Syllables and Self-Esteem
BU’S SPEECH DISORDERS CLINIC HELPS STUTTERERS PUT AN END TO IT
BY CALEB DANILOFF

Stanley Fisher lived much of his forty-year career at BU in fear. For decades, as the School of Law professor lectured at the podium, he could feel the breath of a beast hovering over his shoulder, claws drawn, ready to strike. The monster was his own voice.

“The idea of telling my students I have a stutter was one of the most shameful things I could imagine,” Fisher says. “I thought, they’re paying $50,000 a year, they deserve a law professor who can speak and model the golden-tongued advocate.”

After his classes, Fisher went home wracked with guilt, his self-esteem pummeled. He tortured himself with questions. Did the students catch his speech blocks? Would they complain to the department chair? How would he act in the next class? He never knew when the disorder might kick in, but it was always looming.

“It was very stressful,” he says. “I would just be silent in class, or say things I didn’t mean to say, because otherwise I was afraid I would stutter.”

A little more than 3 percent of children...
can relate. The veteran journalist, who embedded with U.S. forces during the Iraq invasion in 2003 and flew to Haiti after the January earthquake, first found BU’s stuttering clinic in 1994 when he wanted to move from the editor’s desk back to reporting.

“As editor, I didn’t have to confront it that much,” he says, pausing before certain syllables. “You’re working with words, working with colleagues who know the situation. But I wanted to report again, and I was having the same old problems in my social life. I would avoid speaking in public. Just going to the store to order a sandwich was a big event. There were the blocks, but also ph-ph-physical effects — contortions and distortions — and the disappointment emotionally.”

In thirty-three years in the business, MacQuarrie says, he’s met only one other reporter who stuttered. A few years ago, he wrote about BU’s stuttering clinic for the Boston Sunday Globe. He admits he might as well have been writing about himself: “His face turns red, his head twitches, his eyes slam shut, and spittle flies in small darts from the corner of his mouth. He’s trying to say two simple words. What 99 percent of the adult population takes for granted, this man approaches with a weary mixture of dread and fatalism. He is an adult stutterer, navigating a communication-hungry world with a faulty rudder that constantly threatens to take him off course.”

A looming speaking tour for a recently published book brought MacQuarrie back to the clinic last year. He revisited breathing and relaxation techniques, broke down specific muscle movements needed to form vowels and consonants, and communed with fellow sufferers.

“Stuttering continues to be a professional handicap,” MacQuarrie says, pausing before easing into the next sentence. “I have to work with less each time. I’ve had people tell me they can’t believe I’m a reporter because I stutter. I’ve had a couple of people who’ve walked away from interviews. It’s a blow to your self-esteem to have people not give what you thought was the respect you deserved.”

One of Parris’s speech pathology graduate students, Kathleen Tehrany (SAR’09), worked in the clinic last year, helping people like Fisher capture fluency and view their disorders through a less inhibiting lens.

The semester before, Tehrany was a client. “I don’t want kids and adults to have to go through what I went through,” she says. “The feelings and attitude piece is a huge component, and I wish that had been addressed for me.”

Her twin sister stuttered as a kid, as did her older brother and sister. They outgrew the disorder; Tehrany didn’t. She was teased in and out of school, turning to art and sports. “I was different,” she says, “but not in a cool way.”

She never spoke in class and teachers didn’t call on her. The prospect of an oral report was paralyzing. “Whenever I had an assignment where I had to talk out loud, I thought about it every single day,” she says. “All I could think about was what a fool I was going to make of myself.”

A clinical fellow on track for her speech therapist’s license, Tehrany works at a middle school and at the North Shore Children’s Hospital in Salem, Massachusetts. Does she get funny looks as a speech pathologist who stutters?

“Most parents have normal reactions given that their kids stutter,” she says.

Tehrany is one of several hundred participants in a stage-two drug trial. Pagoclone, from Indevus Pharmaceuticals, Inc., in Lexington, Massachusetts, was developed to target panic and anxiety, but didn’t show desired results. A couple of women taking it, however, stopped stuttering. So far, the drug has shown an average 19.4 percent reduction in syllables stuttered compared with 5.1 percent for a placebo. During open-label treatment, a 40 percent drop in syllables stuttered was observed after one year.

