



*Welcome to United Spinal Associations Quarterly Chapter Leadership E-Newsletter*

***A Message from our CEO:***

We are proud to have just completed our fifth annual Roll on Capitol Hill. United Spinal Members from thirty-three states (including Hawaii) as well as the District of Columbia and Puerto Rico attended, as did United Spinal's Board of Directors. Chapter advocates made well over two hundred visits to Congressional offices.

We are making steady progress in our battle with Uber and other Transportation Network Companies.

The number of United Spinal Chapters has increased to fifty thanks to the hard work and organizing skills of Nick LiBassi and growing interest in affiliating with United Spinal expressed by wheelchair users from all over the country.

New Mobility continues to be the nation's leading publication by and about wheelchair users and Ian Ruder provides coverage of chapter activities. I encourage chapter leaders to contact Ian with chapter news and insights.

We are all looking forward to our Chapter Leadership Meeting in October in Las Vegas, Nevada.

See you there,

Jim

***CLM Quarterly Call Update:***

As many of you know we had our quarterly Chapter Leadership Call on Wednesday, July 20<sup>th</sup>. If you missed the call you will be able to view/listen to the presentation by visiting the Chapter Leader Zone. (This will be posted by August 1st). <http://www.spinalcord.org/chapterleaderzone/>

***Our newest Chapters:***

- Scott Porter – Orlando Chapter
- Chris Salas - San Antonio Chapter
- Kimberly Hill & Kathleen Mulvihill – New Chapter Leaders for Louisiana Chapter

**San Antonio Chapter of United Spinal Association:** (Chris Salas)



Christopher Salas, 41, is from San Antonio, Texas. He was injured in 1997 from a motor vehicle accident and is now a C5 incomplete quadriplegic. He has been mentoring newly injured SCIs for the past 15 years as well as fighting for disability rights that entire timeframe. He was a member of Phi Theta Kappa honor society in college and worked for the local community college district as a consultant making all 5 campuses more accessible for all.

Chris also serves as an official peer mentor for the Christopher Reeve Foundation, as well as a guest professor for two of the local colleges. He provides real world application to the info future therapists have learned and will use on patients. His main focus nowadays is Rolling Inspiration, a nonprofit organization dedicated to helping individuals with SCIs and other neurogenic disorders. The first meeting had 4 individuals including Chris but has blossomed to over 40 members plus hundreds of virtual members and has no signs of stopping in sight. It is now the largest group of its kind in South Texas. Their mission is dedicated to improving the quality of life for people with spinal cord injuries and other disabilities. Through fellowship and community reintegration activity programs, they share knowledge and build confidence to show those affected with disabilities that a meaningful, productive life is still possible.

Rolling Inspiration also challenges individuals to stop existing and start living. Chris enforces that challenge be doing various group outings. Those outings include anything from trips to the rodeo, the zoo, as well bowling tournaments, waterskiing and surfing. Those outings are 100% free for individuals and their family members, thanks to grants and donations.

Some of Chris' honors include volunteer of the year, being inducted onto Warm Springs Wall of Fame, also Morgan's Wonderland's Walk of Fame, featured in many articles, newspapers and TV news segments. Rolling Inspiration has also been recognized as United Way group of the year.

Chris is excited to be partnering up with United Spinal and not only be Founder and CEO of Rolling Inspiration but also President of United Spinal San Antonio. He is confident that the pairing of the two will make South Texas a model for programs that every city or region should mimic in order to make this country as user friendly as possible for those with disabilities.

To contact Chris, you can email him at [chris@rolling-inspiration.org](mailto:chris@rolling-inspiration.org).

**Louisiana Chapter of United Spinal Association:** (Kimberly Hill & Kathleen Mulvihill)



Kimberly Hill, MS, CTRS, CCT, is the Director of Outreach and Resources who brings a wealth of professional and personal experiences to her position. She provides a deeper understanding and personal perspective to her role as the mother of a child who survived a spinal cord injury and as a relative to a close family member who sustained a traumatic brain injury. Drawing from these experiences, Kimberly feels compelled to share hope, compassion and understanding with others who have experienced similar challenging situations in their lives.

