# @Momentum



### Grateful for what I could do

Thank you for publishing the piece from Nicole Bradley-Bernard, "Four things I wish someone had told me after my MS diagnosis" (Fall 2019). This put me in a reflective mood. Diagnosed with MS in 2004 at age 50, I didn't suffer the loss of a disease-free youth as Nicole had. Truly, MS is a pig of a disease! We have heat sensitivity and mourning of lost capabilities in common. However, because I showed symptoms later in life, I was blessed to be able to play with our boys when they were little, dance with my wife at our son's wedding and pick up some of my first few grand-nieces and nephews. There are about 20 of them now and I can no longer pick up babies while standing. Nicole's words have caused me to reflect on what I was able to do that many others with MS have not. For that, I will always be grateful.

#### **Phil Hoppert, Wisconsin**



Nicole Bradley-Bernard compiled a list of things she wishes she'd known after her diagnosis to share with others struggling to face MS.

# Four points hit home

Many thanks for this poignant article written by Nicole Bradley-Bernard ("Four things I wish someone had told me after my MS diagnosis," Fall 2019). All four points hit exactly true! I was diagnosed nearly 19 years ago and have never actually come to such finite terms with the disease as Nicole has stated. However, as I read this, it is helping me cope with the pain—or, as she puts it, the monster—taking over my body in a relapse. No one, not even another MS'er, really can feel your pain. It is a lonely, isolated disease that you come to terms with by yourself. That you FIGHT yourself. Continue the fight! My thanks for the article and the continued support.

#### Adriene Helt, Florida

# **Devices that can change lives**

It was fascinating seeing all the new equipment that will be made available to disabled people that can change their lives ("Dream machines," Fall 2019). I think that manufacturers and local dealers think that disabled people have money. The line I always hear is, "You're on disability. You must have money because you don't have to work." People don't realize that you are unable to work and usually your disability covers living and medical expenses. Lowering the price of things that insurance companies do not cover could generate sales from disabled individuals.

Cynthia Jacobs, North Carolina

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

- Tag your thoughts on **Twitter** @MSsociety using #Momentum.
- Like and comment on our page on <u>Facebook</u>.
- Email 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.

### Prevalence study is critical

While the statistic of 1 million people living with MS in the United States is eye-popping, the fact that prevalence data has not been studied since 1975 is equally surprising ("Strength in numbers," Fall 2019). MS can often present with nonspecific symptoms, and the lack of disease understanding and reliable diagnostic tools in 1975 makes those numbers unreliable.

Two snapshots 40 years apart may suggest a "rise in the prevalence of MS," but, unfortunately, the comparison leaves us with more questions than answers. Thank you to the National MS Society for launching and supporting this critical study. My hope is that funding can be found to analyze MS prevalence on an ongoing basis so that the data can be more useful to researchers and clinicians.

#### **Todd Tuttle, Ohio**

# Somebody gets it

Thank you for the excellent Summer 2019 edition of Momentum. I was diagnosed with relapsing-remitting MS about 30 years ago when I was young in my career and on the fast track with two little kids. Reading Momentum keeps me current with progress being made. The main reason for writing is to tell you how much the article and wonderful drawings by Jessie Ace affected me ("Understanding through images"). The old saying that a picture paints a thousand words is so true. I often struggle to explain how I feel at certain times on certain days, but when I saw her pictures, I got a chill because somebody truly gets it! Those pictures were amazing. Perhaps someone without MS still could not imagine what it actually feels like, but the pictures could help. To someone with MS, the pictures say it all, perfectly. Thank you so much.

The other article on volunteering and participating for medical research and trials caught my eye ("Testing ground"). I plan to do this as soon as I retire early in a few short months after a successful career in which MS helped expand my perspective tremendously. Thanks again. Keep up the good work.

#### Scott Jurek, Indiana

## Informative and enjoyable issue

I just wanted to tell you how much I enjoyed reading every page of your Summer 2019 edition. The article on "Acing temperature control" was super helpful.

"A big part of the MS puzzle" showcasing the work of Katerina Akassoglou, who was named a winner of the Barancik prize, was awesome. "Finding Neuro," which references words of wisdom from my physician assistant, Lisa Fox at Johns Hopkins, was very informative. In "Into the wind," it was inspiring and wonderful to learn about this annual regatta.

As a sailor since I was a child, I have reached out to volunteer at next year's event. And finally, thank you for introducing me to Jessie Ace, inspiring and so very talented ("<u>Understanding through images</u>"). What a great resource to help people express and connect as we deal with the many twists and turns that are, in my case, CIS and not actual MS.

#### Rose Gentile, Virginia