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FROM THE CEO

By Vincenzo Piscopo

AN ANNIVERSARY TO CELEBRATE, A TIME TO LOOK FORWARD

As I wrap up my first year as the president of United Spinal Association, I've been thinking about where the organization is and where we need to go.

On the heels of 75 years of advocacy and community building, there is a lot to celebrate. It's no stretch to say that our community would not be where it is, and would not enjoy the freedoms it does today, if not for the efforts of our predecessors.

We have every reason to be proud of all we have accomplished and celebrate our victories, but only if we acknowledge that we are not where we need to be. There is still a lot of work to be done.

The Americans with Disabilities Act changed the way the world thought about disability, but it alone couldn't stop discrimination against people with disabilities. Thirty-one years later, we're still not always included. We still don't have the same access and opportunities that mainstream society enjoys.

The ADA was a big step, but it cannot be the only step. The ADA got us from point A to point B, but we need to get to point Z. We need to build on what we as an organization have accomplished in our first 75 years and start thinking about and fighting for ADA 2.0. We need to push beyond where we are to true inclusion and equality.

Getting there isn't going to be easy. We won't get where we want to go by going alone or being divided. United Spinal is perfectly positioned to unite all of the stakeholders and lead this effort. With our 49 chapters, 59,000 members and our extended hospital and corporate networks, we can reach farther and speak with a more diverse and authentic voice

than any other SCI/D organization.

Now, more than ever, we need to coordinate our efforts. We need to identify our allies and stakeholders and motivate them like they've never been motivated before. We can be the spark that ignites the broader disability community *and* the vision that helps guide it. We can bring together our members, staff, and corporate partners to make the changes we want and need, both nationally and locally.

Equality and inclusion are two of the biggest buzzwords in society right now, but it's up to us to challenge everyone who claims to champion these goals. We have to ask legislators, companies and our friends, family and neighbors if they really want to be inclusive. We have the ability to hold them accountable and show them the steps they actually need to take if they truly want to make the world accessible and equal for people with disabilities.

As an organization, United Spinal has been doing this since its inception in 1946. As members and disabled people, we do it all the time — our advocacy can be as simple as explaining the need for disability parking to a friend or as complicated as working with elected officials to pass legislation.

So, as we take time to celebrate United Spinal's 75th anniversary, let's use this historic moment to reflect, re-energize and refocus. We are better positioned and more committed than we ever have been to lead the rolling revolution, and we're counting on your support to help us bring about a world where people with disabilities are truly equal and included.

Register for United Spinal's free 75th Anniversary Gala at unitedspinal.org.



BULLY PULPIT

By Ian Ruder

SCI FAMILY WEDDING

While putting together the content for this special issue, I reflected on my time at United Spinal Association and everything that has changed since I started. As I think about all the people I've met, the progress made by the organization and the future that lies ahead, I inevitably come back to the first organizational event I attended way back in October 2011.

A few months earlier, United Spinal had completed its merger with the National Spinal Cord Injury Association. The Orlando



Leaders from NSCIA chapters met with United Spinal staff in 2011 following the merger of the two organizations.

gathering was billed as a chapter development workshop, but it was really an opportunity for leaders from NSCIA's network to meet face to face with United Spinal's new blended staff and leadership.

Like two families meeting each other for the first time at a wedding, the vibe was ... awkward. The longtime United Spinal attendees huddled in one corner of the lounge while the NSCIA leaders tried to gauge their intentions from afar. And both sides wondered exactly what they were getting into.

I was only six months into my gig editing a new membership magazine for the merged organization, and I had never met anyone from either part in person. I'd endured two lengthy flights, and a hellish connection to get to Orlando and arrived only to find the airline had mangled my power chair. Instead of worrying about making a good first impression on my new boss and

co-workers, I struggled to stay upright and drive straight, with a luggage strap barely keeping me from falling out of my chair. It wasn't exactly the image of a "strong, active wheelchair user" I'd hoped to project.

United Spinal's then-president Paul Tobin calmed my nerves by introducing me around and reassuring me that most of the people there were just as unsure of what to do as I was. Over the next three days, I listened in as everyone got to know each other and hashed out what the newly merged organization would look like.

I remember some grumbling from the longtime NSCIA chapters about branding and uncertainty about how the chapters fit into United Spinal's plans, but everyone was civil. We were all there for the same reason: to improve the lives of people living with spinal cord injuries and disorders.

Ten years later, this goal still drives every part of United Spinal, including New Mobility. The merger is ancient history, but staple programs like the Resource Center and VetsFirst remain strong, while new programs like the Tech Access Initiative and the Peer Mentoring Program are helping community members all over the country.

The awkward meld of families has evolved into a flourishing home. While the SCI/D community is likely one of the few families where you don't actually want to add new members, knowing that United Spinal provides a welcoming option when newcomers inevitably join is essential.

From this observer's chair, that option is stronger than ever, thanks to the hard work of my colleagues and all the inspired chapter leaders across America. I'd like to think that when the time comes for United Spinal's centennial anniversary, spinal cord injuries and disability discrimination will be a thing of the past. In the more likely event that they are not, I'll be excited to see what the organization is up to.



