.A.

3) The School Clinician: Ways To Be More Effective, a 55-minute videotape featuring speech-language pathologist Peter Ramig, Ph.D.

4) The Child Who Stutters: Practical Advice for the School Setting, a 55-minute videotape featuring speech-language pathologist Barry Guitar, Ph.D.

The information and practical ideas encompassed in this videotape series ensure that they will be a lasting source of help to school clinicians, parents, teachers, and health care professionals. Accompanying handouts make them perfect for in-service presentations. For more information about them, call 800-992-9392.

SFA in Prime Time

The Stuttering Foundation’s public-service announcements for television feature children in a playground setting. They were aired by an ever-growing number of stations and networks across the country in 1998 and the first four months of 1999, thereby increasing the public’s awareness of stuttering and giving them a nonprofit source of help.

The PSA’s are featured on the following networks and stations: ABC Television Network, NBC Network and Affiliates, CBS Television Network, Fox Broadcasting Company, America’s Health Network, Kaleidoscope: America’s Disability Channel.

America’s Health Network has not only aired our PSA but also did a series on stuttering with pediatrician Dr. Alix Cassler and speech-language pathologist, Dr. Barry Guitar, which is still airing. We have received hundreds of calls in response to both.

Kaleidoscope TV has been airing our public service announcement quite regularly and plans to air our new videotape, If You Stutter: Advice for Adults, in its entirety in the coming year.


The annual audit of SFA financial reports for 1998 was recently completed by Ernst & Young, Certified Public Accountants. Following is a recap of funds and expenditures for the year. The 3.8% 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, printing and distribution of educational materials ........................................... $473,787  48.5%
Public information and education ................................................................. 235,382  24.1%
Educational Symposia for Professionals and research .............................................. 149,612  15.3%
Maintain Web site and toll-free Stuttering Information Hotline ....................................... 75,046  7.7%

Total for Program Services ........................................................................ $933,827  95.6%

Other expenditures:
Administration and general ................................................................. 36,764  3.8%
Fund raising expense ........................................................................ 6,191  0.6%

Total Expenditures ................................................................................ $976,782  100.0%

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.
Annie Glenn  
Continued from page 1

stuttering can tremendously impact a wide cross-section of Americans,” said Jane Fraser, president of the Stuttering Foundation. “Despite her isolation in those tough early years, Annie Glenn was never alone. Not enough people realize that approximately three million Americans every day cope with a stuttering disorder. But most can be helped with professional speech therapy.”

“It is difficult to exaggerate how much stuttering can impact a child or adult,” Glenn added. “For years, I avoided speaking on the telephone, giving directions to someone, or even asking questions concerning my children at the school’s parent-teacher conferences.” Like her father, she was faced with a severe stuttering problem as long as she could remember.

“Annie Glenn is an excellent role model because she succeeded in the especially tough task of confronting stuttering in her adult years,” remarked the SFA’s Fraser.

Another Record Year for Public Service Ads in Magazines

This year’s National Stuttering Awareness Week got off to a wonderful start with three generous public service ads featuring Annie Glenn placed by TIME Magazine in March, April and May. Other magazines featuring PSAs in April and May were Newsweek, People Weekly, Kiplinger’s Personal Finance, Family Circle, Golf, Prevention, and Forbes.

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

TIME
Newsweek
GOLF
Business Week
People Weekly
Money
Family Circle
Forbes
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
Southwest Airlines
Kansas City Business Journal
TN Small Business Review
Utne Reader
Penhouse
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
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
Dargon
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.
New Research Targets Neural Bases of Stuttering

by Roger Ingham, Janis Costello Ingham, and Peter Fox

Editor’s Note: Neuroimaging studies have greatly enhanced the potential to understand brain-behavior relationships in complex behaviors such as speech and language. The following is a project which hopes to reveal more about how the brain functions in stuttering.

The purpose of our research grant, Investigating the Neural Bases of Chronic Stuttering, is to develop, validate, and utilize (e.g. for treatment) a systematic level model of chronic developmental stuttering. This grant is the product of a five year collaboration between Drs. Roger and Janis Ingham at University of California-Santa Barbara and Peter Fox, M.D. at the University of Texas Health Science Center in San Antonio.

