

PARAPLEGIA NEWS JUNE 2025

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JUNE 2025 VOL. 79 NO. 6

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Photo courtesy of Paralyzed Veterans of America

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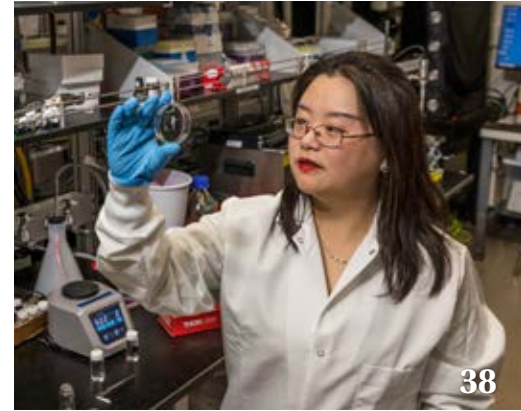
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advocacy cannot be overstated.
It's the beating heart of
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Now in its 79th year and the official publication of Paralyzed Veterans of America, *PN* is a national, monthly magazine that covers news, 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 *PN* should consult the Contributors Guidelines found on our website at pnonline.com. *PN* neither endorses nor guarantees any of the products or services advertised in the magazine. Readers should thoroughly investigate any product or service before making a purchase.

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JUNE Editor's DESK

Getting a look “behind the scenes” to learn how and why places and things work the way they do is always interesting. It’s intriguing to learn about the operations of an amusement park or to see how a movie was made.

One movie that has a neat behind-the-scenes story and also happens to be the subject of one of this month’s cover stories is the 1950 film *The Men*. The movie stars Hollywood legend Marlon Brando in his debut role and is of particular interest to Paralyzed Veterans of America (PVA). A few years ago, late PVA Publications Editor-In-Chief Tom Fjerstad showed the film to the staff here in Phoenix, giving commentary and pointing out various extras who were actual PVA members.

Now, 75 years after the movie came out, filmmakers, including current PVA Publications Editor-in-Chief Al Kovach Jr., are taking a behind-the-scenes look at the movie. Still in early production, *End of the Rope* delves into the film and especially Brando’s efforts to understand his role as a World War II veteran with a spinal cord injury (SCI). The article on page 20 looks at the filmmakers’ efforts.

As always, there’s plenty of other great content in this month’s issue, including *Weighing Risks & Benefits* on page 26 that takes a look at popular weight loss drugs and how they can affect people with SCI. We hope you enjoy those articles, as well as everything else in this month’s issue. And we hope you have a great summer.



Andy Nemann

Andy Nemann, Managing Editor

DIGITAL HIGHLIGHTS

GOING OUTDOORS

Make sure to visit pnonline.com this month to catch photos, videos and stories from the inaugural Paralyzed Veterans of America Grand Teton Outdoor Experience program, taking place in and around the Jackson Hole area in Wyoming June 24–26. The new program will include biking, yoga, sailing and more.

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PVAfromtheTOP

ROBERT L. THOMAS JR.
NATIONAL PRESIDENT

Being Reborn

Happy birthday! Happy birthday! June isn't the month in which my mom gave birth to me, but it is what I consider my "reborn month." Thirty-four years ago, on June 3, 1991, I was injured in a diving accident, which left me a level C5/6 quadriplegic, paralyzed from the neck down.

On that particular day, I can recall exactly what happened. But let me back up a little bit to the night prior. A group of my Army squad members and I went over to the post exchange (PX) to grab a few snacks. Once we arrived, we noticed that the parking lot was full and there were only one or two spaces left, which were disabled parking spaces.

I decided to park in the space and asked one of the guys to stay in the car just in case they needed to move it.

Unfortunately, everyone ended up in the PX, and once we came out, the military police (MPs) were there ready to issue a ticket. I tried explaining that I was only in the PX for a matter of moments, but to no avail. The MPs just handed me the ticket and explained that I could go pay the fine first thing in the morning if I wished.

The next day, after the morning muster and being released from work, we didn't have any equipment back from the desert yet. So, the members of my squad and I decided to go fishing on the property one of the guys was purchasing. After being there for several hours, with no luck catching any fish, a few of us decided to go swimming. Boy, was that a bad idea.

Three of us dove in one after the other, with me being the last one. The next thing I knew, I was saying to myself, "You'd better move something or you're going to drown." At that moment, my squad members began to pull me out of the water and onto the shore. While lying there on my stomach, I asked them if my legs

were bent in the air or if they were still in the water. They told me they were still in the water. I tried to get up, but the only thing I could move was my shoulders; my arms wouldn't move. My legs didn't move again — just my shoulders flopping around like a fish out of water.

To this day, I'm still unsure how the paramedics got there so fast because this was the early 1990s, and I don't recall anyone having a cell phone at that time. I was loaded into the ambulance and taken to the hospital at Fort Bragg in North Carolina, but upon arrival at the emergency room, the doctor immediately turned the ambulance around and sent them over to Cape Fear Valley Medical Center just down the road in Fayetteville, N.C.

As the paramedics began to push me through the halls of the emergency room, I remember being met by the doctor who had what looked to me like a drill, but it could've been a set of clippers. The next day when I woke up, I was lying on a bed that rotated or tilted left or right, with 90 pounds of weight hanging from my head.

While there, I underwent surgery to stabilize my neck. They called it a cervical 5/6 corpectomy, where they took a piece of bone out of my hip and placed it in my neck with a plate behind my esophagus.

I also had to go through the rigorous exercises of blowing in a machine to get a ball to move to ensure I didn't catch pneumonia and to prevent my lungs from collapsing. I was told that I would probably never walk again, and I was given the choice of being transferred to either the Walter Reed Army Medical Center in Bethesda, Md., or the Cleveland Department of Veterans Affairs (VA) spinal cord unit in Ohio to begin a more extensive rehabilitation process. I chose the Cleveland VA because it was closer to family, and I knew that having family as my support system would help me get through it all.

This is also where I realized that my life wasn't over, it was just changed. I was starting my life as a quadriplegic veteran, which opened the door to numerous opportunities and experiences in the next 34 years and beyond. ■

This is also where
I realized that
my life wasn't
over, it was
just changed.



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Gremlins

The term “gremlins” has been in the aviation lexicon since World War II.

An imaginary creature hell-bent on sabotaging aircraft, gremlins were blamed by flight crews for otherwise inexplicable incidents in the air and on the ground. This fictional scapegoat was created as a practical means to pass the buck or deflect blame without pointing the finger at a fellow crew member.

Decades later, gremlins have become a convenient fall guy for mishaps at airports, and despite the best efforts of disability advocacy groups, I’m afraid hordes of these mischievous creatures continue to emerge whenever a wheelchair is loaded into the belly of an airplane.

No matter how hard we try to avert the gremlins’ efforts, those of us who use wheelchairs seem to be their favorite targets.

ILLUSTRATION BY KERRY RANDOLPH/ALL GRAPHICS BY FREEPIK AI



Recently, I found myself a victim of one of these so-called gremlins. My plane had landed at San Diego International Airport, and 30 minutes later, my fellow passengers were already on their way to baggage claim. However, my wheelchair was nowhere in sight, so I couldn’t get off the plane. A flight attendant went looking for it, and as time passed, I began to worry that it was still at Gate C9, Terminal 4, at Phoenix Sky Harbor International Airport.

As the cleaning crew boarded the plane, I received a text from my wife asking me why I wasn’t waiting for her and the kids at the curb outside baggage claim. After all, that’s been our routine since July 2023 when I began working in Phoenix as the editor-in-chief for *PN* and *SPORTS ’N SPOKES*.

My wife was losing her patience, and with two hungry kids strapped in their car seats behind her, the situation was becoming dire. Her subsequent texts began to escalate to a rapid boil, and eventually she called me.

As I was trying to explain the situation to my wife, the flight attendant returned with one of my wheels, followed by her supervisor carrying the rest of my wheelchair. Alas, my wheelchair was broken, which meant I was going to remain in Seat 1D for a while longer.

I said, “What the hell happened to my wheelchair?!” There was no denying that someone screwed up, but the person’s identity would remain a mystery because the supervisor simply responded, “Gremlins!”

Without wasting any more time, my frustrated wife demanded I hand my phone to the supervisor and took control of the situation. Via FaceTime, my wife diagnosed the problem and told the supervisor how to make my wheelchair functional again, albeit temporarily, and I was able to get off the plane.

I could not, in good conscience, keep my wife and screaming, hungry kids waiting any longer, so I chose to forgo the broken wheelchair paper-

work in the customer complaint resolution office, or whatever they call it, and joined my cranky family for a miserable ride home.

Fortunately, I keep a backup wheelchair at home for these kinds of situations, and the following day, my friend, Steve, who built my wheelchair, fixed the damage caused by the gremlins.

Just three weeks later, I returned to the San Diego airport after working in Phoenix for a few days, and, once again, those damn gremlins broke my wheelchair! It was like déjà vu all over again, except the damage was far worse than the previous incident.

Gremlins or not, this time I was going to hold the airlines responsible. After submitting all the paperwork to the airline representatives and receiving a voucher for \$100, they put me on the phone with a company in Chicago called Global Repair Group. The company's representative said they would be responsible for managing the process of repairing my damaged wheelchair and that they worked with a vendor in San Diego who could fix it. I was skeptical. After all, if my wheelchair didn't get repaired properly, who would I blame and what recourse would I have? Are gremlins covered by insurance?

The next morning I got a call from Steve. He said, "I heard the airlines busted your wheelchair again." I asked him how he knew that I needed his help, and he responded, "Whenever the airlines break a wheelchair built by Hands On Concepts, I get a call from Global Repair Group."

He went on to say that Global Repair Group sends him 12 to 18 wheelchairs a year, which shouldn't be surprising because the Department of Transportation reports that the 10 largest U.S. airlines mishandle approximately 31 wheelchairs and scooters each day. Who knew gremlins could create so much havoc?

Nevertheless, after Steve fixed my wheelchair, I returned to my routine of working in Phoenix. While waiting at Gate C7 to board my Southwest Airlines flight back to San Diego, a woman dressed in coveralls, steel-toed boots and knee pads approached me. After removing her heavy gloves and headgear, she said, "Do you have any special requests regarding your wheelchair before I stow it in the belly of the aircraft?" My response was, "Yeah, don't break it."