After completing undergraduate school at Louisiana State University with a degree in General Studies with emphasis in psychology, communications and marketing, Kimberly received her Masters of Science degree in Therapeutic Recreation from the University of South Alabama. She is a nationally board Certified Therapeutic Recreation Specialist as well as a Certified Cognitive Therapist. Kimberly's work experience includes inpatient rehabilitation where she worked with both neurologically and orthopedically impaired patients, private practice working with developmentally disabled children, inpatient geriatric psych hospital working with the elderly population and lastly, Kim worked for many years in outpatient and residential brain injury rehabilitation as a therapist and case manager.



Kathleen Mulvihill is the new Director of Development at the Brain Injury Association of Louisiana/United Spinal Association/LA Chapter. She is responsible for attaining foundation and corporate support as well as major gifts from individuals.

She has a 12-year track record of successful advocacy and fundraising for nonprofit organizations and universities. A native of Boston, Massachusetts, Kathleen returned in 2016 to New Orleans, where she had lived previously for over two decades. She worked in various development roles in the greater Boston area for organizations such as the University of Massachusetts Medical School and American Red Cross, as well as an art therapy nonprofit. Some of her areas of expertise include grant management, donor relations and stewardship, strategic planning, advocacy and medical science.

She has a BA in Journalism/minor in Philosophy and was a Fellow at Loyola University's Institute of Politics in New Orleans. Her previous career was in the news business where she worked in the Los Angeles, New Orleans and Boston markets. Kathleen's personal work/life ethic is: *Strive for excellence and expect extraordinary results without thinking you deserve them.* Kathleen is delighted to be part of the Brain Injury and Spinal Cord Injury team and looks forward to assisting in elevating the organization to new levels of excellence.

## **WELCOME TO THE FAMILY!**

### ***Facebook Group page 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](mailto:iruder@unitedspinal.org) to get connected.

### ***Policy Update:***

It was great to see so many of you at United Spinal's 5<sup>th</sup> annual Roll on Capitol Hill which took place in Washington, DC, June 26-29, 2016 where 150 wheelchair users, clinicians, partners and disability advocates from 33 states, plus Puerto

Rico and the District of Columbia (we beat our own record this year by having the best representation of chapters with the highest number of states and territories represented) attended over 200 meetings with Members of Congress and Congressional staff and advocated on improved access to CRT and urological and ostomy supplies, community supports and independent living and medical and rehabilitation research and data collection at the National Institutes of Health as well as adaptive mobility equipment standards for our veterans as well as housing modifications and homebuyer assistance. Thanks to all your hard work, we have gained 9 cosponsors on the full CRT bill (both House and Senate), 14 new cosponsors on the CRT components bill, (both House and Senate), 3 on the Neurological Diseases Bill (both House and Senate). We now have a House companion bill to S. 2427, the Disability Integration Act which was one of our asks at ROCH, Rep. Chris Gibson (R-NY 19) introduced HR 5689, the House companion bill to S. 2427 and good news around better coordinated research at the National Institutes of Health with more Hill visits with United Spinal and others occurring next month and funding increases approved at the U.S. Department of Health and Human Services which includes the National Institutes of Health's funding for research.

See our post-event press release: <http://www.prnewswire.com/news-releases/united-spinals-5th-annual-roll-on-capitol-hill-gathers-wheelchair-users-to-advocate-for-veterans-and-people-living-with-spinal-cord-injuriesdisorders-300292045.html>. For more policy information, visit <http://www.unitedspinal.org/action-center/position-papers/> and <http://www.vetsfirst.org/vetsfirst-advocacy-action-center/> and to join United Spinal's Advocacy Team for alerts and updates, click here: <http://www.unitedspinal.org/newsletter-sign-up/>.