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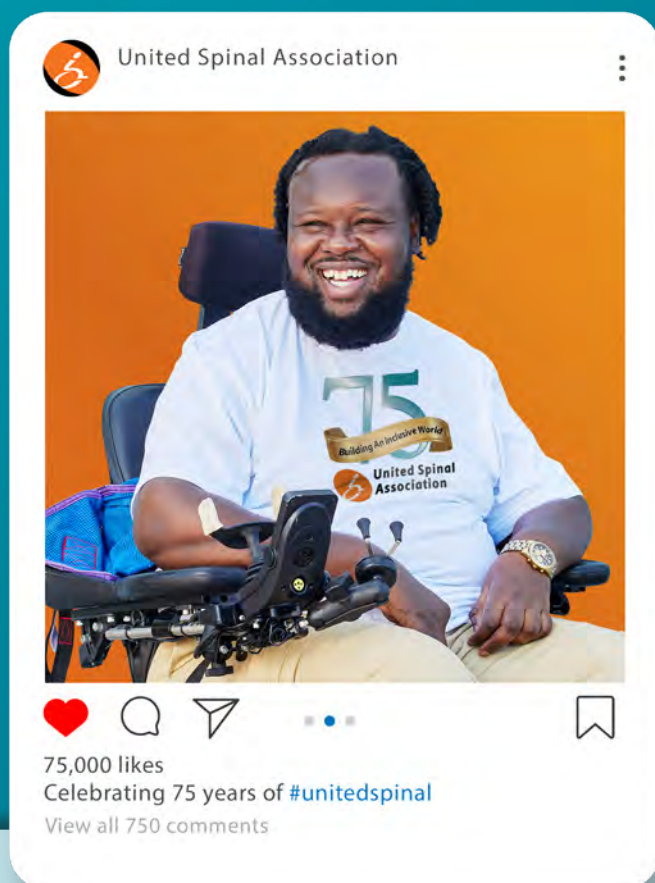
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CELEBRATING 75 YEARS OF UNITED SPINAL ASSOCIATION

Membership, programs, policy and history — these four key elements shaped United Spinal into the premier nonprofit organization for the SCI/D community. We've devoted a section to each component and filled them with stories, posts and infographics in our attempt to cram 75 years of accomplishments and service into one issue. We hope you come away as proud as we are.

Cover and contents Photos by Jeffrey Salter



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MEMBERS

United Spinal Association is the largest membership-based nonprofit dedicated

to improving the quality of life for people with spinal cord injuries and disorders. The organization's 59,000 members are organized within in-person chapters and virtual support groups, or directly connected to each other by helpful United staff members. Together they provide resources, enhance careers, and even drive big projects like creating person-centered rehab options.

"Thanks to connecting with United Spinal, I've had the opportunity to meet people across the country and have great conversations."

— Rhonel Cinous

At the heart of United Spinal Association are the 59,000 diverse members who drive the chapters, support groups and programs and create the rich tapestry that binds the organization's community. But what is it like to be a member?

Meet RHONEL CINOUS

Rhonel Cinous's United Spinal story began when he found a Florida SCI support group in the wake of his 2016 C5 injury. Before his injury, he was a popular Miami radio personality. He joined the group looking for advice and connections to help him continue to pursue his passions.

That pursuit hit a road bump in early 2020 when the COVID-19 pandemic hit. As in-person support group meetings were no longer an option, Cinous and other members moved online. "It became necessary and essential to connect and reach out to different people," he says. "We were able to share our stories and input and even share some supplies."

The support group had recently signed on as a United Spinal chapter, and when Cinous learned the organization was distributing COVID relief grants, he applied. He ended up being one of over 700 individuals to receive a \$500 relief grant. Additionally, his application caught the eye of a United Spinal reviewer who contacted NEW MOBILITY Editor Ian Ruder to suggest Cinous might make for a fun profile.



Photo by Jeffrey Salter

"I'm always looking for people doing interesting things with unique perspectives, and Rhonel struck me as a guy to keep an eye on," says Ruder, who made Cinous the subject of the November 2020 issue's How We Roll profile. "The more we talked, the more excited I was to connect him with other members and resources."

Upon learning of Cinous's podcast *Ramp. It. Up!*, Ruder introduced him to Los Angeles member Paul Amadeus Lane, a media personality and podcast host with over 20 years under his belt as a C5 quad. Ruder also passed Cinous' email to Brook McCall, United Spinal's new Tech Access Initiative director.

"I appreciated the grant, and I didn't expect anything more to come of it," says Cinous. "Ian caught me off guard when he reached out, but it was cool to be in the magazine and even more exciting to make new connections."

Cinous invited Lane on his podcast, and Lane reciprocated by hosting him on *United on Wheels*, a podcast he hosts for United Spinal. "It was like we knew each other for years," says Lane. "We

shared media stories and talked about our careers, the challenges we've faced and how he wanted to stay in the business."

NEW FRIENDS

The *United on Wheels* episode that Cinous appeared in focused on disaster preparedness, highlighting learned lessons and valuable resources for the SCI community. "We were in the middle of hurricane season, and a number of United Spinal members talked about our experiences living in different parts of the country, dealing with different disasters," says Cinous. "It was helpful to hear how different people prepare themselves and to learn some of the tips so we can be prepared when the next disaster comes around."

