The Stuttering Family Research Project—An Update

by Dennis T. Drayna, Ph.D.

Rockville, MD - The Stuttering Family Research Project at the National Institutes of Health is completing its first year with some exciting developments to report. First, within the NIH the project has received increased support from the National Institute on Deafness and Other Communication Disorders. Stuttering research is now an important priority at this Institute, and continued funding of the project is assured for the coming year.

The response to our appeal for volunteers has been excellent. We have heard from over 1,000 people. From these responses, we have been able to identify over 400 qualified families which represents one of the largest groups of families with stuttering ever identified. More than 150 of these families have signed up all their qualified family members, and these family members are now enrolled and participating.

In addition, the project has now been able to identify enough qualified families to move into the next phase of the study which involves speech evaluation for each of the volunteer participants. This process is being carried out with videotaped speech samples from each volunteer, and is being done through the mail. These speech samples will allow us to begin building up the important clinical information needed from each participant.

Right now, one of our most important goals is to get all the members of qualified families to sign up. Participation from all the qualified members of our existing families would bring us long way toward meeting our

No One Stutters in Cyberspace

by Jean Grass

Those who stutter find comfort and help on the Internet.
That’s because the Internet lets the more than three million people who stutter communicate using their computer keyboards instead of their voices.
“It’s changed life and made it really positive for stutterers,” said Barry Guitar, Ph.D., professor of communication sciences at the University of Vermont.
People who stutter frequently feel self-conscious about their speech impairment, and the Internet provides a new way for them to express themselves.
“Those who stutter often end up feeling that what they have to say isn’t worthwhile,” Guitar explained. But on the Internet, stutterers can access electronic bulletin boards and join in discussions in “chat rooms” without worrying about their stutter. “It gives them an opportunity for growth,” added Guitar.

Still, experts warn that those who stutter should not use the Internet to avoid speaking.
“The more you avoid, the more powerful stuttering becomes,” said

Peter Ramig, Ph.D., professor of speech pathology at the University of Colorado in Boulder.

However, Ramig said the Internet contains abundant information stutterers can use to help them better manage their speech difficulties.
“I think the advantages of the Internet outweigh the disadvantages,” Ramig said. “The amount of information already out there is impressive.”

One important source of information is the Stuttering Foundation of America’s Internet site on the World Wide Web (www.stuttersfa.org). The site contains updated information on the Foundation’s books, brochures and videotapes available to the public and professionals, a nationwide resource list, and online resources.

The Stuttering Foundation, based in Memphis, Tenn., is the first nonprofit charitable organization in the world dedicated solely to the problem of stuttering. It has distributed over 3 million publications to professionals and the public since its founding 50 years ago.

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World Congress on Fluency Disorders a Resounding Success

by Eugene B. Cooper, Ph.D.

Three hundred and fifty individuals from twenty-eight countries attended the International Fluency Association’s Second World Congress August 18-22, 1997 in San Francisco, California. The International Fluency Association (IFA) was founded in 1991 to facilitate world-wide interchanges between researchers, clinicians, and consumers regarding the latest developments in

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Dr. Phil Schneider at SFA booth with Karen Eikeland from Norway.
Stuttering Foundation Reaches Out Through New Venue

New York - Two thirteen year-olds recently helped SFA continue to educate children and adults about the nature and treatment of stuttering problems! On August 7th, Katie MeHugh and Kevin Gebraski, accompanied by speech-language pathologist June Campbell, flew from Chicago to New York City to be interviewed by Children's Express.

Steve Craft, 18, CE: I myself have a stuttering problem, and I find that I stutter most when I'm doing public speaking or that kind of stuff. When does stuttering most affect you?

Katie MeHugh, 13: Mostly when I'm nervous or in a tense situation, or when I think I'm going to stutter. It's this whole psychology thing in your head.

Kevin Gebraski, 13: When I'm nervous or reading out loud. One day I can read maybe a whole paragraph to the class, the next sentence it takes one minute to do it.

CE: Kids get teased quite often. How do you handle it?

