

*April 2019*



# **United Spinal Association**

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## ***A message from the CEO:***

I'm looking forward to our Chapter Leaders' call. Lots of action at the national organization level to tell you about—and just as importantly, I am anxious to learn of chapter activities and accomplishments. Two of our chapters—Chicago and Connecticut—have celebrated 40<sup>th</sup> anniversaries. I attended the Louisiana chapter's annual conference, enjoyed it greatly, and was proud of United Spinal's local effectiveness, reach, and representation of people with SCI/D.

As we speak, the Administration is considering ways of reducing the number of people covered by Social Security Disability Insurance, Uber and the other rideshares have begun providing accessible service in some cities, a \$1 billion curb ramp settlement in a class action awaits approval in New York City, and assisted suicide statutes are gaining support in some state legislatures.

At the same time, as chapters involve themselves in advocacy activities, they also provide peer support, recreational opportunities, and the opportunity to participate in wheelchair sports.

It's always a mixed bag. Talk soon.

Yours truly, Jim Weisman

## ***Chapter Membership Lists:***

We sent an email out to each chapter asking that they send us their most current membership list. We do this on an annual basis to ensure that your members become members of the National organization. This will allow them to receive New Mobility magazine, help keep them updated on what the national organization is doing and will keep them better connection to us all.

## ***New Chapters Update: COMING SOON!***

## ***Peer Mentoring:***

We're happy to announce that Hollister, Inc. has generously sponsored our Peer Mentoring program again for 2019! If your chapter is interested in the peer mentoring program and/or scheduling training for this year, please contact me at [lelliott@unitedspinal.org](mailto:lelliott@unitedspinal.org).

## ***Policy and Advocacy Update:***

### **Policy and Roll on Capitol Hill Update**

Of course, it's mid-April and we are in full swing for our 8<sup>th</sup> annual [Roll on Capitol Hill](#). This year, for the Roll, we are focusing on the following two main priorities:

- Advocating for accessible transportation options in the autonomous vehicles/self-driving vehicles space with automobile manufacturers and ride-sharing services
- Maximizing rehabilitation outcomes for individuals with spinal cord injuries and neurological conditions regarding the provision of the appropriate facility setting, team of specialists and correct therapy regimen to ensure the best health outcomes
  - We will be addressing the ACA, of course, as part of this discussion, and the importance of pre-existing conditions protections.

For other updates, the Air Carrier Access Amendments Act of 2019 was just introduced in the House and Senate last month by Senator Tammy Baldwin (D-WI) and Rep. James Langevin (D-RI). United Spinal was a leading supporter of the Air Carrier Access Amendments Act in the last Congress which was signed into law last Fall and sets in place various protections for passengers with disabilities including the creation of an Advisory Committee on the Air Travel Needs of Passengers and increases civil penalties for bodily harm to a passenger with a disability and damage to wheelchairs or other mobility aids. United Spinal continues to ensure appropriate implementation of the Air Carrier Access Amendments Act of 2017. The new law this Congress:

- Strengthens ACAA enforcement by requiring referral of certain passenger-filed complaints to the Department of Justice and establishment of a private right of action;
- Ensures new airplanes are designed to accommodate the needs of people with disabilities by requiring airlines to meet defined accessibility standards. These standards will address safe and effective boarding and deplaning, visually accessible announcements, seating accommodations, lavatories, and better stowage options for assistive devices;
- Requires removal of access barriers on existing airplanes to the extent that it is readily achievable, easily accomplishable, and may be done without much difficulty or expense; and
- Improves the overall safety of air travel for passengers with disabilities.

### **TAKE ACTION**

For the latest advocacy activities on a whole range of issues from emergency preparedness to disability rights protections, please visit <https://www.unitedspinal.org/action-center/>.

