



REACHING OUT

Publication of Friends: The National Association of Young People Who Stutter

Unlocking A Medical Mystery—Stuttering

Jan/Feb 2010

By Stephanie Smith, CNN

(CNN) – A new study brings researchers one step closer to unraveling a medical mystery that has perplexed scientists for thousands of years: What causes people to stutter?

Research appearing in the Feb. 10 2010 New England Journal of Medicine reveals three genetic mutations in the brain cells of people who stutter. The cells are located in the part of the brain that controls speech, which suggests that genes could play a big role in the disorder.

"People have looked for a cause of stuttering for 5,000 years," said Dennis Drayna, a researcher at the National Institute on Deafness and Other Communication Disorders, and a co-author of the study. "Many, many things have been suggested as a cause of stuttering. None of them have turned out to be true. For the first time today, we know one of the causes of this disorder."

"These mutations affect a process inside cells that degrades things that the cells don't need anymore," said Drayna. "This process is called the garbage can, or more like the recycling bin, of the cell. When this process gets interrupted, the cell goes haywire, and that causes problems."

Previous studies have suggested genetics as one possible explanation for stuttering, along with developmental delays and confused speech processing in the brain. But that knowledge can only go so far, said Drayna.

"Just knowing a disorder is genetic doesn't really help us understand that disorder at a level that, for instance, doctors would like to know," said Drayna. "Once we have genes, we know much more about the causes of the disorder."

Fast Facts:

In addition to hosting one-day conferences and the annual Convention, Friends can also be seen volunteering at state speech conferences.

Friends recently hosted a booth at the ISHA—that's Illinois Speech and Hearing Association's-conference. What a great way to get the word out, by none other than parents who know what a difference Friends can make! Yeah!

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If You Stutter, You Have Friends!



Unlocking A Medical Mystery—Stuttering (cont'd from p.1)

Knowing the genetic underpinnings of the disorder could unlock even more genes associated with stuttering, which could lead to more specific diagnosis and treatment.

"People who are helped by one type of therapy might for instance be the people with mutations in one of these genes, whereas the people who are helped by another therapy are people with mutations in another gene that we've identified," said Drayna. "For the first time we can now begin to ask this kind of question, why do some therapies work well in some people and not well in others?"

Roughly 3 million people in the United States stutter, according to the National Institutes of Health. About 60 percent of those with the disorder have a family member who also stutters. The condition is most common among children, although about 1 percent of people carry the condition through adulthood, according to the Stuttering Foundation of America.

Michael Liben, 25, has stuttered for as long as he can remember, "since I began speaking," said Liben, a law student in New York. "I remember my middle school graduation. It was my job to lead the Pledge of Allegiance and it took me a while to get started, and it was probably the lengthiest Pledge of Allegiance in the history of America." Liben said he suspected a genetic connection with his stuttering – his mother Sindy Liben also stutters – but what is most encouraging to Liben, and the stuttering community in general, is the study's confirmation of what they already knew: Stuttering is a problem with neither social nor emotional origins.

"It's just great news for people who stutter to know that it's a gene," said Tammy Flores, executive director of the National Stuttering Association. "It's not anything else. It's a gene."

Added Drayna: "An important point that's reinforced by our findings is that stuttering, at its basis, is a biological disorder. Even today, people seem to think stuttering might be an emotional disorder, or even a social disorder, and it's really very unlikely that either of those two things are true. I think the sooner that stuttering is recognized as a biological disorder, people can get down to using that understanding ... to better treat the disorder."

Drayna emphasized that finding the genes for stuttering does not automatically mean a cure, but that better treatment and diagnosis is on the horizon. Groups like the National Stuttering Association are excited nonetheless.

"[Stuttering is] something that you will be able to identify," said Flores. "You will be able to couple that with speech therapy and support groups, and get help. It's very, very exciting to have all of this happening now."

A portion of this article was not re-printed in full due to space constraints.

You can find the complete article at: www.cnn.com/2010/HEALTH/02/10/stuttering.genes.cell

Speechless



Have you ever had so much to say but couldn't speak at all because you were scared of how it would come out? That's what I've felt everyday. As a person who stutters, I realize how important communication and speech really are. Stuttering has been a major part of my life but has helped me grow also.

