

# Gateway Gazette

November/December 2022

Vol.46  
No.6





**VETERANS WITH SPINAL CORD INJURY OR DISEASE, LIVING LIFE TO THE FULLEST**

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**NEED TO UPDATE  
YOUR CONTACT INFORMATION?**

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**DO YOU WANT TO RECEIVE  
YOUR NEWSLETTER BY EMAIL?**

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Contact us at one of the following:

Gateway Chapter PVA  
1311 Lindbergh Plaza Center  
St. Louis, MO 63132

314.427.0393 or 800.426.4058  
Fax 314.427.4183

[info@gatewaypva.org](mailto:info@gatewaypva.org)

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The material contained herein expresses the opinions of the writer and not necessarily the opinions of the editor or the Gateway Chapter, Paralyzed Veterans of America. All material in the Gazette may be reprinted unless specifically prohibited. Readers are encouraged to submit their articles to [info@gatewaypva.org](mailto:info@gatewaypva.org) or via US mail at the address shown above.

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Martha Rampani, Transportation

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4801 Linwood Blvd, Rm. M1-566  
Kansas City, MO 64128  
(816) 922-2882 or (800) 795-3612  
Fax: (816) 922-3369

Brent Follas, Senior National Service Officer

### St. Louis Service Office

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Susan White, Accredited Administrator

### Jefferson Barracks VA Medical Center

JB SCI, Room 2S25  
#1 Jefferson Barracks Drive  
St. Louis, MO 63125  
Office: (314) 894-6467 or (866) 328-2670  
Fax: (314) 894-6465  
Rodney Harris, Senior Benefits Advocate

### PVA National Liaison VP

Josue Cordova



# PRESIDENT'S MESSAGE

by Rose Ganz

## BUSY TIME FOR THE CHAPTER

The past six months have been busy. The Chapter distributed \$110,000 in accessible automobile grants. We also held our annual golf tournament and raised \$45,000.00. The next couple of months will also be busy for us. February 25th will be our Trivia Night to raise money for the Winter Sports Clinic and the National Veteran Wheelchair Games. Any baskets for the silent auction would be appreciated. We could also use volunteers the night of the event. For more information please call the office at 314-427-0393.

## LIFE TO THE FULLEST - Jeremiah DeGuire



PVA's motto is "living Life to the fullest," so I would like to highlight members doing that.

The first member I would like to highlight is Jeremiah DeGuire. Jeremiah and his wife Kristy have

three children, Benjamin, 12, and twins Marie and Jude, 9. Jeremiah was injured when a wall fell on him while seeking refuge from a storm that interrupted his softball game in 2006.

Jeremiah has his own motto: "When you take someone and have them in a place where they can be fully themselves and not inhibited then you see a different side of them." This is what inspired the shared dream of building a retreat in the Great Lakes Region of Wisconsin for people with any type of disability.

Between the two of them they operate three businesses: Wheels 2 Fields Flower farm,

Veteran Supply Warehouse (an electrical distribution company) and D G Design, Landscape and Architecture. Even after running three businesses, there is still time for family. They have three very active children who tend to go three different directions, and so do the parents. Jeremiah participates in the Winter Sports Clinic as well as sled hockey. He is truly an example of living life to the fullest.



# FROM THE DESK OF GATEWAY CHAPTER'S **EXECUTIVE ASSISTANT**

Amber Lee

## **KANSAS CITY MEMBERSHIP MEETING - NOVEMBER 18**

November 18 @ 12pm  
KANSAS CITY AREA  
MEMBERSHIP MEETING

### **LOCATION:**

DAV Chapter 2 Meeting Room  
14605 E. US Hwy 40  
Kansas City, MO 64136

Gateway Chapter President, Rose Ganz, and Executive Director, Chris Blanchard, will be visiting Kansas City to speak face to face with our Kansas City area veteran members. This meeting gives members the opportunity to speak in person with any concerns or praises about the KCVA or surrounding spokes. Lunch will also be provided.

## **HOLIDAY OFFICE PARTY - DECEMBER 13**

December 13 @ 12pm  
OFFICE HOLIDAY PARTY

### **LOCATION:**

Gateway Chapter PVA Office  
1311 Lindbergh Plaza Center  
St. Louis, MO 63132

We are again hosting a holiday party in December in lieu of our Board meeting. We welcome all of our members and supporters to come visit and enjoy some food and each others company. We will also have an ugly

sweater contest! So start planning your awesomely ugly sweater now and be ready to show it off at the party!

