

Volunteering changes lives



Individuals find they get much more than they give.

by Shara Rutberg

After Pedro Valdetaro was diagnosed with multiple sclerosis in 2014, he began volunteering with the National MS Society's Pacific South Coast chapter office, hoping to help others with the disease and learn more about what he could do to manage his own symptoms. He had no idea that the experience would dramatically transform the trajectory of his life.

Each year, about 500,000 people volunteer with the Society, helping in a variety of ways. "They advocate for policy changes at the local, state and federal levels; fundraise at Bike MS and Walk MS events or unique DIY fundraising events; spread awareness; and lead self-help groups and provide peer support," says Elana Sullivan, president of the Society's Michigan chapter. "And thousands of healthcare professionals and researchers partner with us to find solutions for people affected by MS. We could not achieve our goals without the dedication and commitment of volunteers."

While Valdetaro was able to volunteer full time, the Society welcomes people who are able to commit to just a few hours a week, or even a single day. "Volunteer time commitments are as varied as the work," says Sullivan.

Giving back leads to growth

Before his diagnosis, Valdetaro logged 14-hour days as a financial planning analyst for a major corporation in his homeland of Brazil. After his diagnosis, he took time off to wrestle with his fatigue, learn to manage his new medication and research the disease. With a strong support network of his own, Valdetaro was upset by stories he read online about people

abandoned by family, friends and life partners because of MS. “Since I had some time on my hands,” he says, “I wanted to do what I could to help those who aren’t as fortunate as me.”



Volunteers are a crucial part of the MS movement. Photo courtesy of the National MS Society

Valdetaro contacted volunteer engagement staff at the Society, who emailed offices across the U.S. to see who might need a volunteer with Valdetaro’s skill set. Pacific South Coast Chapter President Richard Israel responded within minutes. After a Skype conversation, it was clear that Valdetaro would be a good match for the San Diego-based office, and he made the move.

Beginning in June 2015, Valdetaro was given an increasingly challenging workload of projects that involved analyzing data, creating spreadsheets and PowerPoint presentations, all the while learning more about MS. At the end of the month, Valdetaro returned to Brazil for medication infusions. In October, however, he returned to help with the chapter’s Bike MS® event. And by the time he was finished, he realized that his two monthlong volunteer stints had done more than enhance his job skills.

“It was a critical part of my process,” Valdetaro says. After his diagnosis, he was not sure he could ever be as productive, professionally, as he had been before. But his time with the Society convinced him he could. Currently, Valdetaro is seeking the right position; meanwhile, he serves as a volunteer board member for a Brazilian MS organization developing international partnerships while earning a paycheck as a financial broker.

Seeing the impact

When Denise Belle looked around the room during last year’s Conference for African-Americans and Their Families—the 14th consecutive one she has helped her chapter in North

Carolina host—she could see the impact of the volunteer work she’s been doing with the Society since 1999. She saw it in the people who attended, representing a demographic that had been largely unfamiliar with MS when she first started volunteering, as it was previously thought that only Caucasians developed MS.



Denise Belle, a longtime Society volunteer, can see the positive effect her volunteer work has had on the awareness of MS in the African-American community. Photo courtesy of Denise Belle

“MS is a devastating disease,” says Belle, 40, who was diagnosed 20 years ago, “but it’s even more devastating if you don’t have resources to lean on for support.” For nearly two decades, she’s helped with brochures and videos for the Society tailored to the African-American community. Examples include “Living with MS: African-American Perspectives,” and “MS and African-Americans: Diagnosis and Clinical Courses.” She’s also moderated the “Knowledge is Power” series, specifically for those newly diagnosed.

While Belle’s sustained commitment is extraordinary, more than half of the Society’s volunteers have maintained relationships with the organization for 10 to 15 years, according to Sullivan. “A survey of our volunteers told us that as years of service increase, volunteer satisfaction increases,” she says.

Fueled by a passionate commitment to be a “voice for the voiceless” in healthcare, Belle works professionally as a community health advocate and brings her positive outlook to her volunteer work. She’s shared her story with lawmakers to advocate legislation and served on the National Programs and Activities Council. She is a trustee of the Greater Carolinas chapter board, and she’s also been a member of her local scholarship committee. “I can’t say no,” she says.

As a member of the National African-American Advisory Council, Belle works to increase

representation of diverse populations within the MS community across the country, and to ensure that the Society's publications include information specific to African-Americans and other minorities.

"All groups deal with chronic conditions differently," she says, "and people need to feel the information meets their needs in a cultural sense. For example, many African-Americans value faith within their support networks, so I help cultivate those types of programs and support resources."

Belle has witnessed the impact of her volunteer work on others through the growing level of participation by African-Americans at Society events and a greater familiarity with the disease in the community, but her efforts affect her on a personal level, too. "Twenty years with the disease have not been easy," she says. "Volunteering has allowed me to be more honest, more open about my experience and fears. I've been able to disclose them with others who are dealing with similar situations. There's so much therapy behind being able to be vulnerable when you're trying to cope and to not isolate yourself."

To volunteer with the Society, all you need is passion, says Sullivan. Volunteers do need to maintain confidentiality, adhere to a code of conduct and, for some positions, agree to a background check.

"Volunteers bring unique skills and experience, creativity and innovative ideas to the MS movement," she says. "We share a sense of urgency, and a vision of a world free of MS."

Shara Rutberg is an Evergreen, Colorado-based freelance writer.

Find [volunteering opportunities](#) in your area, or call an MS Navigator at 1-800-344-4867.