She grinned and acknowledged that there have been problems with Southwest Airlines mishandling wheelchairs, but that the company had recently created new policies and procedures to mitigate those issues.

She told me many nightmarish stories about her experiences loading wheelchairs on Southwest flights, and it didn't take long before I began to suspect that I was face-to-face with the gremlin responsible for breaking my wheelchair.

I imagine every airport has its gang of mysterious and malicious gremlins whose singular purpose is to bring about as many inexplicable mishaps as possible. Yet, no matter how hard we try to avert the gremlins' efforts, those of us who use wheelchairs seem to be their favorite targets.

I will never surrender to the gremlins, but I have learned that as long as these tenacious creatures exist, I will always need to plan for the worst and hope for the best. Meanwhile, Steve just built me another wheelchair that I keep in my office in Phoenix. I consider this "gremlin insurance."

All kidding aside, it's easy for us to become angry at airline employees for damaging our wheelchairs, but the Department of Transportation's *Air Travel Consumer Report* found that airlines operating in the U.S. handle on average 1,486 wheelchairs and scooters every day. That's a lot of opportunities for gremlins, or whoever, to do a lot of damage.

Gremlins are omnipresent and inescapable, but I have my reasons as to why I continue to live in San Diego, work in Phoenix, fly on Southwest Airlines and use wheelchairs made by Hands On Concepts. I'm fully aware that I take a chance every time I get on a plane, but I try to be risk-averse whenever possible.

After all, the last thing I want is to be filling out paperwork for another broken wheelchair while my angry wife waits for me in a van with two hungry kids.

As always, please share your stories with me at al@pvamag.com. ■



Driven To Give

One of the country's biggest automotive brands and a longtime Paralyzed Veterans of America (PVA) partner continues to deliver for the organization.

PVA announced in April that it received a donation of \$1.13 million from the Penske Automotive Group's Service Matters campaign. This most recent donation brings the all-time contributions from Penske to PVA to more than \$10 million.

"Paralyzed Veterans of America is grateful to our partners, like Penske Automotive Group, who are driven to make a difference in the lives of veterans liv-

ing with spinal cord injuries and diseases," says PVA National President Robert L. Thomas Jr., in an April 8 press release. "Through their generosity, PVA can provide critical resources and services, advocate for the freedoms of veter-

ans with disabilities and ensure the men and women who served our country have the opportunities they earned and deserve."

The amount of Penske's April contribution includes donations from customers, partners and employees of

the automotive group, as well as matching contributions from the company.

"Since our partnership with PVA started in 2015, we are proud to have contributed more than \$10 million and remain committed to making a meaningful difference in the lives of veterans with spinal cord injuries and diseases," says Penske Automotive Group President Robert H. Kur-nick Jr., in the April 8 press release. "We are grateful to our dedicated team members, partners and loyal customers whose generosity and support continue to help drive PVA's vital mission. Together, we are strengthening our impact and empowering our heroes who have sacrificed so much for our nation."

For information on the Penske Automotive Group's Service Matters campaign, visit pva.org/pagserves.



PHOTOS COURTESY OF PARALYZED VETERANS OF AMERICA

Paralyzed Veterans of America (PVA) CEO Carl Blake, left, and PVA Director of Corporate Partnerships Arthur Crofoot visited Land Rover Paramus in Paramus, N.J., inset, in April to thank the staff there for being one of the Penske Automotive Group's top fundraisers for the company's Service Matters campaign that donates money to PVA.


Grand Fun

Several Paralyzed Veterans of America (PVA) members are marking a bit of history this month as they embark on a "grand" adventure in one of the most beautiful locations in the country.

PVA's inaugural Grand Teton Outdoor Experience is taking place June 23-27 in and around Grand Teton National Park in northwestern Wyoming. The new outdoor program is allowing

10 PVA members and their caregivers to engage in outdoor activities that foster both physical and mental well-being.

Among the adaptive activities planned for the experience are biking at Jackson Hole Mountain Resort, hiking in Grand Teton National Park, yoga, kayaking, sailing and more.

Look for more on this new event in a future issue of PN. 



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Secretary Summit

Paralyzed Veterans of America (PVA) CEO Carl Blake, left, and PVA Chief Policy Officer Heather Ansley, Esq., MSW, not pictured, had the opportunity to discuss key concerns directly with Department of Veterans Affairs (VA) Secretary Doug Collins, right, March 21 in Washington, D.C. The discussion focused on the importance of the VA's spinal cord injury and disease system of care, the accountability offered by PVA's site visits and the training provided to VA clinicians through PVA's annual Summit + Expo.



COURTESY OF PARALYZED VETERANS OF AMERICA CAL-DIEGO CHAPTER

Ready, Set, Eat!

It was a sticky, tasty and stomach-packing win by the Marine Corps at the third annual PB&J Armed Forces Classic April 5 on board the *USS Midway* in San Diego. Benefiting the Paralyzed Veterans of America Cal-Diego Chapter, the annual contest pits members of the United States military branches against each other to see how many peanut butter and jelly sandwiches they can eat in 10 minutes.



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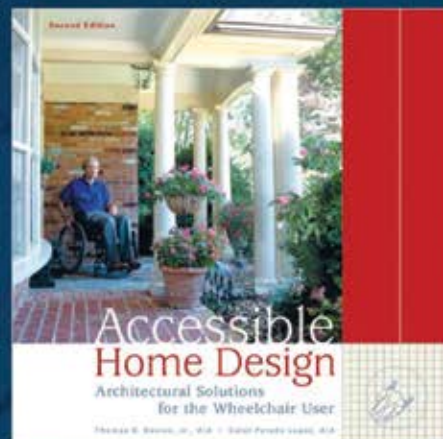
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— Mark Lichter, Director of Architecture, Paralyzed Veterans




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Paralyzed Veterans' architects offer resources and support when planning home design and renovations, including wheelchair-accessible home plans in our publication *Accessible Home Design, 2nd Edition*.

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You Need A Voice

The concept of a “grassroots” movement serves as a potent reminder that real change often begins at the community level.

While national headlines may focus on politicians and policy battles in Washington, D.C., the voices of everyday citizens such as neighbors, friends and family members will drive lasting transformation.

Grassroots advocacy empowers individuals to directly influence the legislative process, often starting with a simple conversation or one letter. Speaking up is one of the most effective ways to ensure legislators make decisions that reflect the public interest. It's more important than ever for advocates to speak up.

It's Essential

Many people underestimate the influence they can have on public policy. There's a common belief that only lobbyists or powerful interest groups can shape legislation, but that's untrue. In reality, lawmakers rely heavily on the feedback they receive from their constituents to inform their decisions. Letters, phone calls, emails and in-person meetings are tracked by congressional offices and are studied and counted.

A flood of messages on a particular issue can elevate its importance in a legislator's eyes. In many cases,

the volume and passion of grassroots responses have decided whether a bill is supported, amended or opposed. Direct communication with elected officials isn't just encouraged — it's essential.

Consider how the legislative process works: a bill is introduced, often created by various interests, and then it begins its journey through committees and potential amendments. At each step, legislators are gauging the public's response. If they hear nothing from their constituents, they may assume the issue isn't important or urgent.

On the other hand, when constituents take time to write heartfelt letters, share personal stories or organize their communities to speak out, it signals that this bill has real consequences for real people. These stories give context to a problem and help lawmakers see the human impact behind their decisions.

Learn about the best way to share your story by watching a Paralyzed Veterans of America (PVA) webinar on advocacy storytelling at pva.org/research-resources/disability-rights-advocacy/webinars.

Motivated To Act

Grassroots isn't only limited to reaching out to Congress. It often starts right at home, in the community. A simple conversation with a friend over coffee, a discussion at a community meeting or an impromptu chat

with a neighbor can spark awareness and interest. Conversations with others build momentum.

When more people understand and care about an issue, they become motivated to act. That action may be signing a petition, attending a town hall or encouraging others to contact their representatives. Grassroots movements are built on relationships and shared values, and they grow stronger as people get involved.

One of the most inspiring aspects of grassroots advocacy is that it's open to everyone. You don't need a political science degree or a law background. You need a voice and the willingness to use it.

Whether it's advocating for more accessible parking, Department of Veterans Affairs (VA) funding or VA health care staffing, every cause can benefit from local support. That personal connection is what makes grassroots advocacy so compelling and persuasive.

It's Not A Spectator Sport

There are countless examples of how grassroots movements have changed the course of history.

For example, during the Capitol Crawl on March 12, 1990, people abandoned their wheelchairs and assistive devices to crawl up the steps of the U.S. Capitol to push for the Americans with Disabilities Act.

ADVOCACY

That movement gained strength through the tireless efforts of ordinary people who spoke up, organized and refused to be silent. Legislators paid attention because the public wouldn't be ignored. That kind of collective action still holds power today.

In a time when political polarization seems widespread, grassroots advocacy reminds us that democracy isn't a spectator sport. It thrives when citizens are informed, engaged and persistent. Writing to your representatives isn't just a symbolic gesture — it's a critical act of civic responsibility.

This month, PVA is using members' voices to speak about the stories that are important to the organization. PVA's spinal cord injury and disease (SCI/D)

system of care petition will be used in meetings with congressional leaders to emphasize the support for the VA system in their states and districts.

The importance of grassroots advocacy cannot be overstated. It's the beating heart of democracy, where real change begins, and every voice matters.

If you haven't done so, write to your legislators and sign PVA's petition to support the VA SCI/D system of care. Change doesn't always start at the top. Often, change begins in a community and grows into a national call for action.

To sign the VA SCI/D system of care petition or for more information, visit votervoice.net/pva/home.


Lisa Elijah is PVA's grassroots advocacy manager in Washington, D.C. ■

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research **update**

BECCA HOFHEINZ

Stem Cell Translation

Researchers continue to look for novel ways to rebuild neural connections and restore limb function in people who've sustained a spinal cord injury (SCI).

A few of those novel and promising developments involving SCI stem cell translation were presented by Mark Tuszynski, MD, PhD, director of the University of California San Diego's Center for Neural Repair, in March.

A neurologist and neuroscientist who researches neural repair and regeneration, Tuszynski presented his latest research at the Paralyzed Veterans of America (PVA) Cal-Diego Chapter's third annual SCI Symposium in San Diego. He says all of our cells have a common beginning.