### **Grassroots Advocacy Update**

We now have 44 chapters with designated advocacy representatives, with new interest seemingly blossoming now that it's spring. Our goals for grassroots advocacy this year are to get you some great materials that will help both share the basics

of advocacy and what it's all about, but also to help facilitate your chapter's ability to start successful initiatives that further impact change for the better.

2019 has gotten off to an excellent start with chapter advocates across the country sharing their stories and advocating for their communities.

Here are just a few of the exciting chapter advocacy highlights:

Boston Chapter: In January, the Architectural Access Board (AAB) Bill will be reintroduced to both Massachusetts houses. Members of the Boston chapter's advocacy team helped develop and recruit support for this bill which seeks to remove all barriers from workspaces and make housing accessible and adaptable.

Minnesota Chapter: Introduced HF 2100 Spinal Cord and Traumatic Brain Injury Research Grant Program and HF 1166 a bill to establish adaptive fitness access grants that will create access opportunities to the modified equipment, space for access, and skilled trainers needed to modify exercise programs for individuals with disabilities. Rob Wudlick, Minnesota's CAR and North-central RAC attended and delivered the keynote address for NIH's SCI 2020 conference addressing SCI research needs for our community.

Iowa Chapter: Rolled on Des Moines with a team of 17 constituents to encourage support of proposed bills looking to right their state's decision to privatize Medicaid. The team made legislators and their wider community aware of the negative impact privatization has long-term support services for those who require care both in their homes and out in the community.

New York Chapter: Starting in January, the NYC chapter began holding their monthly advocacy task force meetings. Additionally, members have been participating as advisors for the Metropolitan Transit Authority's Fast-forward program to make the subway system in New York more inclusive to individuals with disabilities.

Oregon Chapter: During Salem's legislative Program Initiative Exploration (PIE) days, April 15, the Oregon advocacy team invited members to visit the State Capitol to discuss accessibility in recreation and look for support of a bill they helped facilitate that provides an allotment for improved access to Oregon state parks.

Washington Chapter: A large group of members assembled to roll together for the unveiling of Seattle's newest highway tunnel on SR-99 to create awareness for transportation accessibility challenges in their city.

- If your chapter has been out talking to legislators or decision-makers, let us know. We would love to share your work and connect you with others who may be working on the same issue. In addition, if you need any help planning an advocacy event or want to host a "Roll on Your State Capitol" reach out to: [bmccall@unitedspinal.org](mailto:bmccall@unitedspinal.org).
- We are always looking for feedback, so we will be sending out our 2019 survey to see what you're up to and what everyone needs to grow. Please make sure they are completed.
- In addition, a huge piece of being part of grassroots advocacy is being part of a "network" full of connections.
  - This year, one of our overarching goals is to learn about the legislative and influential connections our members currently hold. You will see a follow-up about this, but if you have a personal, professional, or ongoing advocacy related connection with a legislator, we would love to hear the details. You may be a key connection in the future when we need support on an important issue. Share connections here: [bmccall@unitedspinal.org](mailto:bmccall@unitedspinal.org).

## VetsFirst Update:



*(United Spinal Association Staff with Bronx VA Researchers)*

The last months of winter passed in a blur - lots of exciting events, including a fantastic tour of the James J Peters Veteran Affairs Medical Center in February with Jose Hernandez, the NY Chapter Leader and our CEO Jim Weisman. We were able to see three different types of SCI equipment at work (see pics), and learn about the breakthroughs in research that the dedicated VA SCI researchers are working on.