"It was great to get his perspective," says Lane. "I've learned a lot from him."

Joining United Spinal has led to exciting new opportunities and contacts for Cinous.

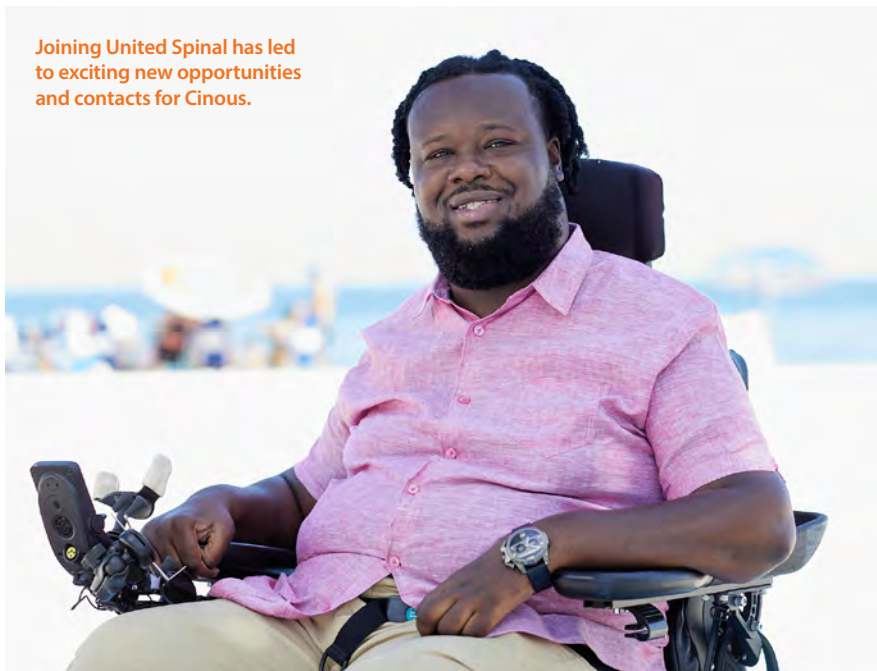


Photo by Jeffrey Salter

United Spinal
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United Spinal member Barb Zablotney leads the South Central Pennsylvania chapter with a flair all her own. [#unitedspinalmembers](#)

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McCall invited Cinous to join United Spinal's Tech Access Group and advocate for accessibility with leading tech companies (see page 17). "His background in media and his general passion for new products and technology made him a perfect fit for the coalition we're building," says McCall, a C4 quadriplegic.

"Thanks to connecting with United Spinal, I've had the opportunity to meet people across the country and have great conversations," Cinous says. "Being at the forefront of new technology coming out or being able to influence the designers to make it more accessible hits the heart of my inner geek. I love to help people, and if there's some way that I can help other people with disabilities with my own expertise or pay it forward, I'm all about that."

Cinous is excited about getting more involved with United Spinal and possibly attending Roll on Capitol Hill or volunteering with Pathways to Employment, the organization's employment program. "I'm trying to figure out where I can fit in career-wise and still assist in the community and help other people who were in my position five years ago," he says.

MM

Realizing a Dream for IMPROVED REHAB ACCESS

Natalie Barnhard: United Spinal's 2021 Finn Bullers Advocate of the Year

BY STEVE WRIGHT

Natalie Barnhard spent most of the 17 years since she became paralyzed supporting people with disabilities by providing and improving access to rehabilitation in her Buffalo, New York, community. Her pre-injury background in physical and massage therapy, combined with her personal experience after sustaining a C5-6 injury, reinforced her belief that her community needed an accessible and convenient rehabilitation option. This June, United Spinal Association honored her as the 2021 Finn Bullers Advocate of the Year for her continued advocacy toward making her dream a reality by raising funds for and launching the Natalie Barnhard Center for Spinal Cord Injury Rehabilitation and Recovery.

"Being named Advocate of the Year has been amazing. It's great to receive peer recognition, and it pro-

"I want everyone to be able to receive the care and resources they need to live their life to the fullest."

vides a forum to share what we're doing with the rehab center," she says. "Before our soft opening, leading up to the grand gala opening, the closest



place for rehab for folks with SCI was about 300 miles away.”

Opening the Center is the latest accomplishment in Barnhard’s impressive advocacy career. She also founded the Motion Project Foundation and the Western New York Chapter of United Spinal Association.

The Motion Project Foundation provides funding for medical equipment, home or vehicle modifications, intense therapy rehabilitation, advocacy, and other services and activities to improve the lives of individuals with a spinal cord injury. In less than a decade, it has raised close to \$500,000 and awarded about \$350,000 in grants.

“Natalie is fulfilling a dream and a passion of hers to help others in her community. This dream has driven her ever since she sustained a spinal cord injury at the age of 24,” says Alexandra Bennewith, United Spinal’s vice president, government relations. “I am in

awe of Natalie’s commitment and achievement in getting this center open and am grateful to her and her family for their

“It’s not like going to PT in an institution. It’s going to a warm, colorful and fun place.”

focus on this critical issue and happy to hear that people in our community now have a place to go for help with rehabilitation.”

