

Stuttering

The Latest Word on Cause and Therapy



Speech language pathologist Kristin Chmela (center) works with client Ben Staub (right) and his mom, Cathy.

By Toni Rocha

Aristotle. Moses. Winston Churchill. Singers Carly Simon and Mel Tillis. Actors James Earl Jones, Bruce Willis and Marilyn Monroe. Basketball great Bob Love, baseball star Ty Cobb and football player Bo Jackson.

They share one thing in common. Each of them has stuttered.

About 1 percent of the world's population stutters to some extent. And while the exact cause is still debated, there's strong evidence that neurological functions and/or genetics may play prominent roles. Stress, lowered self-esteem and other environmental influences can potentially lead to stuttering or aggravate it.

Regardless of the cause, stuttering is of concern to parents who want their children to face the world with as few problems as possible. This summer, many such parents and their children will meet in Chicago for the national FRIENDS: The National Association of Young People Who Stutter convention, which offers workshops for parents, kids and speech-language pathologists.

Naperville teen Ben Staub, 15, has attended the FRIENDS convention the past two years and says it helped him to realize just how many people are challenged in the same way that he is.

"It's a place for people from all over the country," he says. "Kids participate in activities related to stuttering, and talk about its ups and downs. We also listen to speeches from well-known therapists. And it's a lot of fun."

Cathy Staub, Ben's mom, says Ben came away from his first FRIENDS conference a different child. "He bought a T-shirt that said, 'If you stutter, you have FRIENDS,' and wore it on his first

day in a new school," she recalls. "He said he wanted everyone to know he stuttered. I cried, because he was no longer ashamed. I often wonder where he would be now if we hadn't gone."

The conference was an eye-opener for Cathy. "Nothing really prepared me for the sheer power of having a huge room full of kids all talking and stuttering," she says. "Suddenly, Ben wasn't alone. Here was a place where the fluent people were the anomalies."

Ben's stuttering was diagnosed when he was 3 years old, about the time he began speaking in sentences. "The pediatrician said he would outgrow it, but by the time he was 4, it was obvious that wasn't going to happen," says Cathy. "Ben's grandfather had a mild stutter, and my husband's aunt is a very severe stuturer."

"It just developed," Ben says. "I first received therapy with the school's speech therapist. Every day of elementary school, I would leave class and go to my therapy session." Now he works with Kristin Chmela, a speech language pathologist who specializes in fluency disorders. She is board-certified through the American Speech-Language-Hearing Association and owns Chmela Fluency Center in Long Grove.

"We spend a lot of time each session in conversation," says Ben.



Kristin Chmela



New friends meet during a conference of FRIENDS: The National Association of Young People Who Stutter. This year, the group's national conference is in Chicago.

"There's lots of talk. We look for signs of what makes me stutter. Tension on my tongue and lips, and muscles, play important roles in why people stutter." Ben describes his stuttering as a sort of block in which normal syllables or sounds aren't allowed to be expressed. Muscles freeze up, he explains.

"I don't let it bother me," he says. "I stuttered very little for a period of time, but lately, since I've been attending high school, it's been getting worse. I went back to therapy. Everyone who stutters needs a tune-up every once in a while."

While stuttering may be reduced through speech therapy, parents are keenly aware of the emotional impact the condition has on their children, as well. "Stuttering is a complex neurological and physiological disorder," Chmela says. "Genetics and environment play a part in the problem, and stress and additional speech problems can exasperate the situation. The resulting anxiety and acute sensitivity can result in psychological complications."

Cathy recalls a time when 6-year-old Ben learned his father would be taking him to speech therapy that day. "He started to cry and said, 'But Mommy, he can't.' When I asked 'Why not?' he leaned close and whispered, 'Because then he'd know.' It made me cry. I never knew how ashamed he was. He actually thought he was hiding it and that no one in the family knew. He couldn't say three words without stuttering."

For Christy Trevino of Libertyville, whose 4-year-old son, Nicholas, began stuttering around age 2, the first signs didn't seem all that significant.

"I thought it was part of his speech development," Trevino says. "He was learning to talk and I believed it was part of putting sentences together. But the stuttering persisted and increased in a cycle."

Trevino turned to a good friend, a speech language therapist. "Some stuttering resolves itself on its own," Trevino says. "She told me to wait awhile, and if the stuttering persisted or worsened, to let her know. It did get worse. She brought another speech therapist to our home for a general screening."

Soon Nicholas was in speech therapy sessions with Chmela.

"Kristin engages Nicholas in play, using games, books and conversation to help him to decrease and manage his stuttering," Trevino says. "She observes Nicholas to see how often he stutters within a 10- to 15-minute time frame, to determine a stuttering rating. Then she incorporates the Lidcombe treatment."

According to the British Stammering Association, the Lidcombe Program is primarily for children ages 6 and younger, but may be effective for older youths, too. It focuses on two goals: stopping the stuttering, and maintaining control. The techniques are taught to parents, who apply them at home. Parent-child interaction is positive and supportive, and the program is most effective when used as a backdrop for everyday life. The severity of stuttering is based on a 10-point scale,

with success measured against individual criteria. The first stage has a median completion time of about 11 weeks.

Nicholas has another year of preschool before he starts kindergarten, and Trevino will continue to have him work with Chmela.