### ***VetsFirst:***

This year's Roll on Capitol Hill event was only my second, but from a VetsFirst perspective I can tell you it was a great success. Both last year and this year, our VetsFirst members were great when advocating before Members of Congress. What made this year better were the many United Spinal members who are not veterans that spread the word about VetsFirst to the various member offices. It was heartening to me that United Spinal members came up to me with points of contact for offices in which I have never met to express an interest in what we are doing. It has been my desire to get a better handle on identifying the veterans in our ranks so that I can better support their needs and effectively advocate on their behalf. Please continue to let your all of your members know about VetsFirst and let me know of local opportunities where we might find ways to work with like-minded organizations.

Sincerely,

Ross

### ***Peer Mentoring:***

We just wrapped up another successful peer mentor training with our New Hampshire United Spinal Chapter. Training was held on June 11th at the Granite State Independent Living Center. We successfully trained another 15 mentors! The training day was full of great information and resources and the mentors were overwhelmingly pleased with the training day!



\*\*\*We still have a few slots available for trainings if anyone is interested please contact me at [lelliott@unitedspinal.org](mailto:lelliott@unitedspinal.org) so that we can get your chapter locked in for 2016!

## *Development Update:*



### **Special Offers Highlighted for July**

**Mobility Ventures- Summer Celebration Sales Event through September 30, 2018** - \$1,000 discount for United Spinal members in addition to discounts of up to \$6,000 on select models. Veterans receive an added discount of \$1,000. <http://www.unitedspinal.org/mv1/>

**urologyHealthstore.com** – is an FDA registered Urological supply company offering a 10% discount for United Spinal members and products ship free in the US. Use coupon code: 'Unitedspinal', <http://providers.spinalcord.org/651/urology-health-store/>

**RapidSOS** – Advanced emergency technology startup offering free access to its 9-1-1 app for one year to United Spinal members. Their app, Haven, sends important 9-1-1 information, which aids in fast emergency response and better situational awareness for first responders. <http://providers.spinalcord.org/638/rapidsos-inc/>

### ***Development Perspective: Spotlight on Membership & Social Media:***

#### **Don't forget to help increase visibility**

National Membership is free membership, New Mobility monthly subscription included, as well as special offers for our members.

**Link for United Spinal Association membership:** <http://www.unitedspinal.org/join-united-spinal-association/>

#### ***Social Media Followers for United Spinal***

Facebook - <https://www.facebook.com/unitedspinalassociation/?fref=ts>

Twitter - <https://twitter.com/UnitedSpinal>

#### ***Social Media Follower for New Mobility***

Facebook - <https://www.facebook.com/newmobility>

Twitter - <https://twitter.com/NewMobilityMag>



### **Mini Membership Campaign**

- Make sure your chapter's leadership; board, and key members are, in fact, members at the national level.
- Send emails and post the membership link on your website encouraging your members to sign up as members of the National United Spinal Association membership *and* be sure to have them "like" United Spinal's Facebook

and Twitter

- Completing the membership application takes less than 5 minutes, it's easy, free, and they will receive New Mobility free every month free, have access to special offers, as well as visibility to content that is empowering.
- Don't forget to schedule email and social media "reminders" or repeat posts to increase membership sign-up
- Identify opportunities to encourage sign-ups in conjunction with events, meetings, and other initiatives

### ***Business Member Champions:***

We thank our United Spinal Association Business Member Champions, each of which has demonstrated their commitment to partner with us in our mission of improving the quality of life for people with spinal cord injury or disease. Click here <http://www.spinalcord.org/champions/> to view a current list of our Business Member Champions - who support our organization and members.

### ***Disability Etiquette Training:***

We will be offering United Spinal's Disability Etiquette curriculum to chapters to use for training opportunities in your community. Our Disability Etiquette publication (available as a pdf here <http://www.unitedspinal.org/disability-publications-resources/disability-publications/>) is the basis for a PowerPoint presentation, which reviews basic tips for interacting with people with various types of disabilities. We believe this can serve as an excellent opportunity for building relationships in your community as well as a revenue source for your chapter. We will provide more information soon including the PowerPoint, script, information on purchasing the publication for trainings, suggested pricing and ideas on local organizations who may be interesting in receiving the training.

