Surprising Pathway Implicated in Stuttering

Researchers at Washington University School of Medicine in St. Louis have shown that at least some persistent stuttering is caused by mutations in a gene governing not speech, but a metabolic pathway involved in recycling old cell parts. Beyond a simple association, the study provides the first evidence that mutations affecting cellular recycling centers called lysosomes actually play a role in causing some people to stutter.

“This was extremely unexpected,” says senior author Stuart A. Kornfeld, MD, PhD, the David C. and Betty Farrell Professor of Medicine. “Why would impairment in a lysosomal pathway lead to stuttering? We don’t know the answer to that. Partly because we don’t know very much about the mechanisms of speech, including which neurons in the brain are involved. Continued on page 12

Experts Gather at Oxford

Sept. 2011 — St. Catherine’s College, Oxford, was the perfect setting for numerous outstanding presentations by experts in the field.

The Stuttering Foundation provided continuing education credits for the conference, which was sponsored by the Michael Palin Centre for Stammering Children, endorsed by De Montfort University, Leicester, and organized by Elsevier.

“The Stuttering Foundation was able to film several speakers in the hopes that therapists from around the world would profit from viewing their presentations,” said Jane Fraser, president of the Stuttering Foundation.

Joseph Donaher's presentation on ADHD was the first to be produced and has already been received with enthusiasm by speech-language pathologists as well as by parents.

“Because a growing number of children are being diagnosed with ADHD, therapists working with these children are facing new challenges,” said Donaher. In the film, he answers questions and shares charts and guidelines that will help to meet these challenges.

The second film now available features Martin Sommer, M.D., who discusses the neurophysiology of stuttering. During his presentation, Dr. Sommer gives an overview of essential neurophysiological findings that improve our understanding of the pathophysiology of stuttering.

Other professionals filmed included Nan Bernstein Ratner, who spoke on evidence-based practice; Willie Botterill, who discussed truths learned from the long history of speech pathology; and Ann Packman, who spoke about the complex relationship between theory and therapy in stuttering. The consensus from attendees was that this was one of the most successful conferences ever held.

More pics on page 2

Clips from these new DVDs are available on our YouTube Channel, www.youtube.com/stutteringfdn
Reaching Out to Educators

Editor’s note: This was written in response to the October 11, 2011, New York Times article, “Hand Raised High, a Stutterer Struggles to be Heard in Class.”

“The classroom is a challenge for all people who stutter,” said Jane Fraser. “The Stuttering Foundation has a list of 8 tips to help educators.”

8 Tips for Educators

1. Don’t tell the student “slow down” or “just relax.”
2. Don’t complete words for the student or talk for him or her.
3. Help all members of the class learn to take turns talking and listening. All students — and especially those who stutter — find it much easier to talk when there are few interruptions and they have the listener’s attention.
4. Expect the same quality and quantity of work from the student who stutters as the one who doesn’t.
5. Speak with the student in an unhurried way, pausing frequently.
6. Convey that you are listening to the content of the message, not how it is said.
7. Have a one-on-one conversation with the student who stutters about needed accommodations in the classroom. Respect the student’s needs, but do not be enabling.
8. Don’t make stuttering something to be ashamed of. Talk about stuttering just like any other matter.

Compiled by Lisa Scott, Ph.D., The Florida State University

Fluency Workshops

Applications at www.StutteringHelp.org or call 800-992-9392

Eastern Workshop:

Using Cognitive Approaches with People Who Stutter
June 25-29, 2012 — Boston

Co-sponsored by The Stuttering Foundation and Boston University

This unique 5-day program will include training in:
- Cognitive Behavioral Therapy
- Solution Focused Brief Therapy
- Palin PCIT (Parent-Child Interaction Therapy)
- Family Communication Skills

Willie Botterill, MSc (Psych. Couns.), Reg UKCP (PCT), Cert MRCSLT and Elaine Kelman, MSc, Cert CT, Cert MRCSLT of the Michael Palin Centre for Stammering Children; Diane Parris, M.S., CCC-SLP, Boston University

Mid-Atlantic Workshop:

Treating Children and Adolescents Who Stutter
July 9-13, 2012 — Philadelphia

Co-sponsored by The Stuttering Foundation, The Florida State University and The Children’s Hospital of Philadelphia

Skills taught are based on a multidimensional approach to assessment and treatment.

Joseph Donaher, Ph.D., The Children’s Hospital of Philadelphia; Lisa A. Scott, Ph.D., The Florida State University; and Vivian Siskin, M.S., CCC-SLP, University of Maryland

More from Oxford

ARSC Chairman Major General Bryan and Mrs. Dutton.

Frances Cook and Sharon Millard.

Willie Botterill

Kasia Wesierska from Poland holds a new DVD.

Elaine Kelman in the SFA booth.

