Exciting New Developments in Genetics of Stuttering

by Dennis Drayna, Ph.D.

A session at the recent meeting of the American Speech-Language-Hearing Association in Washington, D.C., revealed exciting progress in the genetics of stuttering. While genetic factors cannot explain all stuttering, these factors are clearly involved in many cases. Finding the genes that predispose individuals to stuttering would be a great advance in understanding the causes of this disorder, which have puzzled researchers for decades.

The first report, from a group led by Dr. Nancy Cox at the University of Chicago, detailed studies in a group of Hutarees from South Dakota. Because of their religious and cultural beliefs, this small group has married strictly among themselves for some 200 years. Dr. Cox’s team identified a small subset of this group who stutter.

They then tested genetic chromosomes 1, 13, and 17, that were associated with stuttering in this group of people. This suggests that there are three genes at work that cause stuttering in the Hutarees.

A second report was from a group led by Dr. Dennis Drayna at the National Institute of Health in Bethesda, MD. Dr. Drayna has performed a similar study, searching for genetic markers associated with stuttering; however, his study focused on the general population, and studied family clusters of stuttering from across North America. Dr. Drayna reported progress that will provide similar information within the next few months.

“These two studies complement each other,” said Dr. Drayna. “The Hutarees give us a way to find genes very precisely, while the broader population gives us information about genes that are at work outside this special group.” Knowing the location of these genes is the first step toward finding the genes themselves, which could provide major new insights into the causes of stuttering.

New Videotape Helps Parents Detect Stuttering in the Preschool Child

Parents eagerly anticipate the moment when their child begins to talk. But for some parents, it is a time of anxiety because their child struggles to get words out.

A new videotape, Stuttering and The Preschool Child: Help for Familios, is designed to help parents detect stuttering and take positive action toward helping their child.

Two-and-a-half-year-old Annie frequently repeats syllables and words; five-year-old Sam blocks on words; and two-year-old Heather becomes so frustrated by her inability to speak that she physically lashes out at her mother.

These children are among 20% of preschoolers nationwide whose repetitions and prolongations of sounds are unusual enough to be of concern to their parents.

“Stuttering typically begins in children between the ages of two and five,” says Barry Guitar, Ph.D., professor and chair of communication sciences at the University of Vermont in Burlington.

“The stuttering may begin gradually or suddenly, and many of these children outgrow their disfluencies naturally. However, if a child continues to stutter for several months, or appears to be frustrated by it, parents should seek assistance.”

Guitar appears in the video with four other nationally recognized experts in stuttering: Peter Ramig, Ph.D., of the University of Colorado at Boulder, Diane Hill, M.A., of Northwestern University, Patricia Zebrowski, Ph.D., of the University of Iowa, and Kristin Chimela, M.A., of Barrington, Illinois.

“The videotape lets parents know that there are many things we—and they—can do to help their children develop normal fluency,” Dr. Zebrowski explains. “Speech-language pathologists are much more focused nowadays on early interventions, with the aim of preventing a chronic stuttering problem from developing.”

The video was produced by the Stuttering Foundation, Continued on page 2

Foundation Receives $92,680 Bequest

The Stuttering Foundation received an unprecedented bequest in the amount of $92,680 from the Estate of Earl L. Nissen of Sun City, Arizona.

As a young man, Mr. Nissen stuttered; but those who knew him later in life reported that they had never heard him stutter.

He was for many years a salesman for the Motorola Company and worked in South America where he earned a degree in International Trade. He is reported to have been bilingual, speaking Spanish fluently.

When he retired from Motorola, he became an avid golfer, taking up residence in Arizona where he could golf year-round.

His niece shared that he was an outstanding pianist and had a fine singing voice as well.

“He was such a great guy,” reported Jane Fraser, president of the Foundation. “I received a call from Mr. Nissen’s representative at Merrill Lynch Trust announcing the bequest and hoped I had heard her correctly!”

This superb funding comes at an ideal time with many exciting projects lined up for the year 2001.
**Christopher’s Wish Available**

Christopher Allen is a young man who stutters so severely that people are embarrassed and afraid to be near him. He is rejected by his family, peers, and even his employers. He is plagued by emptiness and loneliness so torturous, he tries to take his own life. Unsuccessful, Christopher awakens to find himself in a hospital where he is befriended by the helpful Dr. Larrabee who brings confidence, love and acceptance into Christopher’s life.

