

May/June 2020 Volume 53 Number 3

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WE CAN MEET THIS PANDEMIC CHALLENGE see president's message



Paralyzed Veterans of America

Gateway Chapter

Veterans with Spinal Cord Intury or Disease, Living Life to the Fullest

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Paralyzed Veterans of America

Gateway Chapter

Time to update your address or email?

Please email us at info@gatewaypva.org or write or call us at the following: Gateway Chapter PVA•1311 Lindbergh Plaza Center•St. Louis, MO 63132 (314) 427-0393 or (800) 426-4058 •Fax (314) 427-4183

We are offering the option to receive our Chapter's newsletter by email. Members taking advantage of electronic delivery will help to reduce the cost of printing and postage. In turn, this will allow the Chapter to put more funds toward our members and member programs. If you have not done so already, please contact Administrative Assistant Amber Lee at amber@gatewaypva.org, or Executive Director Chris Blanchard at chris@gatewaypva.org, if you would like to start receiving your newsletter electronically.



by Stanley D. Brown

The Virus

We are now in uncharted territory for our health and everyday life. As I write this article in late April, there are hopes of the COVID19 pandemic peaking and perhaps subsiding. There is still not enough testing available and the VA response in my opinion has been inadequate. I say that because you would think with our SCI/D at-risk population, we would have testing readily available and personal protective equipment (PPE) issued to us. If, and hopefully when, antibody vaccinations and preventive vaccinations are approved, they would be quickly available for our population in the VA. I have not been in any public place for over three weeks and hopefully you also are taking similar precautions. If you don't have masks that are homemade with cloth or someone gave you some, you can ironically purchase protective equipment manufactured in China on the Amazon website. To my knowledge, they are not available through VA channels. PVA has a very informative website at pva.org/ covid-19.

I can offer no inspirational wisdom to you but perhaps present some comforting thoughts. We have been through worse times in our lives. We have woken up in a hospital unable to move our legs and arms, breathing with a ventilator or perhaps been sitting in a doctor's office for a routine visit when the doctor told us we had a diagnosis of multiple sclerosis or ALS. By the nature of our "club" (Gateway **MAY/JUNE 2020** PVA), we have not had easy lives, and yet we have endured UTIs, falls with broken bones, low and high blood pressure, pressure sores and weeks of lying in bed, all the apprehension of our disease getting worse, spending the night in our chair because the attendant didn't come, and at times encountered society's indifference or hostility toward our disability by allowing airline travel to be hazardous and public places inaccessible. Despite all these challenges, we ski in the winter, take airplanes to participate in the National Veterans Wheelchair Games, go to Royals and Cardinals games (not yet this year), eat in restaurants (soon I hope), and embrace and live Gateway's vision statement of "living life to the fullest." I have yet to hear of any of our members testing positive for the virus. If you're so inclined, I would encourage you to pray, like I do, for our members and their families. We are a seasoned and battle-tested group of veterans; we can meet this pandemic challenge. Please call our office and leave a message for staff or me, or email us at: stan@ gatewaypva.org, chris@gatewaypva. org or amber@gatewaypva.org direct for assistance or information. Our service officers don't work in the office yet, but are working from home and can be emailed at: RodneyH@pva.org and JeremyL@pva.org in St. Louis, and BrentF@pva.org in Kansas City.

Gateway PVA FY21 Elections In this newsletter you will find a ballot for our FY21 election that includes

President's Message

The Virus Gateway PVA FY21 Elections Baseball Ticket Giveaway

> all four officer positions and seven board seats. The president's term is three years and the rest are all one year. At the first meeting of the new board, three long-distance members will be chosen. Follow the directions on the ballot to include: All mailed voting ballots should be sent to us by June 8, 2020, to the address shown on the ballot. A member may also hand-deliver their ballot to the GPVA Chapter office or to Administrative Assistant, Amber Lee or Executive Director, Chris Blanchard, by June 8, 2020 at the Chapter office. ALL member ballots will be opened and counted at the June 9, 2020, Board of Directors meeting. Fiscal Year 2021 Board officers and members will also be announced on June 9, 2020.

Cardinals and Royals Baseball Tickets

As we announced in the last edition of the Gazette, The Chapter purchased tickets for the entire St. Louis Cardinals home game schedule and 22 Kansas City Royals home games. Although there is not a set date for this year's baseball season to begin, you can still request tickets so that we have a record if the season does get underway at some point. You can find all game dates on our website for the available games at gatewaypva.org by clicking the "Events" tab. As in the past, you are able to purchase games (2 seats) at half price to ensure you get the games you want or merely choose those games you want and we will draw names by the lottery again.

