



United Spinal Association

Welcome to United Spinal Associations quarterly Chapter Leadership E-Newsletter

A Message from our CEO:

United Spinal Association now has 50 chapters. Nick LiBassi, Director, Chapter Relations, should be congratulated for the exponential growth. We have over 45,000 members whom we are trying to affiliate with chapters.

Our Resources Center and “Ask VetsFirst” websites and hotlines receive hundreds of rave reviews every month (we ask users to evaluate the service we provide).

United Spinal’s efforts to get Medicaid/Medicare and private insurers to pay for appropriate wheelchairs, equipment and supplies have gained traction in Congress and influenced HHS regulation writers.

Our transportation advocacy continues as it has for 40+ years, and we had great success, particularly in NYC, making taxis accessible and, finally, holding meetings with Uber to discuss their new accessibility sensitivity. Nothing to announce yet, but stay tuned for big developments.

We frequently hear from United Spinal members and chapter leaders about health, access and rights issues. If you are active in your community, we would like to hear from you and assist if we can. If you are not active in your community, you are probably a self-advocate. Use us as a resource, please.

We are here for you!

Sincerely,

Jim Weisman (President & CEO)

CLM Quarterly Call Update:

As many of you know we had our quarterly Chapter Leadership Call on Wednesday, April 20th. If you missed the call you will be able to view the presentation by visiting the Chapter Leader Zone. (This will be posted by April 29th). <http://www.spinalcord.org/chapterleaderzone/>

Our newest Chapters: (Sacramento & Eastern Washington)

Sacramento Chapter of United Spinal Association: (Jeanette and Sonny Ali)



Sacramento Spinal Foundation's goal is to make the road to recovery easier for individuals with SCI. We stay updated on the latest news, advancements, and programs that can have an impact on someone with a SCI. We know that sometimes a simple item or service will enable someone to live a more functional independent life, but financial strains keep it out of reach. SSF helps bridge that gap. We pair individuals with supporters who can help meet their needs. We have fundraisers where we team up with an individual to raise funds for specific items or services, or you can create your own crowdfund. And we provide financial assistance through our Quality of Life Grant program.

<http://sacspinalfoundation.org/>

Eastern Washington Chapter of United Spinal Association: (Betsy Hadden)



The Mission of the National Spinal Cord Injury Association-Eastern Washington Chapter is to support those with spinal related injuries or diseases along with their families by advocating for their rights while serving to motivate and inspire change that will promote overall quality of life. We will provide individualized support and furnish information to afford greater awareness of disabilities, spinal cord research, prevention, purposeful community reintegration, and education.

WELCOME TO THE FAMILY!

Facebook Group page for Chapter Leaders:

Facebook Group for Chapter Leaders

We've created a Facebook group to make it easier for us to communicate directly with chapter leaders and to help facilitate discussions amongst yourselves. The new group is called United Spinal Chapter Leaders and is a closed, invite only group. In addition to serving as a channel for communication, we want this to be a tool to help with your social media efforts. We will share news, opportunities and events that might be of interest to you and your chapters, and we encourage you to do the same.

To keep the group to a reasonable size, we are limiting each chapter to three members. If we need to revisit this later on we can. Look for an invite in your Facebook notifications during the next week and please accept the invite. If you, or one of your fellow chapter leaders, have not received an invite it is probably because we can't find your Facebook profile. Please email Ian Ruder at iruder@unitedspinal.org to get connected.

Policy Update:

As our mission states, United Spinal is dedicated to enhancing the quality of life of all people living with spinal cord injuries and disorders (SCI/D), including veterans and, providing support and information to loved ones, care providers and professionals. So is the case with the policies that we advocate on, such as access to quality affordable healthcare; independent living, employment and self-sufficiency; consumer-directed quality health care and community integration, and the preservation and protection of social security benefits and disability rights.

Our upcoming annual policy conference, Roll on Capitol Hill, our 5th annual is June 26-29, 2016 where we will focus on better access to durable medical equipment and urological supplies, community supports and medical and rehabilitation research as well as adaptive mobility equipment standards for our veterans as well as housing modifications and homebuyer assistance. For more information, visit, <http://www.unitedspinal.org/roll-on-capitol-hill-a-closer-look/> and <http://www.unitedspinal.org/action-center/position-papers/>

VetsFirst:

United Spinal Association's history began in 1946 when a group of paralyzed World War II veterans from New York City and the surrounding area banded together and formed the congressionally chartered Paralyzed Veterans of America (PVA). When United Spinal, formerly known as Eastern Paralyzed Veterans Association (EPVA) chose to leave PVA, they divested themselves of the veteran aspect of advocating for veteran specific health issues. However, United Spinal later chose to return to its roots and advocate for veteran related issues by the creation of VetsFirst (VF). Ask VetsFirst, a VF service that allows all veterans to receive help and advice to navigate the complex VA benefits arena, is but one venue where United Spinal and VetsFirst helps this nation's veterans. VetsFirst also lobbies and informs this country's leaders about the interests of her veterans. In order to better serve our United Spinal Association members, I need your help in identifying your chapter veterans. By identifying our chapter veterans we can accomplish the mission of advocating for spinal cord injuries as well as adding our voice to that of other veteran service organizations that serve all veterans.

