



THE STUTTERING FOUNDATION

A Nonprofit Organization

SUMMER 2010

Since 1947 ... Helping Those Who Stutter

Byron Pitts of *60 Minutes* Joins Famous People Poster for National Stuttering Awareness Week, May 10-16

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Starkweather Receives Malcolm Fraser Award

C. Woodruff Starkweather, Ph.D., received the 2010 Malcolm Fraser Award during the January meeting of the Special Interest Division for Fluency and Fluency Disorders. Barbara Amster, Ph.D. made the following award presentation:

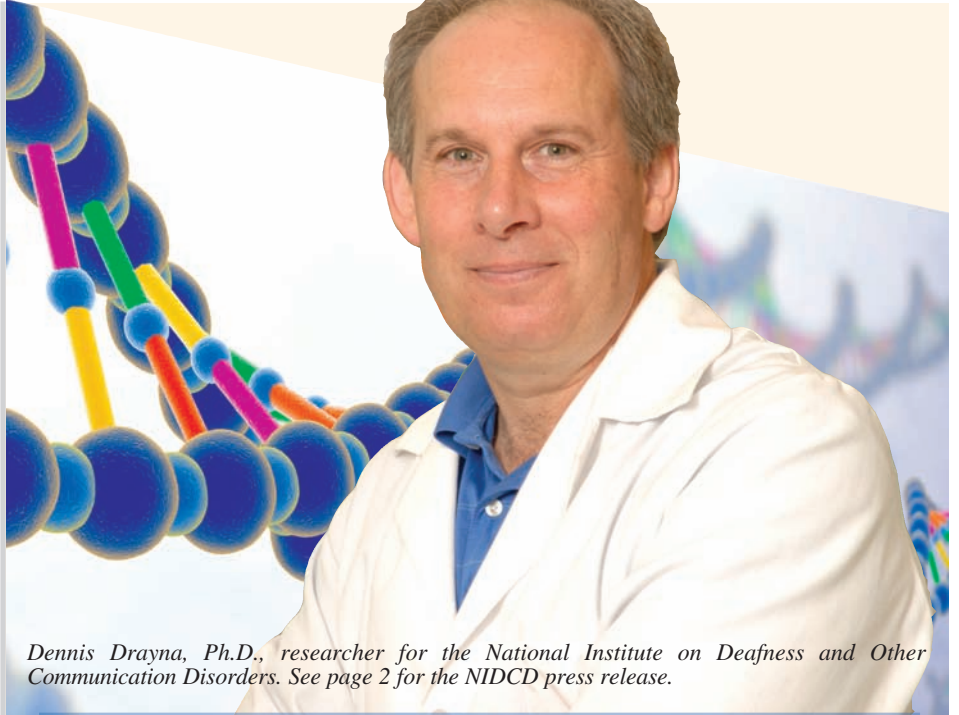
I was asked to give the highlights of the awardee's career. This is not an easy feat as his CV is more than 25 pages long, but I will try to give you only the highlights.

Woody Starkweather is an individual whose contributions over more than 40 years have promoted and enhanced public and professional understanding of the nature of stuttering and its treatment. He has demonstrated excellence in the field of stuttering as a master teacher, advocate for people who stutter, and scholar/researcher. In the words of one of his nominators, "I believe that he is one of only a few people whose contributions to the field of stuttering go beyond a listing of research, teaching, and service accomplishments.

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Jean Gruss, grandson of SFA founder Malcolm Fraser, and C. Woodruff Starkweather at the award ceremony.



Dennis Drayna, Ph.D., researcher for the National Institute on Deafness and Other Communication Disorders. See page 2 for the NIDCD press release.

Researchers Discover First Genes for Stuttering

The mystery behind a complex disorder called stuttering became a little clearer with the announcement of the discovery of three genes for stuttering by Dennis Drayna, Ph.D., a director of the Stuttering Foundation and researcher for the National Institute on Deafness and Other Communication Disorders.

"This research is important because it's another indication that emotional factors such as anxiety or 'bad parenting' do not cause stuttering. It could also point the way for a cure one day," says Jane Fraser, president of the Stuttering Foundation.

"We hear every day from parents worried that they have caused their child's stuttering. Parents don't cause stuttering, and this research should lift the burden of guilt from their shoulders," Fraser noted. "But because a cure may be years away, speech

therapy and early intervention with young children remain the best option for now."

"We have long known that stuttering runs in families," says Fraser. "We want to emphasize that a genetic predisposition for stuttering does not mean a person will have a lifelong problem. Early treatment in young children can effectively prevent stuttering."

Developing an understanding of the biological basis of stuttering may someday lead to better early diagnosis, differential treatments for people with genetic indicators, and a better understanding of how speech production happens differently for people who stutter. Although Dr. Drayna notes that his findings are unlikely to have any immediate impact on treatment, they nonetheless represent a giant step forward.

Press Release from the National Institute on Deafness and Other Communication Disorders:

Findings Suggest Stuttering, in Some Cases, May Actually be an Inherited Metabolic Disorder

Feb. 10, 2010 — Stuttering may be the result of a glitch in the day-to-day process by which cellular components in key regions of the brain are broken down and recycled, says a study in the Feb. 10 Online First issue of the *New England Journal of Medicine*. The study, led by researchers at the National Institute on Deafness and Other Communication Disorders (NIDCD), part of the National Institutes of Health, has identified three genes as a source of stuttering in volunteers in Pakistan, the United States, and England. Mutations in two of the genes have already been implicated in other rare metabolic disorders also involved in cell recycling, while mutations in a third, closely related, gene have now been shown to be associated for the first time with a disorder in humans.

“For hundreds of years, the cause of stuttering has remained a mystery for researchers and health care professionals alike, not to mention people who stutter and their families,” said James F. Battey, Jr., M.D., Ph.D., director of the NIDCD. “This is the first study to pinpoint specific gene mutations as the potential cause of stuttering, a disorder that affects 3 million Americans, and by doing so, might lead to a dramatic expansion in our options for treatment.”

Stuttering is a speech disorder in which a person repeats or prolongs sounds, syllables, or words, disrupting the normal flow of speech. It can severely hinder communication and a person’s quality of life. Most children who stutter will outgrow stuttering, although many do not; roughly 1 percent of adults stutter worldwide.