## **GATEWAY CHAPTER TRIVIA NIGHT - FEBRUARY 25**

February 25 @ 5pm  
GPVA TRIVIA NIGHT

### **LOCATION:**

Crestwood Elks Lodge  
10261 Bauer Rd  
St. Louis, MO 63128

To help fund our Sports program, we will be hosting a trivia night full of games, contests and of course trivia! We are in need of confirmed volunteers to help the night run smoothly. Additionally, we are asking members to reach out for silent auction items. Please let me know if you would like the letter and/or event flyer to hand out to places you frequent.

We are going with a Mardi Gras theme this year, and a costume contest to go with that theme (keep it family friendly please)!

## Introduction of New Drug for ALS

by Brent Follas, Senior National Service Officer

I attended the ALS Walk on October 1, 2022 and joined Anthony Vicks group. He is a Member of the Gateway Chapter and he and his family are very active in spreading awareness for ALS. I see him in the KU Medical Center Clinics frequently. His wife, Karen, Father, Mother-in-Law and many of his other family and friends were there. It was a beautiful day at Kauffman Stadium and there were hundreds of signs posted from people that suffer(ed) from ALS. Some I recognized. One was a personal friend and many I represented and helped with their claims along with the survivors.

There was something else mentioned at the Walk about a new drug called Relyvrio (marketed as Albrioz in Canada). Hopefully, soon, the VA will have it on its formulary list. It was mentioned that, because of the Ice Bucket Challenge in 2014, it helped streamline the research and production of this drug due to the extraordinary monetary donations provided from the challenge.

### History and Birth of Relyvrio

The U.S. Food and Drug Administration approved Relyvrio (sodium phenylbutyrate/taurursodiol) to treat patients with amyotrophic lateral sclerosis (ALS), commonly referred to as Lou Gehrig's disease.

“This approval provides another important treatment option for

ALS, a life-threatening disease that currently has no cure,” said Billy Dunn, M.D., director of the Office of Neuroscience in the FDA's Center for Drug Evaluation and Research. “The FDA remains committed to facilitating the development of additional ALS treatments.” ALS is a rare disease that attacks and kills the nerve cells that control voluntary muscles. Voluntary muscles produce movements such as chewing, walking, breathing, and talking. ALS causes the nerves to lose the ability to activate specific muscles, which causes the muscles to become weak and leads to paralysis. ALS is a progressive disease that continues to get worse over time. Most cases will result in death from respiratory failure, usually within three to five years from when the symptoms first appear. Approximately 5,000 individuals in the United States are diagnosed with ALS annually, and approximately 20,000 Americans are currently living with the disease.

Relyvrio can be taken orally by combining one packet in 8 ounces of room temperature water. It can also be administered through a feeding tube. The recommended dosage for the first three weeks is one packet (3 grams sodium phenylbutyrate and 1-gram taurursodiol) daily. After three weeks, the dosage increases to one packet twice a day. The medication can be taken before a snack/meal.

The efficacy of Relyvrio for the treatment of ALS was demonstrated in a 24-week, multicenter, randomized, double-blind,



placebo-controlled, parallel-group study. In the trial, 137 adult patients with ALS were randomized to receive either Relyvrio or placebo. The patients treated with Relyvrio experienced a slower rate of decline on a clinical assessment of daily functioning compared to those receiving a placebo. Additionally, longer overall survival was observed in a post hoc, long-term analysis of patients who originally received Relyvrio versus those who originally received placebo. The most common adverse reactions experienced with Relyvrio were diarrhea, abdominal pain, nausea and upper respiratory tract infection. Relyvrio contains taurursodiol, a bile acid, which may cause worsening diarrhea in patients with disorders that interfere with bile acid circulation. These patients should consider consulting with a specialist before taking Relyvrio.

[continued on page 7](#)

# 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 vehicle is more than two years old, you may even qualify for a brand new conversion. Veterans discounts available. Check out our daily rental rates!

