



### Origin Stories!

Starting from when you experienced your first symptoms to the steps you took to get your diagnosis, everyone's MS journey is different. Please consider submitting your story for inclusion in a future newsletter to inspire a newly diagnosed person and help them feel less alone. Consider what you wish someone had told you and be that person for someone else. I'll start with my own in this edition of the MS newsletter.

Thank you and submit drafts to Ben Hofmeister at [bahof18d@gmail.com](mailto:bahof18d@gmail.com).

Now that the MS Committee has been formed, there are a few things we still need to take care of. Here are some things you should be aware of:

- Each chapter received a supply of our new MS wallet cards in May. Please contact your chapter office or your chapter lead (see last page) for a copy if you have not received one already. If you are not a chapter member, please contact [ShyanneH@pva.org](mailto:ShyanneH@pva.org) for a card.
- In August, the annual PVA Healthcare Summit and Expo will be taking place in Orlando, Florida. Several committee members attended last year's Summit, where there was an entire track of programming dedicated to the latest care guidance, treatment innovations and research on MS. We will be holding our MS Committee meeting at the Summit and may be able to include some additional members. If you would like to be considered, please email [izzy@mscpva.org](mailto:izzy@mscpva.org).

Sincerely,  
*Izzy Abbass*  
PVA MS Committee Co-Chair

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## **We Need Your Input... Join an MS Committee TODAY**

As we work on initiatives, we need more input and assistance from you. While we don't need you to get involved with everything, we do need you to think about doing something! Check out more about our MS Committee Teams below.



### **Recreation Team**

We know MS presents unique challenges when it comes to participating in traditional sports and recreational activities. Among some of the events we'd love to coordinate or highlight include: a PVA MS Committee Retreat, similar to the annual PVA Women Veterans Empowerment Retreat, as well as Chapter-led events like local MS Walks. This team will work with PVA's Sports & Recreation Department to explore and organize new opportunities for Veterans living with MS.



### **Newsletter Team**

We are happy to announce that Ben Hoffmeister from the Mid-South Chapter and Sarah LaBrada from the California Chapter have stepped up to lead our MS newsletter efforts.

If you are interested in helping out or have questions about the teams, email us at

**[MSCommittee@PVA.org](mailto:MSCommittee@PVA.org)**.

## **Interested in becoming a PVA MS Mentor? We Need You**

As a Veteran with MS, you are in a unique position to help those who've recently been diagnosed with MS, and who are still coming to terms and adjusting to life post-diagnosis. PVA's MS Peer Mentor program hopes to bring Veteran role models and peers together to help newly diagnosed Veterans cope and thrive

with a diagnosis of MS. No one understands what it is like to live with MS better than another Veteran with MS. Through the Christopher Reeve Foundation, PVA is providing education on being a Peer Mentor through an accredited online training program, which is recognized by the VA. If you are interested in becoming a Peer Mentor, please reach out to Hack Albertson at [HALbertson@pva.org](mailto:HALbertson@pva.org).



## Upcoming Events

**PVA Healthcare Summit and Expo  
(Orlando, Florida): August 14-17**



## How My MS Diagnosis Journey Became My Origin Story

The following [article](#) was first published in *Multiple Sclerosis News Today* on 04 August 2022.

If I were a superhero (or a supervillain, for that matter), I'd have an origin story. As it stands, I'm not even a minor hero in real life, and only a mediocre one when appearing in my own stories. I'm just a guy with multiple sclerosis, and all I have is a diagnosis story — and not even a very thrilling one at that. However, since it has a bearing on future columns and I'll occasionally refer back to it, I'll subject you to it now.

Looking at me today, you'd never know I was once in the military and had a fairly active lifestyle. While running in 2009, I felt myself slowing down and having my

first issues with what I now know was foot drop. Later that year, I slipped and slid down the stairs while entering my wedding reception. I wrote the former off to knee and ankle injuries that I'd been ignoring, and the latter to general clumsiness and nervousness.

Over the next year, the issues progressively worsened, and by 2011, as I got ready for a trip overseas, it became impossible to ignore. I was struggling on runs and had developed enough foot drop, along with a right-sided limp, that the members of my military unit took to referring to me as "cricket" due to my energetic hop. I reinjured my right ankle while running downhill, which was becoming increasingly difficult due to problems with balance. And I hurt my left knee in Iraq, while moving on uneven terrain.

