Medical Aspects of Stuttering

by Glyndon Riley, Ph.D., Professor Emeritus, California State University, Fullerton

If a medication is developed that is useful for people who stutter, it will not be a "cure" that can work in the absence of other forms of therapy. There is a rationale for including some medical aspects of stuttering in our diagnosis and treatment protocols, but not for excluding established therapies.

The history of stuttering theory parallels the history of other complex disorders.

First, environmental factors were thought to be the primary cause and it was labeled "functional" or "emotional" and mothers got most of the blame. Stuttering fell into this category in the 1940s and '50s when it was supposed to start in the ears of the listeners.

Second, genetic evidence began to emerge for stuttering as it had for such disorders as heart disease, autism and schizophrenia. Environmental factors seem to present an incomplete picture. For stuttering, the genetic influence is even stronger than for other complex disorders. Monzygotic twins have a concordance rate of about 60% or more and dizygotic twins and brothers have a concordance of 20-26%. In addition, the fact that stuttering, like most childhood speech disorders, occurs in three times as many boys as girls implies that something in addition to environment is part of the etiology.

Third, neurological findings led to new theories that included medical aspects of each of these disorders, and treatments were modified to include medical management (especially medications) as part of the overall treatment.

Stuttering is a multi-dimensional, multiple risk disorder that includes such aspects as social interactions, emotional reactions, auditory processing, language production and speech motor programming. Smith and Kelly describe this perspective in more detail. The results of studies that evaluate the possible relation of dopamine to stuttering need to be considered in a context of these parallel, contributing systems.

A Dopamine Hypothesis

The hypothesis under consideration states that adults who stutter, as a group, have excessive dopamine in the striatal (sub-cortical) regions of the brain. Recently, Costa & Kroll provided an update for physicians who need to apply medical findings to treating people who stutter. They stated that, "...research data and the effectiveness of dopamine receptor antagonists..."

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Back for 2002, Brendon Has Year-Long Impact on Stuttering Awareness

As Xander in the TV series Buffy the Vampire Slayer, actor Nicholas Brendon has won celebrity status. As Chair of National Stuttering Awareness Week 2001, his starring presence kept SFA's awareness campaign in high gear all year, with public service announcements running in Time, Good Housekeeping, Forbes, People, Cosmo Girl, and others. Now, Nick's back as Chair for NSAW 2002, May 13-20, with a new twist to help others who stutter.

On April 12, fans wished Nick a "Happy Birthday" and benefitted SFA through an eBay auction of items signed by the actor. Check Nick's Web site, www.nick-brendon.com for future auction dates.

Auction items include copies of the Buffy Season One DVD set; a poster from the recent Buffy musical episode, Once More, With Feeling; a Psycho Beach Party movie poster; and the first issue of the recently re-launched official Buffy magazine.

Fans may also donate directly to the Stuttering Foundation in honor of Nick.

Stuttering Wasn’t the End of His World

Zoologist Alan Rabinowitz has literally been to the ends of the earth and back to save endangered animals. But stuttering nearly restrained him from being the remarkable conservationist and author he is today. Whether struggling through challenging circumstances in childhood or facing incredible danger in remote uncharted regions, he has never given up. Perhaps one of Dr. Rabinowitz’s greatest discoveries was that stuttering didn’t have to be the end of his world.

Rabinowitz’s new book, Beyond the Last Village, tells the fascinating and sometimes harrowing story of his 500-mile journey through Asia’s forbidden wilderness on a quest to discover and preserve endangered wildlife. In many ways, stuttering set his feet on the path. Now, he’s speaking out for others who stutter.

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Cuban Visit Helps Bridge Information Gap on Stuttering

Forget international politics and off-limits countries. When it comes to helping those who stutter, there’s a will, a way, and always someone committed to the Foundation’s work.

Dr. Fred Murray traveled recently to Cuba. Among his baggage were Stuttering Foundation books and videos for a populace starved for information and help on stuttering.

“I first went to Cuba on election day, November 1932, when I was seven-years-old,” said Murray, now 76 and retired from the faculty of the University of New Hampshire. “Hoover was running against FDR. The local [Cuban] politics were not the best at the time.”