The Right Honorable Ed Balls and Jane Fraser.

The Stuttering Foundation®
A Nonprofit Organization
Since 1947—Helping Those Who Stutter

2.9 CEUs

With People Who Stutter

6.25 CEUs

Using Cognitive Approaches

2.9 CEUs

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Mid-Atlantic Workshop:

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Deadline to apply: March 19, 2012

Each course is offered for 2.9 ASHA CEUs
Intermediate level, Professional credit
Pediatricians Issue TV Warning!

The temptation to rely on media screens to entertain babies and toddlers is more appealing than ever, with screens surrounding families at home, in the car, and even at the grocery store. And there is no shortage of media products and programming targeted to little ones. But a new policy statement from the American Academy of Pediatrics (AAP) says there are better ways to help children learn at this critical age.

The AAP first provided guidance on media use for children under age 2 in 1999. This consisted of a recommendation in the Academy’s policy statement, Media Education, which discouraged TV viewing for children in this age group.

The new policy statement, “Media Use by Children Younger Than Two Years,” was released in October 2011, at the AAP National Conference in Boston and published in the November 2011 issue of Pediatrics.

In 1999, there was limited data on the subject, but the AAP believed there were more potential negative effects than positive effects of media exposure for the younger set.

Young children learn best from - and need - interaction with humans, not screens.

Newer data bears this out, and the AAP stands by its recommendation to keep children under age 2 as “screen-free” as possible.

“The concerns raised in the original policy statement are even more relevant now, which led us to develop a more comprehensive piece of guidance around this age group,” said Dr. Ari Brown, a member of the AAP Council on Communications and Media.

The report set out to answer two questions: Do video and televised programs have any educational value for children under 2? And, is there any harm in children this age watching these programs?

The key findings include:

• Many video programs for infants and toddlers are marketed as “educational,” yet evidence does not support this. Quality programs are educational for children only if they understand the content and context of the video. Studies consistently find that children under 2 do not have this understanding.

• Unstructured play time is more valuable for the developing brain than electronic media. Children learn to think creatively, problem solve, and develop reasoning and motor skills at early ages through unstructured, unplugged play. Free play also teaches them how to entertain themselves.

• Young children learn best from - and need - interaction with humans, not screens. This is particularly true for children who stutter.

• Parents who watch TV or videos with their child may add to the child’s understanding, but children learn more from live presentations than from televised ones.

• When parents are watching

Young children with heavy media use are at risk for delays in language development...

• When parents are watching

Young children with heavy media use are at risk for delays in language development once they start school, but more research is needed as to the reasons.

The report recommends that parents and caregivers:

• Set media limits for their children before age 2, bearing in mind that the AAP discourages all media use for this age group. Have a strategy for managing electronic media if they choose to engage their children with it;

• Instead of screens, opt for supervised independent play for infants and young children during times that a parent cannot sit down and actively engage in play with the child. For example, have the child play with nesting cups on the floor nearby while a parent prepares dinner;

• Avoid placing a television set...

Continued on page 12
Shelby Railroad Remains Reliable Friend

Kirk and John Tarver and their Memphis-based Shelby Railroad Service Inc. raised a record $7,800 to help those who stutter at their Annual Tin Cup Tournament and Bar-B-Que held October 6 at the Wedgewood Golf Club in Olive Branch, Miss.

Jane Fraser and Lisa Hinton represented the Stuttering Foundation to receive this outstanding gift at the end of the busy day. The Tarvers have used this event, held in appreciation of their clients and employees, to honor the late Ruth McGuiness Tarver, mother of company president and founder, John Tarver, with a gift to the Stuttering Foundation.

“My grandmother stuttered all of her life,” recalled Kirk Tarver, vice president of Shelby Railroad. “Back in the ’30s, there was no help for people who stuttered, but today we have resources and avenues of help, like the non-profit Stuttering Foundation. She would have loved it – especially that we are both Memphis-based!”

“We are so grateful for the dedicated friendship and support the Tarvers and Shelby Railroad have shown us. We know Ruth, a great lady, would be proud!” said Fraser during the event.
New Doors Open for Kids Who Stutter

Malcolm Fraser Honored

Stuttering Foundation President Jane Fraser and Vice-President Joe Fulcher joined therapists, supporters, and trustees of the Association for Research into Stammering in Childhood, ARSC, and staff of the Michael Palin Centre on Sept. 20 to celebrate the opening of the newly-refurbished facility, which includes a high-tech room named for Malcolm Fraser.

The new centre opened in August and this special event marked the move.

The purchase of the new building was funded by charitable donations and the refurbishment was made possible by a grant from the previous government with support from the Right Honorable Ed Balls MP.

During the celebration, Michael Palin gave a personal speech about his father’s stammer. He described the difference it would have made if specialist therapy had been available all those years ago.

