



**June 2024**

## Welcome

News and highlights keeping you informed as we work together to accelerate life-changing treatments for people with progressive MS worldwide.

### **Watch the June Alliance Global Webcast:**

#### **Mobility Challenges in Progressive MS**



#### **[Watch Now](#)**

Learn more about three current research projects aiming to help identify and measure mobility challenges in progressive MS, and how early detection of and intervention for mobility changes leads to better quality of life.

The webcast features Peter Feys, PhD, Professor, Rehabilitation Sciences, University of Hasselt (Belgium); Sarah Donkers, PhD, Associate Professor, College of Medicine, University of Saskatchewan (Canada); and Brad Willingham, PhD, Director of MS Research at Shepherd Center (U.S.). Candace Maenza, PhD, Managing Director of the Neuromechanics in Translational Rehabilitation Program at Penn State College of Medicine (U.S.) leads the discussion and provides perspective from both a researcher and a person living with MS.

## Welcome Bristol Myers Squibb to the Alliance Industry Forum

Bristol Myers Squibb recently joined the International Progressive MS Alliance as a member of our Industry Forum. The pharmaceutical company is committed to addressing the unmet needs within the global progressive MS community.

The Industry Forum was developed to convene industry and other for-profit stakeholders to provide advice and guidance to the Alliance's Scientific Steering Committee (SSC) as well as provide financial support.

## Amplifying the Voices and Roles of People Affected by MS

### Meet Marie Vaillant, Member of the Alliance People Affected by MS Engagement Coordination Team



**Resides:** Ottawa, Canada

**When she was diagnosed with MS:** In 1996, while walking to the YMCA for step class, Marie noticed that she'd get part-way there and her foot would drop out.

Her family doctor referred her to a neurologist who diagnosed her with progressive MS. She was 40 years old. Over the next decade, as her symptoms intensified, a new neurologist suggested she consider going on disability. "I was using a cane, and working was getting harder," Marie says.

Although she loved her job in marketing and found it tough to leave, she soon began volunteering with the MS Society of Canada, which helped fill the gap.

**How MS has impacted her life:** After a fall 12 years ago that fractured her wrist, Marie and her husband moved from a three-story townhouse to a bungalow, where being on one floor has made her life easier. To get around the house and outdoors she uses a small walker, and for navigating places like Costco and for traveling, she got a custom wheelchair—"it looks slick," she says. Fatigue is a big problem—"I have to nap every afternoon. People think it's a luxury but it's a necessity," she says. She also now has arthritis in her knee that's made worse by an altered gait. Marie does physical therapy and exercise to try to strengthen it. She still goes to the gym—doing weight-training and Zumba classes, but she modifies the movements and asks for help when she needs it.

“I manage my environment to fit,” she says. And instead of playing tennis and skiing like she used to, she now rows at her cottage in a single rowing scull that her husband helps her get in and out of. When it comes to her marriage, she feels lucky to have met her husband two years before her diagnosis. His attitude was: “We’re in this together—we’ll get through it.” He’s got a great sense of humor, too, Marie adds, which helps a lot.

**What the Alliance means to her:** When Marie was first diagnosed, there was limited research on progressive MS, and there were no medications. “It was like, ‘you have progressive MS, well, good luck!’” When she heard about the Alliance, she was on the board of the MS International Federation (MSIF), which is one of the Alliance’s founding member organizations. “I was thrilled to see a concerted effort on progressive MS when there hadn’t been one for years,” she says. “I wanted to get involved as a person with MS.” Indeed, the Alliance has given her the opportunity to put her corporate skills to good use. “It gave me a *raison d’être* to bring something to the table,” she says. As a bonus, she’s met wonderful people from all over the world, including Lebanon, India, and Australia. “It’s broadened my world perspective,” she says. “It’s been a win-win experience.”

**Why the perspective of people with MS is so critical:** “Researchers don’t always understand that it’s hard for people to participate in studies,” Marie says. “You have to think about what it takes to get there,” she says, adding, “I’ve declined research trials because they involved a 20-minute drive twice a week.” This is where lived experience comes into play. Marie would recommend adding remote options and considering the fact that people may not have access to technology—“you might need to bring the research to the person,” she says. “We have to look at creative ways to engage people with MS, thinking of alternative ways of doing tests and treatments that will take into account the issues that people with MS have.”