Nor are they now, but Murray wanted to see Havana’s harbor, with its fortress, the Morro, and the lighthouse that he remembers as a young boy. He discovered that, as a professional educator and researcher, he is eligible for a government waiver to visit the country that, while only 90 miles off the coast of his home state of Florida, is out of reach for most Americans. The news was a revelation and a beneficencia.

Before he left for Havana in January, Fred called Jane Fraser at the Stuttering Foundation and offered to take some materials along.

“Jane sent me all the Spanish books that she has. I wanted to form the link, so I went to the University of Havana. They were very happy to get the books,” Murray said. “Then I felt that I’d better make an effort to set up a link with the national department of education.”

So he took copies of 10 different books, brochures and videos—everything the Foundation publishes in Spanish—to Vedado, the section of Havana that houses the Dirección de Educación de la República de Cuba where he spoke to program director Tatiana Chkout.

“She was very interested in this. Stuttering is a stubborn, stubborn thing. There’s no cure, but there is management, very effective management. I think the seeds are there, and now they are going to be able to multiply these materials. The Foundation has given permission for them to publish,” Murray added. “It was a very successful visit.”

The visit was also successful for Murray personally. “There’s a certain spirit about Cuba that is absolutely amazing,” he said. “They are shaping up certain sections of the city and others are just falling down. The old section is fascinating. Paint is very scarce, so the houses look very faded on the outside, but inside they’re in good shape. There are old American cars, but also newer German models. I rode in a 1998 Mercedes taxi, then went and met the taxi man’s family. They took me down to his mother-in-law’s, and there she was sewing on her treadle machine from about 1920, with the foot pedal, and the father was in the garage repairing electric appliances. I’d like to go back.”

What Worked for Me: Tips for Success

by Bill Peterson

When I tell people that I used to have a speech problem, they can’t believe it. I have had a successful progression of executive sales and marketing positions at companies like IBM and Dell. Today, I lead meetings and give presentations daily, occasionally deliver presentations to hundreds of people at seminars, and I’ve even been on national TV a few times. People say that I’m one of the more effective communicators around. But it wasn’t always that way. For my first 25 years, my stuttering problem was the most profound negative influence on my life.

In elementary school, I was referred to by many as “B-B-Bill.” In high school, I covered the back row of class in a cold sweat, desperately hoping that the teacher would not call on me. And while obtaining my bachelor and master degrees, I volunteered to answer a question exactly once during those five years. My lack of confidence kept me from joining most social activities and I never had many friends. People who stutter know exactly what I’m talking about.

Like many stutterers, I mastered the art of “word substitution,” and when I spoke, I did so with lightening speed, often unintelligibly. I was terrified of the telephone. I hated to tell people my name because I knew I would stutter. But mostly I didn’t say anything.

During my junior year of college, I reached the conclusion that I must address my speech problem. I researched stuttering at the library, and read every article and book I could find (including Self-Therapy for the Stutterer, a 20-year-old copy of which remains on my shelf). That set me on a successful course of action, which included:

- Talk about it. The single most effective thing I did to become more fluent is to discuss my problem with a close friend. It took weeks to work up the courage, and when I did discuss it, years of frustration and humiliation flowed out in uncontrollable tears. The greatest weight imaginable was lifted off of my chest, knowing that I wasn’t facing this challenge alone. Parents of children who stutter: don’t let a lifetime of frustration build up—provide an open environment for your child to discuss and get help with stuttering.
- Be prepared when you know you will have to speak. Rehearse. Use a tape or video recorder. Your personal secret weapon? Visual aids. Use effective PowerPoint charts, or props, or anything—the best people have ever seen—to take pressure off of your speech and give you confidence.
- Seek out opportunities to talk. I sought out a sales job where I could practice my speech constantly. I took the Dale Carnegie speaking course. For my first speech, I chose to discuss my stuttering problem, which took the pressure off for the remainder of the class. Invent reasons to talk on the phone, or to a store clerk, or to friends. Practice breeds success. And success breeds confidence. And confidence is stuttering’s enemy.