Speaking on behalf of the trustees, Lord Egremont described with great passion his memories of being a youngster with a stammer and his commitment to the work of the specialist therapists at the centre.

Ed Balls discussed the challenge of being a senior politician with a stammer and the impact on him of seeing the young people working with therapists at the centre to overcome stammering.

Among the guests were Travers Reid, life president and co-founder of the ARSC, and Emily Thornberry, Member of Parliament for Islington South and Finsbury.

The Malcolm Fraser Room is equipped with teleconferencing equipment that enables therapists to reach children worldwide.

“My father would have been amazed and delighted by the marvelous work being done at the new Centre!” said Fraser.

Lord Egremont recalls his struggles with childhood stammering.

The Right Honorable Ed Balls shares what it means to stammer in the world of politics.

Michael Palin discusses his own father’s struggles with stammering.

Malcolm Fraser Honored

Jane Fraser and Joe Fulcher in the Malcolm Fraser Room.

Winter2012newsletter_newsletter 1/16/12 7:38 AM Page 5
**High Tech at ASHA Convention**

QR codes, Facebook, YouTube and Twitter helped the Stuttering Foundation communicate with therapists during the 2011 convention of the American Speech-Language-Hearing Association in San Diego in November.

The efforts seemed to have paid off with the Stuttering Foundation’s selling a record number of resources during the three-day event.


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**Step 1:** Download QR app to smartphone from http://gettag.mobi

**Step 2:** Scan QR Code.

**Step 3:** Here Mitch Trichon and Renee Shepherd watch a video clip.

**Step 4:** Try it yourself. Download the app at http://gettag.mobi and scan the QR code at the top of this page.

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**Reaching Out to Pediatricians from Around the World**

*By June Campbell, M.A., CCC-SLP, BRSFD*

They came from near and far, the young and the old, those unfamiliar with the Stuttering Foundation, and those very knowledgeable about its literature and mission.

Attendees at the American Academy of Pediatrics Annual Conference held in Boston, October 2011, represented fourteen countries and thirty-three states.

“My mother is going to love this. I stutter,” commented a nine-year-old boy as he picked up materials while perusing the exhibits on his own.

One physician stopped by to thank the Foundation for its dedication to educating pediatricians. Others stopped by to discuss children and families they treat, their own stuttering, or stuttering in their immediate family. Many pediatric residents were grateful to receive information that has barely been addressed in their training.

This was the sixteenth year I represented the Stuttering Foundation. I was grateful for the consistently warm welcome, positive responses and desires of the physicians to take the time to study the materials we offered. Many asked questions to improve their own understanding of fluency disorders.

Pediatricians came from 33 states and 14 countries.
What Are They Up To Now?
An Updated Look at Spokesmen

John Stossel’s new book is due out in April 2012. Plus, he hosts Stossel, a program on the Fox Business Network.

Byron Pitts is busy staying on top of the news as chief national correspondent for CBS Evening News and a contributing correspondent for 60 Minutes.

Panthera CEO Dr. Alan Rabinowitz was honored with Lifetime Achievement Award at the Jackson Hole Wildlife Film Festival.

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Kenyon Martin, who is now a free agent, signed a one-year contract to play in the Chinese Basketball Association. This contract reportedly makes him the highest paid player in the Chinese league’s history.

Darren Sproles, now a New Orleans Saint, has entered his 7th season in the National Football League.

Bob “Butterbean” Love, is not only a legendary basketball superstar but is now a motivational speaker to more than a quarter million teenagers and adults every year.

Bill Walton is currently executive chairman of Connect SD Sport Innovators, a nonprofit, business accelerating, trade organization that connects and drives growth of the Southern California’s sports economy.

James Earl Jones recently starred in the Broadway production of Driving Miss Daisy and will portray a former United States president in the revival of Gore Vidal’s The Best Man, a political play scheduled to open in the Spring.

Nicholas Brendon recently guest starred in the ABC drama Private Practice and the season finale of Criminal Minds.

Ken Venturi wrote and published his autobiography Getting Up and Down: My 60 Years in Golf.
Dennis Drayna, Ph.D., has served on the Stuttering Foundation Board of Directors since 2006. He is senior investigator at the National Institute on Deafness and Other Communication Disorders, National Institutes of Health.

His current research focuses on using genetic methods to identify the underlying causes of stuttering.

“Stuttering is a remarkably difficult disorder to study. It only occurs in awake, behaving humans that are otherwise normal, and it likely has its origins in the brain, which is inaccessible for direct studies,” Drayna explained. “The fact that genetics plays a role in stuttering gives us one of the few avenues available to study this disorder, with the advantage that genetic studies can lead us to the cells and molecules that are involved.”

