

## @Momentum



**Readers sound off on empowerment, heat and MS heroes.**

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### **More than my MS**

I was diagnosed with MS in 1975, and I am now 61 years old. While **Momentum** has many great tips and information, I'm afraid that someone who was recently diagnosed could be scared to read it. It seems like most of the articles make having MS a person's No. 1 point of identity. I have been a farmer, nurseryman, successful musician, father, landscaper and travel agent, all since I was first diagnosed. The fact that I have MS comes up about as frequently as the fact I am right-handed, or have thinning hair. Granted, I have been extremely lucky with the form of MS that I do have. But I think the way I have been able to handle it also helps.

I have found one thing to be true: By concentrating on what you can no longer do, you will never know what you CAN do! I have accepted the fact that I have this weird disease. I don't want it, I didn't ask for it, and there is no cure for it (yet), so I might as well make the best of it.

**Joe Bushue, Oregon**

### **The financial costs of MS**

Thank you, Society President [Cyndi] Zagieboylo, for all you do in the fight against MS, and thank you for eliciting opinions from those of us living with the disease as to what the Society's priorities should be (Forward, Summer 2014).

I was diagnosed with relapsing-remitting MS in 1994 at age 24. I transitioned to secondary-progressive MS five to 10 years later. I've been a full-time wheelchair user for more than 10 years now, and have lost most of the use of my left arm. I'm starting to lose the ability to even sit up straight and worry that "bedridden" status may be in my not-too-distant future. I am a long-time Society volunteer and am, in fact, a member of the Society's Programs & Services Volunteer Hall of Fame. I still volunteer at the office once a week and at the Bike MS: City-to-Shore Ride, co-lead a self-help group and participate in Walk MS. (In my case it's roll MS!)

For me, there should be two main priorities. No. 1 is funding research to halt and reverse the disease. I think it is very realistic to think MS repair treatments are possible in the not-too-distant future. It would be a terrible shame if lack of funding for promising research were an obstacle to such treatments becoming a reality.

The second priority should be helping those living with MS deal with many of the very real financial burdens that come with this disease. This very day I have a contractor coming to evaluate converting my shower into a zero-entry accessible shower. I'm sure it's going to be expensive.

I probably have more resources than many in my health situation but still could use help paying for something like this. I imagine many living with MS go without things that could make their lives easier or, more importantly, safer, due to financial limitations. I'm just one person, but suspect many share my experiences and views.

**Fred Schwartz, New Jersey**

### **Beautiful art**

Thanks for the article by Elizabeth Jameson ("[Beautiful brain](#)," Summer 2014); it made me smile, laugh and cry. After reading the article online, I visited her website to see more of her art. Her textile piece "Circuitbreaker Narrative" is my favorite. Having MS, that is what I feel like sometimes—that my brain is falling apart into pieces. Her work is so moving. I wish I had my MRIs turned into art.

**Holly Sammons, Delaware**

### **Summer lovin'**

The entire Summer 2014 issue of **Momentum** resonated with me. I have such extreme trouble with heat. I have found each year is worse. When it is summer, I can be outside only a few minutes and I am wiped out. Thanks for the many suggestions about keeping cool. I have found that a slushy is perfect for me. It cools me right down from the inside out. Also, I am giving copies of your magazine to my stepchildren to help them understand why I am not able to do some things well, especially those related to heat, periodic limb movement disorder and cognitive issues. Best issue ever!

**Amber Callahan, Indiana**

### **More tips on beating the heat**

I was very pleased to read "Beating the Heat" (Summer 2014). I struggle with heat sensitivity and felt that this article provided the most thorough list of do's and don'ts that I have read thus far. That said, I wanted to add a couple more tips from my anecdotal experience:

1. I have found that not only do I need to seek out cool drinks, but more specifically, I must avoid hot foods and drinks. Even eating a hot soup in winter can greatly increase my MS fatigue and other MS symptoms.
2. I sometimes lower the temperature of my bath or shower to stay cool.
3. I try not to overeat. When I eat large quantities, I give my body a lot of work to do, which can make me feel warmer and more fatigued. Therefore, I spread out my meals over the course of the day so as not to tax my body all at once.