"We all started as one embryonic stem cell which goes through millions and billions of cycles of division," Tuszynski says. "Eventually, some of those cells decided to become cells of the nervous system, which are called neural stem cells. They also undergo many cycles of division. Eventually, some commit to be ... neurons of the nervous system or support cells of the nervous system called glia."

New Connections

SCI is the disconnection of the wiring of the nervous system. The nervous system works through biological wires called axons. These wires have an insulating sheath (myelin), which makes conduction more efficient.

Through a fully functioning nervous system, a command is sent from the brain through the spinal cord to another set of cells or neurons to then generate muscle movement. With SCI, there's no connection and a loss of axons, so there ends up being empty



Mark Tuszynski, MD, PhD

fluid-filled cavities, which means the wires (axons) cannot regrow.

The overarching idea of Tuszynski's model using neural stem cells is to take the empty injury cavity and fill it with neural stem cells. In this hypothetical model, the stem cells will support the regeneration of the cut wires (axons) of the nervous system coming down from the brain.

These will hypothetically regenerate and form new connections (synapses), which will send out new wires (axons) below the injury to reconnect the circuitry. Basically, in this model, the circuit is spliced in an effort to regenerate function.

This is a different method from what has been done in SCI clinical trials before. In those trials, researchers have tried to illicit activity from the small population of spared and uninjured axons in the hope of creating some recovery. Tuszynski is skeptical of this approach because in most cases, there are too few spared axons to gen-

erate a meaningful function recovery. His model is trying to illicit growth in the injured axons rather than use only the few uninjured axons.

Tuszynski says prior to 2012, efforts to promote regeneration of injured axons resulted in the best pacing growth of about 100 axons across the injury site, for a distance of about a millimeter. Now, using neural stem cells, the growth is up to 200,000 new axons over a distance of about 2 inches. For a mid-cervical injury level, this could initiate hand circuitry or potentially restore function.

For Tuszynski's animal model, researchers start with neural stem cells that are capable of generating both the neurons and glia (support cells). They implant them typically two to four weeks after the initial injury. Current work is being done in monkeys to study implantation up to two years after the injury.

To get the stem cells to consistently fill the lesion site, they must be supplemented with both a matrix (a glue) and growth factors. Then, they are grafted to mice, rats and monkeys.

The first half of the model is implanting the neural stem cells into the injury site with the hope they will grow below the injury and connect with the host neurons. The second half is getting the cells from the brain to grow down into the implant, regenerate and form connections to create a relay.

Modifying The Method

The model had a good outcome in rats — not a full recovery, but some. Because of the positive results, the researchers want to take this into human trials. But before that, it had to be conducted on primates.

When this study moved to monkeys, the researchers learned that what worked in rats didn't work in monkeys. Tuszynski says they had to review and

revise by increasing the concentration of growth factors, increasing the concentration of cells and taking measures to mitigate the flow of cerebral spinal fluid that washed into the injury and took away the implants. If this method had gone straight to humans, Tuszynski says it would have failed and no one would have known why because researchers can't inspect a human spinal cord the same way a monkey spinal cord can be studied following a study.

After modifying the method, researchers conducted a study with 10 rhesus monkeys, with four in the treatment group and six in the control group. They were grafted one month after the injury, and a nine-fold functional recovery was found. They tested

the monkeys by cutting their spinal cords on the right side at a C7 level. This causes a closed fist and the inability to grip. The monkeys were then tasked with grabbing a food reward. The non-grafted monkeys took time to pull in the treat, and some even cheated by using their other hand because of the inability to grip. The grafted monkeys, however, saw a 50% recovery with slight use of a grip-like motion.

"Now, imagine this slight change in a human with a C5 level injury now being able to use their hand and do things like control a wheelchair better than they can currently," says Tuszynski. "This would be probably enough control to hold a glass and bring it up to one's mouth or maybe to type very

slowly on a computer keyboard. But in my opinion, this would be transformative for one's quality of life."

Looking forward, Tuszynski is hoping to move to human clinical trials in the next one to two years, with recruiting of patients happening in California and Arizona.

The trials will include 20 patients with injuries two to four weeks old. Two of the patients will be below a level T4 SCI to ensure safety, and the other 18 will be level C5 and below. According to Tuszynski, there is still a lot of research to be done, but the recent results are promising.

To learn more about Tuszynski or the San Diego SCI Symposium, visit sandiegoscisymposium.com. ■



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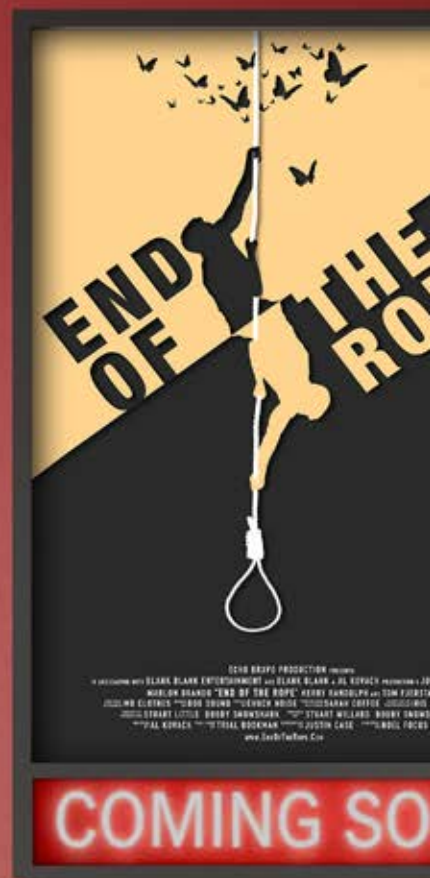
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END OF THE ROPE

Filmmakers are going
behind the lens of
The Men.



by Becca Hofheinz

Legendary actor Marlon

Brando's first foray onto the silver screen, *The Men*, changed health care for and attitudes toward paralyzed veterans everywhere.

Now, 75 years after the movie's official release, a new set of filmmakers are examining it from a different perspective — Brando's.

The project, spurred by PVA Publications Editor-In-Chief and Navy SEAL veteran Al Kovach Jr., and filmmaker and Army veteran Justin Roberts, was a session topic during the Paralyzed Veterans of America (PVA) Cal-Diego Chapter's third annual Spinal Cord Injury (SCI) Symposium in March.

The symposium brings together researchers, patients, doctors and others for discussion and dialogue regarding spinal cord injury and disease (SCI/D). This year's event was held at Admiral Baker Clubhouse in San Diego, with 10 speakers bringing their expe-



BECCA HOFHEINZ



Filmmaker Justin Roberts, right, spoke during the Paralyzed Veterans of America Cal-Diego Chapter's Spinal Cord Injury Symposium, left, in San Diego in March.

BECCA HOFHEINZ



Justin Roberts, left, and Al Kovach Jr., right, show scenes from *The Men* during their presentation.

tise to participants who attended both in person and virtually.

Like An “Evil” Infliction

Kovach and Roberts spoke about their screenplay, *End of the Rope*, which they have been working on for the past two years. The third draft of the script was recently completed.

The film will be about Brando’s true experiences when he asked to be admitted to the SCI center at the Birmingham Veterans Administration Hospital in Van Nuys, Calif., in order to prepare for his starring role in *The Men*.

The 1950 film follows Ken Wilocek, played by Brando, an Army lieutenant who was paralyzed by a sniper’s bullet in World War II. Wilocek finds himself in the SCI ward of a VA hospital, and the film shows how he navigates the mental and physical struggles that come with learning to live with SCI.

The movie was a low-budget film with a big impact. Brando, a method actor, drew from his real-life experiences when he went undercover in the SCI ward. For 30 days, he lived as though he had a SCI among real veterans with SCI/D. At first, only the hospital staff, including the SCI center’s chief, Ernest Bors, MD, knew he



PVA Publications Editor-In-Chief Al Kovach Jr., with an original poster from the movie *The Men*, starring Marlon Brando.



Actor Tom Cruise, right, with paralyzed veteran Ron Kovic, who Cruise portrayed in 1989's *Born on the Fourth of July*.

was an able-bodied actor. This was a rare look into a world that had never really been seen before.

"People didn't know what paraplegia was because paraplegics didn't live until World War II," Kovach says.

Up until that point, the only post-war film to feature a paralyzed character was *The Sign of the Ram* (1948), starring established Hollywood actress Susan Peters, who had been paralyzed in a hunting accident three years earlier. The movie is about a paralyzed woman who manipulates those around her.

"In Hollywood, there's always a bad guy with a patch on their eye or a hook for a hand, or they're in a wheelchair. It's like this inflection that made them evil," Kovach says. "But Dr. Bors wanted to change that. He worked with the president of the PVA in Long Beach, California, and they approached Stanley Kramer [a producer] and Carl Foreman [a writer], and they wrote a movie about paraplegia."

Not only was the film groundbreaking at the time, but *The Men* also helped with PVA's expansion. The movie spread awareness and helped get the support the veterans needed — support PVA still provides today.

In addition, the movie set a precedent for other actors like Tom Cruise, who spent nearly a year visiting Department of Veterans Affairs (VA) patients, researching the Vietnam War and using a wheelchair to prepare for his role as paralyzed veteran Ron Kovic in 1989's *Born on the Fourth of July*.

Kovach says according to *Tom Cruise: An Unauthorized Biography* (2008) by Andrew Morton, director Oliver Stone, a Vietnam War veteran himself, wanted to push the envelope even further by injecting Cruise with a drug that would temporarily paralyze him for a few days to help him realistically portray the challenges of a paraplegic. However, the insurance company responsible for the film wouldn't cover it.

It's A Need To

What started the ball rolling for Kovach, Roberts and their film partners was Kovach's discovery of an article titled *30 Days in a Wheelchair*, written by Brando and published in the April 1950 issue of *Varsity* magazine.

The article focused on Brando's experiences while living in the VA hospital. Kovach read the article and immediately thought, "There's a movie here!"

"The hope with this is not just communicating an experience of a paralyzed person, but the ability to communicate the suffering and still find the hope." — Justin Roberts

Kovach reached out to Roberts, a filmmaker known for movies including *No Greater Love*, a 2015 award-winning documentary about the "No Slack" Battalion, 101st Airborne Division's combat deployment in Afghanistan.