Studies to date have identified mutations in three related genes, named GNPTAB, GNPTG, and NAGPA that explain approximately 10% of familial stuttering. Several lines of investigation are being pursued to discover exactly how these variant genes lead to stuttering. In one line, biochemical studies of the enzymes encoded by these genes show that the mutations lead to a partial loss of enzyme function, apparently enough to cause some sort of damage to a particular set of nerve cells in the brain, but not so much as to cause more severe symptoms.

In another line of investigation, Dr. Drayna and his co-researchers are putting these mutations into mice and measuring their vocalizations (which are largely ultrasonic), in an effort to develop a mouse model of stuttering that could be used for a wide variety of studies.

“When I started research on stuttering in 1996, my goal was to bring this disorder into the larger world of biomedical research,” Drayna said. “I had a strong prejudice that it was a biological disorder, rather than a psychological or social disorder. We’ve been fortunate to identify several causative genes that reinforce this view, although we still have a long way to go to explain all of stuttering.”

Other studies in stuttering families are identifying the location of additional genes that cause stuttering, the identification of which will hopefully provide insights into the cause of stuttering in the wider population.

“One of the biggest influences on my thinking has come from getting to know the stuttering community. This has allowed me to see the impact of stuttering on people’s daily lives,” Drayna said. “It’s allowed me to realize the seriousness of the disorder, and to advocate for a state-of-the-art biomedical research program to address it.”

Drayna received his bachelor’s degree in Genetics from the University of Wisconsin in 1976. He later earned a Ph.D. in genetics from Harvard University in 1981. His postdoctoral fellowship took place at the Howard Hughes Medical Institute, University of Utah, from 1981 through 1985.

From 1985-1992, he worked as a scientist for Genentech. He later founded Mercator Genetics Inc., where he worked as the scientific director until he joined the National Institute on Deafness and Other Communication Disorders in 1992.

“Science can be a maddeningly slow and uncertain process, with many blind alleys and precious few successes,” Drayna said. “In addition, understanding the underlying causes of stuttering can be a long way away from new, more effective treatments for the disorder. But without research, we’re left with speculation and misunderstanding. The cause of stuttering deserves better.”
Camp Shout Out Sizzles

By Julie Raynor

In August 2011, 60 speech-language pathologists, graduate students and young people who stutter (ages 8-16) attended the inaugural session of Camp Shout Out held at Pioneer Trails Camp on Big Blue Lake near Muskegon, Michigan. Camp Shout Out is an intensive speech therapy and recreation program for young people who stutter and a hands-on CEU training opportunity for speech-language pathologists and graduate students.

Participants came to Michigan from nine different states and Guatemala. Training and treatment coordinator and director Kristin A. Chmela, assisted by June H. Campbell, directed and guided the learning process. Throughout the week, campers participated in individual, small and large group speech therapy sessions that focused on personal communication goals. Speech therapists and graduate students planned and led the therapy activities and also participated in daily ‘problem solving’ trainings with Kristin and June.

All participants stayed overnight in cabins on the camp property and ate meals together in the dining hall, which encouraged spontaneous interactions. During the week it was difficult to tell who was having more fun, the campers or the adults, in recreational activities such as the zip line, Capture the Flag, King of the Water Mat, or Therapist Hunt. New friendships were formed and everybody learned about the power of communication. It was not unusual to find a group of campers sitting together working on a project during the day or a gathering of speech-language pathologists and graduate students on the dock each night having quiet conversations and watching the dark sky full of stars.

One speech-language pathologist stated, “My eyes were opened to the world of stuttering. This week has given me insights on how to conduct therapy sessions with techniques and emotional support for children who stutter.”

For the 2012 session we are excited to add a Leader-In-Training program for older teen campers (ages 16-18) as well as the addition of Kevin Eldridge to the program faculty team. We can’t wait!

Visit campshoutout.org or Stutteringhelp.org.

Editor’s Note: A 2009 SFA Iowa Workshop attendee, Julie Raynor is truly a force of nature. She has done a superb job organizing and promoting this camp. The fantastic publicity she generated attracted children from across the Midwest and even a youngster from Guatemala.
El tartamudeo se puede vencer

Ser bilingüe no es un riesgo

Se aconseja a los padres iniciar el tratamiento temprano para poder controlar este problema en sus hijos.
When moviegoers in the U.S. saw the television ads for the October 21, 2011, release of the new Rowan Atkinson movie *Johnny English Reborn*, few, if any, knew that Atkinson, most famous for his character Mr. Bean, is a person who stuttered. Unlike some other famous actors, Rowan Atkinson’s stutter is not widely known. However, stuttering still is a factor in his life. Fans of the British actor might have been surprised to read in the weekly “10 Questions” column of the August 23, 2007, issue of *Time* magazine that one of the ten questions for the famous actor was, “Did you ever overcome your serious stutter?”