I still stutter on occasion. And I’m still more shy than I wish I was. But stuttering no longer controls my life. I believe that, like me, most stutterers will benefit with commitment and not trying to hide the problem.
Oh, What a Month March Was!

March was a very productive month for the Foundation’s programs in public awareness, in providing educational materials for professionals who work with those who stutter, and in disseminating materials worldwide. A few highlights...

A Healthy Read

Thanks to an article in Dr. Paul Donohue’s To Your Good Health column and Dr. Robert Wallace’s ‘’Tween 12 & 20 column about help available through the Stuttering Foundation, the SFA reached over 8.8 million readers of daily newspapers in March alone. Another 769,000 readers of weekly papers read the good word.

Video Translated

Therapy in Action: The School-Age Child Who Stutters video was translated into Lithuanian by Vilma Makauskiene, who writes: “I hope this will help specialists here to better understand stuttering.”

Coming Soon to a Video Screen Near You

From left, Barry Guitar, Carroll Guitar, Patricia Zebrowski, Peter Raming, Jane Frasier, and Diane Hall met the first week in March to complete the script and edit film footage for a new video on counseling parents of children who stutter. The video is expected to be released this fall. A new video for teachers, Stuttering: Straight Talk for Teachers, is also due out this fall, featuring speech-language pathologists Lisa Scott Trautman, Kristin Chimeli and Bill Murphy.

Annual Audit of Foundation by KPMG

The annual audit of the Stuttering Foundation financial reports for 2001 was recently completed by the accounting firm of KPMG. Following is a recap of funds and expenditures for the year.

The 3.4% of expenditures for administration and general expenses and the 8/10 of 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 $601,788 51.2%
Public information and education 277,169 23.6%
Educational Symposia for Professionals and research 162,728 13.9%
Maintain Web site and toll-free Stuttering Information Hotline 82,891 7.1%

Total for Program Services $1,124,576 95.8%

Other expenditures:

Administration and general 40,354 3.4%
Fund raising expense 9,549 .8%

Total Expenditures $1,173,979 100.0%

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.
5,500 Public Libraries Shelve Videos
List of Libraries with Videotapes Available on Web Site

Libraries all over the country recently added Stuttering and the Preschool Child: Help for Families to other Foundation videotapes on their shelves.

An additional 1000 libraries were sent a copy of the popular videotape. Those seeking information on stuttering can now find Foundation materials at more than 5,500 public libraries nationwide.

The list of these libraries is published on our Web site, www.stutteringhelp.org.

For the past seven years, the Foundation has sent its videotapes free to public libraries. If your local library has tapes and they are not listed at our Web site, please notify the Stuttering Foundation. If your library would like copies, have the librarian call 800-992-9392 or write the Foundation.

NSSSLHA Chapters Donate to SFA

College students studying to be speech-language pathologists aren’t waiting until they graduate to help those who stutter.

National Student Speech-Language Hearing Association chapters in Louisiana and North Carolina recently sent donations to the Stuttering Foundation. Earlier, a Pennsylvania chapter held a fund-raiser to benefit the Foundation.

“We are a communicative disorders organization,” wrote Heather Bartley of the Nicholls State University chapter in Thibodaux, LA, and asked that their donation be used for research on stuttering, videotapes and books, and training programs for speech-language pathologists.

The NSSSLHA chapter of North Carolina State University in Raleigh also sent a generous gift.

Helping fund research efforts on stuttering is a popular program among the chapters that have donated. The Foundation supports basic research in the fields of neurology and genetics.

ABC Channel 24 Focuses on Stuttering

Stuttering was the focus of a special on ABC-TV Channel 24 in Memphis. Speech-language pathologist Dr. Lisa Scott Trautman, below, is interviewed for the segment by Channel 24 reporter Tran Bui.

Above, Memphis resident George Rutschman talks to Jane Fraser about techniques he uses to help control his stuttering. The show aired throughout the greater metro area in February.

