

## Stuttering Foundation of America

# NEWSLETER

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A Non-Profit Organization

Since 1947... Helping Those Who Stutter

Volume V, Number 4

## ASHA Leader Review Lauds SFA Video

In a recent review, ASHA Leader, the bi-monthly newspaper of the American Speech-Language-Hearing, had this to say about SFA's new videotape, Do You Stutter: Straight Talk for Teens:

"Do You Stutter is extraordinary. Experts in the field of stuttering provide current research findings and teens share personal experiences. The format is a collection of brief, friendly interviews ... All the essential information is



here. This video answers question after question about what stuttering is, concerns and feelings associated with stuttering, ways to help oneself, and where to find

help. This is must-see TV ... This videotape should be in the home of every young adult who stutters."

Do You Stutter: Straight Talk for Teens, a 35-minute videotape, was produced by Barry E. Guitar, Ph. D., University of Vermont and Edward G. Conture, Ph. D., Syracuse University, in collaboration with Hugo H. Gregory, Ph.D., Northwestern University, Peter Ramig, Ph.D., University of Colorado, and Jane Fraser of SFA.

It is available free of charge to all public libraries across the country. For information on obtaining your own copy, call SFA at 1-800-992-9392.

## Stuttering Didn't Stop His Story 20/20's John Stossel Inspires Others

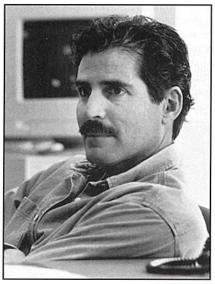
20/20's news correspondent John Stossel is one of the most recognized and articulate reporters today. However, he once considered giving up his broadcasting career because of his stuttering.

Stossel didn't quit, however, and this year he joins the Stuttering Foundation of America in recognizing National Stuttering Awareness Week, May 12–18, and celebrating the Foundation's 50th year of service.

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

During National Stuttering Awareness Week, the Emmy Awardwinning reporter and SFA will work to educate Americans about this little understood speech disorder that affects more than three million people in the United States.

Stossel's childhood and the early part of his career were fraught with the difficulties of stuttering. "I remember terror in the classroom," said Stossel. "In my early days as a reporter, I did



20/20's John Stossel

regular live 30-second segments with the anchor of the news program; I woke up every morning in fear of that. That fear stayed with me all day long."

He considered quitting but, fortunately, sought speech therapy first. "Once I began to see the results of

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self-therapy for the stutterer

Danish and Russian Translations of Self-Therapy

Anders Johansen and the Danish Association for Stutterers, Foreningen for Stammere i Danmark, plan to publish a Danish translation of *Self-Therapy for the Stutterer* by SFA Founder Malcolm Fraser. This new translation will be available in 1997.

From Russia came news via e-mail that Ruslan Shaidorov of Khabarovsk is presently translating *Self-Therapy* and hopes to publish and distribute it in Russia later this year.

Self-Therapy for the Stutterer has been translated into French, German,

Flemish, Persian, Arabic, Finnish, Spanish and Lithuanian and distributed in 62 countries around the world.

Most of these translations have been done by professionals who

stutter themselves and who want to share this book with others in their country as is the case with both the Danish and Russian translations.

## **New Networks Help Stuttering Foundation**

The Stuttering Foundation's new 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 1996, thereby increasing the public's awareness of stuttering.

#### ■ CBS Keeps SFA in Rotation

Support from CBS, Inc. was outstanding all during 1996. We have heard from hundreds of CBS viewers in the following cities in response to the regular airing of our PSA: Spokane, Washington; Burlington, Vermont; Boston, Massachusetts; Cincinnati, Ohio; Jacksonville, Florida; Florence, South Carolina; Las Vegas; Macon, Georgia; Orlando, Florida; Phoenix,



Arizona; Portland, Oregon; Richmond, Virginia; Tallahassee, Florida; Boise, Idaho; and El Paso, Texas.

