

(Un)steady as she goes



Megan White takes MS sitting down — but only when she must.

by Mike Knight

It was 6 a.m. on a Saturday in October 2021, a beautiful fall morning, the first of the two-day, 150-mile-long Bike MS: Arizona fundraiser.

And Laura Leigh Birdwell was ready to go.



After her MS diagnosis in 2006,

Megan White started volunteering to help others living with the disease. Photo by Jeff Noble

Held annually since the mid-1980s, the fundraiser event wasn't held in person the year before, due to the pandemic. Now, pre-ride excitement hung heavy in the morning air.

Diagnosed with multiple sclerosis in 2006, Birdwell had completed the ride many times before, but this was her first ride since 2015. Surrounded by riders, volunteers and onlookers, a small stage for announcements and entertainment stood near the starting line. Sitting on the outside of the crowd, Birdwell was sipping coffee and listening to the music pumping through the sound system when suddenly it stopped for a special announcement: A fan was making her way to the stage to offer words of encouragement for the riders.

Birdwell could see the crowd parting for someone, but she couldn't see who. Then, slowly, a lone woman in a wheelchair appeared, pushing her way to the stage through the soft Arizona dirt.

It was Megan White, a woman with MS Birdwell had met back in 2015. A fixture of the event, White was known for wearing an orange tutu while she danced and jumped and cheered for the riders as they made their way out, then greeting them the same way hours later as they returned. Birdwell assumed the worst as she made her way through the crowd to reconnect.

"I didn't recognize her," Birdwell says. "It was just seven years ago that I saw her, and now she was having trouble standing up," she says. "But then I saw the orange tutu."

"What was so amazing to me was that [White] was still the same person, the same cheerleader, full of smiles, full of optimism and words of encouragement. She was still her same self," Birdwell says. "I actually started crying, and I didn't even catch a lot of what she said, but I caught her last words."

" 'My MS and my wheelchair do not define me,' " Birdwell remembers White saying. " 'We all have something. It's how we choose to live with it that makes us who we are.' "

Life isn't over, it's just different

Born in a small Wyoming town in 1968, White was placed for adoption, in part because her 17-month-old brother was diagnosed with Graves' disease, and her grandmother was worried she couldn't help her daughter raise another special-needs child. Active growing up, White "played sports and lived life," but she remembers being clumsy, falling a lot as a kid and not being "as sharp as I could have been." Still, she went on to be a bodybuilder and even ran marathons.

By the time she was 36, White was living in Mesa, Arizona, and married with three children. She lived the life of a busy mom.

However, she felt exhausted all the time and was unusually forgetful. She also tripped, so much that her friends remarked upon it. “I just chalked it up to being a single mom,” she says.



White's family has been a source of support after her diagnosis. Photo by Jeff Noble

By 2005, White's world was spinning — and not in a good way. “I woke up one day and felt like I had been on a merry-go-round for hours and hours,” White says. At first her doctor thought it might be vertigo or a sinus infection and sent her home to wait it out for a couple of weeks. “I was just in bed most of the time, spinning and spinning,” she says. “And everything was so loud. Swallowing was loud. Blinking was loud.”

White's world kept turning out of control. She was sent to have an MRI, after which she received a slip of paper to share with her doctor. “There were lots of things on that piece of paper,” she remembers. “One of them was multiple sclerosis.”

In 2006, White went to see a neurologist for a definitive answer. Her appointment was at 8:30 a.m. She remembers the doctor's important-looking wooden desk, stacked high with equally important-looking papers. “We sit down in these plush chairs,” she remembers, “and he pulls up my MRI and says, ‘Well, this will be quick. I know what you've got. You have relapsing-

remitting multiple sclerosis.’ ”

Riding the storm out

After she returned home, White made a hurried call to her pastor.

“I have multiple sclerosis,” she said.

“What’s that?” her pastor asked.

“I don’t know,” White answered.

Nonplussed, White’s pastor reminded her that her God was “a big God” and, therefore, unsurprised by the diagnosis. “And I felt like, ‘OK, God’s with me. I got this,’ ” White says.

Next came telling her family. Before leaving her neurologist’s office that day, White was told to reach out to the National Multiple Sclerosis Society for help when she got home. She remembers speaking with a woman at the Society who assured her “life wasn’t over, it was just going to be different.”

The phrase became White’s mantra, one she used when she shared the diagnosis with her daughters. The middle child, Kaydee, then 14, wanted to know more about the disease. And she wanted to know exactly how different life was going to be.

“We’re going to have to find that out together,” White remembers telling her.

“And then in one breath,” White says, “she goes, ‘Well, can you still take me to the mall?’ ”

After the initial shock of the diagnosis wore off, White contacted the Society again, this time asking how she could help them. “I thought, ‘OK, I have this disease, I have a voice, I love to encourage people, and God blessed me with all of this,’ ” she says. “I wanted to be someone who could say, ‘Everything’s going to be OK’ for the person behind me.”

Signature skirt

At first, White volunteered for Walk MS, then for Bike MS in 2008, too. And she did it all while wearing her signature ballerina’s skirt.

“When I was running marathons, I would run in my orange tutu,” White says, explaining the affectation. “It just sort of became my thing.”



White attends Walk MS and Bike MS events, always sporting her orange tutu.

White also co-founded a support group specifically for active people with MS in Arizona. “The only caveat when you come to our group is you can’t complain and tell us how sad you are or what movement you can’t make because you’re in a wheelchair,” she says. “You can still think positively, and you are going to focus on what you can do.”

In May 2021, Chris Marshall became the president of the Society’s Arizona-New Mexico market. He met White at the October ride. Not surprisingly, White’s reputation preceded her.

“I had heard about the impact Megan has,” Marshall says. “I was blown away when I met her in person. She has so much energy and such a positive attitude.”

Nearly 300 participants raised more than \$260,000 at 2021’s Bike MS Arizona event. In all, the event has raised millions of dollars since its beginning.

Despite being in a wheelchair during the humid months of the year, White remains active, visiting schools, malls and wherever she can to help people learn about MS and its effects. When she can stand, she often wears one swimming fin and one high heel to mimic the loss of balance, rubber gloves for the loss of touch and feel, and glasses with impossibly thick lenses to demonstrate vision problems.

And she always wears her orange tutu.

Always.

Mike Knight is a writer in Indianapolis, Indiana. He was diagnosed with MS in 2013.