# @Momentum



### What a cure means to me

#### A world without MS

A cure for MS would be half my dream (Forward, Summer 2018). The first half is a world without MS. No more devastation and destruction to those diagnosed and their families. No more lives robbed of what could have been. Step one: Cure and stop MS. Hooray for that day! Countless people will be spared the horrors that too many have and are now suffering. My other wish is to fix the damage MS has already done. In the end, all I can say is stay active, stay positive and stay hopeful.

Kenneth Swiderski, Oregon

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

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

#### No discomfort

As a 62-year-old woman diagnosed in my early 30s, I believe a cure will only be a cure when

it doesn't inflict any discomfort. In the medical community today, there are healthcare professionals treating conditions of all sorts, but if these treatments even appear worse than the conditions they were designed to treat, they will not be used to their greatest abilities. Every time I read about new testing for MS, it sounds more and more as though researchers see people with MS as guinea pigs. We are not. It is high time to be looking not only for more effective testing, treatments and cures, but people-friendly ones as well.

#### Renee Ducker, Montclair, New Jersey

#### Stop it from getting worse

When I was diagnosed about 45 years ago, I was a healthy and active 23-year-old, and my doctor advised me to go on with my life, and I would probably live to the age of 55. Well, trick's on him: I am now 71 and still active with five grandchildren. My doctors now identify my situation as progressive MS. My idea of a cure is "first things first." Whether it is relapsing, progressive or whatever, just stop it from getting worse. With the new diagnostic procedures, MS can and should be identified relatively early. My idea of a realistic "cure" for the next few years is to "stop the bleeding"—not a real cure, but "do not let me get any worse."

#### Rand Garrett, Virginia

#### To live a normal life

To me, a cure means I can walk, run, skip and jump again. I can think of what to say. I will feel alive, play with my granddaughter. My feet, legs and hands won't be numb anymore. It means to live a normal life. It has been my dream since 1991—when I was diagnosed with MS—to be able to walk next to my husband, have friends and go out for lunch and shopping again just like I used to. Thank you for searching for a cure for all of us with MS.

Jayne Almonrode, Tennessee

## **Additional letters**



Robin Franklin, PhD, received the 2017 Barancik Prize for Innovation in Multiple Sclerosis Research. Photo courtesy of Robin Franklin

#### **Attention to research**

The article about Robin Franklin, PhD, and his award-winning research into myelin generation clarified my understanding about how regeneration sometimes works and sometimes doesn't ("Beautiful melody," Summer 2018). The broad focus—across articles—about specific research projects and about the broader strategic approach that the MS Society is crafting was very helpful. The articles about research focused on cognitive function and everyday stress in its various manifestations gave interesting information and specific ideas that you could use in this very moment. I especially appreciated hearing about the different ways people think about a cure. Thank you for the description of the process behind research decisions. I applaud the broad circle of stakeholders who inform the research process. It's not an easy task when trying to balance a broad set of needs with both short- and long-term horizons.

#### Dan Hammang, California

#### Less alone

The article "<u>Out-stressing stress</u>" (Summer 2018) really hit home. I know my own thoughts of defeat are what cause much of my anxiety and stress. I know I just need to calm down, reassess the situation and start again after relaxing and taking in a deep breath. I need to give myself credit for what I have accomplished, which makes my list a little less daunting, or just put the list out of sight and go with the flow of the day. That being said, I also can accomplish so many of my day-to-day tasks and still feel that I did not get anything done unless I do something creative, such as sending a greeting card, thanking someone who has helped make my life easier, watering my tomatoes, or just relaxing and breathe nature in. Then, I feel like I have not wasted the day. Thank you, Aviva Patz, and all the people she interviewed for their stories, especially Clarisa Walcott. Thanks for sharing the beautiful photo in your yoga pose. I feel less alone in this mean disease by reading Momentum.

#### Darla Petersen, Utah



Scott and Donna Rice have remained strong throughout the course of

#### Donna's MS.

Photo courtesy of Scott and Donna Rice

#### The fun grandma

I was diagnosed with MS in 1980 and have experienced just about everything that Donna Rice has ("Outward appearances," Summer 2018), especially her fears about grandchildren. I have four grandchildren ranging in ages from 13 to 21. I was there when each of them was born, and in May 2018, I was there for my granddaughter's college graduation. Over the years, I have found ways to be a "fun grandma." The grandchildren couldn't wait to be able to sit on my lap and "drive" my scooter or to be tall enough to push my wheelchair. They grew up with a handicapped grandmother and have learned to appreciate people with disabilities. I send them text messages that say, "Have a good day" or "Love you and miss you." They always respond. Being smart, determined and stubborn, you will find a way to be the grandma that you want them to see and love.

#### Barbara Fratamico, Smithtown, New York

#### **Determined** as ever

Thank you, Scott Rice, for writing about your wife, Donna, ("Outward appearances," Summer 2018) and thank you, Momentum, for publishing it. My wife, Natalie, was diagnosed with MS in 1964 at the age of 28. She remains determined as ever, remaking herself as MS slowly progresses. Neither employers nor our social contacts had any clue what it took at home for Natalie to meet those commitments. She often states how fortunate she feels to have "pulled it off" as well as she has over such a length of time. The phrase, "Well, you don't look like you have MS," resonated with Natalie. The other is, "I just can't see what that dog does for you," about her three service dogs. Some family members still believe Natalie is either mentally ill or is "malingering," and that I do too much for her. Others said they were no longer including us because Natalie probably couldn't come anyway, or they didn't want to be around to see Natalie "go downhill and die." Natalie is now 82 years old.

#### James Rowe, Oregon