Please feel free to contact me directly with any questions.

Ross Meglathery, MPA, Director

VetsFirst, a program of United Spinal Association

Office: 202-556-2076 ext. 7103

E-mail: rmeglathery@vetsfirst.org

Peer Mentoring:

There is no greater support than that of your peers, which is exactly why United Spinal Association's national peer mentoring program is growing in leaps and bounds. Connecting newly injured or diagnosed individuals with others who not only understand their issues but how to overcome them is extremely valuable. It can change someone's state of mind, provide a positive outlook and lead to new opportunities that were never even considered possible.

The goal of the peer-mentoring program is to ensure individuals across the country are connected to the very best resources to help people with SCI/D maintain independent and active lives. The peer-to-peer mentoring is not only provided to people with SCI/D, but also their caregivers and family members, and shares guidance on all facets of living with SCI/D, including: employment, affordable housing, transportation, health care and education. Interested mentors attend a daylong interactive training which includes role-playing and group discussions—focused on how to develop critical mentoring skills such as self-management, goal-setting and problem-solving skills, and effective communication.

We're certainly off to a great start in 2016! To date we've conducted trainings all over the country, including: Houston, Texas; Pittsburgh, Pennsylvania; Las Vegas, Nevada; Boston, Massachusetts; Oklahoma City, Oklahoma; Madison, Wisconsin; Des Moines, Iowa; Rochester, New York; Minneapolis, Minnesota; Raleigh, North Carolina; Richmond, Virginia; and Nashville, Tennessee. A total of 169 mentors have been successfully trained throughout this incredible network. The program has grown and flourished thanks to the generous funding from Hollister, Inc.

We plan on training at several additional sites this year so if your chapter is interested in learning more about the program and/or setting up a training please contact Lindsey Elliott at lelliott@unitedspinal.org and get your training scheduled for 2016!



Affiliated Service Provider Program:

All of the Affiliated Service Provider Program information is now posted on the Chapter Leader Zone.

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

- Content:
 - Program Details (*including payout information*)
 - Find Your Chapter Referral Code
 - Affiliate Service Provider Directory
 - Online Membership Form For Business
 - Flyers for Business
 - Flyers for Public

For questions regarding the ASP program please contact Megan Lee: mlee@unitedspinal.org

General Fundraising Guidelines: (attached as a PDF)

As discussed on our Chapter Leadership Quarterly Call this document was created by AJ Assaadi (Director of Engagement). It was designed to provide an outline to assist in targeting potential sponsors/donors.

- The document contains:
 - Overview
 - Directing your ask to the right person
 - Who makes the funding/sponsorship decision in the company?
 - The “Ask”
 - Sample text

******This is posted on the Chapter Leader Zone******

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

CARS Automobile Donation Services:

United Spinal will be promoting the availability of this program at the national level through our various outreach vehicles (no pun intended).

- CARS will also market and assist our chapters in notifying their donors that you now have this program to support them.

Step 1:

- Donors can either:
 - Call CARS directly to donate their vehicle
 - Or visit the United Spinal dedicated website and complete the on-line form
 - <http://unitedspinal.careasy.org/>
- A CARS donor representative will answer the phone or respond to an online donation directly
 - They will answer any donor questions
 - Complete the required sections in the CARS database.

Step 2:

- The donation will then be reviewed by a live person at CARS.
- After review, the donation will then be sent to the appropriate vendor.
 - CARS works with over 400 vendors across the United States
 - Vendors include direct buyers, public auctions, private auctions, specialty auctions and on line auctions
 - Boat, trailers, RVs, airplanes will take a bit longer for evaluation and transportation.
 - Donors are informed of this.
- The assigned vendor will then contact the donor within 24 hours to arrange pick up around the donor's needs.
- Once the tow company picks up the car, they will give the donor a pick up receipt.

- This receipt has the nonprofits name on it, and if a duplicate is ever needed, they just need to give us a call and we can email it to them.