When the article was found, both Kovach and Roberts already had plenty going on. Kovach was in and out of the hospital for surgeries, and Roberts was in Ukraine documenting the war going on there. Although they had busy schedules, they decided to move forward with this idea and started the writing process.

"This is one of those projects that just needs to happen," Roberts says. "This isn't a want to; it's a need to."

The idea for the movie was originally a documentary style. But Kovach reached out to a friend and neighbor, who is an award-winning Hollywood producer, for another opinion. She suggested it should be more of a scripted feature with a character study and a character arc, so people could feel the emotions and really learn what it was like to live with SCI/D back then and now.

"The hope with this is not just communicating an experience of a paralyzed person, but the ability to communicate the suffering and still find the hope," Roberts says.

Kovach liked the idea because it helps them share the story, while also allowing him to add in his own experiences from living with a SCI. He was paralyzed after a 1991 parachuting accident during a combat training exercise.

"One of fun things about this is I get to inject all of my personal experiences over the last 35 years of being a patient into the film, including those peculiar butterflies on the ceiling tiles in the hospital [at the VA SCI center in La Jolla, Calif.]," Kovach says. "But there is a story behind those butterflies, you know, how we checked into the hospital as a larva, and then we come out as a butterfly at the other end. That idea plays a major part in our film, about that transition that we go through with an SCI/D."

Making An Impact

Kovach and Roberts plan to make the movie a fundraiser for PVA and other veterans organizations.

"Imagine this, on Veterans Day, you can get a preorder copy of this, the director's cut, which is only available through this method," says Roberts, who will direct the film. "It's going to be \$20, which is the same amount you would spend on any movie. But the majority of this movie's shares is going to veteran organizations. And so, by purchasing this film on Veterans Day, you're not only going to get an amazing film, but you also get an exclusive director's cut with exclusive footage that helps support veterans."

In early April, Kovach and Roberts were in the process of assembling a team of readers, or experts in SCI and filmmaking, to give input on the script.

Kovach says they are talking with producers and hope to start production on *End of the Rope* within the next year.

"We are hoping this movie has an impact, just like *The Men*," Kovach says.

For more information about the film project, visit echobravoproductions.com/end-of-the-rope. ■



For assistance, please refer to the directory below to identify the Paralyzed Veterans of America (PVA) Service Office nearest you. Also, you may contact the PVA Veterans Benefits Department located at our headquarters in Washington, D.C., at 866-734-0857.

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Weighing Risks & Benefits

There are several anti-obesity drugs available, but the jury is still out on their safety and efficacy for people with SCI/D.

If you've watched television, browsed the internet or listened to the radio recently, chances are by now you've heard or seen advertisements for weight loss medications, especially a class known as glucagon-like peptide-1 receptor agonists (GLP-1 RAs).

These medications — semaglutide arguably being the most well-known — were originally intended to treat Type 2 diabetes and have been shown in the general population to have many benefits, includ-

ing weight loss, appetite suppression, blood sugar control and reduced risk of cardiovascular events.

This is especially important for people with a spinal cord injury (SCI), since multiple studies have shown they are at a higher risk for obesity, metabolic disorders and cardiovascular disease due to multiple factors, such as decreased movement, muscle mass, basal metabolic rate and caloric needs.

Obesity is a major risk factor contributing to heart attack and stroke in people with

by Brittany Martin

Ozempic

Rybelsus

Tirzepatide

Zepbound

Qsymia



ILLUSTRATION BY KERRY RANDOLPH/
GRAPHICS BY FREEPIK

Weight loss drugs can help people with obesity manage their blood sugar and appetite, but there are many considerations for people with a spinal cord injury or disease before taking them.

SCI, according to clinical practice guidelines published by the Consortium for Spinal Cord Medicine. People with SCI are also more than twice as likely as the general population to develop Type 2 diabetes, according to a 1994 study by William A. Bauman and Ann M. Spungen.

However, there have been limited research studies focused on the safety and efficacy of GLP-1 RAs and other anti-obesity medications in the spinal cord injury and disease (SCI/D) population.

Still, for those with obesity, who have Type 2 diabetes, high blood pressure or high cholesterol, it could be worth discussing the options, risks and benefits of these medications with your doctor.

How They Work

Because there are several types of anti-obesity medications and because everyone's body is different, it can be a bit confusing to determine which one is best for you.

Each drug has a different action mechanism, adverse effects and benefits, says Sherri LaVela, PhD, MPH, MBA, a senior health research scientist at the Edward Hines Jr. Department of Veterans Affairs (VA) Hospital in Hines, Ill., and a research professor in Northwestern University's Department of Physical Medicine and Rehabilitation.

"However, they all promote weight loss through mechanisms such as decreasing hunger, decreasing appetite, increasing feelings of satiety, leading to reduced



ingestion and/or absorption of calories,” says LaVela, who presented findings from a study in which researchers looked at health care providers’ beliefs about using anti-obesity medications in individuals with SCI/D at last year’s Paralyzed Veterans of America Summit + Expo. GLP-1 RAs are

tor agonist, was approved under the brand name Mounjaro in 2022 for Type 2 diabetes and then as Zepbound in 2023 for chronic weight management in adults with obesity.

GLP-1 RAs like semaglutide work both in the gut and the brain to promote weight loss. Injected once weekly, they mimic the body’s natural GLP-1 hormone, increasing insulin production and decreasing inappropriate glucagon secretion in the pancreas to regulate blood sugar. Turning on GLP-1 receptors also slows gastric emptying and decreases appetite and caloric intake by binding to and activating these receptors in the brain.

“It’s promoting the weight loss because it actually decreases your hunger and appetite while also increasing your feelings of satiety, which is your feeling of fullness. As a result, this leads to reduced intake and fewer calories being ingested.” — Erin Klumb, MPH, CPH, RDN

hardly new. The first was exenatide, which was marketed as Byetta, and was Food and Drug Administration (FDA)-approved to treat Type 2 diabetes in 2005. Others were added over the years, including Victoza (liraglutide injection) in 2010, Trulicity (dulaglutide injection) in 2014, Ozempic (semaglutide injection) in 2017 and Rybelsus (semaglutide oral tablet) in 2019.

Then, in 2021, the FDA approved the semaglutide injection Wegovy for the treatment of obesity.

Shortly thereafter, a similar type of injectable medicine called tirzepatide, which is a dual-acting GLP-1 and glucose-dependent insulinotropic polypeptide (GIP) recep-

“It’s promoting the weight loss because it actually decreases your hunger and appetite while also increasing your feelings of satiety, which is your feeling of fullness. As a result, this leads to reduced intake and fewer calories being ingested,” says Erin Klumb, MPH, CPH, RDN, a



Injectable glucagon-like peptide-1 receptor agonists target receptors in the gut and brain to regulate blood sugar and slow gastric emptying.



ILLUSTRATION BY KERRY RANDOLPH/GRAPHICS BY FREEPIK AI

dietitian in the SCI/D Center at the Clement J. Zablocki VA Medical Center in Milwaukee.

Likewise, tirzepatide mimics the GLP-1 hormone, but it also mimics GIP hormones that stimulate insulin production.

While compounded GLP-1 medications — which claim to have the same active ingredients and can be cheaper and more accessible than the manufacturers' brands — have been available from a variety of online retailers and other companies, they aren't FDA approved. The FDA allows compounded versions to be sold if a popular drug is on its shortage list. However, the FDA lifted that designation for both Mounjaro/Zepbound and Ozempic/Wegovy earlier this year, which could restrict compounded GLP-1 drugs.

Several other FDA-approved weight loss drugs include Saxenda (liraglutide), Qsymia (phentermine/topiramate extended release), Contrave (naltrexone/bupropion extended release) and Alli/Xenical (orlistat). However, some of these oral medications can have interactions with medications people with SCI are already taking, have gastrointestinal (GI) side effects or have high abuse potential, according to Sarah Clay, PharmD, an SCI/D clinical pharmacy specialist at the Rocky Mountain Regional VA Spinal Cord Injury Center in Aurora, Colo.

Who Qualifies?

Qualifications for anti-obesity medications like semaglutide and tirzepatide include a body mass index (BMI) greater or equal to 30, or a BMI greater than 27 with at least one associated comorbid condition, such as obstructive sleep apnea, cardiovascular disease, osteoarthritis, depression, anxiety, acid reflux, high blood pressure or Type 2 diabetes.

Providers thoroughly screen patients to ensure they are the right candidates for these drugs.

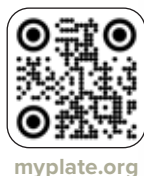
"[We] assess the patient for prior history of pancreatitis, complex neurogenic bowels, diabetes, history of medullary thyroid cancer, diabetic retinopathy or any other contraindications," says Joanna Zakrocki, FNP-C, a primary care nurse practitioner in the SCI/D Center at the Rocky Mountain Regional VA Medical Center.

Zakrocki says her team goes through a checklist and counsels patients about side effects, then makes sure they're willing to connect with a dietitian to learn about dietary changes, lifestyle modifications and ways to increase movement.

"My biggest thing that I always say is, 'You have to have the motivation and the will to try to work on weight loss.'" — Jason Gehring, NP

Before prescribing semaglutide, Jason Gehring, NP, an outpatient nurse practitioner in the SCI/D Center at the Clement J. Zablocki VA Medical Center, says he also assesses patients' kidney and liver function, risk of gallstones, how willing patients are to use the drug to help lose weight, baseline cardiovascular health, blood sugar and how well they are taking care of themselves in general.

"My biggest thing that I always say is, 'You have to have the motivation and the will to try



myplate.org



to work on weight loss,” Gehring says. “It’s one of those things if the person just wants to start taking it because they think they’re going to lose weight, nobody’s going to lose weight unless you’re motivated to put the effort in as well, besides just taking a medication to lose weight.”

Klumb agrees medications should be an additional weight loss aid. She takes an individualized approach to eating habits before the drugs are prescribed.

“We just want to ensure that they’re able to demonstrate the ability of balanced eating [typically eating three meals a day based on MyPlate recommendations] and meeting their target calorie needs, meeting their target protein needs,” Klumb says. “With the weight loss, there is a goal range of about half a pound to 2 pounds per week as the target. Anything above that 2 pounds can actually lead to unintentional weight loss and eventually muscle loss if severe enough. This can actually increase your risk for malnutrition. So, we try to monitor the weight as closely as possible.”