Katie: I don't get a lot of teasing. I went to a very small school. There's only 10 kids in my class, so we all know each other. They know I'm sort of sensitive about that—even though about half of them are complete jerks.

Just ignore it. I don't really respond to it, because it's going to be a really tough situation unless you prepare yourself with a comeback.

Kevin: Most people who know you and like you won't do that because it's not worth it.

Katie: Certain kids tease in order to make themselves feel better. It's pretty much all the same reasons why kids tease other kids. Sometimes they might understand a little better if they would see themselves in our shoes, and see that it does hurt to be teased.

Kevin: They don't know what it's like. They'll never know.

Katie: I have been working on it for about three years now and it's a whole lot better. There are occasions where it gets worse, but you just have to practice to make it easier.

Kevin: Although my mom goes with me to my therapy classes and my therapist is very supportive, I think that self-motivation is most important.

Katie: My mom goes with me to all of my classes in therapy, but I think the person that really encourages me is myself. I always want to get better.

'Stuttering feels like when you swing a bat in water, really slow.'

Kevin: Stuttering feels like when you swing a bat in water, really slow, that's kind of how it is. Therapists are great. They know how children feel and they help correct it, but they don't know what we feel like unless we tell them. I was so bad, I couldn't even talk to you. It's gotten better and better over the years. I read (aloud) much better.

Children's Express

"By Children... for everybody"

Kids who stutter speak out

CE News Team: Steve Craft, 18 and Asher Lindo, 12
Edited by: Julia Kim, 15 and Stella Lee, 16

More than 3 million people in the United States have some sort of speech problem; stuttering is one that many Americans, both kids and adults, have to deal with. Kids with stuttering problems are not abnormal and can do all the things that other kids can do. Sometimes inconsiderate people hurt stuttering kids because they don't know how it feels.

Children's Express conducted a roundtable discussion with two kids who stutter. We found their experiences very moving. We realized that although stuttering is a problem, people who suffer from it are not much different from anyone else. We sympathized with their hurtful experiences, and learned that something must be done about the situation.

The interview at Children's Express.

SIDEBAR:

June Campbell is a speech language pathologist who specializes in working with children and adults with stuttering problems. She is part of the Stuttering Foundation of America, an organization that educates both parents and other adults on how they can best interact with children with stuttering problems to help prevent the problem from ever developing.

Children's Express recently talked with Campbell about her job and what the Stuttering Foundation is doing to help out stuttering kids all across America.

CE: What causes stuttering?
Campbell: There have been years of research done, and there are different kinds of stuttering and different reasons for it. There may be hereditary factors as well as psychological factors. There are also emotional overtones to stuttering. When someone fears they're going to stutter, they tend to stutter even more.

CE: What would you hope to accomplish in speech therapy?
Campbell: We would never say we're curing stuttering but that we go through a

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Malcolm Fraser Honored Posthumously at National Communication Awards Ceremony

Actor James Earl Jones Co-Hosted 16th Annual Ceremony

Washington, DC - Malcolm Fraser, founder of the Stuttering Foundation of America, was honored posthumously at the 16th annual National Council on Communication Disorders (NCCD) Awards Ceremony at the Lansburgh Theater in Washington, D.C. on September 9, 1997.

For his commitment to help people who stutter, Fraser was honored with the Charles Van Riper Award. Established by the American Speech-Language-Hearing Association (ASHA) two years ago, the Van Riper Award was named in honor of the late Charles Van Riper, pioneer in the field of speech pathology.

Fraser founded the Stuttering Foundation in 1947. Today SFA staffs a stuttering hotline, publishes 23 books and eleven brochures on stuttering, and distributes over 500,000 publications and videocassettes a year to those who stutter, their families, speech-language pathologists, and other professionals.

Jane Fraser, daughter of Malcolm Fraser and current president of the Stuttering Foundation of America, accepted the award from Van Riper’s son John.

NCCD, the umbrella organization for ASHA and 32 other national organizations serving people with communication disabilities, recognizes those who devote their time and energy to increase public awareness of communicative disorders as well as those who have met challenges presented by speech, language, and hearing disabilities and who have inspired others by their achievements.