Maintaining and Enhancing Your Mental Health and Well-Being During the Novel Coronavirus Disease (COVID-19) Outbreak

by Brent Follas, Senior National Service Officer

Taking care of your well-being, including your mental health, is essential during this time. Everyone reacts differently to stressful situations. Many people may experience stress, fear, anxiety, or feelings of depression. This is normal. There are things that you can do to manage your stress and anxiety:

- •Exercise regularly, try to eat well-balanced meals, and get plenty of sleep.
- •Take showers and get dressed as you would normally do during a regular day.
- •Limit alcohol.
- •Practice breathing exercises and/or meditation. VA has many free mental health apps for Veterans.
- •Take breaks from the news (see below for tips).
- •Stay connected with others while practicing social distancing (see below for tips).
- •Participate in activities or hobbies that you enjoy, or learn a new one.
- •Keep your current mental health appointments. VA offers both video and phone telemental health options that do not require you to go to your closest facility in-person should you have a medical concern or need to follow specific social distancing guidelines in your community.
- •Learn ways to connect with VA providers using telehealth options and schedule or reschedule your appointment online. If you are requesting a new mental health appointment, please call your local VA and they will work to arrange an appointment for you. If you need same day access for mental health services, call your local VA to request this and you will be connected to care.

Also, see these great resources on managing stress and anxiety related to COVID-19:

- •Moving Forward
- •National Center for PTSD Guidance on Managing Stress
- •CDC Guidance on COVID19 Mental Health Support

Sometimes it is wise to take breaks from watching, reading, or listening to news stories. It can be upsetting to hear about the crisis and see images repeatedly. If you feel anxious or stressed from the information, struggle to turn off the TV or log off of social media, or have trouble sleeping, you might want to limit the amount and type of news you are viewing. Try to do enjoyable activities, return to normal life as much as possible, and check for updates between breaks.

It is important to realize that during times of social distancing, it is normal to have increased feelings of loneliness, sadness, fear, or anxiety. It is imperative for everyone to stay connected. Seek support from family, friends, mentors, clergy, and those who are in similar circumstances. While face-to-face communication may be difficult, be flexible and creative using phone, email, text messaging, and video calls. Sign up or join a virtual social network that includes service members and Veterans.

Additionally, keep in touch with fellow Veterans and assist them in navigating this new environment if they are having a hard time. Teach them how to use VA Video Connect through the VA mobile app store as VA increases virtual health and mental health appointment availability. As a Veteran, you have been uniquely trained in emergency response situations. Your resilience and strength can assist others during these times. Connection can also happen when you give back to your community by sharing your expertise and support with family, friends, and neighbors through acts of kindness and volunteer opportunities which will arise.

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Moreover, stay engaged with VA information as it becomes available so you can continue to maintain your health. VA's Novel Coronavirus Disease (COVID-19) webpage has the most current information and VA's Coronavirus FAQs page provides answers to many important questions. Stay connected of Coronavirus information as it becomes available by visiting the CDC's Coronavirus page. Finally, stay up-to-date on what the federal government is doing in response to the pandemic at the USA.gov page.

Remember, we are all in this together. We are struggling together; we will triumph together. As veterans, we are trained leaders and we have overcome many different obstacles, as well as, sacrificed our lives to protect our country. Although, this is an adversity unlike our generations have ever seen, we will be victorious because of our strength, resolve, passion and because, we are Americans. God bless America!

Be Kind, Be Safe and Be Healthy.



Spring has sprung, but WOW are things different then this time last year. I hope all of you are keeping safe, and know that your SCI team is here if you need us. When this comes out we may be back at Building 52, but if not, we are all checking our messages from home, so there should be no delay in reaching us. All admissions have been cancelled thru May, and when given the okay we will begin rescheduling in person appointments and admissions as directed by the VA.

The bowel and bladder program continues to have its challenges. Some of you may be receiving a letter from me asking you to change your practice address on your NPI account to your home address. It is something with the new system exams, that will kick out your time card and delay payment. If you remember your NPI account log on information, you can go into your account information on line change the practice address online. Otherwise wait for the letter from myself with the form needed to send to NPI office. I am trying to share information as I receive it, but am being advised that all calls about bowel and bladder issues need to go thru the National Call Center at 1-877-881-7618.

