



**Paralyzed Veterans
of America**

New England Chapter

CORDWORD

The Monthly News Magazine of the New England Chapter of Paralyzed Veterans of America



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PASSAGE OF ACAA

STOP AND SHOP 5K



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Passage comes following the 32nd anniversary of the original landmark Air Carrier Access Act designed to protect passengers with disabilities

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...continued on page 5.



Out Front

Michael G. Negrete, President

Well, October has been a busy month of activities and events. First, I represented our Chapter at PVA's Mid-Fall Convention in Orlando, FL. There were some relevant resolutions introduced with some passing and some being sent to Committee for refinement. Look for details on these in the coming months. It was also a time to network with other Chapters and learn what they're doing successfully that we can apply here in New England.

Next, we held our Annual Membership Banquet, which is always a great time to get dressed up and share a night of dinner, dancing and prizes with our Chapter members and VA Staff. From the smiles on everyone's faces, I think a good time was had by all. A special "Thank you" to Joanie Lynch for arranging transportation to the Banquet for our members and staff at the Brockton VAMC. It was a bit of a last minute challenge, but as always, she found a way to make it happen!

Then on to a major event on October 17th in the New England VA SCI Healthcare - the opening of the new SCI Clinic at TOGUS VAMC in Augusta, ME! The new clinic was eight long years in the making. It's somewhat of, what Dr. Sunil Sabharwal, VISN1 SCI/D Services Chief, would call a "Super Spoke" in the SCI Hub and Spoke system, as it offers a number of specialized services not typically available at a traditional Spoke's SCI Clinic. Our roughly 225 Maine Chapter members will be well served by this new clinic.

Finally, I had an opportunity to represent the Chapter at 30th Anniversary Celebration of the Partnership between Yale University and the Paralyzed Veterans of America in New Haven, CT on October 25-26th. In addition to a banquet on the evening of the 25, I was able to tour Yale's Center for Neuroscience and Regeneration Research. I witnessed some amazing research projects in pain management, spasticity reduction to mention just a couple. Look for more and pictures in next month's edition CordWord.

Michael G. Negrete
President and Paralyzed Veteran

From the Director's Desk

Debra A. Freed, Executive Director

This is a For Your Information brief. The New England Chapter is changing its fiscal year to match the National organization. Therefore, the 2019 fiscal year began October 1st and will end June 30th, 2019. Because we are changing our fiscal year, it requires that we also develop policies to ensure some of our programs and or events can easily adapt to this change. I ask you to keep tabs on my articles over the next month or so.



September may be long gone, but the Fall season is in full swing. Noteworthy is PVA made national news this month with the passage of The Federal Aviation Administration Reauthorization Act (FAARA) of 2018 (H.R. 302). Why is that important? For several reasons but two important ones come to mind: First, of course, is how many of you recently traveled to events in Florida, New Mexico, or California? Did your chair arrive in the same state as you left it to board your plane? Are you forced to sit in areas that prohibit your ability to let other folks out to use the restroom or stretch their legs? Another important matter this year are Mid Term elections. Again, how you vote and who you vote for are your affair. You don't get to complain if you don't vote because there really are numerous options to assist any and all types of folks with any type of physical limitation.

Debra A. Freed
Executive Director

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CHAPTER ADMINISTRATION

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Vice President	Mike Guilbault
Secretary	Peter Moore
Treasurer	Charles Schena
National Director	Neal Williams
ADA Coordinator	Neal Williams

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Mark Sanders	Neal Williams
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PROGRAM DIRECTORS

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Amauris Polanco
Veterans Health & Benefits Specialist II

CordWord is the New England Chapter, Paralyzed Veterans of America's (New England PVA) monthly magazine that covers news, health, research, lifestyle and issues of interest and concern to Veterans and others with spinal cord injury and disease. Anyone interested in submitting an article to *CordWord* should email media@newenglandpva.org. The assertions and opinions expressed in articles and announcements in *CordWord* reflect the views of the author(s) and do not necessarily reflect the views of the New England PVA. New England PVA can in no way whatsoever be held responsible for the content of such views nor can it be held liable for any direct or indirect damage that may arise from such views.

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Paralyzed Veterans of America Applauds Passage of Bill Making Air Travel More Accessible

Originally posted on www.pva.org



Passage comes following the 32nd anniversary of the original landmark Air Carrier Access Act designed to protect passengers with disabilities

WASHINGTON (October 3, 2018)—Paralyzed Veterans of America is hailing the passage of the Federal Aviation Administration Reauthorization Act of 2018 (H.R. 302) through the U.S. Senate today by a vote of 93 to 6. The

legislation includes a 'bill of rights' and an advisory panel for passengers with disabilities, as well as revised training and procedures for TSA screenings of people with disabilities.