A COMMITMENT TO SERVICE

Before sustaining her spinal cord injury in 2004, Barnhard was a physical therapy assistant and a licensed massage therapist. She used her hands to help people heal. “I was at work when a 600-pound weight machine toppled over on top of me,” she says.

Following her rehabilitation, Barnhard adapted the way she worked to continue helping others. The ultimate result was the Motion Project Foundation. The opening of the new 6,000-square-foot rehabilitation center takes the foundation’s work to another level. Barnhard notes that it is not a general rehab facility but focuses on improving function and helping clients in nontraditional ways.

“We help educate clients and families, so they know what to expect moving forward with a spinal cord injury,” Barnhard says. “Motion Project is not just about the physical gains — we strive to get clients back to work, to school or into sports pursuing their dreams. Our goal is to support each client to reach

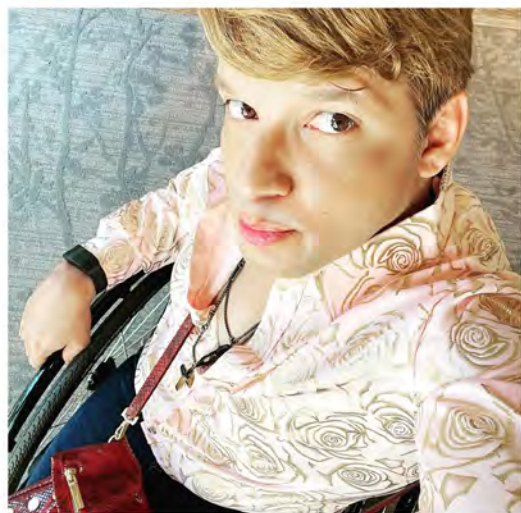
their goals and live a full, productive, healthy life.”

“We focus on the client’s weaknesses and work on coordinating the entire body in a very functional and complete style of rehabilitation,” she says. “Many facilities tend to focus only on the client’s current abilities and don’t work with the affected areas to improve motor function overall. Motion Project works to support the whole person to assist with advocacy, care navigation and spiritual healing.”

On top of all that, clients will have access to state-of-the-art specialty equipment such as the Lokomat gait trainer; Armeo Spring, an arm weight support for reach and grasp movements; ZeroG, a robotic bodyweight support system; and Madonna ICARE, an intelligently controlled assistive rehabilitation elliptical trainer.

“The equipment is adapted [to SCI and related needs], and the trainers understand what the goals and expectations are. It’s not like going to PT in an institution. It’s going to a warm, colorful and fun place,” Barnhard says. Noting the Center’s proximity to the airport and numerous amenities such as hotels and restaurants, she envisions starting something that goes beyond rehab.

“We believe that this should be an accessible place where people can come to enjoy their time in our gym but also socialize with others,” Barnhard says.



United Spinal thanks Andy Arias for leading our first-ever LGBTQI+ discussion group!
#unitedspinalmembers

View all 345 comments

"We have created a unique space with a fun, vibrant environment to exercise in and also a holistic environment with an infrared sauna for relaxation, peer support and general wellness."

To realize this vision, Barnhard and the Motion Project have collaborated with many of the key stakeholders in the local community, including the University at Buffalo School of Public Health and Health Professions, Erie County Medical Center, Greater Buffalo Adaptive Sports and WNY Adaptive Recreation.

"Our goal is to continue to make essential partnerships and collaborate with various other businesses and organizations to enhance the recovery process for our clients in and outside of western New York," she says. "I believe we cannot only help people within the Buffalo area but nationally as well."

Barnhard knows that providing the financial resources to help people get the rehab they need is as important as providing the physical facility. She understands she was fortunate that workers' compensation paid for most of her long stay at Shepherd Center, as many people do not have the funding for ongoing care and other essentials such as durable medical equipment.

"I want everyone to be able to receive the care and resources they need to live their life to the fullest," she says. She is pursuing fundraising, grants, donors and sponsorships to create a larger endowment "so no one ever gets turned away regardless of ability to pay."

Bennewith singled out Barnhard for her commitment to addressing one of SCI's most vexing issues. "Unfortunately, insurance plans do not cover our community's rehabilitation needs sufficiently," she says. "Which is why Natalie's work fills a huge gap in this space for our community and the broader disability community and why her advocacy work must be acknowledged and recognized."



About United Spinal Association's Finn Bullers Advocate of the Year Award

Finn Bullers was a journalist and advocate who fought for better Medicare and Medicaid coverage and ratification of the Convention on the Rights of People with Disabilities. A longtime reporter at the Kansas City Star, Bullers had Charcot-Marie-Tooth, a form of muscular dystrophy that affected his mobility. He worked with stakeholders across the country on the Accessible Icon Project to update the traditional symbol for disability.

Bullers died from pneumonia at age 56 in 2016. United Spinal Association named its Advocate of the Year Award after him in 2017 and has awarded it annually to deserving member advocates at the Roll on Capitol Hill. The award was not given out in 2020 when ROCH was canceled due to COVID-19.

Previous Winners

2019: Kenny Salvini & Rob Wudlick

In 2015 Salvini, a quadriplegic since 2004, founded the Here and Now Project to empower and serve the paralysis community in Washington State. The nonprofit has steadily grown since and now hosts multiple support groups, get-togethers and events every year. It doubles as a chapter of United Spinal.