VetsFirst and United Spinal Assoc is sponsoring the [Ride from LA to DC](#) (#RideForParalysis), which began in LA on March 10th, and will end here in DC on May 15th. Many thanks to the chapter leaders along his route (Rick, Megan, Alison, Gena) who have already provided much support by showing up to events and doing outreach to aid us in bringing to light the challenges faced by the 6 million people in America who have paralysis. United Spinal Assoc chapter members have participated in meet-n-greets, basketball and baseball games, happy hours, and won gym memberships. Over the next month, we have events in TN and Virginia, to include a charity concert, winery event, and scavenger hunt - please let me know if you'd like more information! ([dcorazza@vetsfirst.org](mailto:dcorazza@vetsfirst.org))

In early April, I was proud to join the DC United Spinal Association chapter at Georgetown University for their 2nd annual Wheel 2 Win wheelchair basketball game. Competition was fierce, with over 200 participants, and a great time was had by all. I'd love to see this sort of effort repeated throughout the country - it was a great day for spreading awareness and fostering community connections. Big kudos to Harsh and Dallas for their excellent event!

Last, but not least, we've developed a new outreach information card - it's a 4x6 double-sided postcard of sorts with United Spinal Association information on one side, and VetsFirst information on the other. If you are interested in outreach supplies or materials, or have an event coming up that we could support, please let me know.

Proud to be part of this fantastic team- **Danielle Corazza**, Vice President, VetsFirst



*(Danielle with Harsh Thakkar and Dallas Disbro from the Washington DC Chapter)*

## ***Development:***

Greetings from Development! Our main message is we are working with corporate partners on special offers for United Spinal members! The more members we have, the more offers we can secure to bring you accessible choices and discounts, as well as consumer power!

- Please have your members apply for United Spinal membership <https://unitedspinal.org/join-united-spinal-association/> to receive special offers
  - Remember, United Spinal membership is free and it takes minutes to apply
  - Currently Scootaround and Teladoc offers are included on the membership page (scroll down)
  - Look for more special offers coming soon!
- Please link on your website and schedule social media posts about United Spinal's [Product & Services Guide](#) to communicate to members the many valuable resources available. It's all about choices!  
<https://unitedspinal.org/disability-products-services/>
- **Thank you Michigan Chapters** for members who volunteered April 5 & 6 at Detroit's Cobo Center for a public autonomous vehicle (AV) demonstration hosted by PAVE ([Partners for Automated Vehicle Education](#)). We are working to ensure AV's are accessible as policy and test vehicles are being developed.



Special Announcement – Hot off the press! – Roll Forward Grants for United Spinal

### Members

United Spinal Association and the Permobil Foundation have partnered to offer United Spinal members the opportunity to apply for a *Roll Forward* grant of either a Smart Drive or seat elevator. Awards are limited and will be given based on financial need. In order to qualify you must:

- Be a United Spinal member, membership is free and it takes less than 3 minutes to [apply online here!](#)
- <https://unitedspinal.org/join-united-spinal-association/>
- Applications must be submitted to the Permobil Foundation and approved PRIOR to ordering a Permobil wheelchair. If approved the wheelchair quote will be revised to reflect the donation. The revised quote will be sent to the provider/dealer of the wheelchair. Donation credit cannot be issued if the chair is ordered prior to approval.
- Please email AJ Assaadi @ [aAssaadi@unitedspinal.org](mailto:aAssaadi@unitedspinal.org) for application and FAQ.

## ***New Mobility Magazine Update:***

We've got a lot of exciting stuff in the pipeline over the coming months of New Mobility, and as always, are counting on your input and suggestions to help make the magazine the best it can be.

Here's a for-your-eyes-only peek at some of the upcoming topics we were planning to cover over the next quarter: Airbnb and its impact on accessible travel, the inspiration trap, post-SCI spinal problems and solutions—including syringes, loss of function, and untethering, the new I-Bot and much more.

We're always looking for more people to be featured or involved in bigger stories. If you, or someone you know, might have an interesting angle to be included in one of the stories, please let me know. Likewise, if there's another pressing topic you'd like to see us cover—we're here to listen.

We've had a great run of members featured in our How We Roll column, but we could use some new fresh faces. If someone in your chapter fits the bill, send them our way.

You can always reach me at [iruder@unitedspinal.org](mailto:iruder@unitedspinal.org) or 718-803-3782 ext 7224.