## St. Louis North

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

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980 S. Highway Drive  
Fenton, MO 63026  
Local: (314) 292-5150  
Toll-Free: 877.501.8267



We're here to help!

Call us today or stop by and take a test drive.



Proud Supporters of the



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The prescribing information includes additional information on risks associated with Relyvrio. The FDA granted this application Priority Review designation.

It also received orphan drug designation, which provides incentives to assist and encourage the development of drugs for rare diseases. The FDA granted the approval of Relyvrio to Amylyx Pharmaceuticals Inc.

In March, the Peripheral and Central Nervous System Drugs Advisory committee concluded that the Amylyx study did not provide



“substantial evidence” that its drug was effective. Then in September, during a rare second meeting to consider a drug, the panel reversed course and voted in favor of approval.

The second vote came after Dr. Billy Dunn, director of the FDA’s Office of Neuroscience, encouraged the committee to exercise “flexibility” when considering a drug that might help people facing certain death. A much larger study of Relyvrio, the Phoenix Trial, is under way. But results are more than a year off. A negative result from that study would be a major blow to Amylyx and ALS patients.

“If you’ve got a drug that’s extending life by five months,” Rind says, “you ought to be able to show that in a larger trial.”

In the meantime, he says, perhaps Amylyx should charge less for their drug.

Relyvrio (marketed as Albrioza in Canada) is the only product made by Amylyx, a company founded less than a decade ago by Joshua Cohen and Justin Klee, who attended Brown University together.

Klee defends the drug’s price, saying it will allow the company to develop even better treatments. “This is not a cure,” he says. “We need to keep investing until we cure ALS.”

Klee and Cohen have also promised that Amylyx will re-evaluate its drug based on the results of the Phoenix trial.

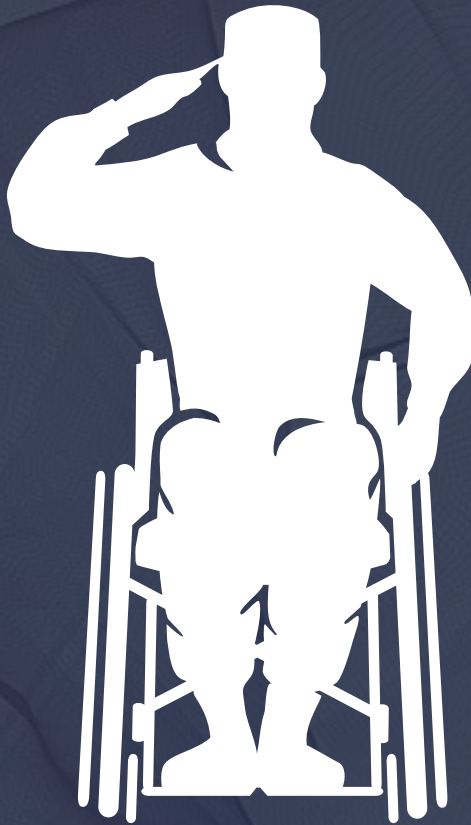
“If the Phoenix trial is not successful,” Klee says, “we will do what’s right for patients, which includes taking the drug voluntarily off the market.”

But that the decision would require support from the company’s investors, and its board of directors.



Neurologists and Spinal Cord Physicians should be well aware of this new drug so when it is available inside the VA, you can inquire about it and they can place a consult for Relyvrio. Reference: <https://www.fda.gov/news-events/press-announcements/fda-approves-new-treatment-option-patients-als>





# GATEWAY G.I.

## WELCOME TO OUR NEW MEMBERS

Dusty Armstrong  
Terry Bratton  
Brent Sellhorn  
Corey Tabb  
Bradford Young

## MISSING IN ACTION

Have you seen or know the whereabouts of these members? They are in danger of being dropped from the PVA roster. Please contact the Gateway office with current contact information for the following members:

Ronnie Anderson  
Amos Brown  
Jarid Hill  
Kevin Jackson  
Robert Melchior  
Charles Packard  
Sylvester Roddy  
Laurice Sappington  
Robert Schneider  
Donnell Thames