Stuttering tends to run in families, and researchers have long suspected a genetic component. Previous studies of stuttering in a group of families from Pakistan had been done by Dennis Drayna, Ph.D., a geneticist with the NIDCD, which indicated a place on chromosome 12 that was likely to harbor a gene variant that caused this disorder.

In the latest research, Dr. Drayna and his team refined the location of this place on chromosome 12 and focused their efforts on the new site. They sequenced the genes sur-

rounding a new marker and identified mutations in a gene known as GNPTAB in the affected family members. The GNPTAB gene is carried by all higher animals, and helps encode an enzyme that assists in breaking down and recycling cellular components, a process that takes place inside a cell structure called the lysosome.

They then analyzed the genes of 123 Pakistani individuals who stutter—46 from the original families and 77 who are unrelated—as well as 96 unrelated Pakistanis who don’t stutter, and who served as controls. Individuals from the United States and England also took part in the study, 270 who stutter and 276 who don’t.



The researchers found some individuals who stutter possessed the same mutation as that found in the large Pakistani family. They also identified three other mutations in the GNPTAB gene which showed up in several unrelated individuals who stutter but not in the controls.

GNPTAB encodes its enzyme with the help of another gene called GNPTG. In addition, a second enzyme, called NAGPA, acts at the next step in this process. Together, these enzymes make up the signaling mechanism that cells use to steer a variety of enzymes to the lysosome to do their work. Because of the close relationship among the three genes in this process, the GNPTG and NAGPA genes were the next logical place for the researchers to look for possible mutations in people who stutter. Indeed, when they examined these two genes, they found mutations in individuals who stutter, but not in control groups.

The GNPTAB and GNPTG genes have already been tied to two serious metabolic diseases known as mucopolysaccharidosis (ML) II and III. MLII and MLIII are part of a group of diseases called lysosomal storage disorders because improperly recycled cell components accumulate in the lyso-

some. Large deposits of these substances ultimately cause joint, skeletal system, heart, liver, and other health problems as well as developmental problems in the brain. They are also known to cause problems with speech.

“You might ask, why don’t people with the stuttering mutations have more serious complications? Why don’t they have an ML disease?” posed Dr. Drayna, senior author of the paper. “ML disorders are recessive. You need to have two copies of a defective gene in order to get the disease. Nearly all of the unrelated individuals in our study who stuttered had only one copy of the mutation. Also, with stuttering, the protein is still made, but it’s not made exactly right. With ML diseases, the proteins typically aren’t made at all. Still, there are a few complexities remaining to be understood, and we’d like to learn more about them.”

The findings open new research avenues into possible treatments for stuttering. For example, current treatment methods for some lysosomal storage disorders involve injecting manufactured enzyme into a person’s bloodstream to replace the missing enzyme. The researchers wonder if enzyme replacement therapy might be a possible method for treating some types of stuttering in the future.

The researchers estimate that roughly 9 percent of people who stutter possess mutations in one of the three genes. Among the next steps, they are conducting a worldwide epidemiological study to better determine the percentage of people who carry one or more of these mutations. They are also conducting biochemical studies to determine specifically how the mutations affect the enzymes. A long-term goal is to use these findings to determine how this metabolic defect affects structures within the brain that are essential for fluent speech.

In addition to the NIDCD, researchers at the University of Punjab, Lahore, Pakistan; the Hollins Communications Research Institute, Roanoke, Va.; the National Human Genome Research Institute (NHGRI); and the NIH Clinical Center contributed to this work.

More than 100,000,000 People Reached!

Feb. 10 was a blockbuster day with news of the discovery of the first three genes for stuttering.

Stephanie Nano's Associated Press wire story reached more than 1,700 newspapers, 5,000 radio and television outlets in the United States, and radio, television and newspaper subscribers internationally. In her article, Nano quotes Dennis Drayna as saying "stuttering is almost certainly a biological problem." She also included SFA's Jane Fraser's comment that "in terms of mythbusters, this is really an important step forward."



Richard Knox's NPR segment for *Morning Edition* reached more than 20 million listeners. He interviewed Dr. Drayna extensively as well as speech-language pathologist Kristin Chmela and Fraser. Chmela shared her excitement about the new research not only from the viewpoint of a therapist, but also of a person who stutters herself.



Fraser shared with Knox how thrilled her father, Stuttering Foundation founder Malcolm Fraser would have been to learn of this discovery. "He always felt that if he just tried hard enough, he wouldn't stutter. This research would have lifted a heavy burden of guilt from his shoulders."



The news appeared around the world at lightning speed with additional articles and segments by Agence France Presse, the *China Daily*, AAJ Pakistan TV, *The Tehran Times*, *The Watan Daily* in Kuwait, the *Brisbane Times*, and a live interview in Sydney, Australia with Dr. Drayna.

Other U.S. outlets featuring the findings include HealthNewsDigest, *The Philadelphia Inquirer*, *The Commercial Appeal*, the *Arizona Daily Star*, *El Paso Times*, *Cleveland Plain Dealer*, *Newsday*, MarketWatch, ABC, CBS, Fox News, CNN, the *Miami Herald*, and many more too numerous to list.



Coverage of the discovery of the first genes for stuttering included the Stuttering Foundation's being featured on marquees in Times Square.



Annual Audit

The annual audit of the Stuttering Foundation financial reports for 2009 was recently completed by the accounting firm of Cannon and Company, Certified Public Accountants, Memphis, Tenn. Following is a recap of

funds and expenditures for the year.

The 3.8% of expenditures for administration and general expenses and the 7/10 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.

The Foundation is a 501(c)(3) private operating foundation which expends its funds on its own programs and operations and does not make grants to other institutions.

Funds expended for:

Creation, production, printing and distribution of educational materials	\$503,615	36.5%
Public information and education	300,781	21.8%
Educational symposia for professionals	172,360	12.5%
Research on causes/treatment of stuttering and therapy	254,687	18.4%
Maintain Web site and toll-free information hotline	87,169	6.3%
Total for Program Services:	\$1,318,612	95.5%
Other expenditures:		
Administration and general	51,984	3.8%
Fund-raising expense	10,318	0.7%
Total Expenditures:	\$1,380,914	100%



Michael Palin



Prince Charles



Jane Fraser, Lady Caroline Egremont and Prince Charles.



