

RT '23

Rollin' Times from the Michigan Paralyzed Veterans of America



Board Members proudly recite their oath of service to our Chapter for another Fiscal Year by President, Michael Harris, in Plymouth, Michigan.



About this Issue:

The MPVA enthusiastically rolled into a new Fiscal Year this past October and anxiously awaits all the excitement our new calendar brings! Check out all the details on what's happening at the Michigan Chapter this winter by reading through this edition.

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Disclaimer:

The Rollin' Times is a publication of the Michigan Chapter of Paralyzed Veterans of America. It is designed to inform the members of the PVA and other interested parties on veterans' issues, legislation, legal decisions, medical technology and other matters deemed to be relevant to the disability community.

The contents of this publication do not always reflect the views or policies of Michigan PVA, and no endorsement or approval is made or should be inferred with respect to products or services advertised herein. Consult an appropriate professional before making use of any product or service mentioned.

Inside this Issue

President's Report	3
Executive Director's Report	5
Veterans' News	7
Government Relations & Advocacy	9
Sports & Recreation	13

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The Michigan Paralyzed Veterans of America (MPVA) is a chapter of the Washington, D.C.-based Paralyzed Veterans of America. A Congressionally chartered veterans service organization, MPVA has been assisting veterans with spinal cord injuries or diseases, including Multiple Sclerosis and ALS (Amyotrophic Lateral Sclerosis, better known as Lou Gehrig's Disease), in Michigan since 1961.

MPVA programs include:

- Veterans' Benefits
- Wheelchair Sports and Recreation
- Spinal Cord Injury Research
- Equipment Donation
- Advocacy to eliminate architectural barriers and protect civil rights for persons with disabilities
- Referral Services for assistive devices, housing, employment and transportation
- Literature on a variety of topics including self-care, independent living, and disability rights.
- MPVA is a nonprofit organization and receives no federal funding. MPVA relies on grants, sponsorships, and private and corporate donations to support its programs.

The MPVA headquarters is in Plymouth, Michigan. Our service officers are based out of the McNamara Federal Building in Downtown Detroit.

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President's Report

By: Michael Harris, President, MPVA

Wheeling to a Record: 2022 Detroit Free Press Marathon

After a two-year pause, the Marathon resumed its popular route across the Ambassador Bridge to Canada, returning to Michigan via the Detroit-to-Windsor Tunnel--the only international underwater mile.

This past year's Detroit Free Press/Chemical Bank Marathon took place on October 16th, 2022, welcoming 26 hand-cyclists and wheelchair/push-rim racers to take on the 26.2-mile course. Once again, the Michigan Paralyzed Veterans of America (MPVA) were proud sponsors of the race's Disability Division.

The Achilles Freedom Team of Wounded Veterans brought veterans from across the country to participate in this year's Marathon. The temperature at the start of the race was unseasonably warm (45 degrees), making it an enjoyable experience for everyone involved in the hand-cycle portion of the Marathon.

Last year, Matt Tingley had to duel for the lead over many of the course's miles before finally winning the Disabilities Division on his handcycle. This year, he not only topped the field again, but Tingley, from Rochester Hills, beat his previous time by nearly 2½ minutes with a time of 1:16:15. In second overall was hand-cyclist John Masson from Southern Pines, North Carolina, with a time of 1:23:45, followed by the third-place finisher Andrew Hairston from Jacksonville, North Carolina, with a time of 1:31:50.

Leigh Sumner from Newton Grove, North Carolina, was the first female hand-cyclists to finish with a time of 2:03:03, followed by Laura Stark, Canton, Michigan with a time of 2:40:27 and Margaret Sprouse, hailing from Bowling Green, Kentucky with a time of 2:47:24. It was great to see that three females participated in

this year's Marathon. Also, Corey Peterson was the first wheelchair push-rim racer to cross the finish line with a time of 3:23:36.

Guiding the hand-cyclists were more than 26 bicycle escorts, supplied by cycling clubs across southeast Michigan, and coordinated by the Royal Oak-based Wolverine Sports Club.

The addition of the bicyclists seemed to be a hit with the participants, who sometimes encounter problems with their race equipment--ranging from flat tires or broken chains that can hinder their race time. Likewise, the bicycle escorts came across the finish line expressing their admiration and marvel over the tough feat that hand-cyclists and wheelers have accomplished.

Jaclyn Kochis, MPVA Executive Director, stated "I am always impressed by the athletes that participate in this race. Each year, I witness the work that goes into the race, from both planning for the event and for the dedication and commitment that the athletes go through to complete the Marathon."

There are only 50 spots available for the wheelchair division, so if you want to guarantee participation in the 2023 Marathon I would recommend that you register as soon as possible. Hopefully, we can increase the number of participants from Michigan.

