

Annual walk raises awareness of multiple sclerosis

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CANFIELD

Nikki Villella enjoys her job as a crisis counselor, spending time with family and living a normal life in nearly all respects – all of which make it difficult to believe she was diagnosed a few years ago with multiple sclerosis.

That contrast also illustrates what nearly everyone with MS and those who know someone with the disease will point out: that no room exists to adopt a one-size-fits-all approach.

“I take meds orally twice a day and exercise at a gym, and I take barre classes,” explained Villella, who was diagnosed in March 2014 with a type called relapsing-remitting MS after having experienced unusual tingling in her hands and feet as well as blurred vision. “I get fatigued easily if I don’t sleep enough.”

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WALK

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Villella initially went to a chiropractor because her neck "felt out of whack," but an MRI showed lesions, all of which led to her diagnosis, she recalled.

Villella, who works for Coleman Behavioral Health, was among the 30 members of KV's Krew, one of the estimated 34 teams that took part in Saturday morning's annual Walk MS Mahoning Valley at Canfield Fairgrounds.

Participants gathered with friends, family and support members to walk about 1.5 miles around the fairgrounds during the fundraiser event in which money was raised to provide services and programs to those with MS, noted Jennifer Hamilton, vice president of marketing and development for the National MS Society's Ohio Buckeye Chapter.

Funds also were to go toward research, Hamilton said, adding that 15 disease-modification therapies are available, compared with only three in 1999.

Symptoms vary in severity and type from person to person and are unpredictable in any given individual. They include gait and walking problems, tingling and numbness and, in more extreme cases, paralysis and blindness, according to the National Multiple Sclerosis Society.

Villella recalled having feared that her diagnosis might make it harder to find people who would want to

MULTIPLE SCLEROSIS

Fast facts

An estimated 240 people on 34 teams took part in Saturday morning's annual Walk MS Mahoning Valley at Canfield Fairgrounds to connect and join with those who have this disease, along with others who care for them. Some facts about the disease:

◆ **Unpredictable and** often disabling, it affects the central nervous system by damaging the myelin coating around nerve fibers, disrupting and interfering with the flow of information within the brain and between the brain and the body.

◆ **Common symptoms** include fatigue, numbness or tingling, spasticity, difficulties with walking, general weakness, dizziness, bladder and vision problems, pain, depression and emotional changes.

◆ **Less common** symptoms are headaches; hearing loss; seizures; tremors; itching; and speech, breathing and swallowing difficulties.

◆ **Most people** are diagnosed between age 20 and 50, though specific symptoms, their progress and severity in any given person cannot yet be predicted.

◆ **Two to three times more** common in women than in men.

◆ **Treatment options** include rehabilitation, comprehensive care, medications, exercise and good diet.

date her. Nevertheless, she is thankful for others' support and encouragement, including her boyfriend, Ryan Snyder, she said.

"I feel wonderful," added Vilella's mother, Kathy Vilella, who uses a wheelchair after having received a diagnosis in 2008.

Despite Saturday's persistent light rain and temperature around 50 degrees, Kathy Vilella, with assistance, finished the entire length of the route, she said.

Also part of KV's Krew was Nikki's sister, Samantha Vilella, a district activist with the Buckeye chapter.

Many walkers wore stickers announcing whom they were supporting. Some had names of individuals while others were on behalf of those in general with the disease. Besides KV's Krew, other top fundraising teams included "No MSing Around," "Team Pavlich" and "Improvise, Adapt and Overcome."

One of those on the "Improvise" team who didn't let a little damp weather slow him down was Nick Giangjordano, who learned about 10 years ago that he has MS.

"I've been relapse-free for two years. I had clean scans, no symptoms, but that could always change tomorrow," he said. "I'm thankful for what I have today."

Giangjordano, who works as a behavioral interventionist for a school in Pennsylvania and served in the Marines, recalled having

numbness from the waist down. While in Germany on a tour of duty during the war in Iraq, an MRI revealed the MS, which he had never heard of before his diagnosis, Giangjordano said.

Such news can be devastating for some, but those in that situation can take practical steps to make life easier, he explained.

"Take one day at a time; don't look too far ahead. Live now, and do all you can do," he advised.

The Ohio Buckeye chapter's Hamilton said she's pleased that continued research is moving closer to finding a cause and treatments continue to evolve.

Information at Saturday's walk was available on Ocrevus, a prescription medication recently approved by the U.S. Food and Drug Administration, and manufactured by Genentech, a San Francisco-based biotech company.

The drug is mainly for adults with primary-progressive and relapsing-remitting MS. Infusions are given once every six months, noted Donna Delis, a clinical specialist with Genentech.

Certain local physicians and neurologists are able to give the infusions, added Delis, who also cited the importance of looking at the individuality of those with multiple sclerosis.

"MS patients are as different as snowflakes," she said. "They're very individual in how they present with their disease."