Education Secretary Ed Balls, Michael Palin and Prince Charles.

Prince Charles Supports Stammering Centre

Stuttering Foundation President Jane Fraser attended a luncheon reception at Clarence House hosted by Prince Charles to announce His Royal Highness' support of an appeal to fund treatment for children who stutter. The appeal was launched by the Association for Research into Stammering in Childhood (ARSC), our Foundation partner in the United Kingdom.

"It was a great honor to meet Prince Charles and work to increase awareness and support for stuttering," Fraser said.

The Prince of Wales commented, "I am so pleased to be Patron of this Appeal particularly in memory of my grandfather, King George VI, who, as many of you will know, was afflicted with a stammer for many years. His stammer cut him off I think in so many ways from his parents and his brothers and sisters and drove him into himself as I suspect so many stammerers will understand. Above all he experienced that awful fear of feeling different from others."

[Read more about this event, view press coverage, and find the Prince's entire speech at www.stutteringhelp.org.](#)



Prince Charles greeting Travers and Sandra Reid. Travers is Life President and co-Founder of ARSC.



Renowned author Lord Max Egremont with Prince Charles.



Dame Gail Ronson and Major General Bryan Dutton greet Prince Charles.



Jane Fraser is seen meeting Prince Charles on the TV news.



Prince Charles and Frances Cook.

National Stuttering Awareness Week
May 10-16, 2010



In response to the exciting genetic findings, our Friends on Facebook let us know what they thought:

Ray
 As I listened to the NPR broadcast regarding the new genetic finding about the cause of stuttering, tears were streaming down my cheeks. I reflected back on the 60 years of my life, and it just seemed as though so much of the ridicule, self doubts and struggles melted away; in their stead were knowledge, understanding and a feeling of inner peace. I now think that I know how Atlas must have felt when he was allowed to remove the weight of the world from his shoulders.

Katie
 As an SLP and Mom to 3 beautiful kids ages 8, 7, and 5 who've all stuttered to varying degrees this research is very exciting! Our oldest and youngest responded positively to modifications at home to promote fluency (modeling reduced speaking rate, daily one on one time, etc.), but for our middle daughter who also had multiple articulation errors and relatively weak language skills, the modifications weren't enough. She has been in speech for 3 years, and is doing great! As an SLP I knew that there were many misconceptions about stutters and their parents. However, until I faced these misconceptions as a parent, and encountered people's reactions to my children's stuttering; I didn't fully appreciate how painful they can be to stutters and their loved ones!

Susanne
 As a mother of a 12 year old who stutters, I've been told numerous times that it is nothing the parent has done to cause this stuttering, yet the doubt was always lingering there. This is great news for all who have been affected by stuttering.

Brandon
 As a teen that stutters I really hope that it is a gene defect and doctors can somehow change it. I've always joked around with my speech teachers about that and now it may actually happen.

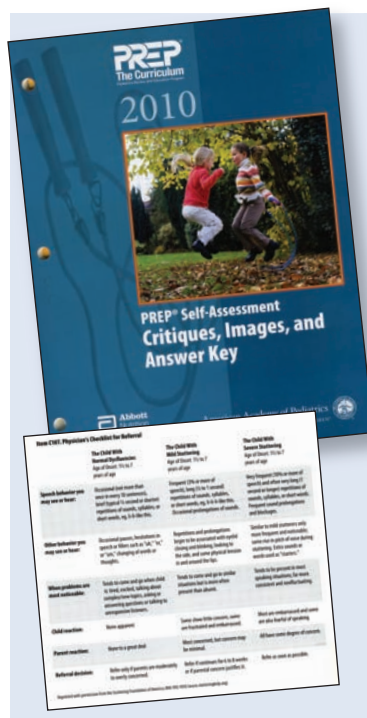
Alan
 As a life long stutterer this could finally lead to better treatment, too late for me but for the younger people this is potentially good news.

Jackie
 As a mom of a 7 year old boy who has struggled with this for 2 years it is heart breaking knowing there is not a pill, cure or simple fix. And as with Susanne, I was told there is nothing we could have done to cause it, you still always question yourself. But this study helps with relieving some of that doubt. The Stuttering Foundation has provided our family with a lot of information & the SLP & my son's teachers have been amazing. Thank you all!

National Stuttering Awareness Week is May 10-16

60 Minutes Correspondent Byron Pitts Joins the Team of Famous People

If you stutter, you are definitely in good company!



Outreach to Pediatricians

The new Pediatrics Review and Education Program, *PREP The Curriculum 2010*, displays the Stuttering Foundation's Physician's Checklist for Referral.

This Checklist helps physicians know when and how to refer their young patients to a speech-language pathologist for treatment.

Barry Guitar, Ph.D., and Edward G. Conture, Ph.D., compiled this Checklist; and it is part of the bestseller, *The Child Who Stutters: To the Pediatrician*, published by the Stuttering Foundation.

"Reaching pediatricians with accurate information on stuttering is one of our most important goals," said June Campbell, M.A., CCC-SLP, who represents the Foundation at the American Academy of Pediatrics convention every year.

T-shirts featuring running backs LaDanian Tomlinson and Darren Sproles have sold out.

Greathouse Screen Printing cranked out thousands of these special edition Chargers shirts with the headline "Thunderbolt and Lightning, Very, Very Frightening."

Each player donated the proceeds from the sale of the t-shirts to charities close to his heart. Sproles, an SFA spokesman, chose the Stuttering Foundation.



T-shirt supports Foundation



Malcolm Fraser and Woody Starkweather in the 1970s



Woody Starkweather and Jane Fraser



Woody Starkweather and Janet Givens



Woody Starkweather and Vianne Bjornberg



Barbara Amster, Ken St. Louis, Hayley Arnold and Vianne Bjornberg



Woody Starkweather and Sheryl Gottwald



Rossanna Portley, Hayley Arnold, Courtney Byrd and Jane Fraser



Woody Starkweather and Vivian Sisskin



Jennifer Watson and Susan Cochrane



Glen Tellis, Kathy Scaler-Scott and Marilyn Langevin



Rossanna Portley and Shelley Brundage



Woody Starkweather, Vivan Sisskin and Liz Edwards

Award *Continued from front page*

Woody truly cares about people who stutter, and has worked tirelessly to give them a voice through his writing, his leadership, and his creative vision.”