The Good & The Bad

Besides weight loss and blood sugar regulation, semaglutide has been shown in clinical trials with non-SCI patients to reduce stroke, heart attack and death by cardiovascular events by 20% compared to a placebo. Meanwhile, late-stage trial data on tirzepatide released in August 2024 suggests patients were 38% less likely to be hospitalized, need to increase their heart failure medications or die because of heart complications compared with those who received a placebo.

Zakrocki says a good starting point for weight loss is 5% of body weight in 12 to 16 weeks, and data shows that a 5% loss in body weight is enough to make improvements on markers like cholesterol, diabetes and blood pressure.

Beyond the internal benefits, weight loss can make wheelchair transfers easier, and wheelchairs won’t have to be adjusted to compensate for extra weight. In addition, Zakrocki says having excess weight makes it more difficult to achieve rehab and physical therapy goals and increases the likelihood of pressure wounds and makes them harder to treat.

“People just feel better, which also helps with mood and depression,” Zakrocki says.

However, of the many possible side effects, including nausea and dizziness, one of the most concerning for people with SCI/D, who may already have a neurogenic bowel and chronic constipation, is that slower gastric emptying increases the risk of a bowel obstruction.

Clay believes some GI effects can be managed with close monitoring and adjusting a bowel regimen or bowel medications. Her approach with anti-obesity drugs is to start low and go slowly to monitor for adverse effects.

Gehring says rare risks such as inflammation of the pancreas, gallbladder issues and gallstones can also be a concern for SCI patients because they might not exhibit the same symptoms as an uninjured patient, and the absence of sensation might not allow those issues to be detected until they are severe.

Klumb says another concern is that anti-obesity medications might contribute to poor eating habits and lead to nutritional deficits.

"I think one concern is that individuals will rely solely on the medication and neglect those healthy dietary choices that need to be implemented and need to be seen to have this weight loss be indefinite or lifelong, or prevent that weight gain from happening once you stop taking the medication," Klumb says.

Klumb says decreased hunger may cause people to skip meals, and consuming adequate protein and hydrating are important for maintaining muscle and avoiding pressure wounds.

"Also, it has been seen to increase your risk of body dysmorphia, as well, and then there's concerns with the medications just resulting in a disordered eating pattern," Klumb says.

One Piece Of The Puzzle

Clay has had some personal experience with the ups and downs of anti-obesity medications, although she's careful to note her opinions are not those of the VA. Clay, who sustained a level T4 complete SCI in an ATV accident at age 17 in 2001, has been taking Wegovy for weight loss since last November and by

"It's really an interdisciplinary approach, especially in spinal cord injury, to make sure that we're not doing harm and that we're maximizing the benefits of the medications." — Sarah Clay, PharmD

"I noticed that I kept putting on the weight, and mounting enough exercise was not ultimately enough to take the weight off in addition to calorie restriction," Clay says. "I just felt like my appetite was getting in the way of maintaining a healthy weight. And then I started to notice things like transferring got harder. I had increased pain in my joints from transferring and pushing my chair, so I needed to get a SmartDrive [wheelchair power assist device]."

She says she's had to pay attention to constipation and adjust her bowel program accordingly, and she's noticed some acid reflux since she started taking Wegovy.

"There's simple medications that don't come with a lot of risks that I can take to prevent or manage those side effects at this point," Clay says.

For now, she says the benefits outweigh the side effects. In January, she weighed 159 pounds, and her goal weight is 135-140 pounds. She no longer has cravings, which makes the weight loss feel sustainable for her.

"And that gives me hope because before, it would just be like, 'Oh, potato chips or chocolate,' or whatever is sitting around that I just like to eat. If I'm bored, I like to eat," Clay says. "Now, sometimes it doesn't even occur to me that I should have a snack. So, that makes me have hope that I will reach that goal weight."

While a general lack of evidence, clinical agreement and guidelines about the safe and effective use of anti-obesity medications in the SCI/D population remain, Clay says the drugs are ultimately just one part of the weight loss puzzle.

"It's really an interdisciplinary approach, especially in spinal cord injury, to make sure that we're not doing harm and that we're maximizing the benefits of the medications," she says. ■

COURTESY OF SARAH CLAY



Sarah Clay, PharmD

late January had lost 13 pounds over 11 weeks. She says she wanted to try the medication after some test results gave her cardiovascular warning signs.



PVA members return to Capitol Hill for the annual advocacy and legislation seminar this month.

by Heather Ansley,
Esq., MSW

photos courtesy of
Paralyzed Veterans
of America

There's a new adminis-tration in the White House and there are new members of Congress, but the mission of this month's annual Paralyzed Veterans of America (PVA) Advocacy/Legislation Seminar remains the same.

PVA members from across the country will gather in Washington, D.C., June 10–12, to learn about the organization's policy priorities and advocate for them with our nation's leaders. Like last year, PVA will use virtual meeting

technology to shorten the in-person training and maximize time on Capitol Hill.

PVA is looking forward to taking full advantage of this opportunity to express support for its 2025 policy priorities (pva.org/research-resources/policy-priorities) with these leaders.

Rejuvenating The System

During the 2024 Advocacy/Legislation Seminar, PVA focused its advocacy on five priority bills.



ILLUSTRATION BY KERRY RANDOLPH
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Two of the five bills advocates spoke to their members of Congress about became law — the Senator Elizabeth Dole 21st Century Veterans Healthcare and Benefits Improvement Act (PL 118-210) and the Veterans Expedited TSA (Transportation Security Administration) Screening Safe Travel Act (PL 118-238). PVA members' voices helped get these crucial pieces of legislation across the finish line.

Additionally, PVA's advocacy for the Department of Veterans Affairs (VA) spinal cord injury and disease (SCI/D) system of care was on full display during a June 13, 2024, House Veterans' Affairs Committee hearing, titled A Call to Action: Meeting the Needs of the Spinal

Cord Injury and Disorders (SCI/D) Veteran Community.

In his testimony, PVA National President Robert L. Thomas Jr., focused on the importance of care provided to veterans through the VA's SCI/D health care system. PVA CEO Carl Blake's statement took exception to the VA's claims that staff vacancies are low, as he outlined staffing deficiencies in the SCI/D system of care and their impact on paralyzed veterans.



Paralyzed Veterans of America National President Robert L. Thomas Jr.



Paralyzed Veterans of America (PVA) CEO Carl Blake, left, PVA National President Robert L. Thomas Jr., center, and PVA Chief Policy Officer Heather Ansley, Esq., MSW, speak at last year's PVA Advocacy/Legislation Seminar.

"Some real effort needs to be put into rejuvenating this system or it's going to collapse on itself," Blake stated during the hearing.

The testimony resulted in two follow-up letters from Committee Chairman Mike Bost (R-Ill.) to the VA seeking further answers to questions regarding staffing in the SCI/D system. Those inquiries have resulted in the VA taking a hard look at this issue and have helped continue the conversation in the 119th Congress.

A Dire Need

This year, PVA has continued to build on its efforts to ensure paralyzed veterans and their families, caregivers and survivors have access to the care and benefits they need.

One of PVA's primary goals is to raise awareness about the VA SCI/D system of care and the crucial role it plays in ensuring the ongoing health and independence of PVA members. Over the last couple of years, the organization has seen VA health care staffing shortages, a lack of investment in infrastructure and an overall growing trend toward providing care in the community.



Paralyzed Veterans of America (PVA) National President Robert L. Thomas Jr., left, and PVA National Treasurer Tom Wheaton chat during last year's PVA Advocacy/Legislation Seminar.

In light of PVA's ongoing concerns about changes at the VA, an online petition was created to quantify the need to improve funding and support of the VA's SCI/D system of care (votervoice.net/pva/petitions/5455/respond). PVA wants to ensure Congress knows paralyzed veterans are committed to the VA's direct care system.

Thomas testified March 4 before a joint session of the Senate and House Veterans' Affairs Committees regarding PVA's public policy priorities, including opposing dismantling the SCI/D system of care.

He once again stressed the importance of restoring the VA's specialized care services, which are in dire need of adequate funding and staffing, and the vital role that VA-provided care and life-sustaining research play in the lives of PVA members. Thomas noted in his testimony that thousands of PVA members and their supporters had already signed the petition in support of the SCI/D system of care. He also unveiled PVA's 2025 policy priorities, which will guide advocacy efforts throughout the year.

Rep. Cory Mills (R-Fla.), left, meets with Paralyzed Veterans of America (PVA) Central Florida Chapter Executive Director John DeMauro, center, and chapter Government Relations Director Tim Wolf, right, during last year's PVA Advocacy/Legislation Seminar.



While in Washington, D.C., Thomas and other PVA Executive Committee members met with Senate Veterans' Affairs Committee Chairman Jerry Moran (R-Kan.) and Ranking Member Richard Blumenthal (D-Conn.), as well as Bost and House Veterans' Affairs Committee Ranking Member Mark Takano (D-Calif.).

During their visits, PVA leaders expressed concerns about the status of the VA's SCI/D system of care and the effects of current efforts to reduce the size and scope of the federal government on veterans' care and benefits. PVA leaders also discussed the importance of long-term services and supports for veterans with catastrophic disabilities and the need for Congress to ensure proper implementation of the Senator Elizabeth Dole Act. These visits were crucial in moving PVA's priorities forward.

Congress members increasingly want to hear from the individuals who are directly affected by proposed legislation and policies. Now, more than ever, all members and their supporters need to promote PVA's priorities.

PVA looks forward to heading to Capitol Hill this month with members and chapter leaders from around the country, as the organization pushes Congress members to support paralyzed veterans. Advocacy/legislation seminar participants will have the opportunity to explain why Congress should invest in VA care and benefits and defend the freedoms of veterans with disabilities.

Time For Change

PVA's top priority continues to be protecting VA's specialized health care services.

PVA knows the VA is the best care provider for veterans with SCI/D and intends to make sure legislators know paralyzed veterans choose VA care. That means making sure the system is properly staffed.

The VA must be able to hire needed medical professionals and support staff to ensure veterans' care needs are met in a timely manner. Even when facilities can hire needed staff, the VA's bureaucratic hiring practices cause monthslong delays that result in professionals taking jobs elsewhere. This must change.

The VA also must have the resources needed to address infrastructure deficiencies that compromise veterans' care. The average age of an SCI/D center is nearly 40 years. The VA doesn't prioritize projects that support the unique services VA provides that aren't readily available in the community. This, too, must change.