The SFA launched its Web site, http://www.stutteringhelp.org, three years ago. It continues to draw several hundred hits every day. Parents, teens, and adults who stutter around the world are finding help and making comments on the information they find.

A student in Florida writes, “I think this is a cool site for people with this problem. Thank you!”

Another student adds, “Your Web site is very informative and a great resource to not only those who stutter, but those who are curious about this mysterious condition. I decided to write a research paper on stuttering and its effects. Your website was extremely helpful and your handbooks have been wonderful as well. Keep up the good work. You are a light to those who have nowhere else to turn.”

“Great Web site,” writes a speech pathologist. “I have had several people contact me as a result of your efforts. Great work!”

From Australia: “This site is excellent. I’m 34 and have stuttered all my life. My 2 1/2-year-old daughter is starting to stutter. I am really concerned about her.”

Insurance information and new versions of If You Think Your Child Is Stuttering, The Child Who Stutters At School: Notes to the Teacher and Turning On To Therapy can be downloaded from the Web site.

From a young man in New York: “I want to thank you for putting a site on the Web that can lend support to young stutterers. As a stutterer, I know the struggles and agony of not being able to fluently speak... I have found that if I don’t have a problem with myself stuttering, I receive less criticism and I’m able to deal with my problem better.”

“I’m a stutterer and I’ve had this all my life. I’m 15 years old and am passing through high school. It is very difficult to deal with this problem in the school and for that I need help. This site is very good for those who stutter like me, and I want to say to keep that up and God bless you.”

“I received information from you which helped me tremendously. Thank you!” writes a college student. “By my stuttering problem, I got my college education paid for. They consider stuttering a disability. People can learn more about this from a college or their human services department.”

From a consultant in Pakistan: “It is a great site I have visited.”

“You cannot [know] how happy I was when I found your site in one of the magazines I was reading. I had a feeling that someone is sharing my emotions and suffering towards stuttering.” – from Morocco.
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nists in developmental stuttering seem to support the theory of a hyperdopaminergic origin of stuttering. In an earlier study, dopamine levels in the striatum of three people who stutter (moderate to severe stuttering) were compared with levels in six people who do not stutter. All of the subjects were male. Positron emission tomography used 6-FDOPA as a marker of pre-synaptic dopaminergic activity. Stuttering subjects showed a 100-200% increase in dopamine activation in areas related to the hypotheses under consideration. The authors conclude, “Elevated 6-FDOPA uptake in ventral limbic cortical and subcortical regions is compatible with the hypotheses that stuttering is associated with an overactive pre-synaptic dopamine system in brain regions that modulate verbalization.”

More recently, 12 males and 4 females who stutter (mean age 40.8 years) were enrolled in a double blind, placebo controlled study of the effects of low doses of risperidone versus a placebo on stuttering. There were no significant differences between groups in age or gender. Stuttering severity varied from mild to very severe in each group at baseline. The percent of syllables stuttered was reduced from 9.6 to 4.7 (50.4%) by the active medication compared with a reduction from 7.0 to 5.1 (27.1%) by the placebo. The median score on the Stuttering Severity Instrument-3 (Riley, 1994) were reduced by 7.8 (25.3 to 17.5) following the medication and 3.5 (24 to 20.5) following the placebo. Both of these measures reached statistical significance at p < .05.

In other findings, 23 people who stutter were included in a double-blind, placebo controlled study to examine the effects of olanzapine (another dopamine blocker) on stuttering; 12 received olanzapine and 11 received a placebo. This group on active medication reduced their SSI-3 scores by an average of 33%; the group on placebo by 14%. Based on a clinical global impression obtained from the examiners who worked most closely with 14 of the group, 5 of the 7 were clinically improved by the medication compared with 1 of 7 on the placebo. All participants filled out a self-report Subjective Stuttering Scale (J. Riley & G. Riley, 1998). Those on the medication reported 22% less stuttering and the ones on placebo reported 13%. All three of the measures indicated statistically better effects of olanzapine than of the placebo.

