

# @Momentum



## **Less alone**

I appreciated the article "[A new phase](#)" about secondary progressive multiple sclerosis in the Winter 2018-19 issue. Made me feel less alone and it gave me a boost, too!

**Mary Zimmerman, Oregon**



**Victoria Reese has created a community for women of color living with MS.** Photo by Joseph Gray

## **Encouraged by fellow warriors**

I was pleasantly surprised to see the article about a young black millennial with multiple sclerosis who created a community that she could relate to ("[Still dope](#)," Winter 2018-19). The hip hop inspiration of WeAreILLmatic was sweet icing on the cake! I am not a millennial but am a woman of color with MS who feels encouraged by the strength and inspiration of fellow MS warriors! Another great surprise would be to see more articles about cannabis, holistic health and other alternate therapies.

Seneca Iscove, New York

### Inspired by WeAreILLmatic

Thank you for the article "[Still dope](#)" (Winter 2018–19) profiling Victoria Reese and the WeAreILLmatic movement. Reese's initiative to start a campaign designed to unite women of color diagnosed with multiple sclerosis is truly inspiring—that community is too often forgotten in the conversation. I immediately made a donation to them and shared their campaign on Facebook. I would love to know if there is anything else I can do to support them as a white ally.

Chapin Cole, California

### It is better to know

I would like to share my MS experience in hopes of offering some guidance to L.G., California ([@momentum](#), "Is it better to know?" Winter 2018–19). I was diagnosed with multiple sclerosis 21 years ago. My symptoms were very mild and the only medications at that time were Avonex, Betaseron and Copaxone.

## Let's hear it! Share your thoughts and comments about this issue's stories.

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- Like and comment on our page on [Facebook](#).
- Email [editor@nmss.org](mailto:editor@nmss.org).
- Or send mail to **Momentum** Editor, National MS Society, 900 S. Broadway, Suite 200, Denver, Colorado, 80209. Letters to the editor must include your name and a way for our staff to contact you. Letters should be no more than 100 words and may be edited.

I was crazy about putting these strange medications into my body, not knowing what they would do to me, and my doctor didn't push the issue. Three years later, my MRI showed some new lesions, and I still didn't go on medication because I felt fine. Six months later, I had a major relapse and decided to go on medication. That summer, I began to have issues with my left leg and knee and both of my feet. I felt like I was walking on rocks. I still do and have a difficult time finding comfortable shoes. I have been on this same medication now for almost 18 years and wouldn't change a thing. I guess I'm one of the more fortunate ones in that my MS has not progressed since I've been on disease-modifying therapies. I have read everything I can about MS, the new medications, where MS can progress, and feel like I am better prepared now than I was before. I believe it's better to know in advance than to react after the fact and not be able to change something that happens. Talk with your doctor. If you find the right medication and feel good about it, you can't go wrong. Good luck!

**Harriet Pinchouck, Florida**

### **Keep trying**

I read “Is it better to know?” by L.G., California ([@momentum](#), Winter 2018–19) and felt compelled to respond. I also was diagnosed about 15 years ago, and my right leg and foot, stamina and energy levels are also affected. Until I received this new infusion, I had a poor outcome with all the prescription drugs. I felt that reading the side effects and knowing all the possibilities set me up to be looking for them. With my current medication, I went into it not knowing what could happen, and so far I’ve had nothing but success.

I think I finally received something that actually worked for me. I struggled with whether I did myself a disservice by avoiding knowledge and not taking action sooner. I did try numerous therapies and finally got the one that works, but as I have learned, things often will get worse before they get better. The important thing is we must always try. Success comes from failure.

**Barbara Monroe, West Virginia**

### **No more pie-in-the-sky stories**

You have been my No. 1 go-to people for information about MS. Ten years into my multiple sclerosis I can barely walk around my apartment without my walker and will sooner rather than later be in a wheelchair. Kudos for helping me all these years with financial puzzles, medication decisions and other issues. But please quit with the “I can climb a mountain if I can pay someone to carry me,” “I can run a marathon” (“[Run the world](#),” Winter 2018–19) baloney. While it might be reality for one person, this is BS for most people with MS. I figure skated for more than 20 years, earned a USFSA gold medal through eight years of training, and taught ice dancing to both children and adults. I obviously do not skate anymore as I cannot figure out what kind of footwear to put on the walker. No amount of wishful or positive thinking is going to change this. Shame on you for making us feel ashamed that we cannot all run marathons. MS is a physical disease; it is not a moral failing or absence of will power. I face an obstacle course every time I get up from the TV and go to the fridge. Get in the same race as your constituents, or you will get run over (by people with canes, walkers and wheelchairs) and become obsolete!

Your former biggest fan and now your biggest critic,

**Dorothy R. Dickhaus, Indiana**



**Cheryl Hile became the first person with MS to**

**run a marathon on all seven continents in one year.** Photo courtesy of Cheryl Hile

### **Perfect timing**

I was diagnosed with multiple sclerosis in 2001. I was always active and exercised. I started riding the City to Shore in New Jersey every year and the local MS Walk with my team. When I turned 40 in 2008, my doctor told me I should go on high cholesterol and high blood pressure medicine. I said, “No way, I can lower my numbers without medication.” I did just that through exercise and weight loss, mostly due to running. Ever since, I kept making personal goals to run farther and farther. I prefer the distance over running for speed.

I ended up running two marathons, including the New York City Marathon in 2016. But during my training for the NYC marathon, I started to have problems, mostly foot drop, which caused me to stumble and fall many times. Yet I finished the marathon—before dark! I’ve been getting more down over the past year over the foot drop, and I was running less because of it. The article “[Run the world](#)” (Winter 2018–19) and Cheryl Hile’s determination made me feel so inspired! It was published at the most perfect time. It is making me get out there and just do it! I wanted to give her a huge “thank you” for her story. I don’t think I will ever run another marathon, but I definitely want to continue running 5Ks, 10Ks and some half marathons.

**Leslie Touchton, Pennsylvania**