When I returned home, I took a desk job and began to sort out my problems, beginning with old injuries. A knee surgery was followed by a complete ankle reconstruction in 2012, but even after rehabilitation, the problems remained. Besides the gait and balance issues, I began to develop a feeling that I was constantly falling forward whenever I descended stairs.

#### *Finally, some answers*

I remembered an unexplained illness in Afghanistan almost six years prior, and on a whim, I asked to be tested for Q-fever (yes, it's a real thing). Sure enough, I was still positive, with antibody ratios high enough to warrant 18 months of treatment for a chronic infection. My symptoms did not improve, and toward the end of this two-drug regimen, the infectious disease doctor noticed some abnormal reflexes and sent me to a neurologist.

After our first visit, the neurologist did a thorough examination, then ordered an MRI of my brain and spinal cord. When he viewed the images, the lesions were obvious enough that he decided a lumbar puncture was unnecessary and made his decision. I was diagnosed with multiple sclerosis on Valentine's Day in 2014.

When he told me the news, I can distinctly remember him saying, "You're taking this well." Looking back, I suppose I was. Initially, I was just happy to have an answer, especially a nonfatal one. Later on, I did not take it so well. Even now, eight years later, there are plenty of times when I don't.

For several years, I found myself telling people that my diagnosis was quick and straightforward. When I finally considered my own diagnosis story, the realization dawned on me that it really took almost five years of searching. That seems to be

consistent with other people in the MS community — people who are heroes to me, people I want to be like.

Maybe it's my origin story after all.

Ben Hofmeister  
Midsouth Chapter  
PVA member since 2021

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## **CAN DO Webinar Series**

**Can Do MS** is a national nonprofit organization that provides education, resources, and support for people with MS and their support partners. Educational programs are opportunities to learn, connect with others and identify solutions to challenges faced when living with MS. All programs are led by healthcare professionals who specialize in MS care, including rehabilitation professionals, psychologists, nurses, doctors, and nutrition specialists. All programs are free of charge for individuals living with MS and their support partners. You can learn more about their programs on their [website](#).

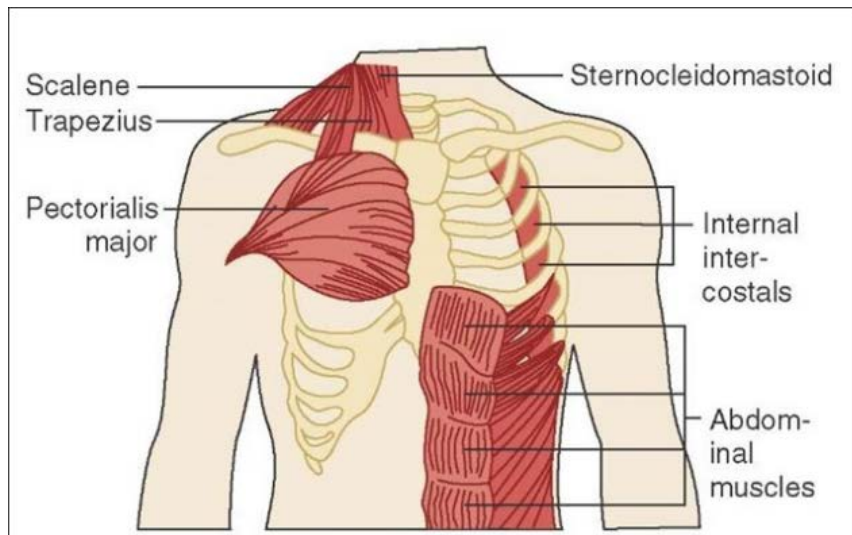
### **2023 Webinar Series:**

July 5 - Shared Decision Making  
August 2 - Integrative Medicine  
September 6 - Healthy Nutrition  
October 4 - Sleep  
November 1 - Communication  
December 6 - Balancing Life With MS