Many of his writings have changed the way speech-language pathologists evaluate and treat stuttering. His work on the Demands and Capacities Model has had a profound impact on stuttering prevention and has influenced our understanding of factors that contribute to the onset and maintenance of stuttering behaviors, thus setting the stage for multi-factorial views of stuttering.

He has had a stellar career as a scholar and researcher. His book *Stuttering*, co-written with Janet Givens, received the Choice Magazine Award as the “Best Academic Book of 1997.” This was the first time that this “Oscar of Academic Publishing” had been given in the field of Speech Pathology. Other books he has written are now considered classics in the field including: *Stuttering Prevention: a Clinical Method* (1990; co-authored with Sheryl Gottwald & Murray Halfond) and *Fluency and Stuttering* (1987). He is the author of more than forty articles and chapters concern-

ing: learning processes in stuttering, the Demands and Capacities Model of stuttering, stuttering development, stuttering prevention, the assessment of stuttering, the experience of stuttering, and the efficacy of stuttering therapy.

In the words of one nominator, “his contributions go far beyond the walls of the classroom and clinic. He has made the greatest contribution of anyone I know towards connecting people who care about stuttering, and developing mechanisms for allowing them to learn and support one another. He demonstrated this through his leadership as president of the International

Fluency Association, helping develop and nurture it as it grew from a fledgling organization into a recognized avenue of exchange and communication among the international community in stuttering. He was instrumental in the development of ASHA’s Specialty Recognition program. He served on ASHA’s Special Interest Division 4, Fluency and Fluency Disorders, helping to write guidelines and to unify professionals otherwise

working in isolation in schools, clinics, hospitals and universities across the country.”

His tireless advocacy for people who stutter has given a strong voice to children and adults who stutter. His leadership in the development of support groups provided the model for future support organizations throughout the world. When he founded STUTT_L, an internet discussion list for researchers, clinicians, and people who stutter, individuals from all of these groups had a forum to discuss and share ideas for the first time. He has had a profound influence on people who stutter, their families, and the speech-language pathologists who treat them. It is with great respect and admiration that we present the 2010 Malcolm Fraser award to Dr. C. Woodruff Starkweather.

Lewis Carroll

The recent Disney version of Lewis Carroll's classic, *Alice in Wonderland*, garnered a great deal of media hype. Even though the mainstream media has not made mention that Carroll was a person who stuttered, his family history gives credence to the discovery of the genetic link to stuttering. Carroll was born to parents who were first cousins; almost all of their eleven children, three girls and seven boys, struggled with stuttering past childhood.

In *Lewis Carroll: A Biography*, author Morton N. Cohen stated, "The newborn son was the third of what eventually became a family of eleven children, and if these bloodlines deserve credit for the creative genius we know to be Lewis Carroll's, so perhaps they bear the blame for the stammer epidemic in Charles' speech and in the speech of much of his brothers and sisters."

Lewis Carroll, the pseudonym of Charles Lutwidge Dodgson, was born in 1827 to Charles Dodgson and the former Frances Jane Lutwidge. In addition to being a writer, Carroll was a mathematician, a logician, an Anglican deacon and a photographer. His most notable literary works are *Alice's Adventures in Wonderland*, *Through the Looking Glass*, *The Hunting of the Snark*, and *Jabberwocky*.

Biographer John Pudney expressed in *Lewis Carroll and his World* how Carroll's childlike fantasies were not only the spark for his creative genius but also brought him into a new world where stuttering did not exist, "This 'perfectly hard crystal' containing childhood was his



"Rules & Regulations"

Learn well your grammar
And never stammer...
Eat bread with butter
Once more, don't stutter.

~Lewis Carroll

true essential life, expressed in the Alice books and in some poems When he spoke to these children, he lost his habitual stammer. He simply became one of them This perennial childhood, together with the fantasy and poetry that sometimes expressed it, was his reality."

In 1859, Carroll undertook speech



therapy lessons from James Hunt, who was considered the foremost speech correctionist in Great Britain at the time and was estimated to have treated 1,700 people who stutter. In *The Mystery of Lewis Carroll*, biographer Jenny Woolf stated that Hunt boasted he taught the patient to speak consciously in a way that other men spoke unconsciously.

Nothing bothered Carroll more about his speech than how it affected his ministry in the Anglican Church. His father had been an Anglican priest, and Carroll himself became a deacon. Upon one occasion he accepted the invitation to preach and recalled, "I got through it all with great success, till I came to

read out the first verse where the two words 'strife, strengthened' coming together were too much for me, and I had to leave the verse unfinished."



Carroll's nephew, Stuart Dodgson Collingwood,

wrote that his uncle "saw that the impediment of

speech from which he suffered would greatly interfere with the proper performance of clerical duties."

One longtime friend, May Barber, described Carroll's speech, "Those stammering bouts were rather terrifying. It wasn't exactly a stammer because there was no noise, he just opened his mouth When he was in the middle of telling a story he suddenly stopped and you wondered if you had done anything wrong. Then you looked at him and you knew that you hadn't, it was all right. You got used to it after a bit. He fought it wonderfully."

Biographer John Pudney wrote, "Perhaps his failure to correct his speech impediment was the overarching symbol of his entire life. He learned to live with his stammering;

he knew what it permitted him to do, what not, where it would snare him and destroy the effects he sought to achieve and how to avoid the traps."

Stuttering did not stop Lewis Carroll. He brought to life many lasting and imaginative stories for children. It is a shame that his own struggles and family history of stuttering are not well known as they would further inspire as well as help children who stutter.



From One Clutterer to Another ... Strategies that Helped Me

By Lacey Heid

I was diagnosed with a mild cluttering disorder when I was 24 years old. Cluttering is a type of fluency disorder, and it often gets misdiagnosed or undiagnosed altogether. I want to discuss what has helped me improve my speech. Hopefully, this will help others who clutter find some strategies that may help improve their speech, as well as shed some light for SLPs on ways to help their clients with fluency disorders.