His answer was simply, “It comes and goes. I find when I play a character other than myself, the stammering disappears. That may have been some of the inspiration for pursuing the career I did.”

Rowan Atkinson was born on January 6, 1955, in Durham, England. Rowan was the youngest of four boys. He was sent to two boarding schools, both of which were run under the auspices of the Church of England. First, it was the Durham Choristers School, which had the reputation of trying to push students towards the Anglican priesthood. In his 1999 biography, *Rowan Atkinson*, author Bruce Dessau quoted Canon John Grove as remembering Atkinson as “shy with a slight stutter and a slightly rubbery face just like the one he has now.” Later, when at St. Bees School, Chris Robson, Atkinson’s A-level physics master, said, “In class he was very middle of the road. There was nothing outstanding about him. I didn’t expect him to become a fantastic scientist. And he was a quiet lad who walked his own path.”

However, Robson remembered Atkinson’s school drama career more vividly, “But when he walked on-stage he was exceptional.” Dessau quotes another faculty member at St. Bees as saying, “Even an incipient stammer vanished whenever the young Atkinson stepped onto the stage.”

In fact, a March 24, 2007, article in *The Independent* stated that a young Atkinson was bullied at the Durham Choristers School because of his stuttering and appearance. Future Prime Minister Tony Blair, who also attended the school and was two years younger than Atkinson, has stated in the past that he vaguely remembers the treatment that Atkinson endured as a youngster there.

Following in his father’s footsteps, Atkinson earned a M.Sc. in Electrical Engineering from The Queen’s College at Oxford. Still acting on the side, he embarked on a Ph.D. in electrical engineering for awhile before deciding to devote his full attention to acting. While Atkinson was studying for a doctorate in electrical engineering, Richard Curtis remembered the young Atkinson showing up at workshops for sketch material for a summer review at Oxford and never saying a word. Then the silent one got up and did an original sketch in which his stuttering disappeared.

Curtis said, “He did a monologue about driving followed by the thing he does now, where he mimes and talks at the same time. It was unlike anything I had ever seen. It was pure genius.”

He gained attention by doing a series

*Continued on page 16*
Pathway  
Continued from front page

So we can’t fully explain stuttering, but now we have clues.”

Genetic clues to stuttering were first identified in a paper published in the New England Journal of Medicine in Feb. 2010. In it, Dennis Drayna, PhD, a senior investigator with the National Institute on Deafness and Other Communication Disorders and a co-author on the current study, and his colleagues reported results of genetic studies on members of a large Pakistani family, many of whom stutter.

Among most of the stuttering family members, they found mutations in three genes involved in directing proteins to the lysosome. These same mutations were present in many unrelated individuals in Pakistan, North America and Europe who stutter, but not in those with normal speech.

“They found mutations in three genes that encode a pathway for directing newly made lysosomal enzymes to the lysosomes,” Kornfeld says. “And it turned out to be a pathway we discovered years ago. So this is a nice collaboration.”

Until now, one of the three genes, NAGPA, had not been implicated in any human disorder. This is where Kornfeld and Wang-Sik Lee, PhD, research instructor in medicine at Washington University, chose to begin their in-depth biochemical investigation of the mutations that Drayna’s group identified.

NAGPA encodes an enzyme responsible for the last step in “addressing” proteins to the lysosome. Drayna’s work identified three separate mutations in NAGPA in individuals who stutter. And according to Lee’s biochemical analysis, all three of the mutations impaired the enzyme, but each did so in a different way. In general, mutations in a gene often cause the resulting protein to be folded into the wrong shape. Cells are very good at recognizing misfolded proteins and destroying them.

In this case, Lee’s biochemical analysis shows that two mutations appear to trap the proteins in the cell’s protein manufacturing center, though some get out before being destroyed.

“It’s not an all or nothing thing,” Kornfeld says. “Of the material that does get out, its activity is normal.”

But the third mutation causes a larger folding problem and the proteins are destroyed just minutes after being made.

Such findings offer a glimpse at possible future therapies for stuttering. For two of the mutations at least, the problem is not that the protein can’t recycle, but rather that it can’t get out of the cell’s protein manufacturing center and go to the lysosome. If some compound can be found that helps the protein escape, Lee’s work suggests that it would function normally. But Kornfeld cautions that this type of therapy for stuttering is a long way off.

“There are billions of neurons in the brain, and we have very little idea which neurons are involved in speech,” he says. “Our main finding is that these three mutations in NAGPA in people with persistent stuttering all have harmful effects. This is biochemical evidence that these mutations are meaningful, and not just markers of some other genetic change that is the real cause.”

Having described the three harmful mutations in NAGPA, Kornfeld’s group is now performing biochemical analyses on the other two mutated genes Drayna’s group identified – GNPTAB and GNPTG. Drayna and his colleagues estimate that these three mutated genes account for only about 10 percent of people who stutter with a family history. As such, they are continuing the search for additional genes responsible for stuttering.