## IN MEMORY OF

Ralph Haskell of Pleasant Hill, MO	07/23/2018
Carl Billings of Corydon, KY	02/22/2020
Lynda Hauth of Kailua Kona, HI	09/14/2021
Gerry Klenke of Okawville, IL	07/10/2022
William Lacey of Alton, IL	07/17/2022
Edwin Evans of Grain Valley, MO	08/22/2022
Joseph Velasco of Festus, MO	09/03/2022



# GENERAL INFORMATION



## NOVEMBER

NOVEMBER 5 at 9am  
Veterans Day Parade  
10 points for members

NOVEMBER 8 at 11:30am  
Board of Directors meeting  
Via Zoom (contact office for link) and  
in person w/proof of COVID vaccination  
and signed waiver  
15 points for nonBOD members

NOVEMBER 11  
OFFICE CLOSED

NOVEMBER 24 and 25  
OFFICE CLOSED



## DECEMBER

DECEMBER 13 at 12pm  
Holiday Office Party

DECEMBER 15 at 1:30PM  
Quarterly Membership Meeting  
Via Zoom (contact office for link)  
15 points for members

DECEMBER 23 to JANUARY 2  
OFFICE CLOSED



Sales, Service, Rentals, Leasing, & Financing



PROUD SUPPORTER OF



### *Products Offered:*

- New & used, rear & side entry wheelchair accessible vans
- BraunAbility, VMI, & ATC Mobility conversions
- Wheelchair / scooter lifts
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- Hand controls & more

### *Services Offered:*

- VA funding options for qualified conversions and equipment
- Mobility equipment installation & service
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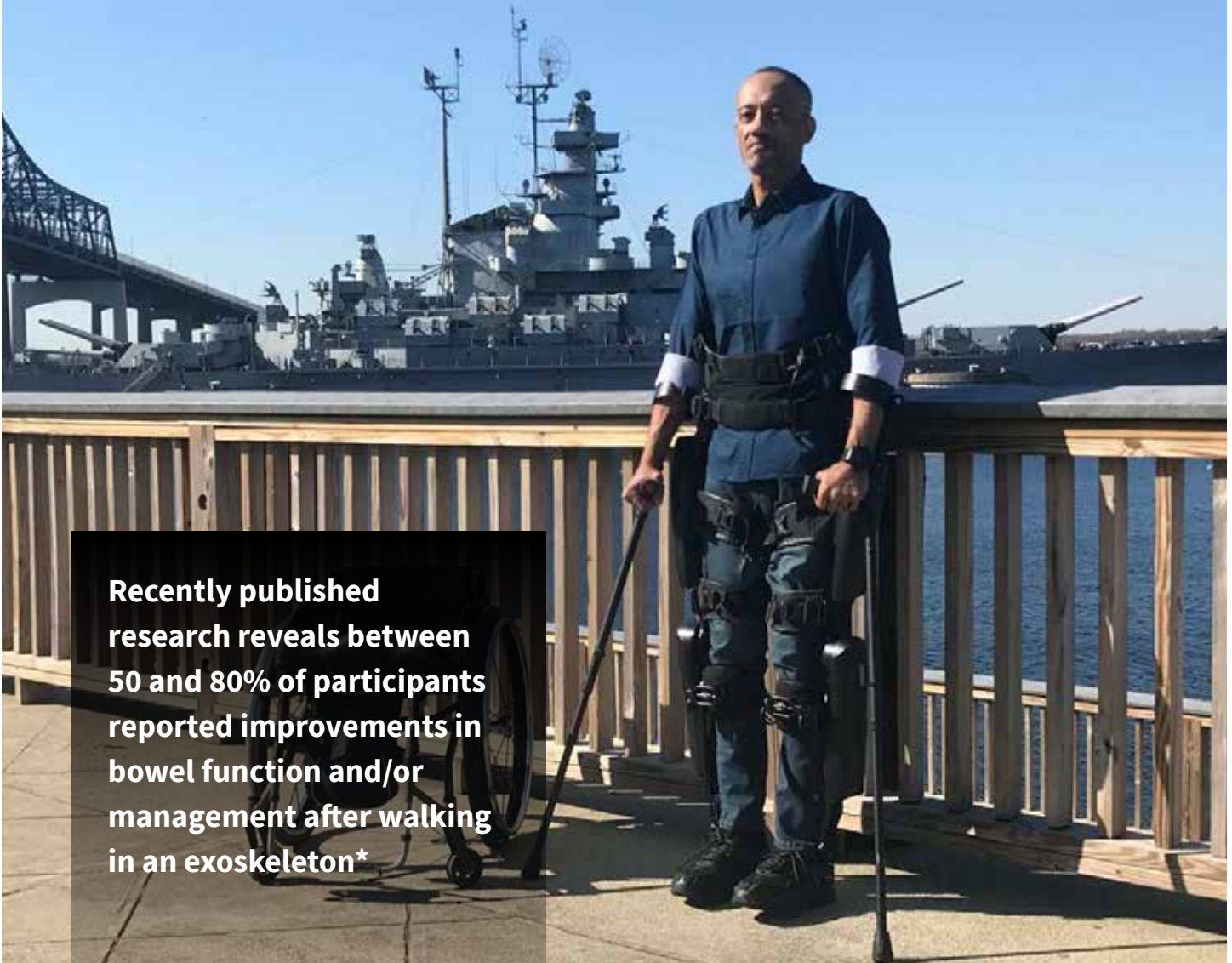
+618-526-4131