As I got older, my peers started reacting to my speech rate. Although I had a lot of friends, there would be that occasional person that playfully mocked my “stuttering” or mentioned that I always talked too fast.

In the working world, it became worse. Co-workers and customers had a hard time understanding me, and it became more obvious to me as their comments became more numerous. I had difficulties speaking to authority figures, as well as talking on the phone. I was constantly told to speak more quietly, and “what’s” and “huh’s” became a more frequent response from my listeners. At age 24, I realized how much I was letting my speech hold me back from better jobs and opportunities. I wanted to be an overall better communicator. I decided to start speech therapy.

And that’s when I learned the truth. I was not a stutterer at all. In fact, I was a clutterer. While stuttering is noted by repetitions, prolongations, blocking, and secondary “escape” behaviors, cluttering is noted by excessive normal disfluencies, rapid bursts of speech (“excited speech”), and slurred/omitted syllables.

While a stutterer can usually hear and feel their speech disfluencies, a clutterer is usually



The Stuttering Foundation offers a DVD and brochure on cluttering.

unaware of them, and therefore, has a hard time self-monitoring. Cluttering is often misdiagnosed, or in my case, undiagnosed, even though onset can occur as early as the preschool years.

After my initial speech and language evaluation, my SLP (who at the time was a student clinician) and I began to work on numerous strategies focusing on slowing my speech rate, and becoming more intelligible.

Although I understood the point to the exercises, I didn’t appreciate their meaning until the day I walked into the room and my SLP told me we were going to record parts of the session, and then play the recordings back so that I could hear myself talk.

Not many people like hearing the sound of their own voice, my being one of them, so I was highly reluctant, but I turned to my positive attitude. It was for my own good.

She had taped our casual conversations at the start of the session, and then she taped my reading samples using the strategies that we were focusing on. When she replayed our conversations, I heard it. I heard how fast I spoke. I heard the missing parts of the words, the rapid speech, and I heard

how strained my voice sounded at the end of my sentences (because I would speak on residual air). Then, we listened to the recordings of the reading samples.

This was the turning point in my speech therapy, because I heard the difference. I heard the pausing. I heard every sound in every word. I understood everything I had said. That is the point when I realized that I could talk more slowly and I could be understood. All I had to do was take these strategies and apply them to everyday conversation.

Self-Monitoring — This was by far the most important strategy for me. I needed to be able to hear my own speech rate as I was speaking and adjust my speech accordingly.

If I couldn’t hear myself omitting syllables, or hear myself “cramming” words together, I wouldn’t be successful in stopping or preventing myself from cluttering.

This is where the uncomfortable recordings of my voice helped so much, because I was able to feel myself performing the action of speaking more slowly, and then I was able to play back and hear myself speak at a normal rate. There was a huge positive reinforcement when I discovered this.

To read more about what worked for Lacey, go to www.stutteringhelp.org.



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.



Another Great Year!

The Stuttering Foundation PSAs are in national and regional magazines as well as newspapers across the country. Readers may spot an ad featuring Winston Churchill, Nick Brendon, conservationist Alan Rabinowitz and many others.

A new PSA with San Diego Charger Darren Sproles has been sent to sports magazines for use in upcoming issues.

Recent PSAs appeared in *Good Housekeeping*, *Redbook*, *ESPN*, *Seventeen*, *Popular Mechanics*, *Time*, *American Baby* and newspapers including the *Philadelphia Inquirer*, *New York Post*, and the *NY Times Magazine*.

The Stuttering Foundation thanks these publications for this valuable donated space that reaches thousands and thousands of readers looking for help.

Help Available in Croatian



The Child Who Stutters: To the Pediatrician has been translated into Croatian by Dubravka Prpic. It can be downloaded from our Web site, www.stutteringhelp.org. Click on "Translations" on the left.

Workshopper Reaches Spanish Speaking Community

Judi Cheng, M.S., CCC-SLP, a Stuttering Foundation Eastern 2009 workshopper appeared recently on Univision Television Network's *Despierta America* for a segment on Spanish speaking kids who stutter.

Immediately following Cheng's interview with Yahaira Maldonado, the Foundation began receiving hundreds of calls and e-mails from Spanish speaking people looking for help with stuttering.

One viewer wrote, "I am 17 years old. I have been stuttering since I was about 5. My mother saw your interview on TV. We saw on your website that you can give us a list of people that might be able to help."

"My son is the only one who stutters at his school," comment-

Did You Know?

The Stuttering Foundation has numerous resources in Spanish as well as a Spanish Web site, www.tartamudez.org.

ed the mother of a 6-year old boy. "I want more information on how to help him with teasing, and I need the name of a therapist."

Another concerned parent

emailed, "My child began stuttering when he was 5 and now he is 7. He is getting therapy two days a week, but we need more help."

"My daughter is 6-years old and has a slight stutter when she

speaks Spanish and sometimes when she speaks English. Can you send me information to help?" asked a mother from New Jersey.

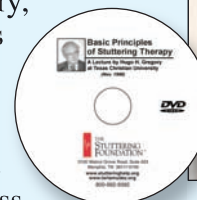
To view the Univision *Despierta America* segment on stuttering, visit www.stutteringhelp.org.



Stuttering Foundation workshopper Judi Cheng, M.S., CCC-SLP, speaks about stuttering on Univision's *Despierta America*.

Gregory's *Basic Principles* on DVD

Clinicians are still receiving training in the treatment of stuttering by the expert speech language pathologist, Hugo Gregory, Ph.D., through footage shot at Texas Christian University in 1998. The new DVD, *Basic Principles of Stuttering Therapy*, is now available at www.stutteringhelp.org. The Foundation is grateful for the tireless efforts of Carolyn Gregory, June Campbell, Diane Hill, Jennifer Watson and Kristin Chmela who worked to make this DVD a reality.





Carol Ecke was ably assisted by Jennifer Watson, Valerie Johnston, Tara Hepler, Montse Vallejo, and Geoff Coalsol at the marvelously successful convention of the **Texas Speech-Language-Hearing Association**. Russ Hicks of NSA provided this fine photo.