Copies of the book Christopher’s Wish have been donated to the Stuttering Foundation by author Patrick Walters of Salt Lake City. Those wanting to receive a free copy of this 280 page book should send $2.00 to cover postage and handling to the Stuttering Foundation of America, P.O. Box 11749, Memphis, TN 38111-0749 and request Publication Number 3.

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**National Stuttering Awareness Week—May 14-20, 2001**

Help increase awareness about stuttering in your community, clinic, school, library, or workplace. Don’t put off ordering your NSAW brochures and posters for National Stuttering Awareness Week, 2001. They feature fourteen famous people who stutter.

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**New Videotape**

Continued from page 1

Foundation of America, it has produced many other videos to help both those who stutter and their families and distributes them free to all public libraries. For those who want their own copy, the videos may also be purchased.

The video describes how treatment plans involve the parents, who can model a slow rate in their own speech and reduce communicative stress at home to help their children overcome stuttering.

“We don’t view the home environment as causing stuttering,” Ramig explains. “However, once stuttering is evident, the home environment can have a positive or a negative effect on easing the child’s stuttering.” If a child has “a rushed or hectic home environment, or if the child is being punished or reprimanded for his stuttering, those factors can have a negative impact on his or her speech. Caring and understanding is the best approach.”

Parents also learn from the video that if their own assistance doesn’t reduce their child’s stuttering sufficiently, the speech pathologist can teach the youngster “strategies to create slower, easier speech,” Ramig says.

Families are relieved to discover that “they are not alone and that other parents share their concerns,” says Kristin Chimera, in private practice in Barrington, Illinois. “The tape shows parents talking about the experience of having a child who is disfluent, and those watching can identify with the experiences and feelings of these parents, who express a broad array of concerns about their young children who stutter.”

“Stuttering remains a mystery to most people,” notes Jane Fraser, president of the Stuttering Foundation. “Watching a young child struggle to speak can be devastating for parents. Our latest video is designed to reassure parents and families that many preschoolers stutter, that they can be helped, and that parents play a vital role in assisting their child to become more fluent.”

Readers may obtain more information free of charge from the nonprofit Memphis-based Stuttering Foundation by calling toll-free 800-992-9392, or by visiting www.stutteringhelp.org.
Stuttering Causes School Woes
New Brochure Offers Nine New Tips for Teachers and Parents

by Joan Gross

When teachers hear a child begin to stutter, the immediate reaction is one of concern mixed with a host of urgent questions.

Should they call on him in class or will that only make the stuttering worse? How should they handle teasing by other children? What should they do about reading aloud?

The nonprofit Stuttering Foundation answers these and many other questions in its updated brochure for the school year 2000–2001, The Child Who Stutters at School: Notes to the Teacher, available in both English and Spanish.

"Young children are busily learning to talk," explains Dr. Lisa Scott Trautman of Wichita State University, who updated the brochure for 2001. "As such, they may make speech 'mistakes,' such as effortless repetitions and prolonging of sounds. In most instances," she adds, "this is very normal. If parents and teachers listen to and answer these young children in a patient, calm, unemotional way, the child's speech will probably return to normal."

"Some children, however, will go beyond the normal and begin to repeat and prolong sounds markedly," explains Scott Trautman. "They may begin to struggle, tense up, and become frustrated in their efforts to talk. These children need help."

"Any time teachers are concerned about a child's fluency," notes Scott Trautman, "they should consult with the school speech clinician as well as the parents to make sure their approach to the child's speech is consistent." She advises teachers, "Talk with the child privately and reassure him or her of your support: let them know that you are aware of their stuttering and that you accept it—and them."

This exciting new brochure has been featured this fall in New York Teacher Magazine, Creative Classroom, MTA Today, the magazine of the Massachusetts Teachers Association, in The Communicator, the magazine of the National Association of Elementary School Principals, in two syndicated columns, Dear Teacher by Peggy Gisler and Nan Eberts and Parent Talk by Evelyn Petersen, the health column of The Arizona Republic, The Staten Island Advance, The Nashville Banner, as well as in numerous other daily and weekly newspapers.

Friends of SFA Represent Foundation at International Fluency Association Meeting in Nyborg, Denmark

Those pictured worked at SFA booth to share materials with speech-language pathologists from all over the world at the Stuttering Foundation booth in Nyborg, Denmark, in August 2000.