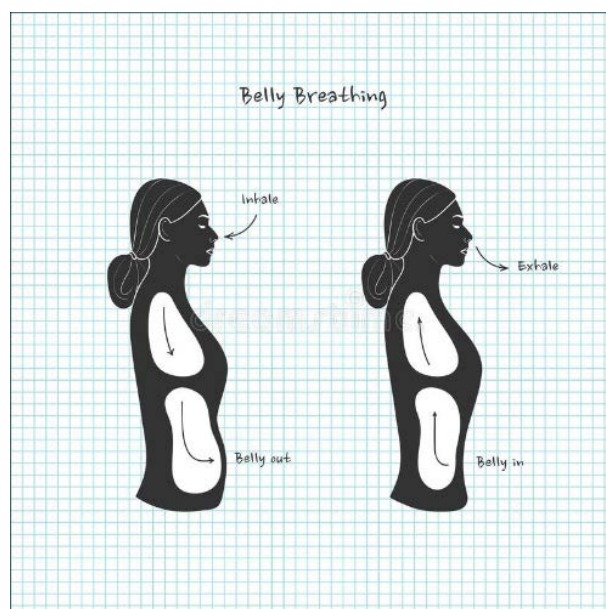
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## **"MS and Breathing"**

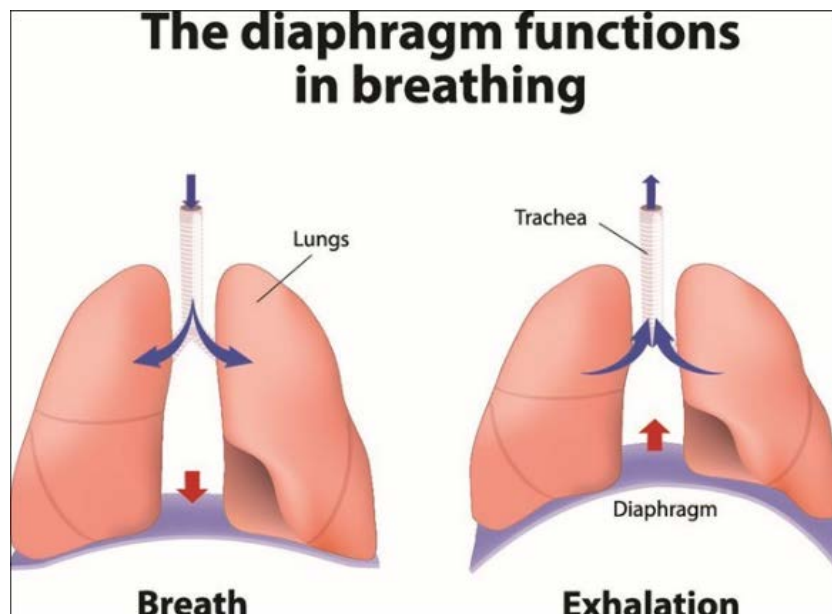
While not as common as other symptoms, breathing problems in MS can occur if the muscles of the chest and abdomen weaken. Respiratory complications are especially common in people with advanced MS, but can also occur early on as a result of an inhaled toxic exposure, or an infection. Below is an image highlighting which muscles help the lungs expand and contract in the mechanical process of “ventilation.”



The most important muscle involved in respiration is the diaphragm. This band of muscle separates the chest cavity from the abdomen. Upon inhalation, the diaphragm contracts and flattens to allow the lungs to expand, creating a vacuum effect which pulls in air. Upon exhalation, the diaphragm relaxes, the lungs deflate, and carbon dioxide is pushed out. If the lungs do not deflate sufficiently, carbon dioxide can be retained in the body. This is not optimal. In order to properly circulate air, oxygen, and carbon dioxide through the respiratory system, it is important to breathe deeply into the abdomen ("belly breathe" as opposed to shallow "chest breathing").