Salvini (right) is a regular contributor to *NEW MOBILITY* and blogs at kennysalvini.com. He wants "to build a community where a group of people in seemingly dire circumstances are able to pool their collective experience, strength and hope in order to successfully achieve an enhanced, more accessible life."

Wudlick (left), a quadriplegic since 2011, is a driving force for SCI/D research and a committed advocate at the national level. He helped devise and push through novel legislation to fund SCI/D research in his native Minnesota and worked with advocates from other states to assist them with similar efforts. In 2014 he cofounded Get Up Stand Up to Cure Paralysis Foundation. Currently, he works to advance medical research for spinal cord injury as a clinical trial research project manager in the Rehabilitation Medicine Department at the University of Minnesota.

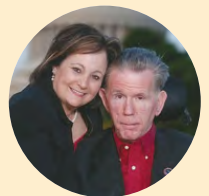
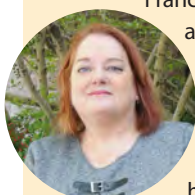
2018: Earle and Kathy Powdrell

The Houston-based husband and wife team became a relentless voice for the SCI/D and broader disability communities after a 2009 brain stem stroke left Earle with "locked-in" syndrome — paralyzed except for eye movements.

Earle, an aerospace engineer, and Kathy, a theater teacher, were regular attendees at United Spinal's Roll on Capitol Hill and leaders in the Houston United Spinal chapter. Earle used eye-tracking software and a voice synthesizer to elegantly articulate the issues and needs of the disability community. Earle and Kathy's energy and passion were magnetic and known to compel even the most hardened audiences. Earle, who championed accessible air travel and the preservation of the ADA, died in 2019.

2017: Frances M. Ozur Cole

Frances M. Ozur Cole is the former president of United Spinal's New Mexico Chapter and a committed advocate for issues that affect the independence and quality of life for people with SCI/D and other preexisting conditions. Ozur Cole, who began using a manual wheelchair in 2004, is also a business entrepreneur, graphic designer and former electrical engineer. She lives with congenital narrowing of the spinal column, and her mobility is impacted by recurring herniated discs. A native of the Washington, D.C., area with politics ingrained in her blood, Ozur Cole attended multiple Roll on Capitol Hills to advocate for greater access to complex rehab technology and medically necessary wheelchairs.





Chapter Leadership Meeting

United Spinal Association's annual Chapter Leadership Meeting brings together leaders from across the United States for three days of collaboration, planning and socializing with the goal of empowering their local SCI/D communities nationwide. Representatives from the majority of United Spinal's ever-growing family of chapters learn from each other by sharing their successes, failures, questions and dreams.

"Our chapters may have different programs, yet all share the same dedication to enhancing the lives of people with spinal cord injury/disease, their families, and those who provide their care," says Nick LiBassi, United Spinal's vice president for partnership expansion. "The Chapter Leadership Meeting offers United Spinal's key staff and chapter representatives the opportunity to collaborate on future initiatives to enhance our organization's mission."

Whether it's fundraising, event planning, legal issues or something else, attendees leave with new ideas, resources and contacts they can use to improve their chapters and help their members.

"Although our chapters have different programs and initiatives, we all share United Spinal's mission to ensure people with SCI/D can regain their independence and quality of life. It's great to come together face to face with other leaders to contribute ideas and resources," says Jose Hernandez, president of United Spinal's New York City Chapter.



(Top-Bottom): In addition to learning skills to help their chapters, attendees make new friends; member Marcela Maraion shares her insights with attendees; former CEO and President James Weisman can always be counted on for a laugh.





(Top to Bottom): It's all smiles in a break between sessions; arranging a group photo can be tricky with such a big group of wheelchair users; a robust sponsor showcase gives members a chance to check out the latest in mobility and medical gear.



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PROGRAMS

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United Spinal Association has a program for that. Other programs assist disabled veterans, teach businesses best accessibility practices, share knowledge with members needing resources and more.

"If we don't make sure our needs are taken into consideration during the development of the innovation, then it becomes too difficult to retrofit for accessibility."

— Vincenzo Piscopo

Technology for EVERYONE

BY AARON BROVERMAN

United Spinal's Tech Access Initiative connects people with SCI/D to tech industry leaders to ensure the future of technology is accessible

Smart speakers, speech-to-text, autonomous vehicles, virtual reality ... ground-breaking technological innovations like these have never been developed with people with spinal cord injuries and other mobility disabilities in the room. Until now.

United Spinal Association launched its Tech Access Initiative in February 2020 to ensure people with mobility disabilities have a voice in the future of technology. It's 18 months later, and that voice is ringing out louder than ever.

At the heart of the Initiative are the Tech Access Group, composed of tech-savvy people with mobility disabilities and the Tech Access Council, a collection of representatives from leading tech companies like Apple, Comcast, Facebook, Microsoft, Google, Teladoc and Zoex. The TAG holds bimonthly meetings to share its experiences with TAC members on a specific technology — what works, what doesn't, what could be better and what's on the wish-list when it comes to accessibility. The meetings give both groups a chance to listen, discuss and ask questions to improve the accessibility of the next generation of technology.

Brook McCall (center) is passionate about connecting tech professionals to United Spinal members. Here she and her caregiver, Stacie Perry, are featured with NFL stars Shaquem and Shaquill Griffin at the Microsoft Ability Summit.