Darlene Sommers, Kavita Kaul, and Maryann Kaminsky at the conference of the **Speech-Language-Hearing Association of Virginia**.



Charlie Osborne and Jessica DeMille at the conference of the **Wisconsin Speech-Language Pathology and Audiology Professional Association**.



SFA's Terri Jones prepares the booth at the **Georgia Organization of School-Based Speech-Language Pathologists Best Practices Conference** in March. Patty Reed joined her at the booth.

Keep a Positive Attitude

I've been a stutterer for as long as I can remember. It has always weighed down my shoulders like I'm wearing a backpack full of rocks. It has stopped me from trying out in plays, doing extra-credit oral reports, running for 7th grade officer, and, in general, speaking aloud to any kind of audience.

When I came to the Center, I was able to learn some new techniques to control my stuttering, ones that actually worked. Sadly, although "prolongation", "pull outs", and "easy bumps" had helped my stuttering, they didn't really help my confidence. I could use the tools and speak okay, but it didn't mean I wanted to talk to an audience.

So Maria gave me a challenge to volunteer to read at school, offer to pray at church, and raise my hand if I knew the answer to a teacher's question. This challenge terrified me, and at first it was like torture. Gradually, I realized that each time I did it, it became easier and easier. Soon it was no big deal when I spoke or read in class, and now I even find it fun.

Stuttering is what makes me an individual, and I'm not ashamed that I'm a little different from everyone else.

We should keep practicing our techniques to stay fluent, but most of the stuttering is in your heart. When you release the embarrassment, the sadness, and the stress of stuttering out of you, it will become little more than the nose on your face, the shape of your eyes, the color of your hair.

Yes, I stutter, but I don't care. It's what makes me, me.

Megan, 14

Sense of Humor Helps

I think it's good for everyone to have a good sense of humor. I like Jeff Dunham and Dane Cook. I like to quote some of their lines to my friends and fam-

ily. It's easy for me to talk to people without bumping when I quote others, and it makes me happy when I tell stories to people that make them laugh.

It's also good to have a sense of humor when other kids say things that hurt your feelings. You just have to remember that they don't understand and haven't learned how to treat anyone with respect.

Remember, bullies have more personal issues than other kids. Ignore them and remember always how great you are.

London, 12

What Listeners Should Know

One percent of the world's population stutters as adults and 1 in every 20 children have a stuttering problem. We need time to get out what to say, and if you insult one of us, are you going to insult all 6.7



Students in the **Wasatch Children's Stuttering Management Program** wrote these stories and presented them to the group on selected topics regarding stuttering.

million of us? We need time to get our words out, and if you ignore us, can you be certain you didn't miss something important? Do not make assumptions about people who stutter, you might be

quite a bit wrong.

I am saying this because I do not want people to assume I have a mental issue, or that I forgot my name, just because I got stuck on the first C. Give us time, let us speak!

Clay, 13

Feels Like a Maze

I'm in a maze, trying to find my way out. It seems like, there's no way out of this never-ending maze. Every stutter, block, and struggle makes me more confused. The only way out is to use my techniques, prolongation, pull-outs, easy/fake stuttering, and responding to my moments of stuttering. Finally, I've found my way out of the maze.

Devan, 14

Turning a Negative Into a Positive

By Dylan Levin

Two years ago Dylan Levin asked friends and family to donate to the Stuttering Foundation as a way to honor his Bar-Mitzvah. Now as a high school student, he is busy making speeches and presentations without letting stuttering get in the way. The following essay is a podcast script Dylan gave recently at his school.



As many of you know or don't know, I have a speech disfluency called stuttering. I have had this since the age of four. My stuttering is an involuntary movement, which I can't control. Stuttering was never an issue at school; I always participated in class and I never felt that there was a problem until one day in sixth grade. That was the day when I realized that my stuttering was never going to go away and therefore I had to work hard on my speaking abilities.

It happened at my school spelling bee. There were two ways people got to be a part of the spelling bee. The first one was where you compete with people in your own advisory and then the winners go against people from all of the other advisories. Lucky for me, I won the spelling bee for my advisory. I didn't think about the fact that I would have to spell words in front of the school at that moment in time because I was just happy that I had won. The day wore on and I started to become really nervous because I had never given an announcement or done anything, really, in front of the entire school. I would participate and give presentations in my class and there I felt very comfortable. But speaking in front of the whole school made me nervous. I was nervous because only the people in my grade really

knew that I stuttered and that bothered me because what if I stuttered during the spelling bee? How would people respond?

At 2 p.m., it was time for the spelling bee. I walked down the stairs to the cafeteria where it was being held and I took my seat on the stage. The problem was that I psyched myself out. I knew that I was going to fail. One by one the kids spelled and one by one they got it right. My turn. The word was population. Dead silence. I must have said uh and um about a hundred times to make it seem like I wasn't stuttering. And the thing was that I knew how to spell the word, but I just could not get the word out. Population is not a hard word to spell. Then the



most horrible thing happened, laughter. Never in my life had anyone really laughed at me like this girl did. Her name was Allie, and I will never forget her.

I purposefully spelled the word wrong, just to get out of this embarrassing situation. I went into the bathroom and started to cry. I was mortified and angry. I began asking God why me, why did you give me this terrible stutter? Why did you make people laugh? I walked backed into the cafeteria and sat in the back. I did not want to show myself to anyone. When I came back the teacher gave some weak speech about being respectful to all of the people in the spelling bee, but everyone

could tell that it was directed at what happened to me. Nobody knew what I had just gone through and nobody understood my situation.

Later that night, the phone rang and it was Allie's teacher calling to discuss what happened at school. I did not tell my mom because I did not want her to get involved. I did not want her to get upset. The truth is that I probably should have told her the moment I got in the car, right after school. Mr. L told my mom the whole situation, and she wanted to come into his class, to talk with the kids about my disfluency and how to be accepting of a person with disabilities. I know that my mom, when it comes to my speech disfluency, will always have my back.

