

Fighting for access



MS activists advocate for more affordable medications.

by Robert Leroose

Great strides have been made in disease-modifying therapies (DMTs) for multiple sclerosis over the last 20 years. Yet, these medications are out of reach for many because of their high cost as well as insurance obstacles.

A study published in 2020 found that the price for MS drugs has tripled in the last seven years. According to a 2019 survey from the National Multiple Sclerosis Society, 40% of respondents said they were not taking their medication as prescribed because of the cost. People with MS said they were delaying filling their prescription, taking less medication to make it last longer or skipping a necessary treatment.

“We know that early and ongoing treatment with an MS disease-modifying therapy (DMT) is the best way for people to manage the course of their disease, slow down the progression of the disability and protect their brain from damage due to the course of MS. That means that people need to be able to find a medication that works for them and need to take it continuously,” says Bari Talente, executive vice president of advocacy and healthcare access at the Society.

Talente says the median price for brand-name DMTs jumped from \$11,000 in 1993 to more than \$90,000 today. Insurers also engage in a practice called step therapy, requiring people with MS to take medication that may not work for them before the insurer will cover or step up to a different treatment. There are 34,000 registered MS activists, “a passionate group of individuals who are taking action to change the world for people with MS,” Talente says.

Some of these activists are taking their demands for greater access to affordable medications to lawmakers. Meet three of them.



Nikki Snyder spoke to her state representatives in an effort to pass legislation requiring insurers to accept any payments to count toward deductibles.

Nikki Snyder

Canfield, Ohio

Age: 39

Diagnosed in March 2014

Nikki Snyder experienced tingling in her hands and feet and occasional blurriness.

She thought it was a neck problem because she spent long hours in front of the computer, so she went to a chiropractor. When the symptoms didn't go away, her family physician arranged for an MRI and quickly discovered that she had relapsing-remitting MS.

You could say that MS was a family affair. Snyder's 70-year-old mother, Kathleen, had been diagnosed with primary progressive in 2008. Snyder's sister Samantha Villella, who does not have MS, has been deeply involved in MS activism since 2009 and co-hosts "Need to Know With Sam & John," a podcast about MS.

Following her 2014 diagnosis, Snyder was on Tecfidera twice a day for about five years. "I did not feel great on that medicine. If I didn't get enough sleep, I would be wrecked. I couldn't function if I didn't lay down or take a nap," Snyder says. "Then, they switched me to Ocrevus infusions twice a year, and now I feel fantastic."

In October 2018, Snyder got a bill for \$2,326.24 for a regularly scheduled MRI to track her MS

progression. She was shocked, as she had already met that year's deductible with her monthly prescription medications.

Snyder discovered that her insurer had buried a change in her policy stating that the assistance she had been getting from the drug company for her medication would no longer be counted toward her deductible — something referred to as copay accumulators. Her copay hit \$4,000, and her annual medication costs were more than \$100,000.

After hearing about the situation from her sister, the Society contacted Snyder in May 2019 about getting involved as an MS activist to pass legislation that would require insurers to accept any payment for deductibles.

In 2021, she retold her story to the Health Committee of the Ohio House of Representatives.

“By stretching out our deductibles, our other needs, such as MRIs, doctors' visits, physical therapy and other medications, are financially out of reach,” Snyder told the legislators. “Ohioans need all forms of payment, regardless of where it comes from, to count toward our out-of-pocket deductibles.”

Snyder has since changed employers and has improved her access to her medications.



**Therese Humphrey Ball
became an MS activist after
taking part in Walk MS in
2004.**

Therese Humphrey Ball

Ogden Dunes, Indiana

Age: 67

Diagnosed in October 2003

Therese Humphrey Ball could run 5 to 10 miles a day effortlessly. When she began getting

tired, zoning out “like a zombie” at nighttime and had abdominal pain, she knew something was wrong. Doctors thought the pain was due to existing liver issues. Eighteen months passed before she found a neurologist who took her symptoms seriously. Her doctor concluded in October 2003 that she probably had MS since she was a child but that it had only now become apparent.

Her frustrating experience with the medical community is ironic given Ball’s extensive career in the nursing field. After starting in South Bend, Indiana, as a registered nurse first assistant in 1992, she left in 1999 to work at a trauma hospital in New Jersey, then switched to NYU/Tisch Hospital in New York.

