

Others like me

Connecting with people with MS is a different — and powerful — experience.

by Shara Rutberg

As days grow shorter and temperatures drop, the urge to hibernate through the winter months might seem appealing. Cultivating and maintaining social connections, however, is critical to wellness. And while a network of caring friends and family can be incredible, connecting with other people living with multiple sclerosis can enrich your life on a whole different, often more powerful level.

“It’s an isolating disease,” says Jean Petrillo, 54, who was diagnosed with MS in 2001, shortly after giving birth to twins.

“Even though your friends and family are there for you, unless you’re living with MS, it’s hard to understand — especially because so many people are living with ‘invisible’ symptoms,” says Cheryl DuFore, a social media specialist with the National Multiple Sclerosis Society. DuFore was diagnosed with MS in 1996. DuFore, who is active in social media groups and has attended in-person meetings, finds a different level of camaraderie among people who have MS. “It’s almost an instant friend who understands what you’re going through, what you’re thinking and what you’re feeling.”

Cheryl Hile, 46, was the first person with MS to complete seven marathons on seven continents in



Cheryl Hile and her husband, Brian Hile, complete the White Continent Marathon in Antarctica in January 2017. Cheryl holds up the custom ankle-foot orthopedic she used for the race.



Jean Petrillo organizes an MS self-help group in the Boston area.

2017. Afterward, to connect the people she met along the way, the California resident formed Run A Myelin My Shoes (RAMMS), a running and walking team. The team meets once a year to complete a running/walking event together and creates and competes in virtual events around the world year-round. Their Facebook group is extremely active.

“Relationships with other people with MS are quite different,” Hile says. “I belong to other running groups, but it’s so different when you have people who understand your

disease, who live with it. They can offer a higher level of emotional support.”

“Each of us recognizes what a victory it is to be still able to run, let alone get to the finish line of a long-distance event like a marathon,” says Gary Pinder, 55, who was diagnosed in 1995 after his first symptoms emerged on his 30th birthday.

“There’s a deep, incredible appreciation of what we’re going through that others can’t relate to in quite the same way. We all understand and have this shared knowledge of what it takes to get out of bed

connect

in the morning,” says Pinder, a Maryland resident and RAMMS member.

RAMMS Facebook group members share typical running tips like favorite running shoes, dealing with plantar fasciitis and what to eat before a long run. But they also have MS-specific conversations about topics like the best running shoes for drop foot, dealing with spasticity in the feet and the best foods to eat to help fight MS fatigue.

Hearing stories

When people with MS get together — virtually or in-person — a range of topics tends to pop up. Brian Gorsich, 54, runs the popular MSPLC (MS Patients Leading Change) Facebook page, a virtual self-help group formed by people with MS for people with MS, from his home in Washington, Illinois. During the spring of 2020, for example, a popular topic was disease-mitigating therapies and how they might affect COVID-19. Perennial issues include different disease-modifying therapies, practical tips for dealing with symptoms (like cooling vests, kiddie pools for feet and ramps into homes), strategies to keep moving, when to consult a professional and, “what I really love,” says Gorsich, “are other people’s experiences — since they carry more weight than most articles.”

“Most people, including the newly diagnosed, are encouraged by meeting and hearing stories of those who have lived with MS for years,” says Petrillo. She started an in-person self-help group for people with MS who live south of Boston. Petrillo wanted the monthly meetings to have a wellness focus, “motivating people to live their best lives.” She finds experts to speak on topics such as exercise, yoga, meditation and sleep. Conversation flows from there.

During the pandemic, the meetings are virtual via Zoom, as are the MSPLC meetings. Petrillo finds virtual meetings so helpful that she plans to continue providing online access to the meetings.