80 S Highway Dr., Valley Park, MO 63088

+636-825-0700



## Want To Improve Your Bowel Function?



**Recently published research reveals between 50 and 80% of participants reported improvements in bowel function and/or management after walking in an exoskeleton\***

**Did you know Paralyzed US Veterans May be Eligible for a ReWalk Personal Exoskeleton?**

**Contact ReWalk for more Information:  
[rewalk.com/contact](https://rewalk.com/contact) or  
508.251.1154 option 2**

\*Chun A, et al. Changes in bowel function following exoskeletal-assisted walking in persons with spinal cord injury: an observational pilot study. Spinal Cord. 2020;58(4):459-466.

The Gateway Chapter has ten total St. Louis Blues games available to win by lottery method (two tickets per game - Section 123, Row R, accessible spots 7 and 8). Members can win one game each. Members can put their name “in the hat” for more than the allowed amount to win.

Per the St. Louis Blues, tickets are solely digital. You MUST have the St. Louis Blues app on your smartphone and register an account. Please email me at [amber@gatewaypva.org](mailto:amber@gatewaypva.org) with your phone number and the email that you have registered your St. Louis Blues app with, and the games you are interested in.

Available games are below:

Must email for below games by November 16, 2022:

November 21 vs Anaheim

November 28 vs Dallas

December 12 vs Nashville

Must email for below games by December 16, 2022:

January 12 vs Calgary

January 19 vs Nashville

February 23 vs Vancouver

March 15 vs Minnesota

March 21 vs Detroit

April 6 vs NY Rangers

April 12 vs Dallas



## National Director Report

by **Don Feldott, National Director**

During the PVA National Convention in May, the Board of Directors passed a resolution having to do with grants for outdoor recreational activities.

National PVA has set aside \$50,000 to be used by Chapters for outside recreational activities. Grants have a \$2,500 limitation per Chapter grant request. Chapters are limited to two grants per year or until funds run out. Grants are open to all 33 chapters. Chapters have to submit a grant request form. Request is submitted to National PVA Sports and Recreational Staff and the Chapters will be notified within 15 business days of the grant's approval or denial.

The intent of these funds is to get veterans out into their communities and enjoy local parks and recreational areas. It could also be used to engage members who are otherwise not active with the chapter, bring novice participants into a sport, and it could also be used as a recruiting tool for new members.

# Jacqueline Black, PT, ATP

Fall is here! And since October is Physical Therapy month, the SCI therapy highlight for this newsletter will be our SCI PT programming.

We have a wonderful team of physical therapists on our SCI therapy team.

Amy Ikpeama PT, Katie Helton PT, and Lars Lifrak PTA primarily serve our inpatient SCI veterans for their physical therapy needs. Our veterans on the inpatient unit present with a variety of needs- including new SCI rehabilitation; rehabilitation following other medical issues, such as deconditioning after a medical issue; wound care; or inpatient SCI Annual Evaluation. All inpatients are screened for PT needs upon admission, and PT will create a plan of care to address those needs, which may include the following: bed mobility and transfer training; wheelchair seating and mobility assessment and training; safety assessment and education; skin care assessment and education; strength and endurance training; home exercise program; SCI education; caregiver training.