Step 3:

- Next, the vehicle will be evaluated, repairs can happen and then sold.
- The vendor will mail CARS a check
 - Net amount after vendor costs
 - Average vendor costs for 2015 was \$109
- CARS will process the check and mail your portion of the check out.
 - Direct deposit is another option
- At the same time that CARS mails you your check, your donor will be mailed out their tax information.
 - Under \$500.00 they will receive a tax letter with details of how they can write off this donations for their taxes
 - \$500.00 and over, they will receive a thank you letter along with a 1098c form for their taxes

Finally:

- Any follow up needed, CARS will respond directly
 - Follow up needed might include:
 - DMV Questions
 - Duplicate tax forms needed
 - Etc.

United Spinal Association Finance Department:



Marly (front), Raymond (back), Vincent (right)

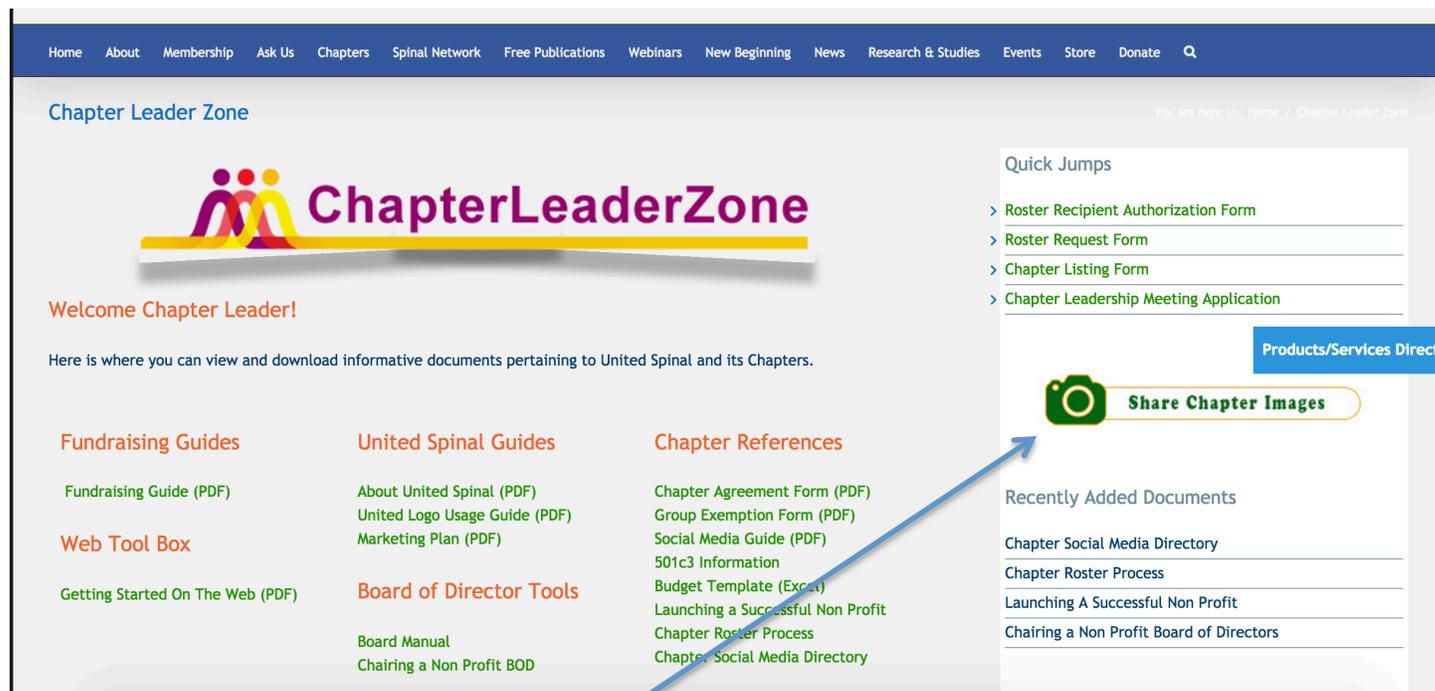
United Spinal Association's finance and accounting team consists of Marly Deonath (VP of Finance and Wheelchair Medic), Raymond Ocasio (Staff Accountant) and Vincent Rozanov. Together they are responsible for the day to day financial activities of the organization including account receivables and account payables, all banking transactions, preparing annual financial statements, creating monthly reports for the Board of Directors, coordinating annual budget audit preparations and preparing end of year financials. In addition they work directly

with all Program Directors in the planning and administration of the organizations financial goals. Lastly they frequently interact with Chapter Leaders to assist in various ways.

Reminder:

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

Resource Center Update:

Since we provided an introduction to our Resource Center Team last newsletter, we thought that you may be interested to see what a typical month statistically looks like in regards to case interactions.

Activity

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 or other email sources such as staff member referrals.