Virtual meetings are powerful connection tools for people who are not ambulatory enough to attend in-person meetings as well as for people who don’t have meetings nearby. Denise Borkowicz, 77, lives in rural Michigan where there is no public transportation and



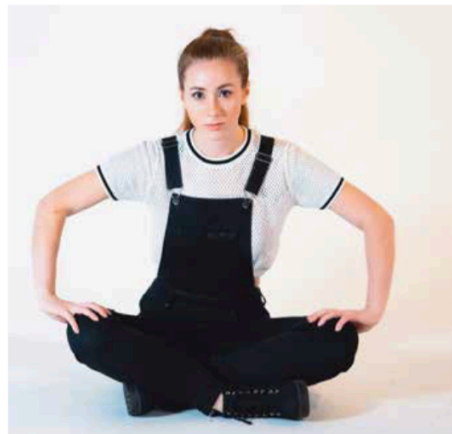
Gary Pinder is a member of Run A Myelin My Shoes (RAMMS), created by fellow runner Cheryl Hile.

little in terms of professional help for people with MS. Diagnosed in 1991, she runs a self-help group that meets twice monthly. The group meets once more socially for lunch, and then has an evening meeting with an educational angle, featuring speakers such as neurologists and Medicare specialists. During the pandemic, she reached out to members on the phone and hosted Zoom meetings. Connecting, especially in a rural area, she says, “helps ease the stress of the disease. People know they’re not alone, that others are going through the same thing.”

Members from around the world

Connections between people with MS stretch around the world. The MSPLC Facebook group “goes way beyond geography,” Gorsich says, with members chiming in from Ireland, England, Australia and all parts of the United States. The RAMMS group includes members from all seven continents and more than 14 countries.

One of the biggest, most internationally diverse MS social media groups is the MS Support Group on Discord (discord.gg/aQ4J2u8). Discord is a group-chatting platform initially built for gamers that has grown into a general-use platform for people who want to connect via voice and video chat. Patricia Abellanida



Patricia Abellanida started a Discord chat group when she could not find what she needed in other online groups.

started the group after a disappointing search for MS chat rooms on Reddit a couple of months after her diagnosis in August 2017. The 30-year-old wanted to communicate with others with MS instantly and not wait 20 minutes, or a day, for a response on a forum or Facebook page. As a gamer, she had launched Discord sites previously, so she decided to create one for the MS community. There are about 600 members. Ninety-nine were online when we spoke. “Turns out, there were a lot more people looking for the same thing,” says the Orange County, California, resident. “People are really looking for a connection with a community that understands what we’re going through — and not everybody has local support groups in their area or can physically get to them.”

On Discord, members can designate their roles as “Have MS” or “Other,” as some channels are limited to only those with MS. Chat channels are set up to cover differing topics. One is “The Vent Chat,” where people are welcome to vent about anything. In the “Small Victories” channel, members celebrate anything from starting a new medication to the first day in a week

they’ve been able to go to the bathroom consistently, according to Abellanida. The group also hosts monthly voice-chat gatherings and virtual events, such as movie and game nights.

The Discord group skews younger than most in-person groups, with most people aged 25 to 35. There’s also been an influx of teenagers that Abellanida attributes to the platform’s popularity with that particular demographic.

Websites (see suggestions at end of article) are a great place to start connecting with others who have MS, says DuFore, who lives in southeast Michigan.

Also, be sure to check out Facebook and Instagram. Search Facebook groups with terms like “multiple sclerosis” and “MS.” “Once you join a group, the Facebook algorithm keeps serving you other groups that might interest you,” DuFore says. Instagram offers easy ways to connect with other individuals. “Search hashtags like #walkms or #bikems, and your feed will be populated with others who have used those hashtags and you can begin to follow one another,” she says.

You can also simply Google “multiple sclerosis” and your area or a special interest. “There is something for everybody,” says Hile. “It’s vital to find a community of people with MS that speaks to you.”

And, when the dialogue develops, it’s a powerful force. “If I don’t keep connecting, I feel at a loss, and I think I’m not alone in that feeling,” says Borkowicz. “Just the fact that you know there are other people out there like you — it’s not so scary.” ■

Shara Rutberg is a writer in Evergreen, Colorado.



Connect with others living
with MS:
ntlms.org/peers
nationalMSsociety.org/SHG

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