

Activists lobby legislators on various MS initiatives

By JORDYN GRZELEWSKI
jgrzelewski@vindy.com

YOUNGSTOWN

For decades, the U.S. relied on data indicating there were approximately 400,000 people in the country with multiple sclerosis, a disease of the nervous system for which a cause and cure are unknown.

Recently, however, the National Multiple Sclerosis Society collected data suggesting the national prevalence of MS is more than double that.

MS activists, including Samantha Vilella of Boardman, a district activist leader for the society, recently traveled to Washington, D.C., to advocate for more research such as this.

During the society's annual public policy conference, activists from across



Vilella

the country lobbied legislators on a number of initiatives. They asked legislators to support funding for the National Neurological Conditions Surveillance System at the Centers for Disease Control and Prevention, which would be the first national system to track the incidence and prevalence of MS.

Activists also asked for \$12 million from the Congressionally Directed Medical Research Programs' MS Research Program to fund high-risk, high-impact research projects.

Another priority was lobbying for more affordable medications. According to the society, people with MS

spend three times as much out-of-pocket than the average person in employer plans.

"They're having to choose between paying bills, paying their mortgage, and paying for their medication. And that's not right," said Vilella, whose mother and sister have MS.

What Vilella wants others to understand about MS is "it's a snowflake disease, and it's different for every single person. With MS, a lot of symptoms are not visibly seen."

"Understand it's a very debilitating disease," she added. "But on the other hand, you can live many years and be stable."

The local Walk MS event will take place May 5 at the Canfield Fairgrounds. For more information, visit WalkMS.org.