March cases closed 295
Total interactions, all closed cases: 737

Closed cases by category:

- 14 Accessibility
- 13 Adaptive Sports & Recreation
- 03 Benefits & Social Services
- 03 Chapter Contact Info

08	Employment & Education
08	Finances
19	Health & Wellness
07	Housing
41	Member Services
16	New injury cases
58	Peer Support
07	Research & Clinical Trials
06	Wheelchair related

Research Study:

(Please share this information with your members)

United Spinal Association is working with MedStar National Rehabilitation Hospital and Children's National Medical Center to learn more about the experiences of people who use intermittent catheterization and who experience urinary symptoms frequently.

The research team at MedStar National Rehabilitation Hospital, located in Washington, DC (*participants can be located anywhere in the USA*), noticed during a past study that people with bladder dysfunction due to spinal cord injury or disease (SCI/D) had much less Lactobacillus (a 'healthy' bacteria) in their urine, compared with those who didn't have SCI/D.

Study participants will be needed for a period of 18 months. The study has three phases, each lasting 6 months, which require different levels of participation.

- Phase 1: Completion of weekly survey
- Phase 2: Completion of weekly survey and Lactobacillus instillation into the bladder when symptoms occur
- Phase 3: Completion of weekly survey

Researchers hope study results will lead to the development of treatments that will reduce urinary symptoms in people living with SCI/D, while improving their health and quality of life.

Those interested in participating or would like more information regarding the study, should contact Inger Ljungberg, MPH at inger.h.ljungberg@medstar.net or by phone at (202) 877-1694.

Employment Program:

United Spinal is launching a new employment initiative to assist members in navigating the journey to employment. We would encourage you to distribute our webinar archive link <http://www.spinalcord.org/webinar-archive/> to your chapter members to who are considering returning to work to view the recent webinars "*Working with a Spinal Cord Injury*" and the very informative "*Your Pathway to Employment Benefits and Incentives for Working with a Spinal Cord Injury*" as well as sign up for upcoming webinars in the series. We will be expanding our partnerships with employers who are interested in hiring people with disabilities, distributing job opportunities from these employers and assisting with other resources and information during the process. If your chapter has employment related programs or resources we would love to hear about it – please contact Abby Fitzsimmons at afitzsimmons@unitedspinal.org to see how we may be able to assist or learn from what you are doing.

Chapter Leaders Webinars (coming soon):

- Record Keeping / Filing taxes

- Creating a business plan and a budget
- Insurance
- Grants

Special Offers Programs:

Join CouponCabin and Support United Spinal Association

Save money using CouponCabin coupons online at Nordstrom, Office Max, Nike, Macy's and over 3,000 more popular stores and your savings will be donated back to United Spinal. [Follow this link to get started!](#)

***Physical link should you need it: <http://refer.couponcabin.com/s/mp4o6>

Scootaround:

Scootaround's DNA Program – Please join, it's FREE, and spread the word!

As a part of United Spinal membership, Scootaround is exclusively offering United Spinal Members its FREE DNA service. Sign-ups have been slow going and we'd appreciate your help to enroll if you have not already and encourage your chapter to do so as well. Scootaround's Disability Number Assistance (DNA) program allows you to store your personal assistive equipment information in a secure database that can be accessed from anywhere you have a telephone or an internet connection to help streamline repair claims, warranty details, and more. DNA is a must have if you're planning air travel anytime during the year. See link to sign up and details to follow outlining the program. If you have any questions about the program or need additional information please contact: Samantha Gorlick, sgorlick@scootaround.com

<http://www.scootaround.com/loyalty-programs/scootaround-dna>

Scootaround DNA includes:

Centralized Equipment Information - DNA allows you to register any or all of your mobility equipment complete with make and model numbers, serial numbers, and other essential information. In the event of damage, warranty repair requirements, or other issues with your equipment you will have full and easy access to your information - even if you are far from home!

Simplified Airline Repair Claims - If you travel with your equipment, DNA is for you! Scootaround handles repair claims for over 30 airlines worldwide - including North America's largest carriers. In the event of travel damage, a great deal of time and expense can be saved by simply providing the airline representative with your ENGAGE identifier when you notify them of damage or loss. Scootaround airline claims coordinators can then greatly speed up parts orders and assessments by having all the information on your equipment at their fingertips - resulting in faster repair and less inconvenience during your trip!

24/7 Access to your DNA Information - The DNA interface is user-friendly and offers easy access anytime you need to view or change your profile. As long as you have an Internet connection, your equipment DNA is a click away.

Secure Information Storage - All equipment information is stored with 128bit encryption in a secure location. No credit card numbers are required or stored.

Coming Soon:

A copy of this newsletter will be posted to the Chapter Leader Zone