Thanks for everything you do. I'm looking forward to seeing many of you at the Roll on Capitol Hill.

Sincerely, Ian Ruder



## ***Chapter Mentorship Call: “Coming Soon”***

## ***Chapter Leader Facebook Group:***

Let's stay connected!!! Join our **Facebook Chapter Leaders Page!** It's a great way for all of us to stay connected throughout the year. The Chapter Leaders Group is a private group; you must be invited to join. If you're not already a member of the group, please contact Brook McCall at [bmccall@unitedspinal.org](mailto:bmccall@unitedspinal.org) and he will send you a link to be added. We are hoping to use this group as an easy communication platform between leaders – a place to ask questions, share encouraging stories, lend support and guidance as well as post photos and build relationships. Many of you are active already but if you are not we really encourage you to remember this as a valuable tool to find help and support. We'd welcome suggestions to make it even more beneficial to the group.

Please share photos and postings of your chapter events or anything going on with your chapter. This is a great way to encourage other chapters to get involved and learn. It also allows you to showcase the great work you are doing!

## ***‘United on Wheels’ Podcast:***



We're excited to introduce “United on Wheels” our new wheelchair lifestyle podcast covering a wide range of disability topics. Check it out here: <http://unitedonwheels.blubrry.net>

Also, not sure if anyone had forwarded these to you already, but they're informational and I think would be welcomed:

### **Transportation Wheelchair Woes – Speak, Act, Solve**

When you face barriers to transportation, you are likely not alone. Sharing your story puts public agencies and private companies on notice and keeps them aware of issues that need their attention. [Make your complaint count!](#)

### **Tips For Employers On Accommodating Job Seekers with Disabilities**

United Spinal's diverse community of people living with spinal cord injuries and disorders is composed of thousands of talented, career-driven professionals striving for success. Many of these individuals have one thing in common, they found employers who were willing to accommodate their needs so that they could become [valuable members of the workforce.](#)

## ***Opportunities for Chapters and your Members:***

### **Empower Spinal Cord Injury**

Empower Spinal Cord Injury (<https://www.empowersci.org/>) is an intensive, residential rehabilitation program for adults with spinal cord injuries, which combines traditional and non-traditional approaches to rehabilitation to address client's self-directed goals in a supportive, safe environment. Participants reside on-campus and days are filled with physical and occupational therapy, peer mentoring, rehabilitation counseling, adaptive sports and recreation, education, and social outings. After 8 years of programming at Stony Brook University in New York, Empower SCI is excited to announce the launch of a 1-week intensive rehabilitation program at the University of Montana in Missoula, which will take place June 9-15, 2019. Applications for both the Stony Brook University Program (July 14-27), and Montana Program (June 9-15) are available now through May 1st and can be found at <http://www.empowersci.org/applications>. Participation fee is \$1750 for Montana, and \$2750 for the 2-week program in New York, and scholarships are available. Please contact Carrie Callahan with any questions: 315 427 2504.

## North American SCI Consortium (NASCIC)

### Chapter opportunity-Join membership of the [North American SCI Consortium \(NASCIC\)](#)

Individual United Spinal chapters and motivated individuals are greatly encouraged to join the membership of the North American SCI Consortium (NASCIC). Chapters would join as principal members, and have one vote per chapter entity on the direction of NASCIC activities. Also, individuals with SCI can join as Patron Members and also can vote. The North American Spinal Cord Injury Consortium (NASCIC) has the mission to bring about unified achievements in research, care, cure and policy by supporting collaborative efforts across the spinal cord injury community through project-based initiatives.

Please join Kim Anderson-Erisman, Ph. D. and Jen French, MBA for an [NASCIC informational webinar on Jan 10<sup>th</sup> 3-4pm ET](#) to be able to ask any questions you may have about NASCIC membership.