Veterans also continue to encounter disability access barriers at VA facilities and while using VA websites. That's why PVA supports the creation of a Veterans Advisory Committee on Equal Access within the VA to ensure compliance with existing disability laws, such as the Americans with Disabilities Act, the Rehabilitation Act and the Architectural Barriers Act.

The annual Paralyzed Veterans of America (PVA) Advocacy/Legislation Seminar is an opportunity for PVA leaders to meet with congressional leaders.





Paralyzed Veterans of America (PVA) Executive Committee members and leaders attend the annual PVA Advocacy/ Legislation Seminar.

Another critical priority is increasing access to long-term services and supports for veterans with SCI/D. The passage of the Senator Elizabeth Dole Act was a great victory for PVA members. This law will expand access to VA home- and community-based services.

Last year, PVA made sure Congress members knew that veterans with catastrophic disabilities couldn't wait any longer for the bill to pass. Now that it's law, it's critical to make sure there are no delays in improving PVA members' home care situation. Congress must ensure the VA implements the law in a timely fashion.

Lend Your Voice

A couple of priorities didn't make it across the finish line last year, including increased support for housing adaptations and for the families of veterans with amyotrophic lateral sclerosis (ALS).

First, the VA's Home Improvements and Structural Alterations (HISA) grant program hasn't seen an increase in 15 years. During that time, the cost of basic home modifications has

increased significantly. Congress needs to pass legislation that would increase HISA grant rates and tie them to a formula that will raise the rates annually to address increased costs.

Next, PVA supports increased access to additional VA benefits for surviving spouses of ALS veterans. Veterans with ALS often don't live long enough to meet the eight-year requirement for their surviving spouses to receive additional Dependency and Indemnity Compensation. The average life expectancy for a person with ALS is three to five years. PVA supports the passage of legislation that would eliminate this inequality.



Paralyzed Veterans of America's (PVA) chapter leaders and staff learn about PVA's policy priorities during the annual advocacy/legislation seminar.



A new priority is supporting legislation that would increase access to automobile adaptive equipment through the VA's medical benefits package. Transportation remains one of the biggest barriers that many veterans with SCI/D encounter. In 2023, Congress passed legislation to include certain vehicle adaptations in the VA's medical benefits package to ensure all catastrophically disabled veterans can access vehicle modifications.

The list of adaptations that could be provided to veterans inadvertently restricted access to only the specific items listed in the legislation, which wasn't Congress' intent. PVA needs Congress to act to ensure veterans with SCI/D have access to needed adaptive equipment for their vehicles.

Even if you will not be in Washington, D.C., for the seminar, your voice is still needed. Anyone can help advocate for PVA's priorities. PVA needs all members, their caregivers and families to help by letting your senators and representatives know about the importance of VA-provided care and by signing PVA's online petition.

Letting your legislators know how you feel about legislation and what it will mean to you



Paralyzed Veterans of America Bay Area & Western Chapter board member Demond Wilson pushes access forward on Capitol Hill.

and your families will add to PVA's collective voice on Capitol Hill. PVA needs your stories to move priorities forward.

Visit PVA Action Force (pva.org/research-resources/pva-action-force) to advocate on PVA's priorities. It's quick and easy. Read more about PVA's legislative priorities in this month's On the Hill article on page 16.

Heather Ansley, Esq., MSW, is PVA's chief policy officer in Washington, D.C. ■



Rep. Troy Carter (D-La.), right, meets with Paralyzed Veterans of America (PVA) Bayou Gulf States Chapter President Rev. Julius Lee during last year's PVA Advocacy/Legislation Seminar.

COURTESY OF ABILITIES EXPO



Abilities International Accessibility Conferences will be held alongside Abilities Expos in Long Beach, Calif., New York and Chicago.

Accessibility Conferences

Raccoon Media Group, organizers of the long-standing Abilities Expo held annually in seven major cities across the U.S., will launch a series of Abilities International Accessibility Conferences in 2026.

The two-day conferences will bring industry professionals in the disability sector together to enhance professional practice and business through education, networking and thought leadership. The events will take place in Long Beach, Calif., along with New York and Chicago.

Working in partnership with a number of industry-

recognized organizations and associations, the three-tier program will focus on delivering insights, expanding market access and driving business growth.

Designed to unite the entire community of disability care providers, service providers and innovative product developers, this conference will be an international platform to network, learn and discover the latest advancements in mobility therapy. Attendees can participate in continuing education sessions and hands-on workshops for practical, real-world knowledge.

Product developers, manufacturers, dealerships and vendors will also have the opportunity to build

alliances through networking and engage in interactive sessions focused on market dynamics, Food and Drug Administration requirements, product distribution and consumer needs.

The Abilities International Accessibility Conferences will sit alongside the existing consumer-facing Abilities Expos.

"Abilities Expo offers those with disabilities, their families and caregivers the chance to get together as a community and discover new products and resources that can lead to more independence and empowerment in their day-to-day lives," Raccoon



Media Group Portfolio Director Katy Roberts says. "As event organizers, we want to expand this mission, bring the wider community together and work with incredible associations and their members to galvanize education, business, distribution and networking opportunities across the sector on a national and international level. By creating this new series of conferences alongside our existing events, we believe we can bring the industry together and ultimately support the

community of consumers we already serve.”

The first Abilities International Accessibility Conference will be in Long Beach in March 2026.

For information, contact Roberts at katy.roberts@raccoonmediagroup.com or visit abilitiesexpo.com.

Neurogenic Bladder Therapy

A modified herpes virus that targets spinal cord nerve cells to treat neurogenic bladder in people with spinal cord injury (SCI) is underway in a first-in-human clinical trial by UTHealth Houston at TIRR Memorial Hermann in Texas.

The therapy is a non-multiplying gene therapy vector, or transporter, which is a modified form of the herpes virus. This vector carries the gene encoding the active part of botulinum toxin, which it will make in the spinal cord to block the sensory nerve signals that result in involuntary bladder contractions. The therapy is named EG110A by its developer, EG 427, a biotechnology company.

“They have modified the herpes virus, which affects nerves, so that it is not virulent and does not multiply and are relying on its innate ability to travel along nerve cells and reside in the sensory cells by the spinal cord. Once the vector

is in place, it will manufacture its medication. It will block the sensory signals in the spinal cord that cause reflexive bladder contractions. This is the science fiction stuff that I dreamed about as an undergrad,” says Argyrios Stampas, MD, MS, lead investigator for the Houston site of the trial and associate professor with the Department of Physical Medicine and Rehabilitation in McGovern Medical School at UTHealth Houston, in a March UTHealth Houston release.

Current treatment with BOTOX for neurogenic bladder requires multiple injections, as many as 30, into the detrusor muscle of the bladder every six months. Preclinical study results showed that EG110A could last for several years.

“When people living with spinal cord injury

are surveyed, bowel and bladder issues are their top priority,” says Stampas, director of Spinal Cord Injury Medicine Research at TIRR Memorial Hermann. “The opportunity to have one procedure that could relieve incontinence for years would be a huge improvement on their quality of life.”

The 52-week, Phase Ib/IIa clinical trial will enroll people from 18 to 75 years old who are at least 12 months post-injury. The trial includes a five-year safety follow-up period. The drug has received investigational new drug clearance from the Food and Drug Administration.

Houston is one of four sites across the country for the study. The others are Rancho Los Amigos National Rehabilitation Center in Los Angeles;

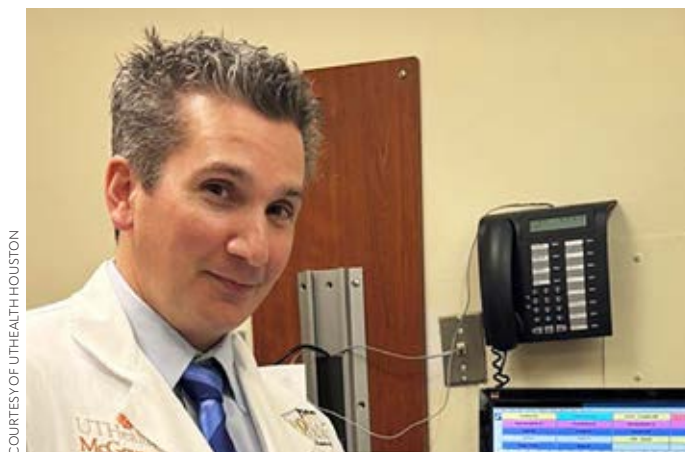
University of Michigan Rogel Cancer Center in Ann Arbor, Mich.; and Sidney Kimmel Medical College in Philadelphia.

Gel To Improve SCI Research

Studying spinal cord injuries (SCI) requires a material that can transmit clear signals yet remain flexible for when patients move around. Researchers at Binghamton University, State University of New York, think they have hit upon a solution that will offer the best of both requirements.

In a published paper in March’s *Nature Communications*, Binghamton University, State University of New York, assistant professor Siyuan Rao, PhD, and her team have created a hydrogel electrode that includes conductive carbon nanotubes to monitor nerve activity. When integrated into bioelectronic devices, the hydrogel enables the recording of electrical signals from spinal cord neurons and leg muscles in mice.

“If you have a rigid material in a soft tissue, especially during movement, it’s going to cause a lot of damage,” says Rao in a March Binghamton University, State University of New York, release. “Our technology solves that fundamental problem, so we can pick up a single cell’s activity



COURTESY OF UTHealth HOUSTON

Argyrios Stampas, MD, MS, leads the Houston site of a clinical trial investigating a modified herpes virus that targets spinal cord nerve cells to treat neurogenic bladder in people with spinal cord injury.

from the spinal cord and maintain the device's functionality for a long time."

The hydrogels used in the research are made from a synthetic plastic polymer that is nontoxic, shows good biocompatibility and has high absorbing capacity. Rao has previously investigated similar hydrogels to inhibit pain using light transmissions.

