A commitment to public policy while living with MS



Mary Rouvelas, who lives with MS, advocates for the National MS Society and the Affordable Care Act.

This <u>World MS Day</u>, May 30, people across the globe are coming together to celebrate the MS connections that are changing the world by building connections to community, connection to self and connections to quality care.

People like Mary Rouvelas are challenging social barriers that leave people affected by MS feeling lonely and socially isolated by advocating for better services, celebrating support networks and championing self-care.



Mary Rouvelas (second from left) goes scuba diving with her husband and children to stay active. Photo courtesy of Mary Rouvelas

Shortly after graduating from law school, Rouvelas was diagnosed with multiple sclerosis. Despite initial tingling in her left foot and temporary vision loss, she experienced only mild symptoms throughout the first few years. "For a good six or seven years, it was more scary and threatening, but it really didn't impact my day-to-day life," Rouvelas recalls.

But in 2006, she started to have mobility issues, which have steadily worsened. Rouvelas now uses a scooter to get around. "You don't realize the world is essentially built for mobile people until you're not one, and then you realize there are just a lot of places you really need to plan for," Rouvelas says. "There are places we no longer go because they are not friendly (to people with disabilities)."

She has taken up therapeutic horseback riding and adaptive scuba diving to stay active and connect with her family. "My husband and I were scuba divers before I was diagnosed with MS," she says. "Now, our children are certified so we can all go as a family, so that's been really fun."

Rouvelas acknowledges that while there is a heavy focus on the medical aspect of the disease when someone is first diagnosed, the psychological and emotional effects are often overlooked.

"There is a large percentage of people with MS who have depression and anxiety, and I don't think it's a coincidence — it's a reflection of how difficult it can be to have this disease,"

Rouvelas says. "That's actually where I think the National MS Society can be really wonderful. It really fills the need for people to have information, outreach, programs and a sense of family that improve the quality of life for people living with MS."

"There is nothing I want more than to use my expertise to help other people with MS."

Rouvelas began advocating for the National MS Society in 2014 when she was doing public policy work for the American Cancer Society Cancer Action Network in connection with challenges to the Affordable Care Act. "I felt the National MS Society should have the chance to be represented in the work I was doing as well," she recalls. "I wanted to represent MS patients in court battles about the Affordable Care Act, so I reached out to the Advocacy team at the Society."

Today, Rouvelas is senior counsel for the American Cancer Society Cancer Action Network and the in-house coordinator for 20 different patient groups, including the National MS Society, which filed a brief with the U.S. Supreme Court in May 2020 urging the high court to uphold the Affordable Care Act.

The brief cites the devastating and lasting effects people would face if the Affordable Care Act is struck down. It provides extensive scientific data showing that access to health insurance improves medical outcomes for a wide range of conditions and studies showing that the health law has made a measurable difference in prevention and care.

"My particular area of expertise is public policy and advocacy," Rouvelas says, "and if I can do some good for people with MS in that arena, I want to do as much as I possibly can.

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