"We applaud the bipartisan passage of this bill," said David Zurfluh, national president of Paralyzed Veterans of America. "This is truly a move in the right direction and we will continue to support efforts to prohibit discrimination based on disability in air travel, whether that's on Capitol Hill or in the courts."

According to Paralyzed Veterans of America, the number one complaint that they receive from members is related to problems with air travel. Shaun Castle, who serves as the deputy executive director of Paralyzed Veterans of America and is a service-disabled U.S. Army Veteran, has had his wheelchair bent, cracked and even lost in separate incidents.

"These are more than minor inconveniences," Castle said. "If my wheelchair is damaged, it may mean I am stranded until I can get it

repaired."

H.R. 302 includes several provisions similar to those found in the Air Carrier Access Amendments Act (ACAAA - H.R. 5004/S. 1318) introduced by Rep. Jim Langevin, D-R.I. earlier this year and by Sen. Tammy Baldwin, D-Wis. in 2017. Some of the Paralyzed Veterans of America supported provisions include increased civil penalties for wheelchair damage or bodily harm, and a study on the feasibility of in-cabin wheelchair restraint systems.

"Passengers with disabilities deserve equal access to the skies," said Congressman Langevin, a quadriplegic who co-chairs the Bipartisan Disabilities Caucus. "As I have seen in my own flying experience, however, our safety and security is often not prioritized. That's why I'm proud of the work Senator Baldwin and I did to make meaningful changes in the FAA bill, including a bill of rights for people with disabilities, to reduce barriers to travel. While there is still considerable progress to be made before we can achieve full equality, I am pleased with our achievements in this legislation, and I am grateful for the work of PVA in advocating on behalf of the broader disability community."

In addition to Langevin, Baldwin was also a sponsor of the bill. "In order to keep America's promise of full equality for all, we must break down the barriers that individuals with disabilities and our veterans face when they travel," said Baldwin.

"Equal access to air travel ensures our veterans are able to participate in today's economy and enjoy their travel opportunities. I'm so proud to partner with Paralyzed Veterans of America to protect the rights of our veterans when they travel and I'm looking forward to the president signing this important legislation," added Baldwin.

2018-19 Chapter Election Results

The Chapter Election Committee completed this year's election in accordance with PVA's updated Election Policies and Procedures. The Election Committee members were: Lawrence Berry, Benjamin Hanberry, Sam Penny* and James Wilcox. *-Alternate

Of the 847 ballots mailed out to Chapter members, 125 cast their vote for Chapter Officers and Board members. The results of this year's election are as follows. *-Elected to Office, **-Elected BOD as Alternate to VP

President

Michael G. Negrete - 96 votes*
Brad Carlson - 3 votes

Vice President

Mike Guilbault - 60 votes*
Brad Carlson - 31 votes
James Wallack - 25 votes
Mark Sanders - 1

Secretary

Peter Moore - 100*

Treasurer

Charles Schena - 7 votes*
Brad Carlson - 5 votes
Wayne Ross - 5 votes
Paul Nyerick - 3 votes
Michael Guilbault - 2 votes
Mark Sanders - 2 votes
James Wallack - 1 vote
Paul Raiche - 1 vote
Peter Falcione - 1 vote
John Brako - 1 vote
Michael Moran - 1 vote

Board of Directors (7 Positions)

Mark Sanders - 87 votes*
Michael Moran - 85 votes*
Michael Guilbault - 76 votes**
John Brako - 75 votes*
Walter Farrington - 73 votes*
Peter Falcione - 72 votes*
Brad Carlson - 71 votes*
Dan Shaul - 68 votes**
Paul Nyerick - 56 votes
Michael Negrete - 42 votes
James Wallack - 5 votes
Wayne Ross - 5 votes
Edward Dusick - 1 vote

Stop & Shop Supports Local New England PVA Chapter with Annual 5K Run and Cookout.

By Chapter President Michael G. Negrete



Saturday at NARA Park in Acton, MA was slightly overcast, but otherwise a beautiful day, compared to last year's blustering cold weather, for the Annual Stop & Shop 5K run and cookout to benefit the New England Chapter, Paralyzed Veterans of America.

It was great again to see the many smiling faces running the course around NARA park and having such a good time. There were runners ranging from early teens through 60's. This year added a Dad pushing his disabled son in a modified chair, and one of our very own chapter members, Wayne Ross, in his hand cycle completing the course!

Steve Rubner, Store Manager of #460 in Action, and volunteers from his and surrounding Stop & Shop stores have been working hard to put this event together. From organizing the venue, the cookout, course layout and timing, collecting donations and registering runners.