The MPVA would like to congratulate each person who competed in this year's Marathon. We look forward to next year's event and to supporting the 2023 Disability Division.



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Executive Director's Report

By Jaclyn Kochis, Executive Director, MPVA

Reflecting on 2022

This past year was exciting as we returned to hosting face-to-face events, offering more support to members and friends, and continuing to expand services. I am proud to say that our Chapter continues to flourish and expand. Our work to enhance the quality of life for veterans has been unwavering, as we continue to provide information, advocacy, education, recreation, fellowship, and above all—hope!

When I reflect on our yearly accomplishments, I am reminded of the mission here at the MPVA—we are an organization whose members are, above all, resilient and tough! Our members constantly adapt and demonstrate that they can overcome any obstacle. We have seen our members and community supporters prove this through their desire to be more inclusive and active. The Chapter's new grant opportunities enhanced these endeavors. Our Rollin' Traveler Grant Program, Membership Grant Program, and Sports & Recreation Grant Program directly supported:

- Mary Free Bed Rehabilitation Hospital in expanding their wheelchair softball program,
- The City of Grand Ledge installation of a fully accessible "We-Go-Swing" at their City Hall Park,
- Multiple individual sports grants that helped members and friends thrive in adaptive activities.

The Chapter also hosted a variety of events ranging in topic. MPVA's informational webinars on adaptive technologies and accessibility allowed members and a

wide range of the public to learn about important topics. We were proud to host several membership events like the one in Frankenmuth, Michigan's Bavarian Wonderland. We also hosted multiple sporting events through our support of Wheelin' Team 457. And our members enjoyed picnics and fundraisers with the Miracle League of Plymouth and the RIM Foundation.

The Chapter is extremely proud to have partnered with the RIM Foundation to relaunch the "Athletes with Disabilities Hall of Fame"! The inaugural event was a tremendous success that we look forward to replicating this year.

The Chapter dialed up all of our communications: through our social media posts, newsletters, and membership calls. We truly love communicating more with our members, as well as sending out birthday cards and gift cards! Each call demonstrates that our members are special and deserving.

I know that our Chapter feels extraordinarily thankful for all the support we have received. We had another "Salute to Veterans Virtual Run, Walk, Wheel", which proved a worthwhile endeavor, producing approximately \$10,000 of monies that will go directly back to our mission.

There has been a lot of hard work, dedication, and passion from the MPVA staff to maintain our eight mandated programs of service. I hope you know how grateful we are to have you as a supporter. Please stay tuned and keep following us as we promise to bring you more information, advocacy, athletics, fun, and fellowship. We'll We look forward to what 2023 brings!

I would like to take this opportunity to thank each and every person that supported the MPVA—you are the reason we are able to continue carrying out our mission. I would also like to especially recognize the sponsors of our Salute to Veterans Virtual Run, Walk, Wheel below. As you read through this edition, you will see ads from these companies that have so graciously continued their support of the MPVA.

Bill Helwig, Creative Mobility, Edward Jones, George Googasian, Indian Trails, James Saliba, Littler Mendelson, Michael Harris, Nyman Turkish, RIM Foundation, Sinas Dramis, Wolfson Bolton Kochis.



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Photo: Stephanie Strickland, Senior National Service Officer

PACT Act Adds Presumptive Conditions for Vietnam War Veterans

What presumptive conditions did the PACT Act add for Vietnam veterans?

The PACT Act has expanded care for Vietnam veterans by adding two new presumptive conditions for veterans who may have been exposed to Agent Orange.

The two new conditions are:

- High blood pressure, or hypertension
- Monoclonal gammopathy of undetermined significance (MGUS)

Prior to the PACT Act, Vietnam veterans who served in the Republic of Vietnam or served in the waters around Vietnam and Cambodia between January 9, 1962, and May 7, 1975, had an already lengthy list of presumed conditions arising from toxic exposure to Agent Orange.

The list included:

- AL amyloidosis
- B-cell leukemia
- Chronic lymphocytic leukemia
- Multiple myeloma
- Type 2 diabetes
- Hodgkin's disease
- Ischemic heart disease
- Non-Hodgkin's lymphoma

- Parkinson's disease
- Parkinsonism
- Prostate cancer
- Respiratory cancers
- Soft-tissue sarcoma (not including osteosarcoma, chondrosarcoma, Kaposi's Sarcoma or mesothelioma)
- Bladder cancer
- Hypothyroidism

How can additional Agent Orange presumptive conditions help Vietnam veterans?

By expanding the list of presumptive conditions for Agent Orange toxic exposure, the PACT Act makes it less cumbersome for Vietnam veterans to receive care through the VA.

Veterans with hypertension and MGUS won't have to search for doctors and scientists to testify that Agent Orange exposure from five decades ago are causing their health problems now; the VA will already know. Instead of filing paperwork to prove their disability is connected to service, affected veterans will be able to walk in, knowing the benefits they earned with their service are there for them.