#### ■ 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: Grand Rapids, Michigan; Cleveland, Ohio; Houston, Texas; Rochester, New York; Chicago, Illinois; Washington, D.C.; and Flint, Michigan.

#### ABC Television Network and ABC Stations

In Chicago, Channel 7 continues to air our PSA several times a week. This invaluable support throughout 1996 and 1997 has enabled us to reach tens of thousands of viewers in the Chicago area. We are grateful for the strong support of the ABC Television Network.

In Philadelphia, WPVI Channel 6 has kept us in their rotation all year long.

In New York, WABC is still using our PSA from time to time after several years of airing it continuously.

In San Francisco, KGO-TV is currently airing our PSA for a six month period, resulting in hundreds of calls from their viewers.

#### NBC Network and Affiliates

We were included in the national rotation of public-service announcements at NBC again in 1996. Each airing, often during prime time, resulted in many hundreds of calls from NBC viewers all over the country.

The support of these stations and networks throughout 1996 have enabled us to reach hundreds of thousands of viewers whose lives have been affected by stuttering. Their public-service programs are to be applauded.

#### America's Health Network

This exciting new network has not only aired our PSA but also did a two hour series on stuttering with pedia-



trician Dr. Alix Casler and speechlanguage pathologist June Campbell. 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. At 9:00 PM on the following dates, this channel aired our new videotape for teenagers in its entirety: April 14, April 18th, April 21st, April 25th, and April 26th, 1997.

## SFA Financial Report for 1996

The annual audit of SFA financial reports for 1996 was recently completed by Ernst & Young, Certified Public Accountants. Following is a recap of funds and expenditures for the year.

The 4.8% of expenditures for administration and general expenses

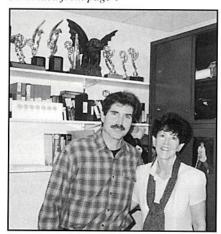
and the less than 1% for fund raising are very low; and since we are fortunate to have an endowment which more than covers our overhead expenses, donors can be assured that their gifts will go directly to support our program services.

Funds expended for:		
Printing and distribution of		
educational materials	460,638	56.3%
Public information and education	170,142	20.8%
Educational Symposia	96,595	11.8%
Stuttering Information Hotline	47,297	5.8%
Total for Program Services	774,672	94.7%
Other expenditures:		
Administration and general	37,158	4.6%
Fund raising expense	6,041	
Total Expenditures	817,871	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.  $\Box$ 

#### Stossel Inspires Others

Continued from page 1



John Stossel and SFA's Jane Fraser meet to discuss plans for National Stuttering Awareness Week. Stossel's Emmy Awards are seen in background.

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 extremely happy to have as our spokesperson someone who has brought important issues and news-breaking topics to the nation's attention through his broadcast voice," says Jane Fraser, president of the Stuttering Foundation of America. "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 their stuttering."

For more information about what you can do about stuttering, write the fifty-year-old Stuttering Foundation of America, P.O. Box 11749, Memphis, TN 38111-0749, or call toll-free, 1-800-992-9392.

#### Coming in the next issue...

- Malcolm Fraser Award
- SFA Media Awards

## New Project for Videotape for Elementary School-Age Children

A week long conference took place March 8 – 15, 1997, to produce a new videotape focused on schoolage children who stutter. Although the video will be targeted to speechlanguage pathologists, it should also be of interest to parents and teachers.

Dr. Edward G. Conture of Syracuse University chaired the conference. Other participants included Dr. Hugo Gregory, Dr. Barry Guitar, June Campbell, M.A., Dr. Peter Ramig, Dr. Patricia Zebrowski, and Jane Fraser of SFA.



Left to right: Peter Ramig, Patricia Zebrowski, Edward Conture, Barry Guitar, June Campbell, Jane Fraser, and Hugo Gregory

The new videotape will be approximately 45 minutes long and features outstanding footage of therapy with elementary school-age children who stutter. It also gives good examples of what stuttering looks and sounds like in this age group. The videotape should be available later in the year.