Last bowel and bladder note; lease mail your time sheets to the address below, they are asking that you not fax them anymore. Please email to the following address: St. Louis VA Health Care System 1 Jefferson Barracks Drive Attn: 04-JB-OCC* St. Louis, MO 63125

A few happenings around Spinal Cord Injury:

•A big thanks to Kat McDonald and Lars Lifrak who have been making calls to all of you regarding how you are coping with the Covid crisis and making sure you are thinking about back up plans for caregivers. They have called over 300 local veterans. We appreciate their teamwork!!!

•Matt and Charlie with RT are doing daily group calls at 10:30, open to all veterans, and staff who want to participate, and they have been the bright spot in my day. They start the meeting with some type of activity tai chi, trivia, etc. If you are interested please reach out to them via email or phone to get the invite. You need a new invite every day.

•Our nurses, housekeeping, dietary, staff are the rock stars of building 52, taking care of our inpatients on a daily basis, and keeping them safe. Other staff is in and out, but this trio is carrying the load for us all.

Please be safe, enjoy those you are quarantined with, and call myself or any of the social workers if there is anything I can do. kim.vonderhaar@va.gov or 314-652-4100 ext. 64819.

Revak

The ReWalk Exoskeleton-Suited for Your Mission



Did You Know That Paralyzed US Veterans May be Eligible For a ReWalk Exoskeleton?

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What is *Your* Mission?

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2020 POLICY PRIORITIES

Veterans must have access to high quality, comprehensive, and veteran-centric health care as well as timely and accurate delivery of all earned benefits.

Strengthen and Improve the VA Health Care System and Services

Protect Access to VA's Specialized Services

Congress must protect access to specialized services within VA, including the spinal cord injury/disorder (SCI/D) system of care, to ensure that it remains strong and effective. Congress must also ensure that VA's health care system is able to effectively meet its staffing requirements.

Improve Access to VA's Long-Term Services

Congress must provide oversight of VA's expansion of its Program of Comprehensive Assistance for Family Caregivers (PCAFC) to ensure it is executed in a fair and timely manner and expand eligibility for the PCAFC to include veterans with serious illnesses like ALS and MS. Congress must also maintain a safe margin of community living center capacity for veterans with SCI/D.

O Access to IVF

Congress must make in-vitro fertilization (IVF) a permanent part of VA's medical care package.

D Care for Women Veterans with SCI/D

Congress must ensure VA is able to meet the needs of women veterans with catastrophic disabilities, including their needs in decisions involving delivery of gender-specific health care.

Strengthen VA Benefits for Catastrophically Disabled Veterans and their Surviving Spouses

Improvement to Veterans Benefits

- Increasing the Automobile Allowance Grant and ensuring that veterans receive appropriate Automotive Adaptive Equipment reimbursement;
- Addressing the transportation needs of non-serviceconnected veterans to help restore, promote, and preserve the highest state of health possible; and
- Prioritizing claims for Specially Adapted Housing grant for veterans with ALS and increasing the amount and usability for all catastrophically disabled veterans.

Benefits for Surviving Spouses

Congress must ensure survivors of veterans who die from ALS receive the full benefits they are due.

Veterans with disabilities must have access to the opportunities and freedoms to allow them to live, work, travel, and fully participate in society.

> Strengthen and Protect the Systems and Civil Rights that Support People with Disabilities

Improve Access to Air Travel for Passengers with Disabilities

Congress must improve access to air travel by requiring airlines to ensure that airplanes meet broad accessibility standards and strengthening Air Carrier Access Act enforcement through referral of certain complaints to the U.S. Attorney General and a private right of action.

Protect and Increase Compliance with the Americans with Disabilities Act (ADA)

Congress must continue to protect the rights of people with disabilities to seek immediate redress of discriminatory barriers in public accommodations under the ADA and increase and expand the tax incentives available to assist businesses with ADA compliance.

• Preserve and Strengthen Financial and Health Security for People with Disabilities

Congress must strengthen and enhance the Social Security system and protect Medicare, while rejecting efforts to undermine these earned benefits programs that represent an economic safety net for millions of Americans.

Disaster Response and Recovery that Meets the Needs of People with Disabilities

Congress must address current gaps in the ability of the emergency response and recovery system to address the needs of people with disabilities and ensure disability inclusive disaster management policies and practices.