**Symptoms associated with weakened respiratory muscles and carbon dioxide retention may include:**

- Air “hunger” (gasping, labored breathing) with or without activity.
- Waking in the morning with a headache or fuzzy headed feeling (morning confusion).
- Frequent yawning or sighing during the day
- Awakening frequently during the night (insomnia)
- Difficulty lying flat
- Fatigue

Since Veterans are trained to "adapt, improvise, overcome," you might not notice a change in your breathing. As a result, symptoms might go unreported and untreated. To offset this tendency, consider asking yourself the following questions:

**In the last few weeks, have you experienced:**

- Shortness of breath at rest?
- Waking up at night feeling breathless?
- Is it difficult to breathe when you lie flat?
- Do you need more than two pillows to sleep?
- Do you wake up with morning headaches?
- Do you have a weak cough?
- Difficulty with chewing or swallowing?

"When the ventilatory (breathing) muscles become weak, inhaling and exhaling become more difficult and tiring. In severe cases, banding or girdling can occur, during which a person feels tightness around their chest, making it difficult to breathe. This symptom is commonly referred to as the 'MS hug.' People with long-standing MS may experience other respiratory complications — including aspiration (inhalation of food or liquid into the airways), lung infections, and respiratory failure. Certain medications used with MS, such as muscle relaxants, tranquilizers, and opioid pain relievers, can also depress (slow) breathing. Health care providers will carefully monitor the use of these medications in anyone with a history of swallowing problems or respiratory issues" (Menard and Shelat).

**According to Multiple Sclerosis Trust, breathing problems may affect other aspects of your health and well-being ("Breathing Problems"):**

- Poor sleep, leading to excessive sleepiness in the day.
- Lower oxygen levels in the blood and brain, leading to brain fog.
- Reduced cough strength, leading to increased risk of chest infections if food particles and secretions cannot be cleared.
- Breathing takes more effort, leading to increased fatigue.
- Weaker voice, leading to social isolation.

**If you have identified a change in your breathing, it is important to communicate this with your MS Neurologist and to request a Respiratory Therapist or Pulmonology consultation.**

**If your breathing is in a crisis state, activate emergency services!**

Juliet Pierce, RN, Associate Director of PVA Medical Services

Sources:

Menard, Victoria, and Amit M. Shelat. "Breathing Problems and Multiple



Sclerosis.” MyMSTeam, 18 Mar. 2021,

[www.mymsteam.com/resources/breathing-problems-and-multiple-sclerosis](http://www.mymsteam.com/resources/breathing-problems-and-multiple-sclerosis).

MS Trust. “Breathing Problems.” MS Trust, 11 Nov. 2018, [mstrust.org.uk/a-z/breathing-problems](http://mstrust.org.uk/a-z/breathing-problems).

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## National MS Committee Members

**Hack Albertson** – Co-Chair

**Izzy Abbass** – Co-Chair

**Joe Bludeau**– External Organization  
Coordination

**Jerrod Harris** – Chapter MS Lead  
Liaison

**Mike Partridge** – Committee  
Member

**Ben Hofmeister** – Committee  
Member and Blogger



To contact your chapter MS lead, please call or email Jerrod Harris at 410-635-0145 or

[jharris@colonialpva.org](mailto:jharris@colonialpva.org)

or reach out to your local PVA Chapter office.

## Staff

**Cheryl Vines** – Director of Research  
and Education

**Juliet Pierce** – Associate Director of  
Medical Services

## PVA Chapter MS Leads (By Location and Name)

### Arizona

Anthony Murray

### Iowa

Jeff D. Cook

### New England

Chuck Houle

### California

Sarah LaBrada

### Kentucky Indiana

### Keystone

Peter K. Townsend

### North Central

Perry Grimme

### Bay Area and Western

Richard Hagan

### North West

Maevette Perkins

### Bayou Gulf States

### Lonestar

### Michigan

Tim Agajeenian

### Puerto Rico

### Central Florida

Sharona Young

### South Eastern

Robert L. Taylor

### Colonial

Jerrod Harris

### Mid America

Rick O'Mara

### Texas

Joe Bludeau

### Buckeye

Joshua Maley

### Mid Atlantic

Kathy Tilbury

### Tri-State

**Florida**  
**Cal-Diego**

**Florida Gulf Coast**  
**Gateway**  
Rose Ganz

**Great Plains**  
Shayna Goerd

**Mid South**  
David Humphrey

**Minnesota**  
Scott C. Little

**Mountain States**  
Izzy Abbass

**Nevada**  
Jason Kelley

Dan Service

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