The research is available in the Journal of Biological Chemistry.


This work was supported by grants from the National Institutes of Health (NIH) and from the National Institute on Deafness and Other Communication Disorders, which is a part of the NIH, and from the Malcolm Fraser Foundation.

TV
Continued from page 3

in the child’s bedroom; and

• Recognize that their own media use can have a negative effect on children.

The report also recommends further research into the long-term effects of early media exposure on children’s future physical, mental and social health.

According to Dr. Brown, “In today’s ‘achievement culture,’ the best thing you can do for your young child is to give her a chance to have unstructured play—both with you and independently. Children need this in order to figure out how the world works.”

Jane Fraser, president of the Stuttering Foundation concurs with these findings, “Television viewing, even if only in the background, can be very distracting for a young child learning to speak; and it reduces ‘talk time’ in the family. All families, but particularly families with children who stutter, will profit from changing their home environment to promote more fluent speech.”
Some History About ‘Specialists in Stuttering’

By Jane Fraser

In the 1970s, Charles Van Riper and my father, Malcolm Fraser, exchanged extensive correspondence about the need for specialty training in stuttering.

Together, they decided that a whole year should be dedicated towards training a specialist and towards deciding what should be included in that training. The very first specialist trained in such a way by Dr. Van Riper was Carl Dell and his training was sponsored by the Stuttering Foundation, known as the Speech Foundation at that time.

Treat­ing The School­Age Child Who Stutters: A Guide for Clinicians is an outgrowth of that year’s work. But having only one person trained a year did not solve the problem of having more specialists available.

So, in 1984 Hugo Gregory volunteered to give up two weeks of his summer towards training 20 therapists to become specialists in stuttering. He was joined by June Campbell, Diane Hill, and Carolyn Gregory; and Dean Williams, our Vice President for Education, represented the Stuttering Foundation at the two week sessions as did Joe Fulcher and I. That was the beginning of the Stuttering Foundation’s “specialists in stuttering” program.

We also sent out press releases in the early 1980s to educate the public about stuttering and recommending that they always seek out a specialist. We continue to use that term, “specialist in stuttering,” as we seek to educate parents as much today as we did in the 80s and 90s.

notes from the introduction

• School-based SLPs provide acceptance, warmth and understanding in a safe environment and help children feel cared for.

notes on indirect therapy for borderline stuttering

• Children with little or no struggle or tension who have neither shame nor guilt but still have too many fluency errors should be seen for treatment. Their stuttering responds quickly to therapy.

• By echoing or reflecting what the child has said, the clinician occasionally provides him with a better model of stuttering than the kind the child demonstrates (e.g. C: “oh, look here’s an a-a-a-alligator,” SLP: “that’s right, an a-alligator”). The child in essence is being corrected without his being aware of it which is vastly different from the kind of direct correction from his parents and classmates (Say it again! Slow down! Don’t stutter!)

• We can reverse the course of stuttering, and it is vitally important that the child learns early on that there is no need to force or struggle (p. 27).

notes on border­line stutter­ing

• Clinicians sometimes have a fear of making the child’s stuttering worse, either by drawing attention to it or by doing something wrong in therapy. These two points can be refuted. It is very likely that many people have already been critical of the child’s stuttering. Because of their resilience, children are rarely affected for very long if something goes wrong.

• Any good clinician will make a mistake occasionally, but she is quick to recognize it and make appropriate adjustments (p. 13).

• For the child with borderline stuttering, it is wise to spread diagnostic sessions over a period of time, such as once a week for several weeks because many children have cycles in which they alternate between fluency and stuttering.

• Some children become very good at hiding their stuttering because they do not want anyone to find out.

• It is important to conduct a thorough evaluation with school-aged children and observe the child in a variety of speaking situations.

• Two important things a clinician can do when talking about stuttering in the evaluation are 1) be casual with your approach to show that you are not shocked by stuttering and you have seen such things before; and 2) to be able to occasionally demonstrate the child’s disfluency, without being upset. This shows the child that he is not the only one who talks like he does and that others can stutter at will and that stuttering need not be involuntary.

• Both of these points can help the child come to the realization that stuttering need not be feared and that it isn’t a shameful thing.

for info@stutteringhelp.org.

Each month Voon presents a Resource of the Month with a brief summary of what he has found to be helpful. Below are some of his notes from Treating the School-Age Child Who Stutters.

notes from the introduction

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• We can reverse the course of stuttering, and it is vitally important that the child learns early on that there is no need to force or struggle (p. 27).
Poem About Me
Sometimes I stutter
People may look at me strange
But do they know me?
They hear my stutter
But I am much more than that.
Please listen to me!