Government Relations Report by Stanley D Brown, Government Relations Director

The first week of March I went to Washington DC as part of PVA's Advocacy and Legislation week. We received training on veterans and disability issues to include pending legislation. I met with representatives from all the Missouri congressional districts, the two Senate offices, and representatives from Illinois Senator Duckworth. As it turned out with the Coronavirus, all the offices closed the week after we left. Page eight of this newsletter is an outline of the 2020 PVA policy priorities that I covered. You only get about 30 minutes with each office, oftentimes meeting in a reception area, and at times in the hallway. Listed below are those issues I covered in order of importance and they had some chance of passing in today's political climate/election year.

1) **Protecting Access to VA'S Specialty Services** means ensuring the VA maintains its SCI/D service to include inpatient spinal cord centers that also offer services for outpatients. Often in the past when a "scandal" is in the news concerning a VA hospital, there is a clamor by some to privatize all VA services and cover everything under the MISSION Act providing for private vendors. I specifically talk about the benefit of having veterans in one setting doing rehabilitation and providing support for each other, as well as peer support coming from area outpatients. As part of this topic I also stressed the VA hire and bring on board more patient aides and nurses so SCI units could actually open all their beds and not have veterans in need of hospital care waiting at home or in nursing homes. I'm convinced the VA HR departments have been and continue to be the biggest problem in actually getting staff "vetted" and working on floors.

2) *Improving Access to VA's Caregiver Supports* means ensuring the timetable of the MISSION Act is followed to provide caregiver (oftentimes spouses) monetary support for those veterans with a serious active duty injury prior to September 11, 2001. The implementation of the Act is already delayed because the IT system is not able to support the changes.

3) *Improving Access to Adapted Automobiles* means that certain service-connected disabilities are eligible for a one time only payment of not more than \$21,488 to purchase an adapted vehicle. The House bill allows those veterans to receive payment every ten years.

4) I spoke in favor of the Senate and House bills that would prioritize veterans with ALS or other terminal illnesses and their claims for Specialty Adapted Housing grants. The bills would also increase the grant amount to \$99,000 for eligible veterans and let them access the grant six times as opposed to the current three times. The end of March the Senate bill passed but did not include authorizing prioritizing requests from seriously ill veterans like ALS veterans.

5) The last issue I usually had time for and had a reasonable chance of passing, was ensuring veterans (both women and men) had VA coverage/access to in vitro fertilization (IVF) which currently is only authorized until September 2020 under a continuing resolution. House and Senate bills would make the coverage a permanent part of medical services offered veterans, just like those on active duty with DOD coverage.

The rest of the bills and issues on page eight were in a packet I distributed and briefly highlighted time permitting. Please feel free to contact me with any questions. To date, nothing has passed both houses. **MAY/JUNE 2020** 9 **VOLUME 53 NUMBER 3**

We proudly support Gateway PVA



If you have a **service-connected disability**, you may qualify for VA funding assistance for wheelchair accessible vehicles or driving modifications. If your current mobility is more than two years old, you may even qualify for a brand new conversion.

> **St. Louis North** 9389 Natural Bridge Rd. St. Louis, MO 63134 Local: (314) 989-1010 Toll-Free: 877.501.8267

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MAY/JUNE 2020

Getting Paralyzed Veterans Walking Again with Indego®



New VA Program offers eligible veterans an Indego[®] Exoskeleton at no cost.

What is Indego?

A robotic device that enables veterans to walk again.

Indego is an FDA-approved exoskeleton worn around the waist and legs that enables individuals paralyzed from spinal cord injuries to stand and walk, offering a new level of independence.

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Email: support.indego@parker.com Phone: 844-846-3346



Watch Marine Veteran Steve Holbert's story at www.indego.com/veterans







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If you have received this publication in error, please call the office and let us know.

MATTERS OF NOTE

•The Gateway office is closed due to the Covid19 pandemic. We are working from home and are periodically in the office each week in order to continue to serve our membership while still keeping our staff and Board members safe. We continue to check our emails through the week, and can return your call when someone is in the office.

•Gateway Chapter Board of Director meetings will be determined on a month by month basis. We will email and post on social media at the beginning of each month to announce if there will be a meeting or not.

•Your FY21 Gateway Chapter ballot is included in this newsletter. Please return your completed and signed ballot to the Gateway office by end of business (5pm) June 8, 2020.

•SCI Recreational Therapy events for the month of May and June have been cancelled. Please check our event calendar on the Gateway website for updates on future events. You may also contact Matt Luitjohan at 314-894-6602 or Charley Wright at 314-652-4100 ext. 64590.

•The National Veterans Wheelchair Games has been cancelled for 2020.

•Gateway Chapter monthly luncheons at Jefferson Barracks Building 52 are cancelled until further notice. The luncheons will resume when the VA determines it is safe to host them again.