Four years have passed since this happened and now it is only a memory lost in the pages of my life. My speech from that time has improved and I owe that partially to Allie. If she had not laughed then I probably would not have experienced real vulnerability. Every person that does stutter, has his or her human form wrapped in a blanket of vulnerability all the time, but it is how we persevere during these hard times that truly define us. I know now that I would not be the same person that I am today if I did not stutter. I carry around this memory with me always because it is a reminder that I must keep on persevering and I must keep on talking because if I let this stutter overcome me, then I have lost all hope. What I am trying to convey is that people must persevere to overcome any obstacle that they are faced with. Maybe one day I will not have a speech disfluency, but until then, I will keep living and talking.

Dear SFA: Reader Response



Send letters to SFA, P.O. Box 11749, Memphis, TN 38111-0749 or e-mail info@stutteringhelp.org.

Friendships Help

Dear SFA:

I feel bad when I stutter. I can't express what I want to say. When I repeat a word I get frustrated. When this happens, I stop and think about what I'm going to say. Sometimes this helps me and sometimes it doesn't. If I'm stuttering a lot, my friends give me signs to do smooth speech. This helps me control my stuttering. Sometimes I tell myself to do smooth speech.

Robbie, 11

Winston-Salem, N.C.

Just Like Dancing

Dear SFA:

I don't like it when people ask me, "Do you stutter?" If they ask me, I say, "Yes, I do," and keep on going. I get embarrassed when I stutter, but I always try to keep going.

I think stuttering is like dancing. If you practice dancing you will become better, just like if you practice the tricks you learn to not stutter, you get better at not stuttering.

It is all right to stutter. So many people do it, even celebrities do. If someone makes fun of you or doesn't talk to you because you stutter, that is their loss. Keep your hopes up and keep on practicing. DON'T FEEL ALONE!

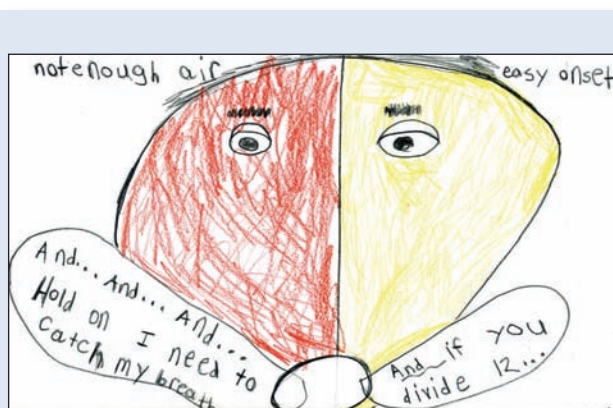
Courtney, 10

Greenwich, CT

Tips for Teasing

Dear SFA:

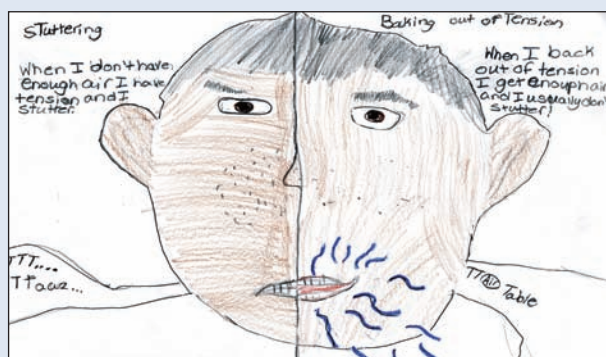
Do you stutter? I know I do. If you do, do your friends tease you about it?



My name is Robbie. I'm 11 years old and I've been in speech for three years. I work on my stuttering by using strategies. The first one is using a speech mountain to remind me to start with air and then come out with my word. The second is "think time"/"black out." It helps me think of words before I start sentences. Another thing I like to use is eye contact because it helps the person I'm talking to know that I'm not finished talking. So, if you stutter, you can try using these strategies.

Robbie, 11

Tallahassee, Fla.



My name is Jordan. I am 10. I stutter with certain letters such as W, L, and B. But I have found some strategies to help me. I've found backing out of tension and think time and they help my stuttering! People used to make fun of my stuttering. But I did a presentation in our class about stuttering. Now they don't make fun of me. Now that I found some speech strategies and the kids in my class know why I stutter, I feel awesome about stuttering!

Jordan, 10

Tallahassee, Fla.

If you do stutter, don't worry, it's all normal. Even some grown people do it. Everyone stutters some time in their life. If you have a friend who stutters, don't tease them about it.

There are some strategies people use to help themselves. Like me, I worked on using a rubber band and stretching out the first word so I don't stutter in the middle of the sentence. There's also using slow, easy speech to help the muscles in your mouth not get all tight and clenched. All of these strategies can help you to stop stuttering if you just take your time and slow down.

Plenty of people stutter. Although some have different reactions when they do it. Some just continue on and don't pay attention. Others feel that they're going to get nervous and start to get worried, and that just makes it worse. To stop you need to be calm and don't even think about it.

If people bully you or tease you because you stutter, just walk away and don't do anything to them because sometimes the people who bully and tease are usually the people who do stuff like that. They do it to let out their anger on other people instead of trying to calm down.

If you just don't worry about stuttering, you will have a good time and not even know you do it. So, if you stutter, don't even worry about it and you will be a happy person.

Max

Carmel, Ind.

Letters

Continued from page 12

Feeling Confident

Dear SFA:

Hi, my name is Kyle and I am 8 years old. I've been stuttering for as long as I can remember. I didn't feel confident, but then started speech class, and learned bouncy talk. Now, I feel more confident and raise my hand in class, and talk to people more. Because when I didn't have speech class, I didn't want to talk.
 Kyle, 8
 Denver, Colo.