“It’s exciting,” Tehrany says. “This is the first one they really think could make a difference. And there aren’t any real adverse side effects. Some headaches, lightheadedness, fatigue.”

Her stutter has softened since she started the trial, but she isn’t able to separate the drug’s role from her work with Parris, the confidence that comes with professional accomplishment, and simply growing older.

“I’m less self-conscious,” Tehrany says. “I still don’t like the fact that I stutter, but I don’t put as many limitations on myself.”

» Approximately 60 percent of stutterers have a family history. But then, 40 percent do not.
stutter, according to the National Stuttering Association. Most kids outgrow the problem, but one percent carry it into adulthood. Fisher is a “covert” stutterer. His speech impediment is mild, but for years he did everything he could to conceal stammers and speech blocks, those random moments when his voice simply wouldn’t work.

For the most part, he passed as fluent, substituting words and starting sentences with vowels rather than nettlesome consonants. He stayed away from the phone, had his wife order food in restaurants, avoided conferences, turned down invitations to speak. For those public appearances he couldn’t skip, anxiety chewed him up.

“I’d been at BU almost forty years before I got what I considered effective help,” Fisher recalls. That help was found along Commonwealth Avenue, at BU’s Sargent College of Health & Rehabilitation Sciences. “I actually read about the stuttering clinic in a New York Times article,” he says.

It was 2005, and he’d just asked to drop his first-year criminal law class and teach part-time because the stress had become unbearable. He was convinced, irrationally, that he’d become inarticulate and his students were suffering.

“When I found the program and Diane,” he says, “it was like a second life.”

Diane Parris is a clinical associate professor and codirector of the Joseph Germonio Fluency Clinic at Sargent’s Speech, Language and Hearing Center. She has run a weekly stuttering workshop with Adriana DiGrande, a lecturer in speech, language, and hearing sciences, for eighteen years. A handful of speech pathology graduate students help facilitate. Each week about twenty people who stutter attend a ninety-minute workshop for $10 a session and can supplement with individual therapy at $25 a visit (reduced rates are offered to full-time students); with no cause or cure, insurance companies are reluctant to cover stuttering therapy.

A motor skills disorder, stuttering has nothing to do with neurotic personality or excessive nervousness. Some experts believe an overactive right-side brain disrupts speech flow.

“It’s a neurophysiological deficit that people are still trying to pinpoint,” Parris says. “There may be a genetic basis for it, because we know that it runs in families — 60 percent have family history. Then there’s the 40 percent who don’t.”

A recent study published online by the New England Journal of Medicine says three gene mutations may be responsible for about 9 percent of stuttering cases. It is the first time researchers have identified genes that may predispose people to stuttering, which affects about three million Americans.

Men suffer three times more often than women. Speech devices and drugs have been developed, Parris says, but yield limited results. Coping with crippling anxiety sparked by the fear of stuttering and overcoming perceived judgments and impatience on the part of listeners are cornerstones of Parris and DiGrande’s program.

“It’s a socially penalizing disorder,” Parris says. “My goal for people in the clinic, whether or not their speech behaviors change, is to help them become more and more OK with being a person who stutters. It doesn’t have to stop them in life.”

As part of his clinic work and his individual therapy with Parris, Fisher practiced his stutter for a year and a half, often at Espresso Royale on Commonwealth Avenue, as part of his individual therapy.

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As part of his clinic work and his individual therapy with Parris, Fisher practiced his stutter for a year and a half, often at Espresso Royale on Commonwealth Avenue, purposefully stammering through his order, maintaining eye contact, taking note of reactions. He read aloud and kept a journal. He drew pictures of his stutter. He wrote letters to his disorder, his “twin, Little Stan.” Spending time with a cross section of stutterers — firefighters, telephone workers, businessmen, high school seniors — eased the loneliness. Now, within the first minute of any class, Fisher announces his problem and warns students he might not be able to speak at times.

“The effect has been amazing,” he says. “The number of times I’ve had a speech block has decreased almost entirely. I’m not trying to hide, not ashamed. I’m not as fluent as other people, but it doesn’t mean I’m not fit for my job.”

Longtime Boston Globe reporter Brian MacQuarrie