A huge Thank you to Steve Rubner and the Shop & Shop family for their continued support of New England PVA! It's supporters like Stop & Shop that allow us to continue supporting and advocating for the critical medical care and benefits of our most catastrophically injured Veterans who have sustained spinal cord injuries or dysfunction.

Again, can't say enough to Thank Stop & Shop, their employees, the volunteers and 5k runners for giving so generously of their time and resources.





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Army Veteran Jim Dahlin Purchases Exoskeleton Through the VA!

This article was written by Army Veteran and Indego user, Jim Dahlin.



My name is Jim Dahlin. I'm an army veteran having served as a combat medic with the 4th infantry division in Vietnam from 1969-70. I was discharged June 1971 and went on with the GI bill to become a nurse anesthetist. When I was 48 I rode a bicycle across the US from Seattle to Williamsburg, VA in 24 days averaging 140 miles a day. Two short years later, at the age of 50, I was unable to even get on a bicycle. I had been diagnosed with a disease called hereditary spastic paraparesis which eventually put me in a wheelchair.

The Minneapolis VA and My Introduction to Exoskeletons



I didn't get involved with the VA until 2014 when I was to have an MRI done at the Minneapolis VA. I needed to have my baclofen pump checked before I could be discharged and had to go to the SCID (spinal cord injury or disease) center. Meeting with the physician there, she told me that my disease qualified me to be seen and treated at the SCID center. As part of my two-day physical I was seen by a physical therapist. She asked me if I would be willing

to try a new therapy device that she was given responsibility for. This new therapy device was an exoskeleton called the Ekso. I attended physical therapy three days a week for five weeks. It was so nice to stand and move. Unfortunately, the Ekso was only for therapy and not for home use.

A few weeks passed when I got a call from another therapist in the SCID who was looking for people to try the ReWalk exoskeleton, which was approved for home use. I went through training for three weeks to learn how to use the device. Since you need to have someone with you using

the exoskeleton, my wife went through some of the training with me. After completing my training, I was approved to take it home for a three-month trial. After my trial period had ended, I returned the device and was asked if I wanted to have it purchased for me by the VA. I had found out that another device was going to be available for trial in the next few months, so I made the decision to trial the new exoskeleton before I would make any decision.

Why I chose Indego?

When the Indego exoskeleton became available for trial, my wife and I went and completed the training for it at the Minneapolis VA. I was then given the opportunity to take the Indego home for a three-month trial. During my trial period, Indego made some changes to the exoskeleton. They sent me the new components with each change so my trial period was extended to give me the opportunity to test all the new components.

I made the decision to go with Indego for a few reasons. I can make adjustments to such things as step height and step length while walking in the device. Its five-piece design makes it easy to assemble and put on, and if I spend some time away from my home, it has a travel case to place it in.

The thing I love most about an exoskeleton is the ability to stand and walk and look someone straight in the face while talking. Those of us in chairs know how tiring it can be on our necks looking up at someone standing and carrying on a long conversation. It's good for the overall body just to stand and move. I generally walk in the device for 30-45 minutes 2-3 times a week. Living in Minnesota, the winter poses some problems when it gets too cold or the sidewalks become slippery from ice and snow. Because Indego is slim and lightweight, I can get in my car while wearing the device, giving me the option to go to a mall or large store and walk with it during the winter months.

I am currently the only veteran to have an Indego. I expect that number



to increase rather significantly in the next few years as more veterans have the opportunity to try it in their SCID centers. If you are currently in a chair you should talk to your physical therapist in your SCID to see if you physically qualify for the use of an exoskeleton. If you do qualify, I highly encourage you to do a trial with your therapist. I know that not every SCID has Indego in house. If yours does not, you need to encourage your SCID to submit a request to get it in.

Annual Chapter Banquet - Another Fun Filled Night of



PIERIK AWARD - JULIA FERNANDES, BROCKTON



PIERIK AWARD - JONLYN GLENN, WEST ROXBURY



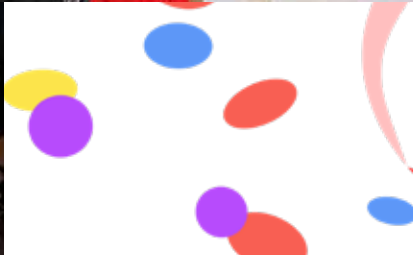
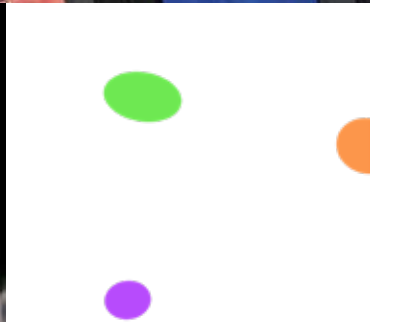
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VOLUNTEER OF THE YEAR - DENISE PEASE



