

Becoming fearless



One woman finds that by educating others about MS, her own fears dissolve and her hope for the future grows.

by Shara Rutberg

In the dark parking lot of her doctor's office on a bitter Wisconsin evening in December 1986, Jane Jacobson barely managed to open the door of her sedan. Sinking into the passenger seat, she pulled her wool coat close. Her hands had been shaking too hard to button it. Jacobson had just been diagnosed with multiple sclerosis. As she leaned forward and rested her head on her icy hands, the car's interior light switched off. She and her husband Doug were left in total darkness.

"It was as if I'd opened the door to my future, and all I could see was black," Jacobson recalls. "I just want to see the children graduate, be able to walk them down the aisle at their weddings, be able to hold our grandchildren in my arms," she remembers saying to Doug. Most of all, the 41-year-old mother of two didn't want to become a burden to her husband. But she was afraid to speak that fear out loud.

An accidental advocate



As an MS research advocate, Jane Jacobson speaks to community groups throughout Wisconsin to share her personal story of being diagnosed, as well as the advancements in research since then. Photo courtesy of Jane Jacobson

Today, Jacobson speaks boldly to strangers about those fears and how she managed them, along with other aspects of her disease, in her role as a research advocate for the National MS Society, one of many things she does in support of the organization. When she speaks to organizations like the Rotary Club and Society-sponsored self-help groups, Jacobson discusses her own diagnosis and how the research the Society helps fund—in areas such as myelin repair, gene studies and vitamin D research—is creating a brighter future.

It all began when Jacobson was moved by a direct mail piece she received from the Society, and called to comment on it. During that conversation, Society staff members realized how much Jacobson, a former teacher, could do to raise MS awareness by connecting with a wider audience.

They asked her to speak with students and members of community groups, applying her skills in a way that balanced both the scientific aspect of describing MS with her own personally compelling narrative of what it was like to be diagnosed and live with the disease.

Walking the talk

She's been a powerful voice ever since. "She's astounding and inspiring and always willing to share her story," says Colleen Kalt, president of the Society's Wisconsin Chapter. Jacobson

has organized fundraising tours of labs where scientists conduct MS research, and helps produce the annual On the Move Milwaukee fundraiser featuring talks by MS researchers, a silent auction, food and music. She also has served on the state and local scholarship committees, where she's able to engage her talents and passion for mentoring students affected by MS.

Jacobson's husband Doug, who owns a packaging and distribution company, has also written two historical novels, and donated the proceeds from their sales to the Society's scholarship program. Together, they participate in Walk MS events and co-host Golden Circle dinners. "They're really a team," says Kalt. "While Jane has the disease, Doug 'has' it too. That emotional support and partnership is critical. They're really fortunate to have one another."

When a researcher spoke about discovering MS markers in 110 genes at a conference in 2014, Jacobson was even further inspired. She'd heard the same scientist speak a few years earlier about his excitement upon finding three such genes. "I was bowled over by the amount of advances that have come about in just a few years," she says. She wanted to help even more.

Already aware of the Society's pledge to commit \$250 million to MS research through its NOW—No Opportunity Wasted—campaign, Jacobson decided it was time her family contributed, and she and Doug donated \$25,000.

Since then, she has been tirelessly sharing her personal story of living with the disease with community groups, as well as the collective story of research progress and work toward a cure.

"No matter how much of an unknown MS still may be, our efforts to raise funds for, and awareness of, MS will move us toward the answers we need to stop MS in its tracks and end the disease forever," she says. "To those of us with MS, these are words of real hope, not just slogans."

The road ahead



Jane Jacobson and her husband, Doug, support each other. Together, they participate in Walk MS events and co-host Golden Circle

dinners. Photo courtesy of Jane Jacobson

Jacobson says her symptoms are far better today than they were in the first few years after her diagnosis. She attributes her well-being to the progress made in disease-modifying treatments, as well as to the strength of her family and faith, and the empowering force of her work with the Society.

“I was determined to set a good example for my family—determined they not see MS rule my life.” Nevertheless, she says, “It’s defined my life—in a good way, through my involvement with the Society, and all the people I’ve met and how I’ve been able to share my story and talk about research. I’m determined to be part of finding a cure.”

“The disease does not get Jane and Doug down,” says Kalt. “It inspires them to move forward. They’re a really great story—a love story.”

Together, they’ve shined a determined light on the future that Jacobson feared so deeply the night of her diagnosis. And yes, she’s been able to walk both her children down the aisle and hold her grandchildren—all seven of them.

Shara Rutberg is a Boulder, Colorado-based freelance writer.

For more information on the Research NOW campaign, visit nationalMSSociety.org.