Special guests included Senator Trent Lott, Senator John Glenn and Mrs. Annie Glenn, and co-host actor James Earl Jones.

Stuttering Family Research

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goals. Participation in our research is completely voluntary, so we are relying on the “volunteer spirit” within our families to help us reach our goal. To help make sure we get there, we are still seeking additional families, especially stuttering individuals with brothers and sisters who also stutter.

Over the past year, advances in genetics research have continued at an astonishing rate. In the past year alone, genes have been identified which contribute to disorders such as asthma, Parkinson’s Disease, and diabetes. Other important discoveries have been made in studies of genetic factors in speech and language disorders, and studies to be published soon indicate that speech and language disorders can yield to the same type of approaches that have been used successfully to understand these other medical conditions.

The tools available for genetic research have advanced equally fast. Scientists continue to discover better and faster ways to look at the genetic differences that exist between all people, and to correlate these differences with inherited disorders in families. Although our project is challenging, we are gratified to see these advances become available to us in our research, and we are more hopeful than ever that our research will be able to give us an understanding of some of the causes of stuttering.

We want to particularly thank all the people who have contacted us and offered to help in our research. We are well on our way to meeting our goal of 500 families enrolled. If you think you and your family may be qualified and you haven’t contacted us yet, please take a minute to contact us now. Every family counts!

Editor’s note: If you believe that you and your family qualify, contact Dr. Dennis Drayna, National Institute on Deafness and Other Communication Disorders, National Institutes of Health, 5 Research Court, Room 2B44, Rockville, MD 20850. Tel: (301) 402-4930; Fax: (301) 480-8019.
New England Workshop Lauded—and Oversubscribed!
Second Annual New England Workshop Held
June 26–30, 1997

by Suellen Wedmore, M.Ed., CCC, SLP

Boston, MA - “Excellent! This was the best professional workshop I've ever attended!” said Vicki McCready, M.Ed., SLP, a participant of the second annual Stuttering Foundation of America New England Workshop.

Here twenty-two speech-language pathologists from the eastern United States and the U.S. Virgin Islands, selected from over 450 applicants, spent five days in Boston, Massachusetts, honing their skills in diagnosing and treating early childhood stuttering.

The participants represented a wide range of therapy settings and experience, but all showed a strong interest in stuttering. “It was so valuable. And I learned a lot from the participants themselves,” said a recent graduate in the field who works in a public school.

The workshop began with an overview of the theoretical framework of stuttering presented by Dr. Susan Dietrich, Ph.D., of the University of North Carolina at Greensboro, and Sheryl Gottwald, Ph.D., of the University of New Hampshire. Next, the presenters shared practical ideas for diagnosis and therapy.

Dr. Gottwald presented The Capacities and Demands Model to help understand and explain disfluency in young children, and Dr. Dietrich presented a direct treatment model, Tension Control Therapy, that provides visual and proprioceptive feedback that students can use to control their speech.

Maureen Tardelli, M.Ed., in private practice in Boston, presented information on stuttering and problems which co-exist with it.

Barry Guitar, Ph.D., from the University of Vermont, encouraged students to develop their own metaphors to help to better understand stuttering and thus to gain control over it.

“All of the presenters were knowledgeable and interesting as well as being empathetic human beings,” said participant Susan Brooks, M.A., of Harvard, Massachusetts. A highlight of the workshop was meeting Jane Fraser, president of Stuttering Foundation of America who presented a history of the Foundation, founded by her late father Malcolm Fraser in 1947. “I was moved that she traveled so far to be with us,” added Brooks, “and by the great effort she made to get to know each of us as individuals.”

One afternoon participants alternated roles as therapists and parent consultants for preschool and school-age children. “I really appreciated the time devoted to intervention and to real therapy situations with hands-on practice. I would recommend this workshop to anyone who is going to work with stutterers,” said Vicki McCready. And Mary Beth Coltharp of Richmond, Maine, echoed this enthusiasm, saying, “It was an incredible experience. I’d go again in a heartbeat!”


Attendees at reception on the last day.