## New Study on Brain Structure

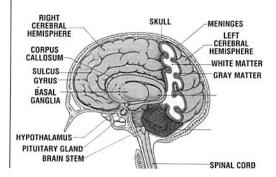
The term "it's a no-brainer" certainly does not apply to Anne Foundas, M.D., and her NIH sponsored investigation of stuttering.

Dr. Foundas, Assistant Professor of Neurology at Tulane University, is using magnetic resonance imaging (MRI) to study the brain structure of adults who stutter.

Her findings regarding brain structure will then be correlated with perceptual as well as nonspeech performance of the same individuals who stutter.

In late December, 1996, SFA representatives Dr. Edward G. Conture and Jane Fraser visited Dr. Foundas to learn more about her research and to provide whatever consultation she might find useful pertaining to the nature of stuttering in adults.

SFA came away very impressed with Dr. Foundas and her work and looks forward to valuable findings coming out of her careful, well-thought-out investigations of the brain structure of adults who stutter.



## Childhood Experience

by Micah Lashar

"I-I-I c-ca-can't," I said.

"Micah, you must read out loud," replied Mrs. Keiphem.

"N-n-n-no," I said. That was just about the most I said in Mrs. Keiphem's class the whole year. I did this because whenever I talked, kids would giggle and laugh. I never spoke or read out loud, so I never was a good reader. I would stay up to one-thirty in the morning just to read ten pages.

I stuttered and didn't like that I did. I went to speech therapy in school every day for four years. In those four years, I also went to a counselor about it. I would just talk to her about my problems. Also about why I didn't talk. I wanted to be like everyone else and not stutter. The problem was that I wasn't like everyone else. I worked so hard to read out loud. That was my goal.

The speech therapy got me to talk a little more but it still sounded bad to me. By third grade, I was talking to kids and was not as quiet. I finally did read out loud in front of the whole class. Sure a few giggled and chuckled, but I felt good. Staying up late to read the last three years helped a lot. So did therapy.

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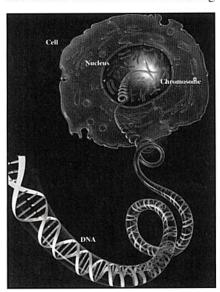
## The NIH Stuttering Family Research Project: Some Questions and Answers

Q. What are genetic factors?

A. The term genetic (also called inherited) refers to things that are passed down from parents to offspring. These factors are called genes, and they reside in our chromosomes. We all have 23 pairs of chromosomes which reside in the cells of our body. One member of each pair comes from our mother, and one member of each pair comes from our father.

**Q.** How do we know stuttering is genetic?

A. Several things tell us stuttering can be caused by genetic factors. Many times individuals who stutter have a close relative who also stutters. In some cases, there are many people who stutter in one family. Identical twins (who are genetically the same) frequently both stutter. Finally, adoption studies have shown that stuttering



Inside the nucleus of nearly every cell in the body, a complete set of genetic instructions, known as the human genome, is contained on 23 pair of chromosomes.

is more likely to be associated with biological parents who stutter, not the adoptive family.

Not all stuttering is genetic. For example, sometimes stuttering can be acquired when the brain is injured, for example by a stroke or in an accident. In addition, we know stuttering is not completely controlled by genes, since many people can overcome stuttering by speech therapy.

**Q.** What will you do with my cheek swab sample?

A. We will first assign an anonymous number to your sample, and the personal identifying information will be removed. We will then purify a small amount of DNA from these cells. DNA is the genetic material in chromosomes. We will test this DNA to determine which parts of the DNA seem to be inherited along with stuttering. In scientific terms, this is called genetic linkage. If we can demonstrate places in the DNA that show genetic linkage to stuttering, we will know that there are genes in these places that can cause stuttering. Finding these places is the first step toward finding the genes themselves.

