



Screenshot from our monthly video call

### MS Newsletter Number 2 - We've got some momentum building!

Happy 2023! I hope you are looking forward to the exciting year ahead of us. We had a great first MS committee meeting in January and the enthusiasm for growth is present throughout the entire organization and in each PVA Chapters. Thanks to those who stepped up to become MS Leads in their respective Chapters and a reminder that there are still many opportunities for other roles within PVA and specifically pertaining to our MS efforts. However, the most important thing any of you can do is take care of yourself - we need you here if we are to help anyone!

Now that we are formed, it's time to execute. Below are a few things to be aware of:

- March is MS Awareness Month! MS Walks are taking place across the country and our Chapter MS leads are looking for help in coordinating our participation in these walks.
- Over the next few weeks, each PVA Chapter will receive a small supply of PVA MS Vet t-shirts to hand out to members participating in MS walks and other MS-themed events. If your Chapter needs more, please email Jerrod Harris at [JHarris@colonialpva.org](mailto:JHarris@colonialpva.org).

- In May, the Consortium for MS Centers (CMSC) will be holding their annual meeting in Denver, Colorado. CMSC has graciously offered a free booth to PVA in their exhibit hall. Several MS Committee members, as well as some PVA staff, will be in attendance. We still have a couple of slots open, if you would like to be considered as an attendee, please email me at [izzy@mscpva.org](mailto:izzy@mscpva.org).

- In August, PVA's annual Healthcare Summit and Expo will be taking place in Orlando, Florida. Last year, there was an entire track devoted to issues relating to MS and this year there are plans to do it again. Additionally, we will be holding our MS Committee meeting at the Summit. A few of us from the committee will be attending and spots still exist for a few more 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 whose world may have been turned upside down by their own recent MS diagnosis. PVA's MS Peer Mentor program hopes to bring Veteran role models and peers together to help people 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. In partnership with the Christopher & Dana Reeve Foundation, PVA is providing education on peer mentorship through an accredited on-line training program recognized by the VA. If you are interested in becoming a Peer Mentor, please email Hack Albertson at [HALbertson@pva.org](mailto:HALbertson@pva.org).



### **Upcoming Events**

**MS Committee Newsletter Team Meeting (virtual):** March 23

**June CMSC Convention (Denver, Colorado):** May 31- June 3

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

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## **MS Blocked My View of the Mountains- Never Again**

Despite the doctors in my life and everything else I've learned; the wilderness is still my favorite medicine. Camping - being out in the woods and mountains - is something I've always loved. Starting as a kid romping around the Big Thompson River in Colorado, I eventually camped countless nights under the stars, spent 15 years on a volunteer mountain rescue team, climbed a huge number of peaks, including a Mountain in Borneo, and of course living outdoors during much of my time an Army infantry unit, though we didn't call it camping at the time. But finally last weekend, I've come to realize how much I miss it. For the first time since my MS diagnosis in 2017, I went camping.

I've wanted to go. I've driven in the mountains of Colorado with my wife a number of times - even made my way to a panoramic spot to gaze up at the Indian Peaks with the Aspens just starting to turn their bright fall colors. However, I had trepidation, fear really, of going camping, not because of wild animals or unpredictable weather, but because of the limitations imposed on me by MS. Actually, it came down to one thing: getting up in the morning. That's right. The effort to get out of my sleeping bag and begin moving in the morning kept me from an experience I deeply love.

Like most of us with MS, I am most at ease lying down. The effort to stand and stay upright is a constant challenge involving work. It's not like I can't do it, it's just a lot of effort. That was what kept me from going camping. I still have tons of gear (more than I should have) and I still occasionally teach avalanche safety and awareness classes which just makes me want to go out more. But I've hesitated to venture too far out. No more.

That first morning waking up in the mountains reminded me of something I had ignored far too long. The sounds of the insects and the breeze moving across

Aspen leaves are magical. The solitary ant moving across the ground by the fire pit mesmerizes me as it negotiates around blades of grass and pine needles. I loved the warm rays of the sun on my neck, contrasting with the coolness of the breeze warming me to the core. I miss this. I miss it so much that my eyes watered as I sat there in the shade-dappled sun looking at everything around me. The deep refreshing breaths I took reminded me how the smells of the forest are much more intoxicating than sipping wine or whiskey.