The PACT Act will also expand the number of VA facilities across the country and will train staff to

screen current VA patients for potential toxic exposure and possible related conditions. This means Vietnam veterans who already receive care at the VA should be made aware that their existing disabilities may not be the only health conditions covered by their benefits.

Ultimately, the PACT Act extends benefits to millions of veterans and their family members, giving them quicker access to the care they earned through sacrifice to their country.

For additional information on all of the new VA presumptive conditions for Gulf War/Post 911 and others, please go to www.va.gov/pactact.



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By: Mike Harris, President, MPVA

The MPVA applauds Congress for passing the Veterans Auto and Education Improvement Act

On January 9, 2023, President Biden signed into law provisions of the *Advancing Uniform Transportation Opportunities (AUTO) for Veterans Act*. This legislation that will reduce the financial burden for severely disabled veterans who require special adaptive equipment to drive a motor vehicle. The legislation will make these veterans eligible to receive a grant through the Department of Veterans Affairs (VA) to help purchase a new adaptive vehicle once every ten years, helping them to drive safely and maintain their independence.

The Veterans Auto and Education Improvement Act of 2022 authorizes the Department of Veterans Affairs to provide an additional automobile allowance immediately to eligible veterans if 30 years have elapsed since the date they received their first automobile grant. Over time, the period will shorten to 10 years.

The legislation will also change the definition of “medical services,” to include certain vehicle modifications like van lifts, which are offered through VA’s Automobile Adaptive Equipment (AAE) program. This latter provision will help ensure veterans with non-service-connected illnesses and injuries continue to receive help through the AAE program. A newly added provision will also designate non-articulating trailers designed to transport powered wheelchairs, powered scooters, or other similar mobility devices as adaptive equipment.

The AUTO for Veterans Act will relieve an enormous burden for many veterans throughout the country who need to purchase expensive adaptive vehicles to drive safely or to drive at all.

Under the previous law, the VA was authorized to provide eligible veterans with a one-time grant of approximately \$21,400 to be used to purchase a new or used automobile and/or necessary adaptive equipment, such as specialized pedals or switches. This grant is often used together with the VA Special Adaptive Equipment Grants, which helps veterans purchase adaptive equipment, such as powered lifts, for an existing automobile or van to make it safe for a veteran’s use. The average cost to replace modified vehicles ranges from \$20,000 to \$80,000 when the vehicle is new and \$21,000 to \$35,000 when the vehicle is used.

Although veterans could receive multiple Special Adaptive Equipment Grants over the course of their lives, they were limited to a single grant to purchase a vehicle. This limitation failed to consider that a disabled veteran will need more than one vehicle in their lifetime. According to the Department of Transportation, the average useful life of a vehicle is 11.8 years, and a vehicle that has been modified structurally tends to have a shorter useful life. Under the Act, disabled veterans will be eligible for a grant to purchase a new adaptive vehicle once per decade.

Michigan Paralyzed Veterans of America (MPVA) members know from firsthand experience, that the life expectancy of a modified vehicle is much shorter than the national average, because Michigan road conditions are the worst in the country. This legislation is long overdue and should help our members eliminate the tremendous financial hardship of replacing their primary mode of transportation.

Wheelchair Users Face Hotel Room Nightmares with Bed Accessibility

By: Mike Harris, President, MPVA

Is It Truly Wheelchair Accessible if Wheelchair Users Can't Access It?

In 2009, I filed a complaint with the Department of Justice (DOJ) and the United States Access Board (USAB) because of the bed heights in my wheelchair accessible hotel rooms. My frustration stemmed from the fact there are no accessibility guidelines to regulate the height of beds in accessible rooms. Thirteen years later nothing has changed.

It has become commonplace within the lodging industry to place extra padding on mattresses: this significantly raises the height of a bed, making it near-impossible for many people with disabilities (like myself) to transfer safely between the bed and a wheelchair. Since many wheelchair users must use the bed as a dressing bench, a transfer may be performed several times per day. Higher platform beds are also trending at hotels, meaning that many beds are not adjustable; they can't be lowered in any way, and there is no space underneath to slide a Hoyer-lift.

The seat height of most wheelchairs is around 19 inches, but the beds in hotel rooms are often much higher, 28 to 33 inches. That's a height difference of nearly one foot! For many wheelchair users, a gap of that size constitutes a mountain they cannot climb independently.

I chose to advocate based on some personal experiences with inaccessible bed heights during hotel stays that speak to a much larger issue for people using wheelchairs. I used to be able to use a sliding board to transfer; however, as the incline of beds has increased, I've often felt as if I'm trying to go up a ski lift on my own power! There have been a few times that it proved to be too much, and I fell. I was forced to make the embarrassing phone call to front desk staff to come pick me up off the floor!