Please don’t look away
Because of my stuttering
Don’t judge me by that….”
Braxton, 10
North Little Rock, AR

Stuttering Can Be Hard
Hello, I am Brian and I am 10 years old. I don’t like stuttering because I can’t have a conversation. I have been going to my speech teacher and doing better in talking. People always make fun of me and start talking like me. I just ignore them or say “you can’t stutter better than me” or “you try to stutter just like me!” Sometimes I cry a little when they ask “why do you do that?” because I think they are making fun of me. I just don’t like it, I JUST DON’T LIKE IT! I just felt kind of bad because I stutter, but now it is kind of okay.
Brian, 10
Atlanta, GA

I Am Unique
Hi, my name is Ethan and I am 9 years old. I live in Wellington, Florida. I work on my speech tools with my speech therapist to help control my stuttering. We work on breathing, stretching, and having a quiet body. One day, someone teased me and I just ignored him. It worked! That was so cool! I don’t let things like that bother me because I know I am a unique kid :)
Ethan, 9
Wellington, FL

Future Racehorse Vet
Hi, my name is Kylee and I am 12 years old. I have stuttered ever since I can remember. All throughout elementary I took speech therapy, but it wasn’t helping so I gave up. Sometimes it’s worse than others. I used to not stutter when I read aloud, but now I do. I hate it when the teachers call on me to answer a question or read. It’s so embarrassing. I know it sounds silly, but little kids make fun of me! Some older ones do too. When I am talking to my friends, I think of this really funny thing to say and finally get it out when it has nothing to do with what we are talking about by then.
I’m smart and make A’s and B’s and want to go far in life. I want to be a racehorse veterinarian and hope I won’t be discriminated against when I get out in the real world and go to college and get a job. Most of the time I stutter on vowel sounds, but sometimes I stutter on consonants.

My dad says he stuttered when he was little but outgrew it before he was my age. I have a 18 year old cousin who stutters every now and then. Dad also says I didn’t stutter at all until my mom had a wreck when I was little, and now my stuttering is worse around bad times (though my mom is fine now).

When we had a tornado a couple of months ago, I was so scared I had bad dreams and I stuttered a lot more after that. But the weirdest thing is, I don’t stutter when I sing. Would you please mail me back with what information you know? Thank you so much.
Kylee, 12
Advance, MO

Editor’s Note: Kylee was sent information about her concerns.

Looking for Good Speech
My name is Trevan and I am 9 years old and in 3rd grade. I have
been stuttering for a long time. I just don’t like having a speech problem. I don’t like stuttering because it makes me seem different and weird. I just feel like I’m looking for a needle in a hay stack. There is only one needle I have to find but I can’t find it or stop it. The needle is for good speech.

Sometimes I am able to find the needle by sticking to my goals. I have help and support from my speech teacher, friends, and family. My speech teacher and family help me with strategies that I have learned.

Trevon, 9
Holyoke, MA

Ignore Teasing
Hi, my name is Waylon and I am 10. I stutter, but it does not bother me. When I am teased I just ignore them. I am going into the 5th grade. I have been going to Bowling Green State University for speech. Now I am better at talking.

Waylon, 10
Ottawa, Ohio

Stuttering Makes Me Special
My name is Sophia, and I stutter. When I was little, my stuttering was ongoing-ish. I stomped, clapped, and did almost everything I could just to talk to my mom.

When I was maybe 4 years old, my mom found a speech therapist named Marcy (her real name is Marsha; I found THAT out years later!). She helped me with my speech a lot. (She still does!) Now, we are great friends! I think that stuttering is just what makes me special.

Sophia, 9
Cedar Rapids, IA

A Letter from France
Bonjour, je m’appelle Jacques et j’ai 9 ans.
Je voudrais vous parler de ce livre qui parle du bégaïement : « Des fois je bégai ».
(Sometimes I Just Stutter)
Alors, moi je bégai tous les jours et j’arrive pas à com-

Continued on page 16

Hi, my name is Grace’lyn. When people make fun of me I just ignore them. When I am with my friends they back me up and say it is not OK to make fun of me. Or sometimes I draw a picture of me happy. Even President Obama stutters sometimes.

Grace’lyn, 10, Evansville, IN

My name is Justin and I’m 9 years old. I think I started stuttering when I was 5 years old. I started going to speech in 2nd grade. I learned about my speech machine. My speech machine is the parts of my body I use to talk. Sometimes my machine breaks down and I stutter. My brain controls my speech machine so I will know what to do when I stutter.

I learned techniques for fluency, such as using slow speech and taking an easy breath when I get stuck. Now I don’t stutter that much. I am proud of myself.

I made a PowerPoint presentation about stuttering. I’m going to show it to my class. I like all of the stories from other kids you printed in your newsletter. They make me feel better about my speech.