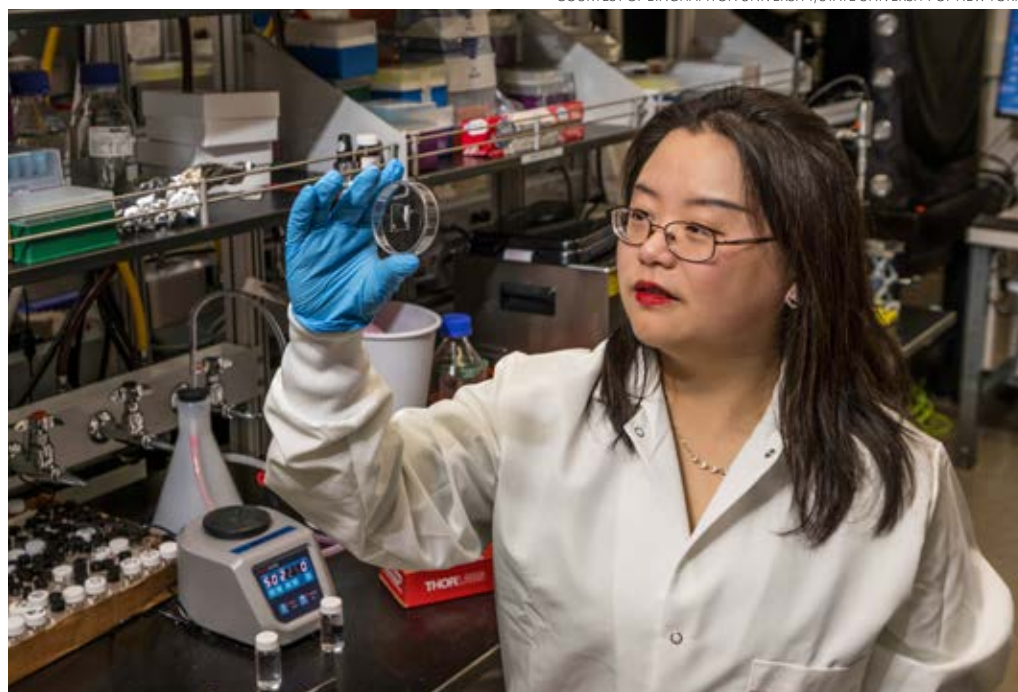
"You can imagine it as a sponge that contains a lot of water and the conductive material, which are the nanocarbon tubes invisible to the naked eye because they're so small," says lecturer Sizhe Huang, PhD. "Those conductive nanomaterials are filling the free space in the 3D network."

Although her previous work focused on the brain, Rao is hopeful that she and her team can leverage their ideas about soft materials engineering to answer questions about the spinal cord system.

"We are strengthening our capability to cover multiple regions of the nervous system," Rao says. "Ultimately, we hope to have an effective tool to probe the different parts of the body and the causal link between the central nervous system and peripheral nervous system."

The next challenge is to research pain inhibition and motor functional recovery in the spinal cord region.

"We specifically want to look at the ventral horn



Assistant professor Siyuan Rao, PhD, from the Thomas J. Watson College of Engineering and Applied Science's Department of Biomedical Engineering at Binghamton University, State University of New York, studies how bioelectronics interface with the brain and nervous system.

motor neurons that control voluntary movement," Rao says. "We will build on our past research to use light to achieve pain inhibition and then use this new conductive material to pick up electrophysiological signals."

Predicting SCI Recovery

By analyzing DNA and proteins in the blood of people with and without acute spinal cord injuries (SCI), researchers at the Johns Hopkins University School of Medicine in Baltimore have developed a novel blood test that has the potential to rapidly predict severity and likelihood of sensory and motor recovery within six months in a cost-effective manner.

Clinicians have long sought a rapid, minimally invasive diagnostic method that confirms injury, sever-

ity and recovery potential. The novel blood test described in a report published in the March issue of *The Journal of Clinical Investigation* may fill this critical gap in care.

"If you have a spinal cord injury, your main question is simple: Am I going to walk again?" says lead study author and neurosurgery chief resident Tej D. Azad, MD, MS, in a March Johns Hopkins Medicine release. "With the new blood test, we are trying to bring a precision medicine framework to spinal cord injury with something that tells you about injury severity and can hopefully predict neurological recovery."

Classically, blood tests have not been considered to offer insights into the spine due to the blood-brain barrier — a protective layer of cells that blocks most viruses, bacteria and other harmful

substances from reaching the brain through the blood. However, researchers hypothesized that SCI causes measurable disruptions in the blood-brain barrier that are potentially detectable in a blood test.

To detect such SCI biomarkers, the researchers built on recent advances in cancer biomarker development, where liquid biopsies of blood detect cell-free DNA (cfDNA) and certain protein levels guide targeted treatments for individual patients while also offering ways to monitor treatment response and disease progression.

Researchers defined the fingerprint of spinal cord DNA using blood samples from 50 patients with acute SCI and 25 patients without injury, of which 68% (51 patients) were male and 32% (24 patients) were female.

The investigators call the resulting blood test the Spinal Cord Injury Index

(SCII). When compared to American Spinal Injury Association (ASIA) scale groups, the results of SCII aligned completely with severity of injury and what would be seen on MRI scans and physical evaluations.

Patients whose blood was used in the study were followed for six months to see if their ASIA grade improved. The SCII effectively predicted with 77% accuracy which patients would show neurologic improvement. This suggests that the new blood test may accurately forecast long-term recovery for most patients, a central focus and

biopsies inform care for cancer patients.

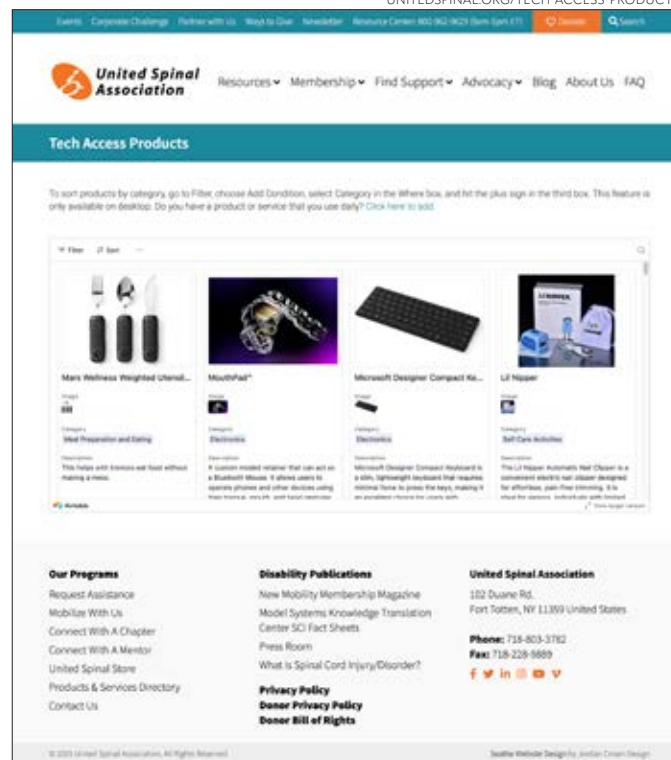
“We are interested in bringing a precision medicine framework to spinal cord injury,” Azad says. “By building this type of blood test, we can begin to sub-stratify these traditional groups, use therapies that may be more beneficial, and for patients who have most severe injury, we can expedite getting them into clinical trials.”

This multi-analyte blood test is a promising step toward next generation diagnostics for SCI and personalized medicine in traumatic injury. Senior study author Chetan Bettegowda, MD, PhD, says further studies are required, as the team is now hoping to test the blood markers in multicenter clinical trials and study ways to improve the performance.

Disability Product Guide

United Spinal Association has launched its digital Tech Access Product Guide, a crowdsourced database of products designed to make life easier for people with physical disabilities, ranging from spinal cord injuries to age-related arthritis.

The product guide offers something for consumers from all backgrounds within the disability community. Users are encouraged to contrib-



ute reviews and reflections on products they submit to the database, making the guide both a unique handbook and a barometer of market sentiment.

Guide highlights include:

- **Meal prep and eating:** Electric can openers, easy-to-hold utensils and adaptive cutting boards are a few of the featured tools to make cooking and eating easier.
- **Electronics:** Gamers will find a collection of controllers and adaptive computer mice. Also featured are ergonomic keyboards, phone holders and charging stations.
- **Home management:** Smart thermostats, voice-controlled devices and keyless-entry smart locks may make your home safer and under your control.

- **Recreation and leisure:** From a nail holder for a hammer to crafting tools, this category is the place to search for items to make hobbies easier and more enjoyable.

The guide also gives special attention to wheelchair accessories, wheelchair add-ons, mobility aids, self-care and mobility aids.

The product guide is the latest contribution from United Spinal's Tech Access Initiative, which now has five years of experience advocating for the rights and interests of consumers with mobility disabilities in the tech industry and representing the disability community's voice during all stages of the product development process.

To see the guide, visit unitedspinal.org/tech-access-products. ■



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concern for patients with SCI and their caregivers.

Researchers say using the SCII to monitor these biomarkers over time could further assist in measuring the effectiveness of treatment options and inform personalized care, as liquid

More For Murphy

Michael Murphy took both of Paralyzed Veterans of America's Citrus Slam Bass Fishing Tournament Bank Division titles April 4–6 on Lake Tohopekaliga in Kissimmee, Fla.

Murphy (Shelbyville, Ky.) took the April 5 Individual Bank title with 1.59 pounds — just edging out Russell O'Bannon (Ballwin, Mo.) by .02 pounds and Susie Lane (Balch Springs, Texas) by .26 pounds. Later, he won the April 6 Bank Team Competition title, as he and Robert

Avery teamed together for 4.57 pounds, defeating O'Bannon and Charles Hampton, who had just .11 pounds.

Meanwhile, Paul Julian won the April 5 Open Division title, catching 15.48 pounds to beat Arthur Hunt (14.29 pounds) and Mike Bidrfruent (11.42 pounds). In the April 6 Open Division Team Competition, angler Mark Boyd and boat partner John Brown teamed up for the title with 16.25 pounds, defeating Julian and boat partner Joseph Caldwell (15.77 pounds) and angler Tony Choe

and boat partner Brandon Pabon (15.08 pounds).

For full results, visit pva.org/sports-recreation/bass-tournament-series.

Florida Bowling

Henry Walters, Debra

Freed, Dawn Varvaro and Kyle Kennon each won Paralyzed Veterans of America Florida Gulf Coast Bowling Tournament titles at the Feb. 19–21 tournament held in Tampa, Fla.

Walters took Division A, while Freed won Divi-

sion B and Varvaro took the Stand-Up Multiple Sclerosis Division. Kennon won the Scratch Division, defeating Dave Nelson and Kurt Wolff.

