

They ran how far? 100 miles



Two men with MS ran 100+ miles to meet with state lawmakers about cutting the cost of MS drugs.

by Mike Knight

It was a February night in the middle of Missouri. Matthew Porter was lying on a path thick with mud and covered with snow and ice, taking a break to stretch leg muscles tightened from running in the muck. Porter and his friend Jon Franko were attempting to run 100 miles to raise money for the National Multiple Sclerosis Society.

Other runners were pacing the pair along the run. A canopy of trees covered the track, making it beyond dark. "It didn't feel like it was black," Porter says. "It just felt like the absence of everything."

And yet, they still ran. And ran. And then ran (and walked) some more: 103 miles in 31 hours from their homes near St. Louis, Missouri, to Jefferson City, the state capital, raising \$125,000. Then, they capped their incredible feat by meeting with state legislators to advocate for more affordable access to disease modifying therapies (DMTs) used to treat MS.

Part of the Society's Do It Yourself (DIY) fundraising program, Franko and Porter's run was years in the making.



Jon Franko (center) with friends John Hadely (left) and Drew Blaylock.

Step brothers

Porter and Franko grew up in St. Louis but didn't meet until circumstances brought them together years later. Porter married, raised three children and, in 2004, began a small business that ultimately grew into a global business with 400 employees.

Porter, 46, took up running in 2010 after his 6-year-old daughter poked him in his stomach, noting it was "squishy." By 2014, he had completed 50- and 100-mile runs. It was also the same year he learned he had multiple sclerosis.

Porter kept his diagnosis private for three years because he wanted to focus on getting his business off the ground, and because he and his wife wanted to wait until their children were old enough to process the information. By 2017, Porter went public about his diagnosis.

Franko started a marketing agency in 2006, and was diagnosed with MS in 2016. After spending a year being "dark" and "really depressed," Franko, 40, came to terms with his MS. "I decided I was going to own it, and it was going to be part of who I was," Franko says. And then a client of Franko's sent him an article about a young St. Louis entrepreneur who had MS and was running 100-mile "ultramarathons."

Franko and Porter had bumped into one another years earlier as young, successful entrepreneurs in mid-sized cities like St. Louis often do. This time, they had MS in common — and more. Franko, who calls himself a "pretty normal guy," enjoys hunting, fishing, biking and running. Franko contacted Porter. They met for coffee and agreed to stay in touch.

They met again when the Society's Gateway area was searching for new trustees. This time, as Franko recalls, Porter had an epiphany.

“I think the light bulb went off for him [about] the impact we can have as people who live with MS,” Franko says. They agreed they could use their MS diagnosis to their fundraising advantage. “If I try to raise money versus a friend of mine who doesn’t have MS but who is going to ride Bike MS, it’s naturally easy for me, as I have the disease,” Franko says.

If every journey begins with a single step, this was his and Porter’s.

A fundraiser is born

Their fundraising run began in earnest in 2020 following Porter’s advocacy visit to the state capital for Missouri’s MS State Action Day. The Society’s annual State Action Days help MS activists visit state lawmakers to raise awareness and influence policy decisions that could help people with MS.

Porter left that day thinking he needed to do something more to truly grab the legislators’ attention. Running the 103 miles from his home to the state capital, he decided, would do the trick. But when COVID-19 hit, Porter put the idea on hold until 2022. At that point, he hadn’t thought of the run as a fundraising tool.



Matthew Porter and Jon Franko ran 103 miles to their state capital to meet with legislators to advocate for affordable DMTs.

Enter Franko.

“I remember I was running when I texted him,” Franko says, “and he ended up calling me to talk through it. I was like, ‘Hey man, do you want any company on this run?’ ”

Ever the marketer, Franko suggested they set their sights on raising \$100,000. “That’s 100 and 100,” he says, “and I like my numbers.”

Porter liked them, too. The pair began their run at 5 a.m. on Feb. 27, 2022, running through the day and night into Feb. 28, returning to the capital to meet with legislators two days later.

“I remember senators saying, ‘OK, before we start, I just want to make sure I understand,’ ” Porter says.

“ ‘You ran here from your house?’ ‘Yes.’ ”

“ ‘In St. Louis?’ ‘Yes.’ ‘Nonstop?’ ‘Yes.’ ”

Their fundraising stunt worked: They exceeded their goal, raising more than \$125,000.

Christie Derbin, president of the Society’s Gateway area, which includes St. Louis, has worked with the Society since 2019 and other not-for-profits before that.

“This [was] honestly one of the most inspiring things I’ve ever seen,” she says. “And the way people rallied around them. We had board members who were shuttling guest runners along the route. Some of them got up at midnight and worked until 4 or 5 a.m. And everybody just had such a great attitude about doing it.”

Franko and Porter are proud of the run and the results. They’d do it again if it meant helping others with MS. More than that, though, Porter says he simply wanted to share a positive story for people living with the disease.

“I wanted to put a story out there that this disease wasn’t me, it’s just a part of me,” he says. “And I was going to continue to push for the life that I wanted and continue to fight and treat every day as a blessing.”

DIY fundraising made easy

Not everyone can — or even wants to — run 100 miles for a Society fundraiser. Katie Million, senior manager of emerging events for the National Multiple Sclerosis Society, oversees the DIY program for seven different Society markets, including St. Louis. According to Million, nearly any activity, hobby or event can be turned into a money-making machine.

“There is such a wide variety of events,” Million says. “People do bake sales, pickle ball tournaments, motorcycle rides, galas, go-kart racing, concerts. It helps if people have something they’re passionate about or something they enjoy doing.”

DIY fundraisers make a huge difference to the Society’s mission, contributing nearly \$10 million since 2019. DIY events are organized and supported by volunteers, says Christina Carro, senior director of emerging events. “There is no such thing as a small idea,” she says. “I continue to be inspired every day with the amazing things that our DIY fundraisers come

up with. Each event brings new people into the MS movement, and it's inspiring to see!"

You can learn more about creating your own DIY event at [DIY MS](#). The page also includes fundraising ideas, a toolkit that includes how-to guides and worksheets, as well as information graphics and videos you can share to promote your event via email or social media. You will also find email addresses and phone numbers if you would like to connect with someone for help.

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

Learn how to create your own [DIY event](#).