Learning About Me

Dear SFA:

My name is Luke and I am in 4th grade. When I realized I sounded different I was five. It sounded like I ran out of air, and it gets quieter, quieter, and quieter. I felt like I hated it. It is easier when I am reading and not talking. I am calm when I am writing. I am less calm in math class when the teacher calls on me. I stutter more when she calls on me. If we are in a crowd I stutter more because I am around more people. This is my story.
 Luke
 Delaware

Strategy Helps

Dear SFA:

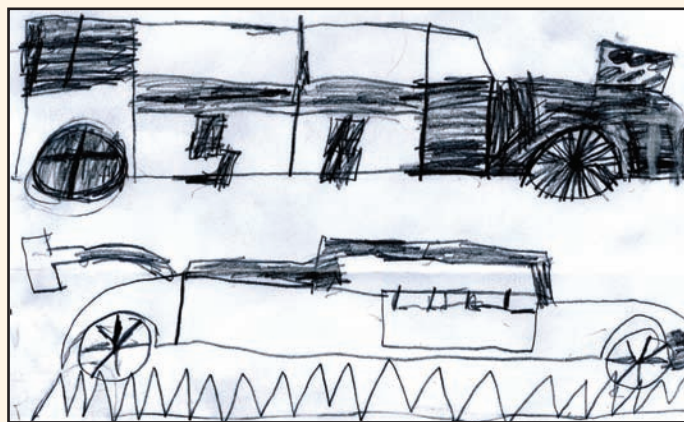
My name is Nathan. I am 9 years old and I am in third grade. I like to play video games and I like to play baseball. I also like to ride my bike and I can ramp really high. I have one brother and one sister. My brother is 10 and my

sister is 8. My friends make fun of my voice because I stutter. They just copy my voice. I have been stuttering for about three years. I mostly stutter at home. Sometimes people tell me to "spit it out." That does not help me say what I want to say. I usually say

"never mind" and I walk away.

My brother also stutters. My sister doesn't stutter. I have learned some strategies to not stutter. One strategy is called "bouncing." Bouncing means that I might repeat a sound or word, but I do it in an easy way. My speech teacher lets me play games about talking. I try to ignore people who copy my stuttering. I am a great kid and I really don't care about my stuttering. I try to not worry about the people who make fun of me.

Nathan, 9
 Anamosa, Iowa



My name is Chetan. I am 10 years old and I am a good person. I live in a brick duplex in Wichita, Kan. I like cars. In my picture, on the first road I am having a good day. On the second road, I am not having a good day and my speech is bumpy. I need to take a deep breath and relax. I think going to speech is fun.
 Chetan, 10
 Wichita, Kan.



I'm 9½ years old and my name is Asta. I live in Tallahassee, Fla. Stuttering makes me feel unhappy because children in my school make fun of me. I like to use easy beginnings because they help me avoid stuttering. I also back out of tension when I am about to stutter. It makes my speech smoother. I gave a presentation about stuttering to my classmates. Now they don't make fun anymore. And because of my presentation, stuttering is much easier for me!
 Asta, 9½
 Tallahassee, Fla.

Eye Contact Works

Dear SFA:

My name is Willie. I like to play video games. I have been stuttering since I was 3. I go to speech class. I think it is fun. We have worked on keeping eye contact. Eye contact is important because it helps others know when you are finished talking. I also learned about the speech machine. I don't like stuttering. I stutter more when I am in my classroom or talking to adults. It makes me feel better to know that other kids stutter too.
 Willie
 Alabama

Continued on page 16



Willie drew this picture.

National Stuttering Awareness Week is May 10-16!

www.stutteringhelp.org • 800-992-9392 • www.tartamudez.org

Letters *Continued from page 13*

No One's Fault

Dear SFA:

I hope kids around the world will read this. I am 10 years old. I love to play sports. I play baseball, soccer, football, and basketball. I started stuttering when I was 5. I know what it feels like to be picked on by other kids. It made me mad.

I go to speech class. I have learned that it is not my fault or my parents' fault that I stutter. There are other kids in the world like me. It's not their fault either. There are even famous people who stutter. I have found that singing helps me talk better. Try it! It might work for you.
Rae' Quan, 10
Alabama



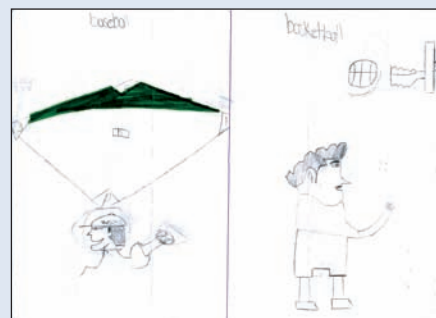
Kids, find more inspirational stories, fun articles, and videos on our Web site, www.stutteringhelp.org. We have a page just for you!



Fourth-grader Rachel of Collegeville, PA, drew cars that are stuck.



This drawing is by Adam, 5th grade, of Trappe, PA.



Rae' Quan drew this picture of baseball and basketball, which are two sports he enjoys playing.

Books

- ▶ *Leap of Faith* by Richard Benyo. (2009) Pennsylvania Heritage Books. Available at www.amazon.com.
- ▶ *Treatment of Stuttering, Established and Emerging Interventions* by Barry Guitar and Rebecca McCauley. (2010) Lippincott, Williams, and Wilkin, Baltimore. www.lww.com.
- ▶ *Research on Stuttering in Pre-school and School Children* by Zbigniew Tarkowski and Ewa Malgorzata Skorek. (2009) University Zielonogorski Press, Poland.
- ▶ *Clinical Decision Making in Fluency Disorders* by Walter H. Manning. (2009) Delmar Cengage Learning, Clifton Park, NY. www.cengage.com.
- ▶ *Practical Intervention for Early Childhood Stammering* by Elaine Kelman and Alison Nicholas. (2008) Speechmark Publishing, Ltd. Milton Keynes, U.K., www.speechmark.net.
- ▶ *Stammering, Advice for All Ages* by Renee Byrne and Louise Wright. (2008), Sheldon Press, London, www.sheldonpress.co.uk.
- ▶ *Speak Freely: Essential Speech Skills for School-Age Children Who Stutter* by Mark Allen, Ph.D., (2007) Speak Freely Publications, Evanston, IL, www.cfst.com.
- ▶ *Beyond Stammering*, Revised edition by David Maguire. (2008) Souvenir Press, London.
- ▶ *Stuttering: An Integrated Approach to Its Nature and Treatment*, Third Edition by Barry Guitar. 2006. Available from Lippincott, Williams & Wilkins, 800-638-3030, www.LWW.com.

See our Web site, www.stutteringhelp.org, for a complete list of books.

This newsletter is published quarterly. Please e-mail address changes and story ideas to info@stutteringhelp.org.

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Renee Shepherd Editor
Scot Squires Designer

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