International colleagues were thrilled to meet author Eelco de Geus at the booth and have him autograph their own copy of Sometimes I Just Stutter. This book is now well known in many languages around the globe.

Left to right: Charles Healey, Susan Dietrich, Edward Couture.

Awesome Library Honors Foundation Book

Sometimes I Just Stutter has earned the distinguished honor of being chosen for and listed on the Awesome Library Web site.

Awesome Library is an Internet library database which promotes communication among students, teachers, and librarians and improves access to online information.

A web site must meet certain criteria in order to be included in Awesome Library. These include its usefulness to teachers, students, parents, and librarians as well as being the "best version available," and easy to download.

It is a great honor for author Eelco de Geus, translator Elisabeth Versteegh-Vermeij, and publisher Stuttering Foundation to be reviewed and accepted by Awesome Library.
Five Day Workshops Reach from East Coast to West Coast

Boston Site of 4th Annual Workshop
by Sheryl Gottwald, Ph.D.

The fourth Stuttering Foundation New England Workshop, The Diagnosis and Treatment of Children Who Stutter: Practical Strategies, was held June 21st-25th, 2000, at Boston University, Boston, Massachusetts. Twenty speech pathologists selected from over 140 applicants were chosen because of their interest in stuttering and their involvement with children who stutter.

Internationally and nationally a diverse group, the selected workshop participants were employed in a variety of settings from medical clinics and hospitals to preschools, elementary, junior and senior high schools to university clinics and private practice.

They lived together in a university dorm facility for the five-day workshop. One participant noted, “Communication with peers outside of the formal classes was a very effective component of this workshop.”

Sheryl Gottwald, Ph.D., of the University of New Hampshire and Susan Dietrich, Ph.D., of the University of North Carolina at Greensboro, directed the workshop and provided the primary instruction. Diane Parris, assistant professor at Boston University, was the University Site Coordinator.

The workshop began with a discussion of the research bases and theoretical foundation for the development and treatment of stuttering followed by discussion of principles and practices in the assessment and diagnosis of children who stutter.

Gottwald shared ideas about working with preschoolers and their families; Dietrich discussed ways to integrate stuttering modification and fluency shaping techniques. “A major strength of this workshop was its practicality. As we learned each new aspect, we related it back to how we can use it in therapy,” commented one participant.

Local children and their parents volunteered their time to participate in therapy sessions with the conference participants. Workshop attendees had the opportunity to use their newly-learned techniques in role playing with these family volunteers before returning to their clients who stutter. The workshop directors were on hand to provide suggestions and to model treatment strategies. One participant noted, “There is no better way to learn than by doing!”

Dr. Patricia Zebrowski from the University of Iowa gave an outstanding presentation on counseling the parents of children who stutter. “To have Dr. Zebrowski’s presentation on the last day made it easy for me to relate the knowledge I had acquired during the previous days,” noted one workshop attendee.

Another noted, “I appreciated the organization and management of the time we had to cover practical information about a variety of topics. I enjoyed the hands-on approach to practicing what we learned and the positive feedback given to us from the instructors. It made us feel so good! The thoughtfulness that went into everything, and all the other details….I could go on and on.”

Next summer, this workshop will be presented at the University of North Carolina at Greensboro and in 2002, it will return to Boston University.

Midwestern Workshop Applauded
by Lisa Scott Trautman, Ph.D.

Wichita State University and the Stuttering Foundation co-sponsored the first annual Midwestern Workshop, held in Wichita, KS July 10-14, 2000. Twenty speech-language pathologists from Kansas, Missouri, Arkansas, Oklahoma, Illinois, Nebraska, and British Columbia participated in the workshop, led by co-instructors Lisa Scott Trautman and Kristin Chmela. Guest speaker was E. Charles Healey of the University of Nebraska-Lincoln.

As with the other 5-day workshops, it focused on diagnosis and treatment of preschool and school-age children who stutter. The primary goals were to increase participants’ skills and confidence in communicating effectively with children, to diagnose the extent and severity of the communication disorder, to develop appropriate treatment plans and design meaningful therapy activities, and to model both fluency shaping and stuttering modification tools. In addition, strategies for working with parents and teachers were discussed.

Learning opportunities included traditional lectures, small-group practice of clinical skills, watching videos of therapy sessions, and interaction with children who stutter who were attending a fluency camp at Wichita State.

