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SPECIAL TO THE VINDICATOR

Nikki Villella, left, and her mother, Kathy, both have been diagnosed with multiple sclerosis. Samantha Villella, Nikki's sister, has won a national award for her service as an advocate for awareness and research on MS.

Valley woman wins national award for her service to MS

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BOARDMAN

Samantha Villella remembers March 10, 2014, as if it were yesterday.

She was at work, regularly checking her phone for updates about her sister Nikki's doctor visit.

She left the room, and returned to find a voicemail from her father.

What she heard in that message made her lean against the wall and slide to the ground.

"I couldn't breathe," she recalls. She remembers her co-workers helping her off the ground and asking her what was wrong.

"Nikki has MS," she told them.

Word of the diagnosis hit the Villella family, of Boardman and Canfield, all



S. Villella

the harder because it was the second time they'd received such devastating news: Samantha's mother, Kathy, was diagnosed with multiple sclerosis in 2008.

MS is a disease of the central nervous system that disrupts the flow of information within the body, and

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between the brain and the body, as defined by the National Multiple Sclerosis Society. Its symptoms include fatigue, numbness or tingling, weakness, difficulty walking, spasticity, dizziness, pain, cognitive changes, depression and many more. They can be mild, moderate or severe. The cause of MS is unknown, and no cure has been found.

Nikki's doctors believe she has relapsing-remitting MS, the most-common form of the disease. It's characterized by attacks of neurologic symptoms that alternate with periods of partial or complete recovery.

Kathy lives with a moreextreme version of the disease (primary progressive MS) that now has caused her to use a wheelchair and robbed her of much of her independence.

Samantha describes learning of their diagnoses as devastating to her family.

"It crushes me knowing that Nikki sees that every day and knows it could progress to that," she said of her mother's condition. "It's like your world comes crashing down. Hearing that diagnosis is very hard."

What's important though, she said, is to push forward when you come to what she calls a "crossroads."

"When you get a diagnosis of any type, such as MS, you come to a crossroads in life, and you figure out how you're going to help that loved one. Are you going to be there for them every day? Are you going to take care of them emotionally, physically? Or do you say, 'That's not me, I'm not a caregiver. ... I'm going to use my voice," Villella said.

She stressed that any effort, public or private, is valuable.

"Taking care of a loved one or friend who has any type

of diagnosis is very challenging, and that is enough," she said.

Her own approach has been to "scream from the mountaintops," she said. Since shortly after her mother's diagnosis, she has volunteered as an advocate for MS awareness and research. Her family (including father, Ed; brother, Brent; and sister-inlaw. Stefanie) is involved in many of those efforts.

Villella, who works at The Lake Club in Poland, started by organizing a team that grew to more than 100 people to walk in the annual Walk MS: Mahoning Valley event. This year's walk is April 16 at Mahoning Valley Scrappers Stadium. For more information, visit www.nationalmssociety.org.

Samantha and her family also run a nonprofit organization that raises money for the NMSS's Ohio Buckeye Chapter and The Oak Clinic for Multiple Sclerosis. To date the group has raised more than \$52,000 for MS research, education and fi-

nancial assistance for people with MS.

After serving as an ambassador for the National MS Society, Villella last year became a District Activist Leader for the group, for which she coordinates with U.S. Rep. Tim Ryan's office to advocate for MS awareness and research. Earlier this month, she was honored for her activism at the NMSS's annual Public Policy Conference in Washington, D.C., where she accepted the first District Activist Leader of the Year Award.

"I've never won anything before, so to have it at that level and to have them recognize something I'm doing just because it's meaningful to me was extremely humbling," she said.

"It makes my heart and my soul happy when I'm doing this work, because it's helping others. I know that someday in the very near future, we're going to find a breakthrough with this, and help so many people who have [MS]."