Ball moved to Chicago in 2003 to be close to her kids, where she worked at three prominent city hospitals. She began taking Copaxone in November 2003, paying \$1,800 a month and wiping out her savings within nine months. She stopped working in 2007 and went on disability in 2008. A grant from an independent charity helped cover her costs until 2017, when her application was not renewed. Her Copaxone costs had soared to \$6,000 a month.

“I had to go off the Copaxone because I couldn’t afford it. I went on Ocrevus for three years, but it did not do its job,” Ball says. “I ended up having advancement in my disease. I have some memory issues. Sometimes I’m dizzy, or I stumble, or my hands and feet tingle.”

After joining a Walk MS event in 2004, she was invited to participate in a Society phone call about advocacy.

“I found the empowerment unbelievable. You cannot do anything with the disease, but you can fight to try and find a cure. That was the thing that ran in my head all the time.”

Ball went to Washington, D.C., in 2012 as an activist for the first time and last went in person in 2019, pressing lawmakers about the need for making prescription drugs affordable. She excelled at telling compelling stories that brought tears to the eyes of Congressional staffers.

Ball became a district activist leader, recruiting other activists and teaching them to tell brief but effective stories of their struggles.

In May 2021, Ball spoke via a WebEx call to the U.S. House of Representatives Subcommittee on Health about passing H.R.3, a bill that would allow Medicare to negotiate better prices for prescription drugs. As Ball told committee members, a year’s supply of the Tysabri she takes runs almost \$90,000.

“Drug companies are not challenged enough,” Ball told them. “We need people in charge to look at this and say: What if it were me?”



During the pandemic, Angel Hardy Heinz started an online community for mothers with disabilities and chronic illnesses.

Angel Hardy Heinz

Chicago, Illinois

Age: 44

Diagnosed in October 2012

When Angel Hardy Heinz developed optic neuritis in her right eye, she was in her first trimester of pregnancy with her oldest child. At the time, she thought the symptom might be due to “a weird pregnancy/hormone change.” After delivering her daughter in August and seeing specialists, she had an MRI and got her official MS diagnosis in October 2012.

While she has occasional fatigue, she says she is living well with her MS today. “My legs can get heavy and tired if I’m pushing it. Sometimes I’m just chasing after my kids, so I don’t know if it’s MS or parenting exhaustion,” Heinz says. When the pandemic struck in 2020, she left her job in talent development for a law firm to look after her kids (Moir, 9, and Brendan, 7), while her husband, Michael, continued his work as a partner at a Chicago law firm. She also did freelance consulting on health equity and inclusion issues. In July 2020, on the 30th anniversary of the signing of the Americans with Disabilities Act, Heinz launched Momability — an online community where mothers who live with disabilities and chronic illness could share their stories.

Momability grew out of Heinz’s activism with the Society. She first got involved with the Society by fundraising but yearned to do more. She was invited to an Illinois State Action Day in 2017 to talk to elected officials about why they should support people with MS.

“I became hooked just realizing that this is how you can effect change. I was partnered with a rock star activist — Therese Humphrey Ball. After that, I got to go to the National Public Policy

Conference [in 2018 and 2020] in Washington, D.C., and do the same thing but on the federal level. I felt like we were healthcare avengers to save the day and fight for the Affordable Care Act,” Heinz says. “I’m fortunate because, right now, it is easy for me to get around, but I don’t take my mobility for granted. Everyone’s MS is different.”

In a national survey by the Society, 40% of respondents living with MS said they’ve altered their treatments or stopped treatment altogether due to cost. Heinz has advocated for lowering prescription drug costs by testifying and speaking at a press conference led by Representative Will Guzzardi. Heinz said: “I have taken an MS disease-modifying therapy since October 2012. This medication first became available in the late 1990s. At that time, it was less than \$10,000 a year. In October 2012, when I started taking the drug, it was \$50,975 a year. Today, the cost of this drug is \$86,554 a year. How is this justified? MS medications cannot work if we cannot afford them.”

Talente says submitting uncontested data and describing the personal impact of high drug prices and other access issues is essential for the Society’s advocacy efforts. “That’s why it’s so important for people and families affected by MS to share their stories with us and elected officials. Just the act of doing that can make a huge difference.”

Robert Leroose is a Long Island, New York-based writer.

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