Grunts Take Military Division

The San Antonio Grunts

held off the Bridge2Sports SharpShooters' late surge and secured their first National Wheelchair Basketball Association (NWBA) Military Division national title.

Juan Soto and Blake McMinn scored 27 points



NANCY MYERS-SCHOLZ

The San Antonio Grunts captured the National Wheelchair Basketball Association Military Division national title April 27.

apiece to lift No. 2-seeded San Antonio to a 68-63 win over top-seeded Bridge2Sports on April 27 in the NWBA Military Division wheelchair basketball championship game at the Plassman Athletic Center at Turnstone in Fort Wayne, Ind.

After knocking off the Military Division tournament's defending champ, the Wolfpack Vets, in the semifinals, the Grunts built a big second-half lead and then survived.

Soto went 10-of-15 from the field and hit 7-of-8 free

throws and was named the Military Division's championship game MVP.

This marked the first year the Military Division was officially part of the NWBA's Championship Series.

San Antonio led 58-42 with 8 minutes and 42 seconds left in the fourth quarter and seemed to be cruising along. But the SharpShooters nearly rallied all the way back. They went on a 20-6 run, with Antoine Gray and Jesse Lind scoring six points each during it, to cut the deficit

down to 66-63, with 31.4 seconds remaining.

But the Grunts' Charles Armstead hit two free throws with 5.2 seconds left to push San Antonio's lead back up to five and give them the win.

The Military Division tournament MVP, McMinn had the hot hand early, scoring eight of the team's first 16 points and had 13 points at halftime. He finished 13-of-21 from the field and had a double-double with 12 rebounds. Armstead finished with six points and four rebounds, Jason

Rainey added four points and four rebounds and Anesi Tu'ufuli had four points and a rebound for San Antonio.

Gray led the SharpShooters with 18 points and had four rebounds, while Lind had 15 points and four rebounds. Joe Wittkamp (10 points and one rebound) and Tee Foster (10 points and four rebounds) also scored in double-digits, while Freddie Smith (six points) and Justin Knowles (four points and 10 rebounds) contributed. ■

NANCY MYERS-SCHOLZ



The San Antonio Grunts' Juan Soto, with ball, was named the Military Division championship game MVP.

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SHAWN INTERRANTE

Bret Clifton and Stephen Keenan each won Paralyzed Veterans of America (PVA) 9-ball titles at the PVA 16th annual Sooner Shootout on April 10–12 at Slick Willie's Family Pool Hall in Oklahoma City. Clifton won the Main Event title over Charles Interrante, while Keenan took the Second Flight title over Adam Lane. Keenan is shown at right in the top photo, with PVA Mid-America Chapter Vice President Shawn Tracy, center, and Lane, left. Clifton, shown at left in the bottom photo, is pictured with Tracy, center, and Interrante, right.

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Dependent Benefits

When it comes to veterans benefits, a lot of focus is placed on the assistance and assets available to the actual veteran, but there's also plenty of help in place for a veteran's dependents.

vides both children and spouses with up to 45 months of support.

This benefit can be used for a variety of training, including college degree programs, cooperative training in a full-time program, certificate programs, apprenticeships, on-the-

tion benefits for veterans with a permanent and total rating by providing a 20-year period of eligibility to spouses effective within three years of the veterans' release from active duty.

For additional information on this benefit, visit gibill.va.gov.

Health Care

Assistance covering the cost of health care is available to qualifying dependents through the Civilian Health and Medical Program of the Department of Veterans Affairs (CHAMPVA).

A cost-sharing program, CHAMPVA helps share the cost of certain health care services and supplies with dependents. The program provides assistance after other health insurance plans, including Medicare, have been used.

There are several eligibility factors for a spouse or child of a veteran who has been rated permanently and totally disabled for a service-connected disability or a surviving spouse or child of a veteran who passed away from a VA-rated service-connected disability.

A spouse, surviving spouse and/or a child's eligibility for CHAMPVA can be impacted by changes in marital status, if they're eligible for Medicare or the active duty TRICARE health care program, or by a child's student status between ages 18 and 23.

For more information, including a CHAMPVA handbook, visit va.gov/family-and-caregiver-benefits/health-and-disability/champva.

Home

Financial help with the mortgage on a family home is available to dependents in the event of a veteran's death.

The Veterans' Mortgage Life Insurance (VMLI) program provides coverage equal to the mortgage still owed, with a maximum benefit not to



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If you're a veteran who has a 100% service-connected disability that's permanent and total, your dependents are eligible for quite a few benefits that range from education assistance to help with health care expenses to home loans.

Education

One such benefit is financial help for qualifying dependents attending college, undergoing vocational training or other educational pursuits.

The Dependents' Educational Assistance Program (DEA), also known as Chapter 35 education benefits, pro-

vides both children and spouses with up to 45 months of support.

The eligibility period for dependent children is from 18 to 26 years old. Their eligibility isn't affected if they get married during that same time period.

For the veteran's spouse, benefits generally end 10 years from the effective date of the veteran's permanent and total disability or the date the Department of Veterans Affairs (VA) notifies the veteran of the permanent and total disability.

There's a provision under Public Law 110-389 that amended VA educa-

exceed \$200,000. The benefit is payable only to the mortgage holder.

Veterans must apply for VMLI before their 70th birthday. This benefit has a monthly premium that's paid



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by the veteran and determined by the amount of the remaining mortgage balance.

VMLI is only available to service members and veterans who are entitled to the Specially Adapted Housing (SAH) grant to help build, remodel or purchase a home, have the title to the home and have a mortgage on the home.

Home loans may be available to an eligible surviving spouse. The benefits of a guaranteed VA home loan include more favorable terms, no down payment, no private mortgage insurance requirement, payment assistance when times get tough and more.

Survivor Assistance

Dependent benefits in the case of a veteran's death could also include direct financial support for a surviving spouse.

The Dependency and Indemnity Compensation (DIC) benefit is for a surviving spouse whose veteran spouse dies either primarily or contributorily from a service-connected condition.

A surviving spouse may be entitled to DIC if the veteran spouse dies

from a non-service-connected disability but was in receipt of service-connected compensation rated by the VA as permanent and total for a continuous period of at least 10 years prior to death. If a veteran is rated at 100% for Individual Unemployability for 10 years prior to death, the surviving spouse may be entitled to DIC, as well.

For help with this or any benefits questions, contact your local Paralyzed Veterans of America (PVA) national service officer (NSO) from the roster on page 25.

The author utilized information from public sources such as va.gov, login.gov and id.me in the composition of this article.



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A Navy veteran, Tami Anderson is a senior NSO in Minneapolis and has been with PVA since 2008. ■

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EVENT

February 2025

Bayou Gulf States Bocchia Tournament	February 1-2, 2025	Gulfport, MS
Central Florida Air Gun Tournament	February 8-9, 2025	Orlando, FL
PVA Wheelchair Rugby Invitational	February 14-16, 2025	Louisville, KY
Florida Gulf Coast Bowling Tournament	February 19-21, 2025	Tampa, FL
USA Bocchia Regional Tournament - hosted by PVA	February 28-March 3, 2025	Dade City, FL

March 2025

Intro to Paracycling Camp - Stop 1	March 6-7, 2025	Phoenix, AZ
Tampa Pickleball Clinic	March 7, 2025	Tampa, FL
USA Bocchia Regional Tournament - hosted by PVA	March 7-9, 2025	San Antonio, TX
Mid-Atlantic Billiards Tournament	March 14-16, 2025	Midlothian, VA
PVA Wheelchair Basketball Camp & Invitational	March 19-23, 2025	Colorado Springs, CO
Wisconsin Air Gun Tournament	March 21-22, 2025	Racine, WI
Bayou Brawl Bass Tournament	March 28-30, 2025	Westwego, LA
Wheelchair Football Camp	March 28-30, 2025	Tampa, FL

April 2025

Citrus Slam Bass Fishing Tournament	April 4-6, 2025	Kissimmee, FL
USA Bocchia Regional Tournament - hosted by PVA	TBD	San Diego, CA
Pocahontas Off-Road Spring Camp & Off-Road Classic	April 9-13, 2025	Chesterfield, VA
Mid-America Billiards Tournament	April 10-12, 2025	Oklahoma City, OK
Bluegrass Bash Bass Tournament	April 11-13, 2025	Kuttawa, KY

SCHEDULE 2025

April 2025 | Continued

National Air Gun Camp	April 14-18, 2025	Centreville, VA
Salt Lake City Pickleball Clinic	April 24-25, 2025	Salt Lake City, UT
Texas Bowling Tournament	April 30-May 2, 2025	San Antonio, TX

May 2025

Puerto Rico Boccia Tournament (Year-end event)	May 2-4, 2025	San Juan, PR
Land of Lincoln Bass Tournament	May 2-4, 2025	Whittington, IL
Intro to Paracycling Camp - Stop 2	May 8-9, 2025	Salt Lake City, UT
Texas Trapshoot Tournament	May 9-11, 2025	San Antonio, TX
Intro to Paracycling Camp - Stop 3	May 21-22, 2025	Milwaukee, WI
Vaughan Trapshoot Tournament	May 23-25, 2025	Elburn, IL
Texas Air Gun Tournament	May 31-June 1, 2025	San Antonio, TX

June 2025

Wheelchair Basketball Camp	June 6-8, 2025	Arlington, TX
Capital Clash Bass Tournament (Year-end event)	June 13-15, 2025	La Plata, MD
Colonial Pickleball Tournament	June 14-15, 2025	Perry Point, MD
Iowa Trapshoot Tournament (Year-end event)	June 20-22, 2025	Cedar Rapids, IA
Grand Teton Outdoor Experience	June 23-27, 2025	Jackson Hole, WY
PVA Bowling National Championship - Great Plains	June 27-29, 2025	Omaha, NE

July 2025

National Veterans Wheelchair Games	July 17-22, 2025	Minneapolis, MN
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NANCY MYERS-SCHOLZ

Hot Hand

San Antonio Grunts player and Army veteran Blake McMinn, right, scored a co-team high 27 points to lead the No. 2 seed to a 68-63 National Wheelchair Basketball Association Military Division title game win over the top-seeded Bridge2Sports Sharpshooters April 27 at the Plassman Athletic Center at Turnstone in Fort Wayne, Ind.

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