**Principal member**-A consumer-based organization may be a member of NASCIC. The organization must be a registered 501c3(USA), Registered Charity not-for-profit organization or the equivalent in its jurisdiction that directly serves, represents, or advocates for the SCI community whether national, regional, or local. In the event that a participating organization represents the disability community in general, participating NASCIC members must have some direct interaction or related focus on the SCI community.

**Patron member**- Any individual living with a spinal cord injury or directly representing a person living with a spinal cord injury, such as a caregiver or family member, with a main objective of representing themselves and not an organization.

***Supporter content: Coming Soon!***

***Resource Center Update:***

### March 2019 Resource Center-Monthly report

United Spinal Association Information Specialists responded to incoming live phone inquiries, returned voice messages and monitored direct email inquiries entering the Resource Center via web form, other email sources, by phone, from chapters or other staff member referrals.

**March cases closed**

**243**

Closed Help Spot cases by category:

- 01 Abuse & Neglect
- 08 Accessibility
- 10 Adaptive Sports & Recreation
- 05 Benefits & Social Services
- 02 Communications Other
- 02 Employment
- 17 Health & Wellness
- 02 Housing
- 30 Member Services
- 10 New injury cases
- 06 Organization/company Inquiry
- 19 Other, unspecified
- 12 Other, SCI/D Related
- 58 Peer Support
- 01 Publications
- 01 Research & Clinical Trials
- 12 Wheelchair related

**Case of note:**

43-year-old C D in Maine sustained vent-dependent quadriplegia in Aug 2019 in a pool-diving accident and has languished since then in an ICU without the benefit of SCI rehab. Information Specialist staff have worked daily for several weeks to help facilitate the provision of appropriate SCI rehab for CD despite significant resistance from the hospital administration. Efforts continue daily. By the end of March, we had fought back negative efforts and started to see some barriers to rehab weaken. Continued efforts are being made until a positive resolution is had.

***Employment Opportunities:***

We have partnered with many employers who are seeking to hire people with disabilities. Attached and below are some of the current opportunities presented by these companies. Feel free to distribute to your networks. Please be sure to indicate United Spinal in referral field.

CVS –

[https://www.dropbox.com/s/6j6hjjgns46lp7b/CT%20NY%20NJ%20CPA%20CDE%20CMD%20CDC\\_14Jan\\_0422.CSV?dl=0](https://www.dropbox.com/s/6j6hjjgns46lp7b/CT%20NY%20NJ%20CPA%20CDE%20CMD%20CDC_14Jan_0422.CSV?dl=0)

**Mobility Ventures** - <http://www.amgeneral.com/careers/>

**Merck** - <http://bit.ly/NJMERCKde>

**American Airlines** - <http://careers.aa.com/en/ac/careers.rss>

**Pratt & Whitney** - <https://jobs.pw.utc.com/>

***Chapter Reminder:***

You should be working with your Regional Chapter Coordinators to make sure that you have your calendars marked for your bi-monthly regional chapter calls. If you do not have the call dates please reach out to your RCC to obtain them.

Important dates to remember:

- Quarterly Chapter Leadership Calls
  - Wednesday, July 17, 2019 @ 5:00 p.m. eastern time
- Roll on Capitol Hill (ROCH)
  - Washington D.C. – June 23-26, 2019
- Chapter Leadership Meeting (CLM)
  - Las Vegas, NV – October 3-5, 2019



