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“Aphasia center focuses first on understanding ”

BY SHAWN BOBURG

An estimated 20,000 people in the metropolitan area suffer from the brain disorder aphasia, but most people don't know what it is, according to a local treatment center that is working this month to raise awareness of the condition — and of what it is not.



AMY NEWMAN/STAFF PHOTOGRAPHER

Don Kober, left, speaking at Sunday's fund-raiser with Adler Aphasia Center founders Mike and Elaine Adler.

"People dismiss you, people think you are retarded. I have a speaking problem, but I'm not mentally disabled," said Terry Vaughan, 60, of Ridgefield, one of many with the disorder who attended a fund-raiser on Sunday held by the Adler Aphasia Center in Maywood to kick off national Aphasia Awareness Month.

Aphasia, which keeps stroke and other brain injury victims from expressing what is going on in their otherwise healthy minds, left Vaughan uttering unintelligible half-words. He said he felt depressed and isolated.

"I didn't want to go to weddings or parties because I couldn't talk," Vaughan said.

Language skills derailed

- Aphasia is a language disorder that results from damage to areas of the brain responsible for communication.
- A person with aphasia typically has trouble speaking and sometimes understanding what people are saying, as well as reading and writing.
- Aphasia does not affect a person's intellect.
- About 1 million Americans, or 1 in 250, have aphasia, in most cases because of strokes.

About 1 million Americans, or 1 in 250 people, have aphasia, with nearly 100,000 new cases each year, according to the National Aphasia Association. Most are stroke victims. The founders of Maywood's Adler Aphasia Center say too many of those people give up hope — and forgo treatment.

"After I had a stroke 14 years ago, doctors said I had plateaued, that I wouldn't get any better, that I wouldn't be able to talk," said Myron "Mike" Adler, who founded the center with his wife, Elaine. "That's not true. I've gotten better every year."

One of about a dozen treatment centers in the nation, the non-profit provides speech therapy programs for 95 victims and support for 40

caregivers. It operates largely on donations. The center, which has opened a second facility in Jerusalem in conjunction with Hadassah College, estimates there are 20,000 aphasia victims in the New York City area. Many of them don't seek treatment because they don't know what aphasia is, said Executive Director Karen Tucker.

The center held a jazz brunch fund-raiser at the Whole Foods Market at Paramus' Bergen Town Center on Sunday morning, drawing about 200 people touched by the disorder.

Sufferers and caregivers spoke about losing onetime friends who couldn't handle the awkwardness of waiting long periods for a single word. About being mistaken for a drunk because of slurred speech. About the frustration of not being able to ask family members simple questions, like "Where are you taking me?" or of saying "boy" instead of "girl" and "night" instead of "day". But treatment can provide hope, many said.

"People need to know that as long as you survive a stroke, all is not over," said John Loughran, 74, of Teaneck, a stroke victim.

Loughran is one of the center's success stories.

He nearly died from a stroke five years ago that left him unable to swallow food or talk. But on Sunday, after two years of speech therapy, he spoke steadily, if haltingly, while eating a Danish.

"Your mind is OK," he said, pointing to his head. "But the path from here to my mouth was gone."

"The center has made me feel alive again," he said. "I never knew what aphasia was. ... Then, when I saw the other people [in the aphasia treatment center], I said 'They are all just like me. I'm fighting, and I will be as normal as I can be.' "

Tucker, the executive director, said that while there are not enough data to prove that the center's treatment programs are working, broader research shows that the brain "has elasticity and can recover." That's why awareness within the aphasia community is also important, she said.

"You improve through practice, but if you sit home alone and give up on speaking, it's not going to happen," she said.

Many at the event said that the center's social atmosphere was critical to their recovery and happiness.

"The most important part was the camaraderie," said Barbara Tillman of Fort Lee, whose husband, Frank Tillman, frequented the center from the time of his stroke eight years ago until he died in April. Tillman's funeral service was held at the center, she said. "There are no words to describe what the center meant to him. He went twice a week. He'd wake up every Tuesday and Thursday, and you'd think he was going to the county fair."

Those who want to contribute to the center can visit its Web site at adleraphasiacenter.org or can call 201-368-8585.

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