### ***Affiliated Service Provider Program:***

We encourage your individual Chapter to promote the Affiliate Service Provider Directory <http://providers.spinalcord.org/> in your monthly e-newsletter. Your Chapter will receive \$50.00 for each provider you get to sign up using your individual code. This is a great way to raise money for your chapter while providing our members with products & services that will be valuable to them.

### ***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

### ***New Mobility - Behind the Scenes:***

A colorful, award-winning lifestyle magazine, New Mobility encourages the integration of active wheelchair users into mainstream society with articles on health, travel, employment, relationships, recreation, media, products and more. Ninety percent of its writers live with disabilities, creating a vibrant culture of disability journalism and advocacy within each monthly edition. As the membership publication of United Spinal Association, New Mobility also advances the organization's mission to improve quality of life of people with spinal cord injuries and disorders by highlighting opportunities for peer support and community involvement.



As **publisher**, Jean Dobbs oversees editorial, advertising sales, circulation, production, web presence, e-newsletters and social media. She also art-directs the covers and works “in the trenches” on editorial and design.



As **editor**, Tim Gilmer shapes the print magazine, assigning articles, working with writers, and content editing. Recently, he began sharing these duties with the other editors, in preparation for retirement.



As **managing editor**, Josie Byzek collects art for the magazine and liaises with the graphic designers (Deanna Fike and Jean Dobbs) to facilitate the layout and proofing process and keep the publication on schedule. Josie also serves as web editor and social media manager for NM. She recently started editing whole print issues, as Tim does.



As **senior editor**, Ian Ruder copy edits and proofs all articles, writes frequently and recently started editing whole print issues, as Tim does. He works closely with chapter leaders to highlight chapter activities in the magazine and serves as social media manager for United Spinal.



As **circulation director**, Beverly Smith manages mailing lists and addresses the subscription needs of members, subscribers, freelancers, advertisers and colleagues. She works to build the list by acquiring prospect names and marketing NM as a membership benefit.



As **national sales manager**, Megan Lee sells advertising space in the magazine and on the website and e-newsletter, as well as business memberships and backpack sponsorships.



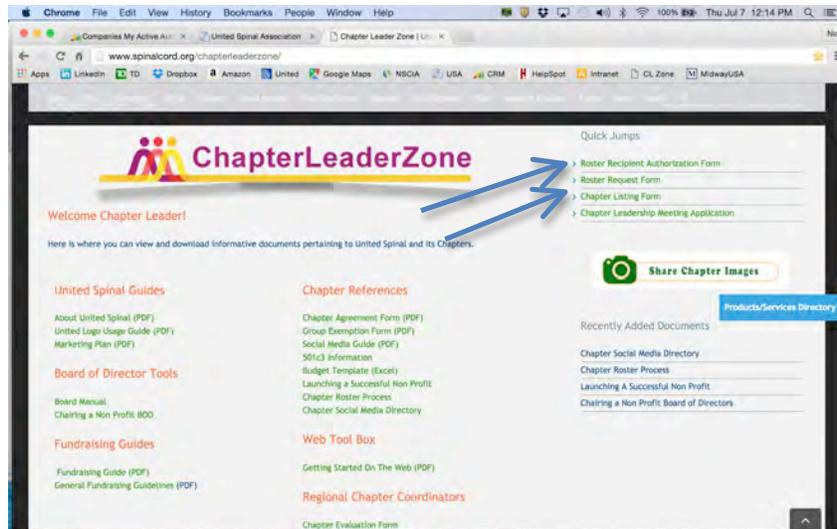
As **graphic designer and production manager**, Deanna Fike lays out parts of the magazine and liaises with the printer to ensure quality production and timely printing of the publication. She does similar work for all other United Spinal departments.