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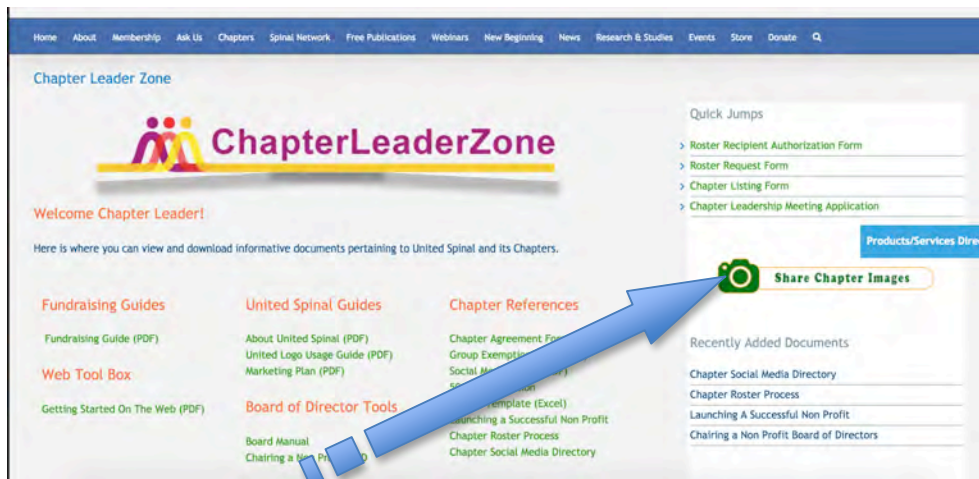
## ***CHAPTER LEADER ZONE WEBSITE:***

In case you have not been to the Chapter Leader Zone recently, we made a change to the website. Please note the change and save the new link.

<http://www.unitedspinal.org/chapterleaderzone/>

**Please send us photos of your events!**

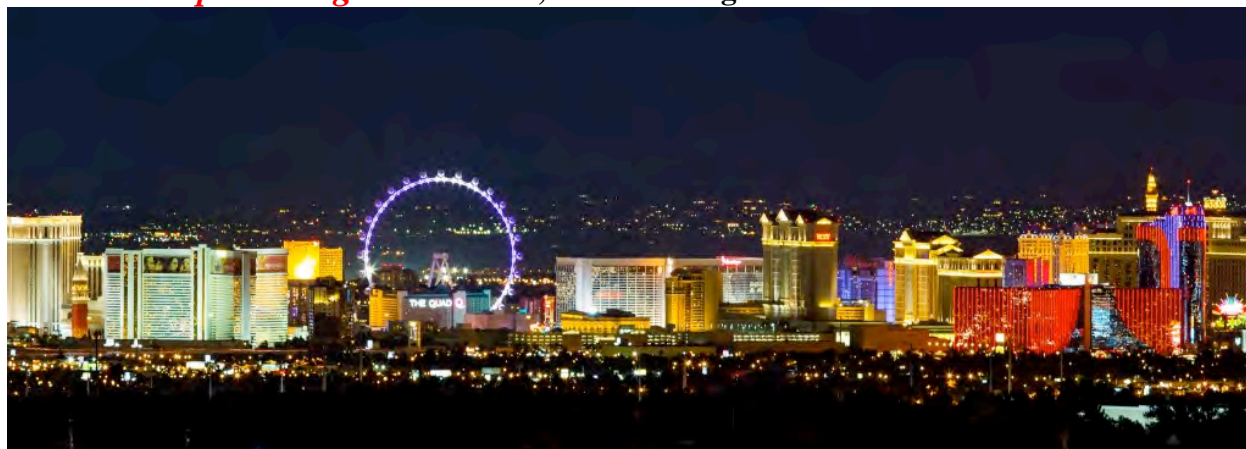
We have created a form on the Chapter Leader Zone for you to quickly upload your photos and add descriptions if you choose.



**Click here to upload Chapter photos**

**Stayed tuned as we are in the process of making enhancements to the Chapter Leader Zone. This is in direct response to some of the conversations that we had at CLM. We plan to create greater resources; these will come from United Spinal Association as well as your peers.**

***Chapter Leadership Meeting: October 3-5, 2019 Las Vegas***



***Technology: Coming Soon!***

***Upcoming United Spinal Association Webinars:***

May 16, 2019: *What rehab is appropriate for SCI and when?* 3:00PM – 4:00PM EDT

Please check the following link for an updated list of webinars: <https://www.unitedspinal.org/webinars/>

***Have a great summer; see you all at ROCH***