**Q.** How will it help to find the genes which can cause stuttering?

A. The underlying causes of stuttering are unknown. Finding these genes will show us what some of these causes are. Understanding these causes will allow us to make better therapies for stuttering.

Q. How long will this study take?

A. This genetic linkage study will take three years. If this linkage study is successful, going on to find the genes themselves will take an additional two to four years.

**Q.** How will I know about the progress of this research?

**A.** We will contact the people who participate in our study at least once each year to bring everyone up-to-date on our progress.

**Q.** Will I find out anything else about my genes?

A. Other than stuttering, we do not expect to find out information about any genetic disorders or diseases. In order to protect the privacy and confidentiality of the subjects in this study, no genetic information about individuals will be provided to anyone outside or inside this study.

Participation in the study involves answering an initial questionnaire, and families that qualify will then be

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## Stuttering Awareness Week Posters and Brochures Available

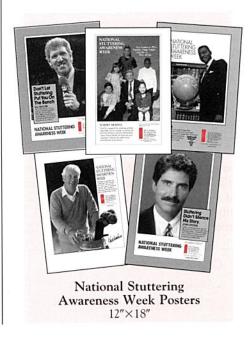


National Stuttering Awareness Week is May 12–18, 1997! New color posters and brochures are available from SFA for this special week. They feature ABC 20/20's John Stossel, one of the most successful reporters in broadcast journalism today.

SFA also has an 18" × 24" poster featuring 11 famous men and women who stutter including Carly Simon, James Earl Jones, John Updike, Bill Walton, and many more.

A 20" × 30" color poster showing Dr. Charles Van Riper, Dr. Harold Luper, Dr. Joseph Sheehan, Dr. Dean Williams, Dr. Wendell Johnson, Dr. Stanley Ainsworth, Dr. Henry Freund, SFA Founder Malcolm Fraser, and Dr. Robert West celebrates SFA's 50th Anniversary.

The posters are a colorful addition to your office, classroom or home. For more information on the eight SFA posters and the brochure, call SFA toll-free at 1-800-992-9392.



## Spanish Translation of *To the Stutterer* and *How to React* Brochure Available

Consejos para el Tartamudo is now available from SFA. This excellent translation of *To the Stutterer* into Spanish was done by Frank Thomas Gallardo of Costa Rica.



The book contains practical advice from twenty-four men and women who stutter, all speech-language pathologists themselves,

advising what helped them and

what they believe will help others who stutter control their difficulty.

Another translation completed by Marina Llobera O'Brien of Palma, Mallorca, is a translation of *How To React When Speaking With Someone Who Stutters* into Spanish.



This popular brochure, Como Reaccionar Delante de una Persona que Tartamuea, is ideal for the workplace, clinic, or school

setting.

#### NIH Project Continued from page 4

invited to participate in further research. There is no cost to participate in the study. If you or someone you know would be interested in participating in this survey, call the Stuttering Foundation of America for a copy of the initial questionnaire at 1-800-992-9392 or Dr. Dennis Drayna at 1-800-934-8441.

Many families are needed, and every family counts! □



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.



## SFA Celebrates 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 ABC 20/20's John Stossel placed by People Weekly, Business Week, TIME, U.S. News & World Report, and Forbes.

U.S. News & World Report donated three generous PSA's within a week of each other, resulting in hundreds of calls from their readers. PSA's also appeared in the April 1997 issues of Golf and Parents.

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 \$1,046,000 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 those names are listed here:

TIME GOLF Business Week People Weekly Money 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 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 Instructor In Pittsburgh Physical Therapy Dragon 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.