"Kristin is one of the top speech language therapists specializing in stuttering," Trevino explains. "She and Nicholas have formed a strong bond and he adores her. He has improved tremendously."

Trevino advises parents who suspect their children might be starting to stutter, not to delay seeking treatment.

"If they have any doubts at all that speech problems are developing, they need to contact a therapist right away," Trevino says. "The earlier stuttering, or any speech problem, is addressed, the better off a child will be. Get help early. Don't wait."

Valerie Ostergaard's lifestyle, both now and when she was a child, has been greatly influenced by her stuttering. Now age 24, the Cary, Ill., resident began speech therapy at a very early age, and is today beginning her final year as a graduate student in speech language therapy. The focus of her future practice will be childhood stuttering, and she believes her experiences will help her to be part of the therapeutic process for others.

Stuttering became a major issue in her life in about second grade. "I was never really made fun of in school, but I always knew I was a little bit different than everyone else," she recalls.

Along with speech language therapy, Ostergaard and her family have greatly benefited from participation in the FRIENDS organization for the past 13 years.

"Having my family support me and get involved with this organization has been great," she says. "FRIENDS is not only a positive way to deal with stuttering, but also a way to finally meet kids just like



Valerie Ostergaard



Kristin Chmela with Nicholas Trevino and his mom, Christy.

yourself. It's hard to believe that people you see only three days a year can become some of your closest friends, but there's no doubt in my mind that I have made lifelong friends. They've become like a second family to me." Ostergaard feels the same way about Chmela, her therapist of many years.

"Early intervention is the key to the prevention of stuttering," says Chmela, who began stuttering as a preschooler. "My parents tried to get help for me from within the school system. The problem with stuttering is that it can be an intermittent or cyclical disorder. When I was being evaluated, I didn't stutter. Some clinicians still believe that, if they don't detect signs of stuttering, the child does not stutter."

Stuttering may include behaviors such as repeating or prolonging parts of words, or "blocking" – the mouth is formed to say a word but no sound comes out. Sometimes individuals develop fears about saying certain words or speaking in certain situations.

"I actually chose the college I initially attended because I knew I could say its name without stuttering," Chmela says. "That's how much stuttering can influence a person's life and behavior. I used to know, prior to stuttering on a word, that I was going to have trouble on it. Children and adults who stutter may feel frustrated, embarrassed and even ashamed of the problem. Not being able to express yourself can lower self-esteem."

Chmela operated privately for 15 years before becoming associated with the Central Speech & Language Clinic in Long Grove. In her new clinic, she sees patients from age 3 to 75.

To Learn More:

- FRIENDS: The National Association of Young People Who Stutter, www.friendswhostutter.org
- National Stuttering Association (NSA), www.nsastutter.org
- Stuttering Foundation of America (SFA), www.stutteringhelp.org

"It's never too late to work on your communication," says Chmela, who also writes, trains clinicians and consults for the Stutter Foundation of America.

While about 75 percent of those who stutter in early childhood outgrow the disorder, Chmela emphasizes that it's vital to begin therapy as early as possible.

"It's not good to allow stuttering to continue more than six months to a year," Chmela says. "The earlier the better, because that window, from about ages 3 to 6, provides the best opportunity for the child to develop normal speech patterns. The success rate can be as high as 90 percent. After a child has stuttered for three years, there's a good chance he or she won't outgrow it, even with intervention."

Treatment for preschool-aged children includes a parent/child interactive approach; teaching different ways to communicate and modify fluency; and the Lidcombe Program, which encourages parents to provide treatment in the child's natural environment on a daily basis. School-age children and adults are evaluated and treated with fluency and stuttering modification techniques, with an emphasis on stabilizing motor speech patterns, as well as mental perceptions. Chmela emphasizes that good therapy "is based on a proper evaluation and an understanding of the unique needs of each client." Working with a clinician who has extensive knowledge of the problem is important.

Chmela urges parents to be alert for warning signs, which can include a family history of stuttering, persistent stuttering for six months to a year and onset after 3.5 years of age. Listen for parts of words being repeated, blocked sounds or prolonged sounds. Boys stutter more often than girls.

Connecting with other children who stutter can lessen the emotional impact of the disorder.

"When children stutter into adulthood, they develop thick skins," Chmela explains. "Getting involved with others through organizations such as FRIENDS and the National Stuttering Association, which offer self-help groups and conventions, helps them not only to appreciate that others have the same challenges, but also to network and find understanding."

Research into the cause of stuttering continues. Scientists are closing in on the responsible genes, but no underlying cause has been found yet. While therapy methods have proven helpful, a better understanding of the cause will be a tremendous aid in that effort. Proving that stuttering is a biological condition would alleviate much of the guilt, which is too often experienced by parents who believe they are somehow to blame.

In addition to the FRIENDS convention this summer in Chicago, children who stutter may attend Camp Speak Up, an overnight recreational speech therapy camp for them and an international clinical training opportunity for a select group of speech-language pathologists. Coordinators of the camp include Chmela and two other recognized stuttering experts, Dr. Kevin Eldridge and June Campbell; the Special Recreation Association of Central Lake County; the Western DuPage Special Recreation Association; the Stuttering Foundation of America; and Northwestern University. ■