I first realized I stuttered when I was 10 years old. I was a pretty quiet 5th grader and my music teacher wanted me to make an announcement at the weekly assembly. I didn't really have much of a choice so I said "yes". As I was walking up to the front of the auditorium, my stomach had a huge boulder sized knot in it and I knew something was about to go wrong. As I started to say the announcements, I stumbled on the word "the" at least 15 times. After I finally got out the sentence, I ran to my seat and cried because I was so embarrassed. I hate having everyone stare at me and make fun of me for something I can't control. That moment has definitely scarred me a lot; it hurt me emotionally and mentally. Over the years, my stuttering got worse, and that was when my life changed completely.

Stuttering varies for each person, I, for example, have a moderate stutter. For others though, it's even worse. At one time in my life, I stuttered so badly that I was scared to talk. I feared raising my hand in class, greeting new people, even talking to my parents. I looked forward to sleeping because that was the only time I wouldn't be nervous about having to speak. Stuttering lowers your self esteem, self confidence, and ruins your communication skills. There is no way to completely get rid of stuttering, but if you love yourself and accept you as who you are as a person who stutters, then your communication skills grow and you become comfortable with difficult speaking situations.

When I finally got over the fact that I was different because I stuttered, I actually stuttered less. It still makes me nervous when I come across a difficult speaking situation but I've learned to calm down. Now I'm much more outgoing and actually introduce myself to people and always talk to new people. I also take speech therapy, it helps a lot. When I do stutter, most people don't notice and I've learned that it's just like another freckle on my face, it's nothing to really be ashamed of.

I believe stuttering has really helped me find the true me, and has allowed me to open up more to people and accept me for who I am. Stuttering is definitely a huge step in my life and I'm glad I climbed over it and that I grew so much from it. -- *Amy Robin*

Amy Robin is 17 years old and writes from Bellerose, New York. She's a high school senior. In her free time she makes her own dresses and other clothes; she wants to be a fashion designer.

I've learned to take time for myself and to treat myself with a great deal of love and respect 'cause I like me I think I'm kind of cool. - Whoopi Goldberg

I was a little scared . . .

and I did it anyway



We will introduce these young people in our newsletter and let others know that there are many cool kids who are doing what they want to do ...and stuttering.

If you would like to send in a photograph with your submission, please do so. We would love to print it.

Mail to:
Lee Caggiano
38 South Oyster Bay Rd.
Syosset, NY 11791

Name _____

Age _____

Where do you live? _____

Three things you want us to know about you

1. _____

2. _____

3. _____

I was a little scared and

My name is Zachary

I am 7 years old and live in Iowa.

I really love football. My favorite player is . . .

I stutter and talked to my class about stuttering so they would know why it takes me a longer time to talk sometimes.

I was a little scared and I did it anyway!

My name is Kristen.

I am 11 years old and live in Tampa.

I have two sisters

I love acting.

I stutter and wrote a letter to all my teachers telling them about my stuttering.

I was a little scared and I did it anyway!

My name is Michael.

I am 9 years old and live on Long Island.

I love baseball. My favorite player is . . .

I stutter and I ran for student council at my school. I won!

I was a little scared and I did it anyway!

My name is Ashlee.

I am 13 years old and live in St. Louis.

I love playing soccer.

My favorite band is . . .

I stutter and volunteered for a part in my class play.

I was a little scared and I did it anyway!

FRIENDS, The Association of Young People who Stutter
www.friendswhostutter.org Toll Free: 866-866-8335

**FRIENDS, the National Association for Young People Who Stutter
and
The Stuttering Foundation of America present:**

2010 One-Day Conferences



**CHILDREN, TEENS AND ADULTS
WHO STUTTER: Families, Professionals
and Friends Working Together**

**March 6, Raleigh N.C.
March 13, St. Louis MO
April 10, Denver CO
April 24, Chicago IL**

**May 22, Phil.,PA
September 25, L.I. NY
October 23, Iowa City, IA**

JULY 22-24, Three-day Convention, Chicago, IL

Young People

- Meet others who stutter
- Have fun talking!
- Learn about stuttering

Parents

- Find out what you can do to support your child
- Meet other parents and share experiences

SLPs and SLP students

- Learn more about stuttering, current treatments and the support services available to people who stutter

Conference Objectives:

At the completion of the conference, participants will be able to:

- Describe effective intervention strategies for children who stutter and their families.
- Understand need for management approach to childhood stuttering that includes parents, professionals and support networks.
- Identify specific social and clinical strategies for supporting children who stutter and their families.