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.
Sertoma Announces Sixth Annual Communicative Disorders Scholarship Program

(Kansas City, MO - December 1, 1997) Sertoma International announced today that it will continue its financial support of master’s students of audiology and speech-language pathology. Currently in its sixth year, the Sertoma Communicative Disorders Scholarship Program has provided more than $400,000 in educational assistance, making Sertoma the largest source of funding for master’s students studying communicative disorders.

“Our annual $75,000 scholarship program accomplishes two very important things: It helps ensure that qualified professionals will be available in the future to assist people who have communicative disorders. Also, it fulfills and perpetuates the SERVICE TO MAN-kind mission,” said Jon C. Haapajoki, president of the 86-year-old, nonprofit volunteer organization.

Sertoma will award thirty $2,500 scholarships for the 1998-99 school year to citizens of the United States, Canada, and Mexico. Qualified applicants must have at least a 3.2 minimum grade point average on a 4.0 scale. The application deadline is 5:00 PM Central Time on Friday, March 27, 1998.

Students interested in the awards, funded by the Sertoma Foundation, should send self-addressed, stamped envelope to Communicative Disorders Scholarships, Sertoma International, 1912 East Meyer Blvd., Kansas City, MO 64132.

World Congress on Fluency Disorders
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the understanding, assessment, and treatment of stuttering.

During the Congress’ five days, one hundred and fifty presentations ranging from day-long seminars to brief reports were made not only by scientists and clinicians who treat stuttering but by those who stutter who are involved in support and self-help groups. One such presentation was a fifty year history of the Stuttering Foundation of America by SFA President Jane Fraser. The Foundation also hosted a reception, giving attendees the opportunity to exchange ideas in a social setting.

At the opening ceremony, Congress President Eugene B. Cooper, Distinguished Professor at Nova Southeastern University in Fort Lauderdale, Florida, applauded what he perceives to be a dramatic shift in the thinking of researchers and clinicians in recent years.

Cooper noted that both researchers and clinicians are viewing stuttering as a syndrome. As a result, they are no longer focusing exclusively on the act of being disinfluent, but are attempting to identify the affective, behavioral, and cognitive components. With stuttering no longer being viewed as a unitary behavioral disorder, clinicians are addressing the stuttering clients’ feelings and attitudes as well as the problem’s behavioral aspects.

The Third World Congress on Fluency Disorders will be held in Copenhagen, Denmark, in the year 2000.

Authors: Marty Jester and Fred Murray confer at SFA reception.

Anders Lundberg of Sweden and Marie-Pierre Poulat of France meet at SFA reception.

Participants from Northwestern Workshop for Specialists attending the JFA Congress are rounded up by Newsletter Editor Nina Reardon for group photo.

Speech-language pathologist from Argentina, Beatriz de Touzet, Karina Couselo-Rios, Mariela Gihson meet with SFA’s Fraser.

SIDEBAR
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A process designed to diminish the problem as much as possible. We would let the child know what our goal is because if they understand what it’s all about, it’s going to mean more to them and they’ll be more cooperative. Our goal is to decrease the stuttering as much as possible and also to help the person be less embarrassed about it.

CE: Is it harder for adults or children to stop stuttering?

Campbell: It’s harder for adults if they haven't had any speech therapy before. And yet with children it's different because the adult has to help the child understand what's happening. We firmly believe in educating parents on how to talk with their child early on. We encourage them to speak slowly yet naturally, and not to rush the child in even non-verbal ways. Early prevention and early intervention is recommended. Most pre-school children while learning to talk go through a stage that sounds like stuttering and it may be totally normal. We don't want the adults in their lives to be pushing them too hard about what to say and how to say it. Instead they should model a relaxed manner of speaking.

CE: Do kids who stutter have harder problems in school?

Campbell: Not necessarily as far as their intellect or their potential in class, but they may have a harder time in school when it comes to feeling uncomfortable with verbal interactions. Stuttering doesn’t make kids abnormal or inferior and this should be a realized fact. We should increase education and promotion of stuttering with things like this article, newspapers or TV, all factors of media. Hopefully once the public knows of the issues, problems such as harassment can be eliminated, and kids can feel that they belong.