My best friend took me camping. He and I had spent many a night outside over the years, but I still began apologizing ahead of time, and telling him he'd have to do a lot of the work. That was the other source of my fear – or at least my hesitancy – in asking him for help. It's an issue for many of us in the Veteran community.

He didn't care. He was happy just to be outside and excited I was willing to go.

We had a fantastic time and will again. And while I let five years slip by without the happy experiences of camping, I won't lose another year. Come join me, and let's get out there in nature, fellow MS'ers.

Izzy Abbass, Mountain States

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## **Looking for a Good Explanation of MS to Provide Others?**

Multiple Sclerosis Awareness Month is a time for everyone to learn more about the neurological disease that currently affects almost one million Americans. About 200 people are diagnosed with MS each week and it is becoming more prevalent every year. It affects all races and nationalities, but is more prevalent in areas further from the equator. Both men and women are impacted, but four times as many women are stricken with MS than men. Despite years of intense research, the cause of MS is still unknown. Risk factors include smoking, stress, low vitamin D levels, inflammation, and obesity.

MS is an autoimmune disease that affects the central nervous system, the brain, and the spinal cord. With MS, a person's own immune system mistakenly attacks their myelin, the outer protective covering of nerves, the brain and the spinal cord. Myelin enables nerve signals to travel effectively without getting short-circuited like the electrical current in a worn electrical wire. Where and how much myelin is destroyed by the immune system determines the type and

severity of symptoms a person will have. As such, people with MS have a wide variety of symptoms. The most common are fatigue, numbness and tingling, loss of balance and dizziness, spasms, tremor, pain, bladder problems, bowel problems, vision problems, loss of strength and mobility, depression, and anxiety.

When someone is suspected of having MS, doctors employ a number of tests to confirm the diagnosis. While there is no specific blood test to diagnose MS, doctors may order blood tests to exclude other diseases that may mimic MS. A spinal tap is often performed to identify antibodies indicative of MS in the cerebral spinal fluid. Evoked potential testing can also be performed to measure abnormalities in nerve transmission seen in MS. Since the widespread use of MRIs, the diagnosis of MS has become more straightforward. Now, in most cases, a diagnosis of MS can be made based on a pattern of symptoms consistent with the disease and MRI changes that confirm it.

There are four types of MS often starting with Clinically Isolated Syndrome (CIS). In CIS, a person has neurologic symptoms that last at least 24 hours and usually either totally or partially resolve. While individuals who develop CIS do not technically have MS, they are at risk of developing the full-blown disease. To delay the progression to MS, these patients are currently treated with disease modifying therapy.

The most common form of MS is Relapsing-Remitting MS (RRMS), in which there are attacks followed by remissions. 85% of people with MS are initially diagnosed with this form. Many patients with RRMS will subsequently develop Secondary Progressive MS (SPMS), where the clinical course is relentlessly downhill without any significant remissions. The last type of MS is Primary Progressive MS (PPMS), in which neurologic function progressively worsens from the time of diagnosis.