***Reminder:***

If you have not done so already please go to the Chapter Leader Zone <http://www.spinalcord.org/chapterleaderzone/> and complete the Roster Recipient Authorization Form. Once this is submitted and it is approved you may go to the Chapter Leader Zone at anytime and complete the Roster Request Form. This will allow us to send you all of the National Members that have affiliated with your chapter.

- *Please note:* we will only approve one representative from each chapter to receive this information
- Also, once you are approved you will receive emails from National whenever a new member affiliates with your chapter (we will send you their contact info)

*The two blue arrows on the screenshot below indicate where the forms are located*



**Resource Center Update:**

**June 2016 Resource Center-Monthly report**

**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 other staff member referrals.

**June cases closed 322**  
**Total interactions, all closed cases: 819**

Closed cases by category:

01 Abuse & Neglect	58 Member Services
18 Accessibility	14 New injury cases
08 Adaptive Sports & Recreation	19 Organization/company Inquiry
03 Benefits & Social Services	13 Other, unspecified
02 Employment & Education	50 Peer Support
12 Finances	11 Research & Clinical Trials
32 Health & Wellness	13 Wheelchair related
10 Housing	

**Featured Resource Center Case:**

**Case:** Initial Denial of SCI rehab

32-year-old Elisha Wells, blind from birth, living independently and a college graduate slated to begin grad school this fall, fell and sustained a complete T-10 injury. Her hospital PT's and OT's were in the process of investigating her possible SCI rehab at Craig Hospital until the hospital Social Worker stepped in and re-directed her discharge plan to a residential nursing home in lieu of SCI rehab.

She had already had her Medicare in place and New Mexico Medicaid pending when New Mexico Chapter BOD member Frances Ozur-Cole contacted Information Specialists in the SCI Resource Center for assistance with Elisha's case. Initial identified challenges included:

- Thwarting the hospital Social Workers plan for discharge to a nursing home in lieu of appropriate SCI rehab
- Expediting NM Medicaid application
- No substantial family support for Elisha
- Providing basic necessities to Elisha that she needed to begin rehab such as clean appropriate clothing

Initial guidance provided:

- Identify and contact the hospital patient advocate where the girl is right now to halt the discharge to a nursing home.
- Contact her state Protection & Advocacy dept. as needed if patient advocate is insufficient
- Contact Senator Udall's office in NM seeking support and involvement of legislative assistants as needed. (Frances had a prior brief interaction with Senator Udall)
- Contact NM State Senatorial and Representatives offices seeking expedited NM Medicaid for Elisha as co-pay for her medical and DME needs
- Check with local branches of national vision loss advocacy organizations eliciting supports for current and future needs as Elisha proceeds through SCI rehab and transitions to home.

Through the efforts of Frances from our NM Chapter Elisha WAS admitted to Craig Hospital June 16<sup>th</sup> for a projected stay of approximately two months. She reports that Elisha is doing great at Craig as of 7/15/16 thanks to the assistance of all involved in her care.

This is a dramatic example of how our Resource Center Information Specialists and chapter representatives in the field can collaborate. Our Information Specialists are not the 'boots-on-the-ground' as chapter members are. But, we all have our various and multiple areas of expertise to share with chapters to insure that all those living with new or ongoing SCI/D are well served. Do reach out to us via [askus@unitedspinal.org](mailto:askus@unitedspinal.org) at any time or by phone at 800-962-9629, M-F, 9am-5PM Eastern.

### ***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](mailto:afitzsimmons@unitedspinal.org) to see how we may be able to assist or learn from what you are doing.

### ***Chapter Leaders Webinar:***

We have released the first in a series of four webinars specifically created for our Chapter Leaders. You may view the first webinar titled "Chapter Leadership Primer on Risk and Insurance" stored on the Chapter Leader Zone located near the bottom in the webinar section. <http://www.spinalcord.org/chapterleaderzone/>

Be on the lookout each month through October, as we will be adding a new webinar with various topics to the Chapter Leader Zone. We hope that they are beneficial to you!

### ***Coming Soon:***

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