United Spinal Association Programs and Projects

United Spinal Association strives to improve the lives of people living with spinal cord injuries and disorders through its programs. Visit Unitedspinal.org or call 718/803-3782 for more information.

Accessibility Services ensures the built environment is accessible to wheelchair users by training design professionals and reviewing and completing inspections nationwide.

- Accessibility-services.com

Advocacy & Policy Network advocates for benefits and regulations that are beneficial to paralyzed Americans and all people with disabilities.

- Unitedspinal.org/action-center

Resource Center connects people with personal guidance and resources to effectively regain their quality of life and independence.

- Askus-resource-center.unitedspinal.org; 800/962-9629

National Chapter Network supports the SCI/D community by promoting health, inclusion, and independence through a wide range of resources and support.

- Unitedspinal.org/support chapter-network; click on the map to find your local chapter.

NEW MOBILITY magazine provides the latest news and resources on active living for wheelchair users.

- Newmobility.com. Find us on Facebook at @newmobility and on Twitter and Instagram at @newmobilitymag.

Pathways to Employment partners with employers to place people with SCI/D in jobs and provide trained mentors, resources, and support to facilitate return to work.

- Unitedspinal.org/pathways-to-employment

Peer Support provides peer-to-peer support for individuals, friends, caregivers and family members through a national network of peer support groups.

- Unitedspinal.org/peer-mentoring; unitedspinal.org/peer-groups

Ready to Roll assists in preserving the health and safety of members during natural or human-caused disasters.

- Unitedspinal.org/ready-to-roll

Tech Access Initiative ensures accessible technology is inclusive to all people with disabilities, including wheelchair users.

- Unitedspinal.org/tech-access-initiative and @techaccessconnection on Facebook

VetsFirst advocates for disabled veterans so they can achieve the highest level of independence and quality of life.

- Vetsfirst.org; 800/404-2898, ext. 7731 or 7732

New Beginning Backpacks are filled with information and resources for people transitioning into their communities after SCI/D.

- Unitedspinal.org/sponsor-a-new-beginning-backpack

Get Involved With United Spinal

There are many ways to stay active and informed and meet other members of United Spinal.

- Join our Facebook SCI/D Support Group
- Participate in our Virtual Social Hour
- Join our monthly Resource Center Live Zoom
- Join our Rolling Revolution Advocacy Network Facebook Group
- Join our Rolling with Pride - LGBTQ+ Discussion Group

United Spinal President and CEO Vincenzo Piscopo is thrilled at the Initiative's early success and the organization's expansion into the technology sector. "Technology advances too fast. If you think about where we were five years ago and where we are now, you see the advances are incredible," he says. "If we don't make sure our needs are taken into consideration during the development of the innovation, then it becomes too difficult to retrofit for accessibility."

GETTING IN ON THE GROUND FLOOR

United Spinal's Grassroots Advocacy Manager Brook McCall, a C4 quadriplegic from Portland, Oregon, got a firsthand view of this problem while working with the organization's policy team on its initiative to make autonomous vehicles accessible for all.

"I saw an absence of our community's voice in tech advocacy opportunities," she says. "It drove home that the needs of the mobility disability community are often overlooked by the people who make the tech products we use daily. While other disability communities have built strongholds that make sure they have access to technology, we had a key opportunity to take that on [as well]."

In February 2020, McCall became the first director of United Spinal's Tech Access Initiative. She

assembled her Tech Access Group from a diverse pool of people with various disabilities, injury levels, and employment backgrounds, including engineers, occupational therapists, and passionate consumers.

"The first three meetings featured a group of people that I knew in the SCI community: strong advocates, United Spinal chapter leaders and folks with interesting perspectives," she says. "I invited them to be





stakeholders and speak for the community in this tech discussion space.”

Paul Amadeus Lane, a tech radio journalist and C6 quadriplegic from Huntington Beach, California, says the TAG’s message is clear: “Hey, listen to our voice. Learn about our frustrations and the discouraging feelings we have when it comes to certain tech products.”

Many tech company’s products either aren’t accessible at all, aren’t as accessible as they claim to be or are marketed as fully accessible even though they are too expensive or so user-unfriendly that the average person with a mobility disability is excluded. Michele Lee, a TAG member, points to voice-rec software as an example. “I use dictation to type a lot of my emails and navigate the internet because I don’t have finger

“We have a key opportunity to create a disability stronghold to make sure we have access to technology.”

function,” says Lee, a C5-6 quadriplegic who recently accepted a position managing United Spinal’s employment and disaster preparedness programs. “It would be great if dictation software could be integrated throughout all the programs that I use, but it only works for some. It’s frustrating when you pull up a different email program, and these different programs don’t always mesh well with accessible technology.”

“The way to counteract such frustra-

tion is to get us in in the beginning, get us in in the planning, get us in at R&D and get us in at the testing,” says Lane.

MUTUAL BENEFITS

To form the Tech Access Council, McCall leveraged United Spinal’s existing relationships with leading tech companies, built from the organization’s work on autonomous vehicles and other advocacy initiatives over the years.

Several companies joined and pledged to financially back the Initiative. By doing so, they support United Spinal’s work and ensure that the Tech Access Group members are compensated for their contributions.