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Norwood, MA 02062
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Essex Junction, VT 05452
802-222-0265

North Attleboro

57 George Leven Drive
North Attleboro MA 02760
508-859-0940

East Hartford

104 Pitkin Street
East Hartford, CT 06108
860-215-4100



www.mobilityworks.com

www.newenglandpva.org

VA Maine Healthcare System is Now a Five Star Facility

Submitted by Chapter National Director Neal Williams

Maine — The U.S. Department of Veterans Affairs (VA) released data showing that VA Maine Healthcare System is now a five-star facility and ranks 16 out of 146 VA Medical Centers across the country. The data comes from SAIL, an internal scorecard for VA that measures, evaluates and benchmarks quality and efficiency at VA Medical Centers (VAMC's).

VA Maine is in the top ranked group in the country for:

1. Veterans' perception about access in Specialty Care Clinics
2. Veterans' rating of Specialty care providers
3. Prevention of Healthcare Acquired infections in acute care
4. Patient's perception of access in Primary Care
5. Unexpected deaths at 30 days post discharge

VA Maine HCS was one of the facilities that made positive strides in the benchmarks and is striving to continue progress. One key area of improvement is Inpatient Flow, which includes Length of Stay and Readmission Rates. Length of Stay decreased by 20% and Readmission Rates decreased by 3%. Additionally, VA Maine maintained a zero percent

Hospital Acquired Infection rate for Central Line Infections, Catheter Associated Urinary Tract Infections, Ventilator Associated Pneumonias, and MRSA Infections for the past two years.

"We are very proud of our team at VA Maine and look forward to continuing to improve our processes, increase efficiencies and always put the Veteran first," said Daniel Dücker, Interim Medical Center Director.

The quarterly SAIL report, which has been released publicly since 2015, assesses 25 quality metrics and two efficiency and productivity metrics in areas such as death rate, complications and patient satisfaction, as well as overall efficiency and physician capacity at 146 VAMCs. It is used as an internal learning tool for VA leaders and personnel to pinpoint and study VAMCs with high quality and efficiency scores, both within specific measured areas and overall. The data is also used to identify best practices and develop strategies to help troubled facilities improve.



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Paralyzed Veterans of America



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New SCI Clinic opens at TOGUS VAMC Maine

By Chapter President Michael G. Negrete, Pictures Executive Director Debra Freed

After 8 long years, the new Spinal Cord Injury Clinic is finally completed and seeing patients!

Myself and Chapter Executive Director Debra Freed traveled to Augusta, ME on Wednesday October 17th to attend the formal open house. Also in attendance from Washington, D.C. were National PVA Vice President Hack Albertson, Executive Director Carl Blake, and Director of Medical Services Angela Weir.

Also in attendance were distinguished representatives from U.S. Senator Angus S. King, Jr., and U.S. Senator Susan Collins offices and

Congresswoman Chellie Pingree and Congressman Bruce Poliquin's offices.

The new SCI Clinic includes 3 patient exam rooms and a separate shower room, each equipped with patient ceiling lifts. Also in the new clinic is a dedicated Telehealth video conferencing room.

It goes without saying, the addition of the new SCI clinic is much needed to serve the over 200 SCI patients throughout Maine.



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Paralyzed Veterans of America