Of course, we all know that there's no such thing as a one-size-fits-all wheelchair accessible hotel room, but it's

perfectly reasonable to expect lodgings to have provisions in place that would allow their staff to quickly lower a bed's height upon request by a wheelchair user. By the way, don't think that bed heights are only a problem for the disabled. I've also heard from little people and senior citizens, all echoing the same complaint.

When I have asked hotel personal if they could remove the platform raising the bed or lower it in some other way, they have said no. The result of their inaction is that I've been forced to sleep from my wheelchair. This should not still be happening as we enter 2023!

Law vs. Promise of the Law

The Americans with Disabilities Act (ADA) requires hotels to make a certain number of rooms accessible. But that regulation with comes some vagueness and omissions: one such is that there are no written specifications for bed heights. Today, the DOJ defines the height of a standard toilet seat for accessible hotel rooms and lodging areas. Yet, the DOJ is silent on an acceptable height range for beds in accessible rooms. In my opinion, if bed height is not regulated there is little point in labeling a room as "accessible".

To fulfill the promise of the ADA, **Michigan Paralyzed Veterans of America** believes it is important that the **DOJ/USAB take the lead by reviewing the standards to see if an improvement can be made on accessibility issues that are known to be problematic.** The DOJ/USAB have been sitting on their hands far too long on this issue.

No two people with physical disabilities and/or those who have the need for a wheelchair are the same. That means that their daily living needs are totally different, as well: this includes how they access sleep. Many manual wheelchair users have no lower body control but have good upper body strength which allows them to self-transfer. Lower beds, or beds that are able to be adjusted, make it much easier for us to transfer safely and comfortably between bed and wheelchair. Wheelchair

users who require a considerable amount of care/ assistance also benefit from having adjustable options for hotel beds. For instance, there may be a need for more space under the bed to roll the supporting legs of a Hoyer-lift.

But what can hotels do, and what should they do? Hotels aren't mandated by law to do anything beyond what the ADA prescribes. Most hotels do not have a different type of bed in their wheelchair accessible rooms. They must be required to purchase height-adjustable beds for rooms designated as ADA accessible. I'm not talking about expensive electric devices; I propose making simple adjustments so that hotel maintenance can remove the legs (as opposed to a full platform) to lower it, or adding bed-raising blocks for a Hoyer-lift user.

Those traveling with wheelchairs need to be aware that a hotel's willingness to accommodate them beyond ADA requirements will rest solely on the mood of the hotel personnel. I've had some who have bent over backwards to make me comfortable (and safe), and others who would have been happy for me to leave and stay elsewhere. It's not fair that we must call every hotel where we'd like to stay and ask about bed specifications (not to mention bathroom photos), but that's become part of the life of a

wheelchair traveler.

Unfortunately, since the ADA did not specify the importance of bed height in consideration of wheelchair access, changes to the federal accessibility codes are necessary.

I'm asking that the DOJ/USAB regulate beds in lodging facilities to ensure that people with disabilities can travel independently and without undue hardship. At a very minimum, I would ask them to require lodging facilities to provide bed height and clearance in their room descriptions.

Advocate with me! Please email me at mharris@michiganmpva.org to share your experiences with towering bed heights and/or difficulty with bed transfers in hotel rooms. Be sure to note if you would be willing to share your story with Michigan's DOJ.

Let's create an environment where people with mobility impairments can have positive lodging experience and where the *"Welcome Mat Truly Welcomes Everyone."*



Wheelin' Team 457

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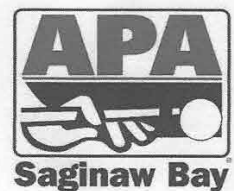
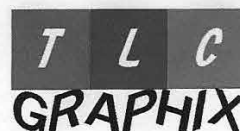
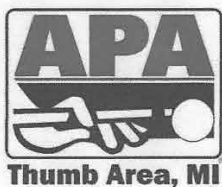
1 Team member must play from a wheelchair

MORE INFO...

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Sports & Recreation

By: MPVA Chapter Sports Team

In Memory of our Friend, Dave



Dave takes a moment to pose with his beloved dog, Jack, at the National Veterans Wheelchair Games.

Dave served in the Navy from 1977 to 1981. In 2011, Dave joined the MPVA and wasted no time joining the MPVA Sports Team. During his time with the team he won 9 Gold, 3 Silver, and 2 Bronze. He had a total medal count of 14; an impressive feat! If there was any kind of a rally competition, you could count on Dave being in that race.

As an avid University of Michigan fan, you could spot Dave in his Michigan blue and gold hat that he always wore. He also would wear his dark sunglasses and had his friend, a dog named Jack, on his lap at almost all times. His wife, Frankie, was also his biggest supporter.

Dave, we will miss you! May you rest in eternal peace.



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