Tony Le is the senior accessibility program manager for Cruise, an autonomous vehicle company based in Fremont, California, and a member of the Tech Access Council. He says participating in the TAC is mutually beneficial.

“I don’t have a disability, and who better to help build up this technology than the folks within the community themselves? It’s a lot harder to work with people one-on-one, but working with a national organization gives me an opportunity to tap into those resources directly. Plus, there are opportunities here. Why not reach out and ask the folks who’ve been leading the charge what would be most effective?” says Le.

Several Tech Access Council member companies have already recruited or hope to recruit Tech Access Group members to their own focus groups to develop accessible products.

John Lee, an assistive technology specialist with muscular dystrophy at California Polytechnic State University with a background in occupational therapy, was invited to participate in a paid accessibility research study for Facebook’s virtual reality headset, the Oculus Quest 2, thanks to his involvement in the Tech Access Group. He enjoys providing constructive feedback



Paul Amadeus Lane interviews *Agents of S.H.I.E.L.D.*'s Ming Na Wen and Clark Gregg.

on products in all stages of development and hopes companies will appreciate the added value the TAG can add at early stages.

"It's a lot clunkier to try to add accessibility in later. It just becomes a dongle that's less streamlined, and the accessibility just feels like an add-on," Lee says. "You have to bake in the accessibility, and the way you bake something in is as an ingredient from the start."

LEVELING THE PLAYING FIELD

As the relationship between the SCI community and the tech industry's leading corporations continues to grow, McCall hopes to grow the TAG and the TAC and amplify the conversation.

"Our next step is to expand our Tech Access Initiative stakeholder pool," says McCall. "We want to have other people get involved and do more of these R&D specific projects because we have so many interesting voices that need to be heard in this space. We all want and need different things out of our technology, so we want to open that up."

Part of opening up those opportunities is making sure the people who can benefit from technology can afford it.

While some on the panel enjoy high-paying jobs and live in big cities, others come from more rural communities or survive on income assistance. All members reinforce the need for affordability that grants universal access to assistive technology tools and connectivity basics.

Michele Lee lives in downtown Chicago and has been working for an international financial services firm, and even she feels the pinch. "Having a disability is expensive on its own with a wheelchair and adaptive equipment, but I also use existing technology to help me be more independent. I use

Amazon to buy things, I use Instacart to get groceries, and I don't drive, so I Uber everywhere," she says. "All these services aren't free. They cost extra money. As a person with a disability, I know technologies don't always work, and then you have to pay more for the technologies that are out there."

The good news is members of the Tech Access Council are also committed to finding ways to make accessible technology cheaper for those who need it most. When Lee brought his colleagues into a Tech Access Initiative meeting, they were blown away by how much those with mobility disabilities must pay to make their technology accessible.

He used the rapidly-changing world of cell phones as an example of how already expensive technology can be even more so for people with disabilities. "It gets cheaper for me every year there's a new phone that comes out, and every year there's a cheaper option, but people with disabilities may need the

John Lee tests Oculus Quest's accessibility features for Facebook.



"You have to bake in the accessibility as an ingredient from the start."



United Spinal is excited to announce that Michele Lee has joined our team as a program manager! [#unitedspinalprograms](#)
View all 127 comments

highest price features just to use a phone,” says Le. He believes the Tech Access Group is perfectly positioned to address this problem and provide equitable solutions for people with disabilities.

A BRIGHT FUTURE

While 18 months isn't enough time to affect widespread change in the tech industry, McCall and her team are already contributing input on projects that are years out and confident that they are planting the seeds for a more accessible, affordable tech future.

“I’ve definitely learned that all of these people who work in these technology companies have really good intentions. I don’t think anyone’s trying to deliberately not design things for people with disabilities. A lot of it is awareness. They don’t even know that the things they’re designing aren’t inclusive,” says Michele Lee. “I used to think big companies are just out to make money, but I’ve learned they actually care, and I think that’s great. I hope it continues this way and more companies decide to join the Tech Access Council and collaborate because the more accessibility, the better.”

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A Commitment to HELPING:

UNITED SPINAL'S RESOURCE CENTER TACKLES YOUR TOUGH QUESTIONS

BY STEVE WRIGHT

Imagine the ultimate help desk for spinal cord injury — a magical place where trained, knowledgeable experts provide the resources and information to resolve all your questions and help you get back to living the life you desire. Now, what if I told you that actually existed, and you could access it for free?

While it doesn't use magic and has no actual physical location, the United Spinal Resource Center has been filling this need for 17 years, establishing itself as the premier destination for all SCI/D inquiries and needs.

The team consists of six professionals — four who live with spinal cord injuries, one registered nurse and one social worker. Bill Fertig, the team's director, served 25 years as a municipal police officer and training sergeant before an off-duty motorcycle accident resulted in paraplegia in 1999. He joined the Resource Center in 2005 and has since worked to expand its offerings and hone its services. He takes pride in personalized, customized and localized assistance.

"We go above and beyond to make sure that everyone who reaches out gets any resources they need."



Resource Center
Director Bill
Fertig loves
connecting
members to
solutions.

The Resource Center helped Chris Dunn get the rehab he deserved.