ANNUAL AIR RIFLE & AIR PISTOL PROGRAM

Cal-Diego Air Rifle and Pistol Tournament

January 28-29, 2019
San Diego, CA

Mid-Atlantic Air Rifle and Pistol Tournament

March 6-7, 2019
Richmond, VA

Wisconsin Air Rifle and Pistol Tournament

March 30-31, 2019
Milwaukee, WI

New England Combined Air Rifle and Boccia Tournament*

April 26-28, 2019
Brockton, MA

Buckeye Air Rifle and Pistol Tournament

April 26-27, 2019
Geneva, OH

**indicates combined events*

PARALYZED VETERANS NATIONAL SHOOTING SPORTS CIRCUIT

North Central Trapshoot

September 8-9, 2018
Sioux Falls, SD

Mid-Atlantic Shooting Sports Tournament and Handgun Shoot

November 9-11, 2018
Charles City, VA

Arizona Shooting Sports Tournament

February 8-10, 2019
Phoenix, AZ

Cal-Diego Shooting Sports Tournament & Pistol Tournament

March 29-31, 2019
Redlands, CA
Pistol Shoot - March 29, 2019
Lytle Creek, CA

Wisconsin Shooting Sports Tournament & Pistol Tournament

May 17-19, 2019
Rifle/Pistol Shoot - May 17, 2019
Green Bay, WI

Vaughan Shooting Sports Tournament

May 31-June 2, 2019
Elburn, IL

Iowa Shooting Sports Tournament & Pistol Tournament

June 14-16, 2019
Pistol Event - June 14, 2019
Cedar Rapids, IA

Lone Star Shooting Sports Tournament

June 21-23, 2019
Waxahachie, TX

PARALYZED VETERANS BOATING/FISHING TOUR

Mid-America Bass Tournament

September 21-23, 2018
Eufaula, OK

Vaughan Bass Tournament

October 5-7, 2018
Whittington, IL

Florida Gulf Coast Bass Tournament

March 29-31, 2019
Tavares, FL

Kentucky-Indiana Bass Tournament

May 3-5, 2019
Kuttawa, KY

Mid-Atlantic Bass Tournament

June 7-9, 2019
Henrico, VA

ANNUAL PVA/NWPA BILLIARDS TOURNAMENT SERIES

Mid-South Billiards Tournament

October 12-13, 2018
Memphis, TN

Mid-Atlantic Billiards Tournament Battle at the Beach

November 16-18, 2018
Virginia Beach, VA

Mid-Atlantic Billiards Tournament Chuck Willis Mem

March 22-24, 2019
Midlothian, VA

Mid-America Billiards Tournament

April 5-7, 2019
Oklahoma City, OK

Buckeye Billiards Tournament

June 14-15, 2019
Wickliffe, OH
Mountain States Billiards Tournament
June 21-22, 2019
Fountain, CO

BOCCIA

Gateway Boccia Tournament

October 18-20, 2018
St. Louis, MO

Bayou Boccia Tournament

November 30-December 1, 2018
Gulfport, MS

Mid-Atlantic Boccia Tournament

January 2019
Richmond, VA

Cal-Diego Boccia Tournament

February 19-20, 2019
San Diego, CA

Arizona Boccia Tournament

April 6-7, 2019
Phoenix, AZ

New England Combined Air Rifle and Boccia Tournament

April 26-28, 2019
Brockton, MA

ANNUAL PVA/AWBA BOWLING TOURNAMENT SERIES

Great Plains Bowling Tournament

July 12-15, 2018
Council Bluffs, IA

Mountain States Bowling Tournament

August 15-18, 2018
Colorado Springs, CO

Mid-Atlantic Bowling Tournament

September 28-30, 2018
Glen Allen, VA

Nevada Bowling Tournament

November 29-Dec 2, 2018
Las Vegas, NV

Florida Gulf Coast Bowling Tournament

February 21-24, 2019
Tampa, FL

Mid-America Bowling Tournament

April 12-14, 2019
Shawnee, OK

Vaughan Bowling Tournament

June 27-30, 2019
Romeoville, IL

HANDCYCLING RACING

Museum of Aviation Marathon

January 12, 2019
Warner Robins, GA

PVA Racing High Performance Camp

January 26-February 1, 2019
Brooksville, FL

Top End Euro-American HC Championships

February 2-3, 2019
Gainesville, FL

Valley of the Sun

February 16-18, 2019
Phoenix, AZ

One City Marathon

March 2, 2019
Newport News, VA

Off-Road Spring Expo

April 19-21, 2019
Chesterfield, VA

PVA Learn to Race Camp

April 23-26, 2019
Gettysburg, PA

Blue and Gray Half Marathon and Criterium

April 27-28, 2019
Gettysburg, PA

NATIONAL VETERANS WHEELCHAIR GAMES



For more information, visit:
pva.org/sports

Paralyzed Veterans of America
New England Chapter
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F 857-203-9685

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www.newenglandpva.org

Office Hours
Mon-Fri, 9:00am - 4:30pm



NEW ENGLAND PVA NEEDS YOUR HELP!

Volunteers do invaluable work that makes a real difference to Veterans, their communities and the Chapter. Volunteering can change your life, too! Your talents and time are always welcome.

We are looking for Volunteers to help out in the office, attend local awareness events, and assist with event planning. Everyone can help somehow and in some way, at any place and during any time. If you might be too busy or can't get out, think about a financial donation. Even if its only \$5 or \$10, every little bit helps. To learn more about Volunteer opportunities and how you can help please contact the Chapter office at 800-660-1181 or email info@newenglandpva.org.

Serving Paralyzed Veterans and the Disabled Community Since 1947.