These three studies provide some support for the hypothesis that excessive dopamine reduces efficiency in the striatal region of the brain on people who stutter. If this is true, stuttering shares many similarities with Tourette’s syndrome in that it is a dopamine based, basal ganglia disorder. Both stuttering and Tourette’s begin in childhood, follow a waxing and waning course, and are made worse by anxiety, and occur in a 4:1 ratio of male to female. The role of dopamine in stuttering development remains unclear. It may not be present in children who stutter but may develop as a by-product of the stuttering.

Because medication does not provide a comprehensive, complete treatment, research needs to be designed and conducted that includes both traditional (behavioral, cognitive, and attitudinal) stuttering treatment and a selected medication in order to better describe the roles of each approach. Medically induced changes to cortical or subcortical regions that are possibly related to stuttering occur in the context of social, cognitive, and emotional conditions and need to be viewed as only part of a very complex, multi-dimensional process. Even if some medications can be demonstrated to be useful in reducing the frequency and severity of stuttering, they will not provide a total treatment. Rather, each person who stutter needs to work with a speech-language pathologist who specializes in stuttering to work out a comprehensive therapy program in which the use of a given medication may play a part. Perhaps people who have given up on therapy will find that some medication can make enough difference to help them get back into a treatment program or support group.

Medically induced changes... need to be viewed as only one part of a very complex, multi-dimensional process.

New Brochure Offers Guidelines on Neurogenic Stuttering

Written by Dr. Lawrence Molt and Dr. J. Scott Yaruss, Neurogenic Stuttering: Some Guidelines has been published to respond to the many calls the Foundation receives from the public and from speech-language pathologists with questions about neurogenic stuttering.

The brochure explains who is at risk, primary symptoms, how neurogenic stuttering differs from other types of fluency disorders, how neurogenic stuttering is diagnosed and treated, and where to discover help and additional information.

Neurogenic Stuttering: Some Guidelines is available through the nonprofit Stuttering Foundation. Readers may obtain more information by calling the toll-free number, 800-992-9392 or visiting the Web site at www.stutteringhelp.org.

Gateway Donates Computer to Foundation

When a familiar cow-patterned box showed up at the Foundation’s office, staff greeted it with glee. They quickly unpacked the computer inside, a gift from Gateway to support the SFA’s work, and in response to concerns about a TV ad that aired this past fall that alluded to stuttering.

Visitors such as pediatrician Brian Smart, M.D., and Brad Heffler, whose 10-year-old son, Jason, has a mild stutter, wrote and asked the company to pull the commercial.

Heffler said Gateway’s Chris Gann quickly responded to his letter, assuring them that they were doing so. Then Brad went one step further and called us.

A “couple of years ago when we were first trying to get some help for our son, my wife stumbled on the [Foundation’s] Web site and sent away for some books. I always remembered that they were very helpful, so I called up and asked if there was anything the Foundation needed.” Heffler said. “Then I called Chris back and asked Gateway to donate a computer.”

The company sent the computer “to express how much Gateway appreciates the work of the Stuttering Foundation,” wrote Gateway representative Anita Gomez. “Gateway is proud to be among the supporters of a nationally recognized organization that has helped thousands.”

References


The Stuttering Foundation two-day conference for speech-language pathologists working with the school-age child who stutters will be held June 7-8, 2002, in Dallas. For more information call the Stuttering Foundation at 1-800-992-9392.


The 5th annual convention of Friends: The Association for Young People Who Stutter will be held in Denver, CO, July 25-27, 2002. For more information call 866-866-8335 or visit www.friendswhostutter.org.

The annual convention of NSA will be held in Anaheim, CA, June 26-30, 2002. For information call 800-364-1677.

The 4th World Congress on Fluency Disorders will be held August 15-19, 2003 in Montreal, Quebec, Canada. For more information contact Dr. Roslee Shenker at rshenker@music.uogiller.ca or Lisa Avery at averlyl@exchange.ubc.ca.

Joe Donaher at turtlcr4@aol.com has created a LISTSERV for doctoral students specializing in stuttering. The list serves as an open forum for doctoral students limited to doctoral students only. To subscribe, send the following to listserve@listserv.temple.edu: subscribe stutterdoc firstname lastname or contact Joe Donaher at turtlcr4@aol.com.