Our research team has been using positron emission tomography (PET) to study neural activity during stuttering and during induced fluency. Initial research has only involved a single population of 10 right-handed males who stutter with a single speech task (oral reading) and with a single fluency-inducing procedure (choral reading). Comparisons have also been made with an age- and gender-matched group of 10 right-handed normally fluent speakers.

From these data, certain focal neurophysiological abnormalities were identified in the subjects who stutter (Fox et al., 1996); it has also been confirmed that these regional abnormalities are not present when these subjects are not speaking (Ingham et al., 1996).

The regional abnormalities during the speech during the speech of stutterers appear to occur within the premotor, motor, and auditory association areas of the cortex. These abnormalities have since been shown to be significantly correlated with the level of stuttering. The resulting intercorrelations among these regional abnormalities have helped to construct a neural system model of stuttering that will aid research and, we hope, guide stuttering treatment.

The current grant will be used to test generality of these findings by applying the integrative mapping and modeling strategy to additional populations, including females who stutter, to spontaneous speech, and with another fluency-inducing procedure, modifying phonation intervals.

These studies will continue to use PET to obtain cerebral blood flow data, but they will be supplemented by fMRI validation investigations. However, in conjunction with this grant, it is also proposed to continue testing for the interconnectivity between the derived regional abnormalities by using transcranial magnetic stimulation (TMS).

Currently TMS is being also investigated by this research team for its usefulness in directly modifying the regional abnormalities and/or system that may functionally control stuttering (Ingham, Fox, Ingham, Collins & Pridgen, in press).

References.


NEWS BRIEFS

This year’s SFA conference for speech-language pathologists working with the school age child who stutters will be co-sponsored with Wichita State University in Wichita, Kansas, on June 18th and 19th, 1999. For an application form and more information, contact SFA at 1-800-992-9392.

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 more information about the workshop, contact the Stuttering Foundation at 1-800-992-9392, or write Dr. Hugo Gregory, c/o SFA, 3100 Walnut Grove Road, Suite 603, Memphis, TN 38111-0749. This unique workshop brings together speech-language pathologists from all over the world.


The NSP Convention will be held in Seattle, Washington, on June 23rd through 27, 1999, at the Sheraton Tacoma Hotel. For more information, call Tammy Floes at 1-800-364-1677.

The 5th Oxford Dysfluency Conference will be held July 7-10, 1999 at St. Catherine’s College, Oxford. For more information, write Lena Rustin, The Michael Palin Centre for Stammering Children, Finsbury Health Centre, Pine Street, London EC1R OLJ, England. Telephone: 444 (0) 171 530 4238.


1999 Canadian Stuttering Conference, Speak Easy, Inc., Saint John, New Brunswick, Canada, August 12-14, 1999. For more information, call Mike Hughes at 800-345-9022. Walter Manning and Ann Meltzer will be speakers. Contact speakez@nbnet.nb.ca.

ABC/CAPS Congres de Montreal, August 19-21, 1999. Principal speakers will be Andre Courcy, Julia Bebog, and Tony Churchill. For more information, call Winston Purdy (CAPS) at 514-485-3015 or 1-888-788-8837, or Pierre Latrane at 1-877-353-1042 (sans frais).

The Third World Congress on Fluency Disorders will be held from August 71-11, 2000, in Nyborg, Denmark. Mark your calendars now. For more information see Per F. Knudsen, The Stuttering Information Center of Denmark, Emderupvej 101, DK-2400 Copenhagen NV, Denmark or call +45 3969 6639 ext. 2531; fax +45 3969 2464; e-mail: per@kdlh.dk.

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 Beggues du Canada, 7801 Rue St. 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 neural anatomical 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 70112-2099. Phone: 504-958-5065 (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.


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. Nasef, Ph.D., published by Carol Publishing Group, Secaucus, New Jersey, 1-800-447-2665.


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 Atmore Publishing Company, P.O. Box 533, Oshkosh, WI 54907. 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.


The Telecommunication Relay Service Handbook by Franklin H. Silverman, Ph.D. Aegis Publishing Group, Ltd., Newport, RI.

Unforgettable Characters I Have Known by Bill Lynde. Published by BookPartners in Wilsonville, OR, 503-682-9821 or 800-895-7323.