I am still struggling to learn the various triggers that impact my personal body heat, but what I would say to others is that if you have a doctor who you trust, discuss with him or her your personal hypotheses of what seems to heat you up. I have!

**Matt Friedman, New Jersey**

### **Cool and stylish**

In response to "Beating the Heat" (Summer 2014), I wanted to reach out to people who may not be comfortable wearing a cooling vest. I compete in barrel racing (a type of rodeo event) and it's sometimes very hard to go to a show when the temperatures and humidity are soaring! At a recent event, I did not want to wear a vest. I wear fancy shirts and I just wanted to look good at the show and not draw attention. But my good friend came into my trailer and said, "You better wear that vest or you'll get sick. Don't leave without it." I was able to fit the ice vest under my fancy show shirt and compete! Boo-Berry (my horse) and I did very well at the show and it proves that you can still be cool and look fantastic!

**Carolyn Richens, Maine**

### **Woman of steel**

Kudos to Ellen Robare for her "[Man of Steel](#)" article (Summer 2014). I appreciate her boldness, and now others may recognize that although someone with MS or other conditions might look good, it does not mean that they don't have daily challenges and obstacles.

**Patty Cyr, Arizona**

### **MS superheroes**

Thank you for publishing Ellen Robare's "Man of Steel" article in the Summer 2014 edition of **Momentum**. There is not a day that goes by since I have read that article that I don't think about it, and it makes me smile thinking someone understands exactly what I feel and how I am an "MS superhero" too.

I will be 36 in September, with 9-year-old twin girls and a loving husband of 15 years. I was diagnosed with MS in mid-February of this year, and I am still dealing with the diagnosis and what it means to my family. My father has MS as well, but he was diagnosed with it when I was 21, so I never experienced the disease while living in the same household or even nearby my family. I truly didn't understand the disease, and I still feel frustrated with the unpredictability aspect of it today.

I work full-time at a high school, along with getting my master's degree, balancing homework, activities, and emotions with my children, fitting in exercise routines, and supporting a husband who does travel because he is active duty. I have chosen to keep my MS diagnosis mostly private, but when I was battling a severe allergic reaction to one of the medicines, I did inform two of the people that I work closely with. Needless to say, they were surprised, and my boss said I made it look easy since it doesn't seem to affect my work effort or priorities with my children. I was flattered, but then I felt guilty, like I was doing a disservice to others with MS. I struggled with the thought that maybe my boss would think this disease is not serious or a daily struggle for me. I guess she wouldn't know what it is like to hear her children cry hysterically over missed family trips from mommy being sick, or dad needing to help mommy up the stairs of a house that has way too many stairs.

My husband and I hear the same stories as Ellen relates in her article about someone who has MS and is doing fine, and I find it aggravating at times, almost dismissive of every struggle. I want my children and others to see me as a fighter without undermining the daily struggle MS can be or using it as a crutch to not fight harder. I have been able to successfully hide the side effects of the medicines and disease symptoms from others, but not from my children and husband. I feel terrible when they tell my husband that mommy is sick again in the bathroom or mommy is having trouble today. I have always prided myself on being super independent, like when my husband left to help others with Hurricane Katrina, and I took care of our then 4-month-old twin girls alone without missing a beat. I want to make sure my girls see that attribute in me. I want them to get up when they fall down, and I remind them daily that they can, because I do. When I struggled with my vision while taking an online graduate course, and I couldn't drive for several months, I hid it from others. I got an "A" in the class because, like Ellen said, we are "tough as nails." Thank you for reminding me that we are all

fighting the same battle together.

**Eileen S., Maryland**