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) 838-8255, Fax: (714) 838-1202.

For those wanting to obtain a copy of Self-Therapy for the Stutterer in Japanese, write to Dr. Shigeki Nakayama, 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 Bégues du Canada, 7901 Rue Ste. Claire, Montreol, Quebec, Canada, H1J 1V8. Please enclose $15.00 Canadian to cover printing, postage, and handling cost.

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.

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“What led me into this career was stuttering,” says the director of the Science and Exploration Program at the Wildlife Conservation Society. “Speaking was an unbearable horror. It was only in the most remote areas that I felt at peace.”

But no place was remote enough to shake the traumatic childhood memories of his stuttering. In Beyond the Last Village, Rabinowitz recounts a moment when, faced with imminent death on a rock ledge high over a river in Asia, his mind involuntarily flashes back to his school days.

“I closed my eyes against the fear and pain, and found myself back in my sixth-grade classroom. The teacher was calling me to read…Now I’d have to get up and stutter, and the whole class would see the spitting, the head jerks, and everything else that made me look like a fool. Some kids would laugh, and others would look away because they pitied me. I dropped my pencil to the floor and then bent below the desk to pick it up. Without stopping to think, I stabbed the point of the pencil into the palm of my hand, hard. The pain was immediate, shooting up into my arm the way the ache from the jagged rock was doing now.”

Such flashbacks fill this most-personal of Alan’s books. The anguish he felt due to his stuttering “is still part of my psyche,” he says. “It was such an horrific incident, when I chose self-mortification over public speaking. Pain was bearable; humiliation was not. I wouldn’t have equated it to falling off a rock ledge at 100 ft. in an earthquake, but my mind equated it.”

Rabinowitz’s early years were fraught with the difficulty and loneliness caused by stuttering. Although bright, he was judged to be mentally deficient and even placed in a class for autistic children.

“They didn’t know how to deal with it in the public schools,” he says. “I felt like the only stutterer in the world.”

It was not until he was in college that Alan received therapy at the Starback Clinic in Geneseo, N.Y. “That was the first breakthrough,” he says. The techniques he learned and subsequent fluency were life-changing.

Now, after years of silence and bottled up emotion, Alan speaks passionately and publicly about preserving wildlife, his travels and writing, and stuttering. “I don’t want others to go through the pain,” he says. He is also very aware of the need to continually practice what he learned in speech therapy. “It doesn’t ever become totally automatic. I can control it if I fall back on old techniques, but if I just let it go it gets worse.”

“Alan’s book and his life prove that, with perseverance, nothing is beyond reach,” said Jane Fraser. “We hope that his story will inspire others to discover what they can do about stuttering.”

Rabinowitz Speaks to National Geographic

by Jean Gruss, SFA Board of Directors

Alan Rabinowitz would much prefer tracking animals in the wild than standing in front of a crowd and delivering an hour-long speech. But his passion for wildlife conservation overrides his occasional stutter as he recounts his efforts to establish conservation areas in some of the most remote regions of the world.

In March, more than 300 people gathered at the National Geographic Society’s headquarters in Washington, D.C., to hear Rabinowitz give a presentation on wildlife conservation activities in the Southeast Asian country Myanmar, formerly called Burma. Rabinowitz spoke about the challenges he faced as he persuaded that country’s military junta to set aside land for wildlife conservation.

As director of science and exploration for the Bronx Zoo-based Wildlife Conservation Society, Rabinowitz and his team helped create Hkakabo Razi National Park, now one of the largest protected areas in Southeast Asia. At the National Geographic, he said the government of Myanmar recently had asked him to expand conservation areas because of his earlier success.

In his book, Beyond the Last Village, Rabinowitz recounts the hazardous expedition into a majestic and undiscovered land where he found mysterious new species of animals and lost pygmy civilizations. Parts of the book also deal with his personal challenges such as stuttering and months of separation from his wife in New York. Rabinowitz’ book is widely available at bookstores and is published by Island Press.