Johanna “Jody” Paniagua PT serves as the team lead for our SCI Outpatient Wheelchair Clinic and SCI Outpatient Annual Evaluation Clinic. She serves our SCI Outpatient Clinic through in-person visits or VVC

visits. She works directly with the veteran on the wheeled mobility evaluation, equipment trials, prescription, fitting, and maintenance of wheeled mobility products. Jody also works with many other team members involved in the wheelchair provision process, including: Prosthetics departments, local VAs (when veteran is not in St Louis area), manufacturer reps and VA contracted repair vendors.

Stephanie Albers PTA serves as our SCI Therapy Equipment Manager. She is your go-to person for equipment questions, and she will triage your equipment needs and get you moving in the right direction. She serves as our liaison between the many people involved in the VA equipment provision process (same as those outlined in Jody’s summary): clinician(s), veteran, local providers, Prosthetics, manufacturer, repair vendors, contracting, to name a few!

Meredith Whitehead PT current serves as the lead for our SCI Outpatient PT program, ALS Interdisciplinary Clinic and Multiple Sclerosis Clinic. She addresses SCI and ALS PT needs on an outpatient basis, which may include the following: transfer training; wheelchair seating and mobility assessment and training; safety assessment and education; skin care assessment and education; strength and endurance training; ambulation assessment and training; home exercise program; SCI education; caregiver training.

I could write a great deal more about the outstanding expertise of our SCI PT team, and I think I will do that in future newsletters to properly highlight the wonderful individuals on our SCI therapy team. Our SCI PT team is truly proud and honored to serve you!

If you have questions, concerns, or kudos about SCI Therapy- please contact me at [Jacqueline.black@va.gov](mailto:Jacqueline.black@va.gov) or 314-652-4100, ext 64691.

PARALYZED VETERANS OF AMERICA  
Gateway Chapter

# TRIVIA NIGHT

February 25, 2023



GAMES

AUCTION

50/50

CASH BAR

FOOD

DRINKS

**COSTUME CONTEST**  
(MARDIGRAS THEME)

**DOORS AT 5PM • TRIVIA AT 6PM**  
**\$200 for a TEAM of EIGHT**

**Crestwood Elks Lodge • 10261 Bauer Road • St. Louis, MO 63128**

**TO MAKE A RESERVATION EMAIL: [barb-wired@att.net](mailto:barb-wired@att.net)**

*Bring your snacks and table decorations (personal alcohol beverages are not permitted)*

*If you are unable to attend but wish to make a monetary donation or wish to donate an item for auction - please make your check out to Gateway PVA and send your donation to Gateway Chapter PVA, 1311 Lindbergh Plaza Center, Saint Louis, Missouri 63132 or contact the office at 314.427.0393*

# 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.

Indego can currently be used with spinal cord injury levels of T3 to L5 in community or home settings.

## Free Indego Webinars

During the first Thursday of every month you can join a free live webinar to learn more about the Indego and hear from a veteran who owns a device already.



Contact us today to reserve your spot or find out if you are eligible to receive an Indego exoskeleton at no cost.

Email: [support.indego@parker.com](mailto:support.indego@parker.com)

Phone: 844-846-3346



Watch Marine Veteran Steve Holbert's story at [www.indego.com/veterans](http://www.indego.com/veterans)





**Gateway Chapter**  
1311 Lindbergh Plaza Center  
Saint Louis, MO 63132



Generosity can be found anywhere.  
Even the back of your closet.

Donating clothes and other household goods  
can help improve the lives of injured veterans.



**Paralyzed Veterans  
of America**

**WHEELS HELPING  
WARRIORS**

Your donated vehicle can go far in helping severely injured veterans. Donations are sold at auction with proceeds going toward programs and services for veterans and their families. You may also receive a tax break, too! Schedule your free, easy pickup today.



[WheelsHelpingWarriors.org](http://WheelsHelpingWarriors.org) / 866-204-4548  
Paid for by the Jeffrey Carlton Charitable Foundation



**Paralyzed Veterans  
of America**

*Goods Inspiring Veterans Everywhere*

**Give G.I.V.E. a try by visiting  
[pva.org/givegoods](http://pva.org/givegoods) today!**