Justin, 9, Clovis, CA

Benny, 6th grade
Clifton, N.J.
Je bégai souvent quand je suis nerveux, un petit peu. Quand quelqu’un ne comprend pas ce que je lui dis parce que je parle vite, je ralentis pour qu’il comprenne et s’il ne comprend pas je lui dis : « si je bug tant pis » je continue à dire lentement et si je « bug » encore, je lui dis : « laisse tomber » et s’il ne veut pas laisser tomber, je lui dis : « j’ai oublié ma phrase ».

Voilà ce qui me gêne le plus dans mon bégaiement.

A bientôt.

Jacques
James Campbell Stuttering Memorial

By Bret Hart, James’ uncle

Almost everyone has a day that they will never forget. It’s a day that can be one of the happiest days or one of the saddest days in a person’s life. October 23, 2011, was one of those days I will never forget. That was the day my nephew James Campbell tragically took his own life. James was only 17 years old. For years to come people will ask “why?” “Why did James end his life at such a young age”? I, too, have been asking this question. As the grief, anger, sadness and disbelief continually swirl in my mind, I keep coming back to the speech disorder that James had suffered through for years. James was a stutterer.

James was a teenager who had a great personality and positive outlook. But in his mind, all the positive features in the world could not trump the negative that he could not shed. His stuttering. Oftentimes, James was a recluse because of his speech disorder. He would communicate with his friends through Facebook. Why through Facebook? Because he didn’t have to talk. A computer could speak for him.

Imagine being a teenager who stutters and has to give a presentation in front of the class? This had to be a frightening feeling for James. Not only will the entire class be watching, but trying to speak fluently was more than a challenge … it was impossible.

As James got older, the stuttering became more and more of a handicap for him. He saw his disability as a hindrance to his future. On Sunday, October 23, James felt he could no longer go on. He made the decision that he wanted to be with his father who had passed away 13 years earlier in a tragic accident. James really didn’t know his father that well, as he was only 4 at the time, but the absence of his father profoundly affected him.

As we say good-bye to James and try to piecet together our own lives, I would hope that we can prevent another loss of life. There is no need to have another teen take his own life with the explanation that they feel the burden of stuttering has become unbearable.

Hopefully, the end of James’ life can be the start of someone else’s.

In honor of James Michael Campbell, we look forward to helping other teens who stutter so they can live a productive and fulfilling life, embracing all that life can offer.

### Gifts In Memory of James Michael Campbell
Through Dec. 15, 2011

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<th>Dale Foster</th>
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<td>Bryan Scott Herr</td>
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<td>Alfred and Carole Poindexter</td>
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<td>Tracy Smith and son, Tyler</td>
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Main Character Stutters

The South Street Gang vs. the Coalcracker Cyclops, by Richard Benyo, is an exciting tale that brings the powers of good and evil to the streets of small-town America. It features a main character who stutters. Available at Amazon.com

SFA Team Wishes You A Happy New Year!

Lisa S., Roberta, Joan, Susie, Pat, Jane, Terri, and Linda H. Not pictured: Patty, Carol, Bob, Greg, Susannah, Renee, Scot, John and Joe.

And the Winners Are...

Congratulations to Chris Harwood and Valero Morris! They both won copies of the DVD The Man Behind the King’s Speech for their essays on how King George VI influenced them.

Another contest asked, “What, if anything, are you doing differently since seeing The King’s Speech?” The winners were Chad D., Leah Fetzer and Barry Shapiro.

Special thanks to Revolver Entertainment for donating copies of the DVDs.


Stutter Across America is planned for 2012. Marshall David Rice, Ph.D., will cycle coast-to-coast across America in 2012 to raise money for research and treatment for people who stutter. His goal is to raise awareness of the challenges that people who stutter face every day and promote the message that stutterers can do anything they want. Donations will help support the important work of The Stuttering Foundation and The Speech & Stuttering Institute in Canada. To donate or for more information on the ride, please visit www.stutteracrossamerica.com.

Our Website, www.StutteringHelp.org, is continuously being updated with new resources. Be sure to bookmark it!

The Stuttering Foundation Five Day Workshop, Using Cognitive Approaches with People Who Stutter, will be held in Boston, Massachusetts, June 25-29, 2012. With Willie Botterill, MSc (Psych. Couns.), Reg UKCP (PCT), Cert MRCSLT and Elaine Kelman, MSc, Cert CT, Cert MRCSLT of the Michael Palin Centre for Stammering Children in London. Conference coordinator is Diane Paris, M.S., of Boston University. For more information, call 800-992-9392 or visit www.stutteringhelp.org and click on “speech-language pathologists.” The Stuttering Foundation pays all tuition costs as well as room and board for this exceptional in-depth workshop.


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Newsbriefs

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