“The workshop was a great success,” “We were so thrilled to have so many clinicians from a variety of work settings devote a week of their summer to learning more about stuttering,” said Kristin Chmela, Lisa Scott Trautman agreed, and added “The dynamics of the group were wonderful, and we know we learned as much from these clinicians as they did from us.”

Workshop evaluations included comments such as “It is so exciting to meet presenters and participants who are so dedicated to this field. This was a wonderful conference and a great opportunity for all of us. Thank you!” “I can’t say enough about this fabulous week. It is without question the best continuing education activity I’ve attended in my professional life.”
career." "This was an amazing experience that further fueled my interest in stuttering and treating the ‘whole’ child. Everything I learned here can be used with a variety of children - not just those who stutter! Thanks for everything!"

The Second Annual Midwestern Workshop will be held at Wichita State University July 25-29, 2001, with Dr. Tricia Zebrowski from the University of Iowa scheduled as the guest speaker. For applications, contact the Stuttering Foundation or Lisa Scott Trautman at 316-978-3319 or scott@twsu.edu.

SFA Booth at 2000 ASHA Sets New Record

The 2000 Convention of the American Speech-Language-Hearing Association held in Washington, D.C., proved a resounding success for the Stuttering Foundation, with the largest number of materials ever distributed to clinicians. The focus of the booth was on the new preschool videotape, Stuttering and The Preschool Child: Help for Families. The excitement generated by this new tape was phenomenal, as over 500 were distributed in just two and a half days! In addition, another 450 tapes and hundreds of books were distributed.

Twenty-two volunteers helped staff the booth as well as provide set up and tear down assistance. It was not unusual to have five or six people in the booth at a time which proved to be necessary because of the heavy demand for materials.

Next year's convention will be held in New Orleans, and we look forward to yet another record convention!

Western Workshop Creates Network

by Marilyn Langevin, M.A.

The inaugural session of the SFA Western Workshop 2000 was held in Seattle, WA from June 21-25, 2000, at the University of Washington.

Speech-language pathologists Susan Hamilton and Marilyn Langevin presented practical strategies for working with preschool through school-age children and David Prins provided a historical perspective and great kick off to our intensive week.

At the end of the week, participants demonstrated their skills during practice therapy sessions with preschool and high school aged fluency clients and their parents. The attendees’ enthusiasm and willingness to participate made this workshop a learning experience for all.

One of the goals of our conference was to establish a network of SLP's in the West who specialize in stuttering. Already our group has established an active email network. Montana and Washington attendees have started discussing plans for presenting at state conferences, and our Utah representative Kristen Walton has the approval of administrators in her healthcare system to require basic and advanced competencies for SLP's who diagnose and treat children who stutter.

The twenty participants, who came from Montana, Idaho, British Columbia, Wyoming, Washington, Oregon and Utah, were all very enthusiastic about having had this opportunity to further enhance their knowledge base and skills in working with children who stutter.

Their comments reflect the outcomes and enthusiasm generated: "I have 5 students that I will immediately begin developing more effective treatment plans for..." "I now understand the great importance of working on attitudes and emotions. I have done it but I guess I never quite understood why. Now — this will be completed with more conviction and emphasis..." "I can honestly say this is one, if not the best, professionally advancing workshop I’ve been a part of."
In Memoriam
James Kilshaw

The Stuttering Foundation sadly notes the passing of Mr. James "Jimmy" Kilshaw, of Baton Rouge, Louisiana. A lifelong stutterer, Jimmy served in a number of posts in local government. He was an enthusiastic sports fan, so much so that he served as an announcer at local sporting events, not letting his stuttering get in the way.

Upon his retirement in 1996, Jimmy launched himself into a second career, working in conjunction with the Stuttering Foundation to help enroll families for the genetics research study taking place at the National Institutes of Health.

Dr. Dennis Drayna, leader of the NIH study notes that "Jimmy is probably the only lifelong severe stutterer who loved to talk on the telephone. His wonderfully personable style and his determined nature contributed greatly to the success of our work."

He will be missed by the many people whose lives he touched.

NEWSBRIEFS

The SFA conference for speech-language pathologists working with the school-age child who stutters will be held June 1st and 9th, 2001, in Salt Lake City, Utah. For more information and an application form, 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 9-20, 2001. For an application form, 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. Special guest is Dr. Richard Carroll.