ASHA CEUs Sponsored by:

THE STUTTERING FOUNDATION

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www.stutteringhelp.org



The Stuttering Foundation of America is approved by the Continuing Education Board of the American Speech-Language-Hearing Association (ASHA) to provide continuing education activities in speech-language pathology and audiology. See course information for number of ASHA CEUs, instructional level and content area. ASHA CE Provider approval does not imply endorsement of course content, specific products or clinical procedures.



Stepping Up Mentoring Program Really Taking Off

Stepping Up is moving full speed ahead! As you may or may not know, *Stepping Up* is a mentoring program that encourages interaction, insight and builds friendships among teenagers and children who stutter. Currently, we have ten wonderful teen mentors and over fifteen mentees who are participating in this program.

Recently, some of our great teen mentors wrote:

"It's been such a rewarding experience to touch the lives of younger kids. It's very touching to know we can make a difference. Thanks for being there for us" - Rylan Maeda

"Stepping Up encourages me to take control of my stuttering and to not hide behind it as much because I feel responsible (in a good way) to helping and giving actual experience to other people. I also see different perspectives on handling a situation that I may want to try next time I experience something like it. It is a great program for teens and children who do not have daily contact with other stutters or who feel alone. In this program, everyone can relate to each other because we all have experienced something one time or another." Aileen Quattlander

"Stepping Up is an awesome program that gives young adults the opportunity to mentor young teens and provide them with advice and personal experiences about stuttering. As a nursing student, I work with patients in hospitals, nursing homes and community centers, but I enjoy being able to help out another person who stutters without medical supplies or terminology. I wish I would have known about this program while I was in middle, junior and high school, but I enjoy emailing and talking on Facebook with my mentee about stuttering as a high school student and ways to work on speech or relax while speaking in public. Over the summer, I signed up to participate in a speech clinic at Illinois State University, which gives me the opportunity to work on my stuttering and help a graduate student gain experience working with clients. Information I learn from the speech clinic, I share with my mentee. Also, it shows my mentee that no matter how old you are, a little speech therapy will go a LONG way." Myia Thompson

And a 10 year mentee wrote:

"We talk about life and how stuttering affects our everyday lives'. It helps me learn not to treat myself like there is something wrong with me".

So many teens and kids are getting involved in this program and getting involved from all over! Our mentors and mentees are from all over the country, even as far as Hawaii (who always offers his mentee some Hawaiian culture) and Ireland. As part of the program we also encourage many speech-language pathologists to initiate this program for their students in speech therapy. By using the speech pathologist's email address, students are able to gain a mentor during their speech therapy session. And if a teen would rather talk to someone their own age, that is also a possibility! As you can see, there are many opportunities that the program offers! If you would like to be get involved and get contacted with a mentee or a mentor, please contact Leslie Eckenthal at Leckenthal@gmail.com or Lee Caggiano at LCaggiano@aol.com

FRIENDS News & Notes:

Our newsletter is offered both in print and electronically. You will receive both versions, unless you tell us otherwise.

The e-version allows us to reach a wider audience, and make use of technology. E-RO can be found linked on the Friends webpage. Check it out.

If you know someone who could benefit from Friends, make an extra copy of the newsletter for them, or give them a copy of the Mentor program application form.

Parents—leave newsletters in your doctors or dentist's office and at your child's school. Good old fashioned word-of-mouth really does work. Spread the news!



The National Association of Young People Who Stutter

145 Hayrick Lane, Commack, NY 11725-1520

E-Mail: LCaggiano@aol.com

Call Toll -Free: 1-866-866-8335

Co-Founders: Lee Caggiano and John Ahlback

Director: Lee Caggiano / **Reaching Out Editors:**

Print RO: John Ahlback **E-RO:** Pamela Mertz

Reaching Out is published eight times a year. Send articles to: jahlbach@sbcglobal.net and pamela.mertz@gmail.com

The annual subscription rate is \$35. You can subscribe or order our books, posters, and other materials online at:

Website: www.friendswhostutter.org

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Friends Face book Page

Hey Kids, Teens, Adults, Parents, Professionals and Anyone who cares about people who stutter, Friends has their own Facebook page:

www.facebook.com/youngpeoplewhostutter

Friends Convention 2010

Thursday, July 22 - Saturday, July 24, 2010

Embassy Suites Chicago - O'Hare/Rosemont

5500 North River Road, Rosemont, Illinois

(847-678-4000)

CEUs offered for Speech Language Pathologists * Educational Grants Available * Discounts for Speech Language Pathologists who attend with a client.

For more information: Online: www.friendswhostutter.org or Toll-free: 866-866-8335