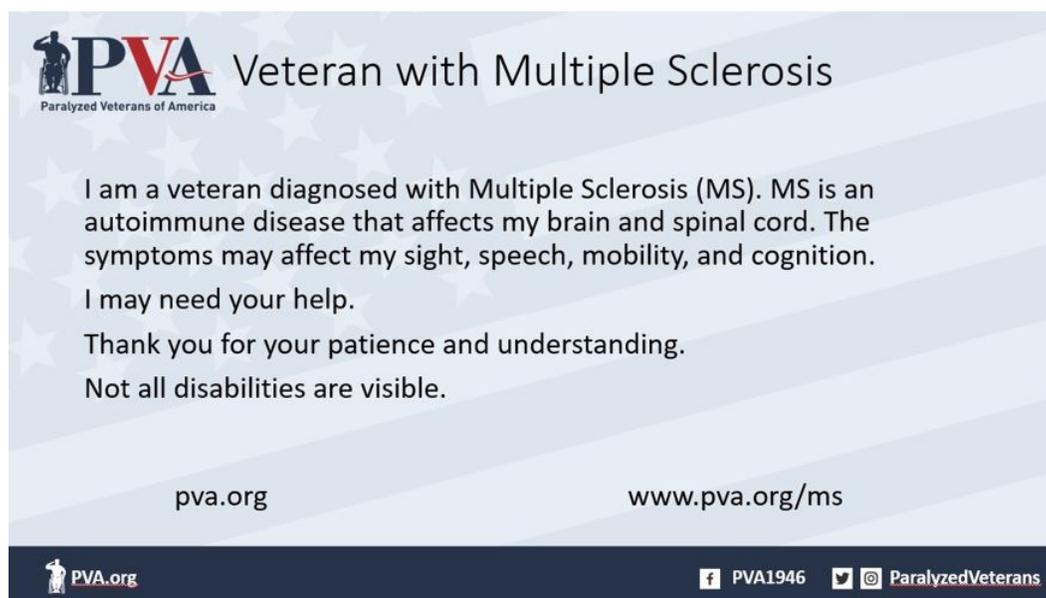
Unfortunately, there is no cure for MS. However, in recent years more than a dozen Disease Modifying Therapies have been developed that can significantly slow the progression of MS and limit disability. They are particularly successful with RRMS, less so with the progressive forms of the disease. They are available in oral formulations, as well as injectable and infused types. Hopefully, continued research will uncover the cause of MS and a cure will be developed.

Stephen Yerkovich, MD  
Chief of Medical Services  
Paralyzed Veterans of America

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## Coming Soon!

As was discussed in our February MS Committee meeting, the PVA National office is developing wallet cards identifying you as a Veteran with MS and highlighting some of the numerous issues that come with the diagnosis. While we hope you never need it, when you are having difficulty, this card is an easy way for you to let those around you know what you are dealing with and why you may not be on top of your game in any given situation. These cards will be free to all Veterans with MS and made available in the coming weeks. The card will look as follows:



 **PVA** Veteran with Multiple Sclerosis  
Paralyzed Veterans of America

I am a veteran diagnosed with Multiple Sclerosis (MS). MS is an autoimmune disease that affects my brain and spinal cord. The symptoms may affect my sight, speech, mobility, and cognition.

I may need your help.

Thank you for your patience and understanding.

Not all disabilities are visible.

[pva.org](http://pva.org) [www.pva.org/ms](http://www.pva.org/ms)

  PVA1946   ParalyzedVeterans



 **PVA** Symptoms of MS may include  
Paralyzed Veterans of America

- Numbness
- Pain
- Fatigue/Weakness
- Dizziness/Vertigo
- Trouble Walking
- Impaired Vision
- Bladder Problems
- Heat Sensitivity
- Speech Problems
- Confusion

[pva.org](http://pva.org) [www.pva.org/ms](http://www.pva.org/ms)

  PVA1946   ParalyzedVeterans

## National MS Committee Members

**Hack Albertson** – Co-Chair

**Izzy Abbass** – Co-Chair

**Joe Bludeau**- External Org  
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 443-814-3777 or [jharris@colonialpva.org](mailto:jharris@colonialpva.org) or reach out to your local PVA Chapter office.

## Staff

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

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

## PVA Chapter MS Leads (By Loca on and Name)

### Arizona

Anthony Murray

### California

Sarah LaBrada

### Bay Area and Western

Richard Hagan

### Bayou Gulf States

### Central Florida

Sharona Young

### Colonial

Jerrod Harris

### Buckeye

Joshua Maley

### Florida

### Cal-Diego

### Florida Gulf Coast

### Gateway

Rose Ganz

### Iowa

Jeff D. Cook

### Kentucky Indiana

### Keystone

Peter K. Townsend

### Lonestar

### Michigan

Tim Agajeenian

### Mid America

Rick O'Mara

### Mid Atlan c

Kathy Tilbury

### Mid South

David Humphrey

### Minnesota

Scott C. Little

### Mountain States

Izzy Abbass

### New England

Chuck Houle

### North Central

Perry Grimme

### North West

Maevette Perkins

### Puerto Rico

### South Eastern

Robert L. Taylor

### Texas

Joe Bludeau

### Tri-State

Dan Service

### Vaughn

Cheryl Gerdes

### West Virginia

Kelly Goddard

### Wisconsin

Amera Schaefer

**Great Plains**  
Shayna Goerd

**Nevada**  
Jason Kelley



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