The Stuttering Foundation of America Southeastern Workshop, "Diagnosis and Treatment of Children Who Stutter: Practical Strategies," directed by Dr. Susan Davis, will be held at University of North Carolina-Greensboro, June 20-24, 2001. Call the SFA at 800-992-9392 for an application. Special guest is Dr. Peter Ramig.

The Stuttering Foundation of America Midwest Workshop, "Diagnosis and Treatment of Children Who Stutter: Practical Strategies," directed by Dr. Scott Troubanski and Kristin Cohn, MA, will be held at Wichita State University, July 25-28, 2001. Call SFA for application. Special guest is Dr. Patricia Zebrowski.

The Stuttering Foundation of America Western Workshop, "Diagnosis and Treatment of Children Who Stutter: Practical Strategies," directed by Susan Hamilton, M.A. and Marilyn Langevin, M.A., with David Prus, Ph.D., will be held at the University of Washington, Seattle, June, 2001. Call SFA at 800-992-9392 for information.


The NSA Convention will be held in Boston in June, 2001. For more information, call the NSA office at 1-800-364-7677.

The 4th Annual Convention of Friends, the Association of Young People Who Stutter will be July 26-29, 2001 in Chicago, IL. For more information, call Jeanne Murphy at 773-299-9992 or visit www.friendswostutter.org.

The Canadian Association for People Who Stutter will hold its annual conference in Calgary, Alberta, August 23-26, 2001. For more information, contact Mary Schoendorfer at capsworkshops@home.com or visit www.bhecyak.com/caps.

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 wanting to obtain a copy of Self-Therapy for the Stutterer in Japanese, write to Dr. Shokichi Nakajima, 2-1-1 Ogawa Machida-cho, Tokyo 194, Japan; tel. 0427 (90) 5967.

For those looking to obtain a copy of Self-Therapy for the Stutterer in French, write to the Association des Bougres du Canada, 7801 Rue Ste. THERE, Montreal, Quebec, Canada, H1V 1L8. Please enclose $15.00 Canadian to cover printing, postage, and handling costs.

For those wanting to obtain a copy of Stuttering and Your Child: Questions and Answers in Hindi, write to: Dr. Sajit Adaksha, Adaksha Speech and Hearing Clinic, 77, Sant Nagar, East of Kailash, New Delhi-110065, India, or call at 011-91-628-8636. E-mail: adakshas@hotmail.com Those interested in joining a fluency and public speaking skills group should also contact Dr. Adaksha at the above address.

Books on Stuttering or Related Topics Available from Bookstores:

- Stuttering Intervention: A Collaborative Journey to Fluency Freedom by David Allen Sharpe, published by Pro-Ed, Austin, Texas.
- The Bob Love Story: If It's Gonna Be, It's Up to Me, by Bob Love with Mel Watkins, available through bookstores or call NTC Contemporary Publishing Group, 1-800-323-9000.
- Paroles de parents by Anne-Marie Simon, L'Ortho-Edithion, 76, rue Jean Jaurès, 62330 Stbergues, France.
- Nature and Treatment of Stuttering: New Directions by Richard F. Carter, Ph.D. and Gerald M. Siegel, Ph.D., published by Allyn and Bacon, Needham Heights, MA.
- Special Children, Challenged Parents, by Robert A. Nance, Ph.D., published by Carol Publishing Group, Secaucus, New Jersey, 1-800-447-2665.
- Elements of Stuttering by Courtney Strovas. Ph.D. Available from Ainsworth Publishing Company, P.O. Box 333, Oshimo, MI 49077. Please send $10.50 plus $3.00 handling charge.
- Stuttering: A Search for a Cause and a Cure by Oliver Broadstone, Ph.D. It is published by Allyn & Bacon, Needham Heights, MA.
- The Telecommunication Relay Service Handbook by Franklin H. Silverman, Ph.D. Aegis Publishing Group, Ltd, Newport, RI.
- Unforgettable Characters I Have Known by BILLY LYnde. Published by BookPartners in Wilsonville, OR, 503-682-9821 or 800-895-7323.
- Speak Monolingual Not Dialect by SLP Elizabeth Haynes. Available through Thistledown Press Ltd., Saskatoon, Saskatchewan, Canada, 306-244-1722 or www.thistledown.sk.ca.

Happy New Year from the staff and consultants of the Stuttering Foundation of America!

Left to right: Tracy Pitt, Anne Edwards, Jean Hillman, Roberta Burrows, and Pat Shanahan.

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