There's no guarantee that the teasing will stop though because some kids want to be mean and that's their prerogative, while others just don't care. Kids put other kids down to hide insecurities about themselves, and that makes them feel better. Also, if everybody's making fun of someone else and they want to be part of the crowd, they may join in, succumbing to peer pressure. But kids who stutter can join speech classes that will help and the best thing is not letting it get to you, because if there are friends and people who care for you and support you, then you'll be okay.

The Stuttering Foundation of America can be reached at 1-800-992-9392.

Children’s Express is a news service reported by children ages 8 to 18. For more information call us at (212) 741-4700 or visit our website at http://www.ce.org
Stuttering Foundation Reaches Pediatricians at Annual AAP Convention

Because many parents turn first to their pediatrician for help when they hear their child begin to stutter, making sure pediatricians have up-to-date information on stuttering is of utmost importance to SFA.

Speech-language pathologists June Campbell, M.A., and Diane Hill, M.A., were on hand at the Stuttering Foundation booth in New Orleans for this year’s convention of the American Academy of Pediatricians.

They fielded questions about stuttering and shared Foundation books, brochures, and videotapes with the more than 9,000 pediatricians and allied medical professionals in attendance.


The Foundation also reached out to those in the nursing profession in 1997 with informational booths at the conventions of the Association of School Nurses and the National Association of Pediatric Nurses.

Diane Hill discusses publications with two pediatricians.

New Books on Stuttering Available from Bookstores:

- 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.
- Stuttering: A Life Bound Up in Words by Marty Jezler. 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.
- Stuttering: A Search for a Cause and a Cure by Oliver Bloodstein, Ph.D. It is published by Allyn & Bacon, Needham, MA.

Claire, Montreal, Quebec, Canada, H1L 1V8. Please enclose $15.00 Canadian to cover printing, postage, and handling costs.

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 obtaining a copy of Self-Therapy for the Stutterer in Japanese, write to Dr. Shokichi Naka-
jima, 2-21-1 Ogawa Machida-shi, Tokyo 194, Japan, telephone/fax: 0427 (96) 5092.

For those obtaining a copy of Self-Therapy for the Stutterer in French, write to the Association des Begues du Canada, 7801 Rue Ste.
New Videotape Offered Free to Public Libraries

The new 38-minute videotape, Therapy in Action: The School-Age Child Who Stutters, is getting rave reviews from speech-language pathologists, parents, teachers and physicians. The tape is an excellent resource and is certain to further the understanding of stuttering and what can be done to help the school-age child.

It was produced by Edward G. Couture, Ph.D., of Vanderbilt University, Barry E. Guitar, Ph.D., University of Vermont, and Jane Fraser of SFA in collaboration with June H. Campbell, M.A., Northwestern University, Hugo H. Gregory, Ph.D., Northwestern University, and Patricia M. Zebrowski, Ph.D., University of Iowa.

For the past four years, the Stuttering Foundation has sent its videotapes free to thousands of public libraries. “There are few other more compelling problems for teenagers than stuttering. We are delighted to be able to make this invaluable resource, Do You Stutter: Straight Talk for Teens, available to them,” said Mary Louise Abrams, director of the Paramus Public Library. Sue Corcoran of the Ontario March of Dimes was also enthusiastic. “I believe that this video is a valuable addition to our present collection.”

Dianne Page of the Sammy Brown Library adds, “I want to thank you for the donation of the three videotapes on stuttering. These videotapes are a great addition to our library and will benefit many people of Panola County.

The SFA will continue to offer free tapes to public libraries, and the newest videotape for the school-age child is no exception. If your library would like a copy, have them call the Foundation at 1-800-992-9392, or write to the address on the back of the Newsletter.

Once the library has shelved the tape, SFA will send a press release to local newspapers to apprise people of its availability.

National Stuttering Awareness Week
May 11–17, 1998

Don’t put off ordering your NSAW brochures for National Stuttering Awareness Week 1998. The brochures feature thirteen famous people who stutter and are an addition to any clinic or classroom. For information on how to order, call 1-800-992-9392.