## **NEWSBRIEFS**

- The International Fluency Association is holding its Second World Congress on Fluency Disorders, August 18–22, 1997 at the San Francisco Hyatt Embarcadero, San Francisco, California. Many exciting programs and activities are planned. For more information, contact Thomas A. Crowe, Ph.D., at phone:(601) 232-7652; fax: (601) 232-5717; or E. Charles Healey, Ph.D., at (402) 472-5459; fax: (402) 472-7697; or chealey@unlinfo.unl.edu.
- The Stuttering Foundation of America New England Workshop, "Diagnosis and Treatment of Children Who Stutter: Practical Strategies," will be held at Boston University, June 26–30, 1997. For application and information about traineeships, write to: Susan Dietrich, c/o SFA, or call 1-800-992-9392.
- This year's SFA conference on the school age child who stutters will be cosponsored with the University of Memphis and held in Memphis, Tennessee, on June 20th and 21st, 1997. For more information, contact Dr. Walter Manning at the University of Memphis, or call 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 14–25, 1997. 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.
- Annual convention, National Stuttering Project, Buffalo, New York. For convention information, call Annie Bradberry, 1-800-364-1677; fax: 714-693-7554
- Speak Easy will hold its annual 1997 Canadian Stuttering Conference on August 14–16, 1997, in Saint John, New Brunswick. Dr. Carl Dell will be the keynote speaker. For more information, call Mike Hughes at 1-506-696-6799. For hotel reservations, call Howard Johnson's, 1-800-475-4656.
- For those interested in joining Toastmasters International as a way to im-

- prove 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.
- National Convention, Canadian Association for People Who Stutter, Vancouver, British, Columbia, August 14–17, 1997. Contact: Anthony Intas at 1-416-788-8837 or fax 1-417-252-0720.
- 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.
- Special offer: *Elements of Stuttering* by Courtney Stromsta, Ph.D. This book, described by Dr. Charles Van Riper as "something new and exciting" is available from Atsmore Publishing Company, P.O. Box 533, Oshtemo, MI 49077. Please send \$19.50 plus \$3.00 handling charge for the 256-page book which is fully indexed and includes 33 figures and tables.
- Dr. Daniel Weiss is looking for adults who stutter in the greater Cleveland area interested in participating in a clinical trial. The study is a placebo controlled double blind 32-week trial of fluoxetine. Medication and participation will be provided free of charge. Interested persons contact Daniel Weiss, M.D., at 216-292-6150.

#### Excellent New Books on Stuttering Available from Bookstores:

- Clinical Decision Making in the Diagnosis and Treatment of Fluency Disorders by Walter H. Manning, Ph.D., published by Delmar Publishers, Albany, New York.
- 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 and Science by William H. Perkins, Ph.D. It is published by Singular Publishing Group, Inc., in San Diego, California.
- Stuttering: The Search for a Cause and Cure by Dr. Oliver Bloodstein, PhD. It is published by Allyn & Bacon, Needham Heights, MA.

#### Childhood Experience

(Continued from page 3)

The next year I didn't go to a counselor but still went to speech. It was no longer 5 days a week now, now only 3. I was now reading in front of the class and socializing with many of the kids. My speech was getting better.

I thought to myself and thought if I got to read out loud, I was going to stop stuttering. In speech therapy I would get videotaped and watch myself.

Another problem I had was using the phone. I never liked it and was afraid to use this. In therapy I would call hotels and restaurants asking their prices or what's on the menu. This helped some. I was still very nervous about the phone. Then I started to just get the hang of it and my speech improved not only on the phone but off.

In seventh grade, I only went to speech two days a week. Things were improving. In eighth grade, speech was only down to one day a week. I felt good. It may have taken eight years to do this, but I felt good with my speech. (I still had problems, but my speech was good.)

In ninth grade, I got nervous the first day, so my speech wasn't its best. I still went to speech one day a week. My new speech teacher kept on talking to my teachers and finding how my speech was.

My sophomore year rolled around and things were looking fine. I'm just about out of speech, and things are good.

I consider myself a hard worker, and I think this story made me that. I just didn't give up and not talk. I did what I had to do. It may have taken a long time, but it was worth it.

Now I work hard at just about everything. I pick a goal and when I reach it — I just don't stop. I go for more, just like the story.

This story was sent in by SFA Patron, Jeffrey Lashar, and written by his son, Micah.



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