“Our six information specialists have a combined 100 years of experience living with SCI and 68 years working as information specialists,” he says. “They take a great deal of pride in providing timely, helpful guidance to others dealing with the many complexities of living with SCI.”

Whether the request for assistance comes by email or phone, his team members try to call the person back to get the full details so they can deliver the proper resources. Resources range from help finding personal care attendants, transportation, housing and home modifications to advocacy in dealing with insurance companies and medical facilities. In addition to responding to inquiries and member problems, the team receives between 200 and 300 new member applications with embedded member questions every month. Every application gets assigned, read and responded to quickly and thoroughly.

“We go above and beyond to make sure that everyone who reaches out to us gets our full attention and any resources or help they may need,” says David Heard. He’s an information specialist who also serves as United Spinal’s membership coordinator.

“We’re a collaborative group within our Resource Center, each with our own strengths, knowledge and experiences,” says Jane Wierbicky. “Together, we truly aim to provide hope, direction and much-needed information to help people get back to doing the things they love.” She’s an information specialist with over 35 years of experience working as a nurse exclusively in the field of spinal cord injury and related disabilities.

Longtime Resource Center specialist

Daniela Castagnino says responding to inquiries is as much about making personal connections as solving the immediate issue at hand. “When you answer the phone and can tell they are very stressed and upset, and you’re empathizing, and you are familiar with the issue, you can almost sense them start to see that things are going to be OK,” says Castagnino, a quadriplegic. “Having a positive effect on people — helping people who are family members of people with new injuries — you can transmit to them the idea you’re not alone. It will get better. And you will get through this. There’s a whole and rewarding life that’s available.”

“Hearing that message from someone living with a spinal cord injury can make a big difference,” says José Hernandez, a Resource Center information specialist. With 26 years of life as a C5 quadriplegic under his belt, Hernandez brings a deep blend of lived and professional experience to his work. “I take pride in being able to relate with callers and emailers on a deeper level and going beyond what the textbook or doctors may tell them.”

Fertig and his team note that the best success stories are when the person’s issue is resolved, and they are given the tools to better advocate for themselves. “It’s not that we do it all for the person in a vacuum — we make them part of the

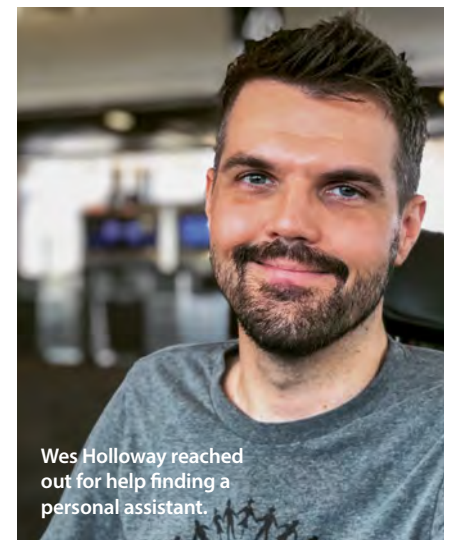
team, let them know they are on the right track. We give them factual, current information to base their appeals on,” he said. “That empowers them to go further and be more successful.”

Here are five notable cases that demonstrate the breadth and expertise the team brings to the Resource Center.

“ALL I NEEDED TO CROSS THE FINISH LINE”

Chris Dunn survived a diving accident in July 2018 that left him paralyzed, on a ventilator and mostly blind. A father and concrete worker, Dunn spent a year in a Maine ICU, fighting for his right to rehab and get back to living his life. “I’m pretty sure they just wanted to kill me,” he said in a 2019 interview.

Dunn’s family was repeatedly told there was nothing more that could be done for him and, even though he was in his early 40s, they should put him in hospice to die. After seven months of reaching out to hospitals and rehab centers all over the



Wes Holloway reached out for help finding a personal assistant.

country and receiving nothing but rejections, Chris' mom, Carol, filled out the online form to join United Spinal Association, writing: "We are desperate. We need help, please."

Wierbicky fielded the question and emailed Carol the next day. That started a partnership between the Dunns and United Spinal that eventually got Chris back to living his life.

Dunn relied on a ventilator, pacemaker and feeding tube. His complications were challenging, but Wierbicky was determined to help.

"It's always shocking to me when we see cases where that doesn't happen," she says. "It became clear to me through

this case that people living in rural states that don't have dedicated spinal cord injury programs and those who are on ventilators are in an especially vulnerable position. All Carol ever wanted was for him to be evaluated by people who understand his condition. That seemed like a very reasonable goal."

to, up in Maine, was a hospital administration that looked at the injury level he had as not being any kind of quality of life. So they denied him care that would have given him quality of life," says Resource Center director Bill Fertig. "Here is a guy with a very, very significant disability. But through it all, he has almost



Shannon Cobb says the Resource Center has her back.

Working together, Carol and the Resource Center team enlisted Disability Rights Maine, state legislators and federal representatives and held weekly calls with hospital staff and the state's Medicaid program. Ultimately, their advocacy got Chris into Shepherd Center in Atlanta — one of the nation's premier SCI rehab centers.

"What it came to down

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universally maintained a strong perspective. He has taken all that came to him, and he's happy.

At Shepherd Center, respiratory therapists went to work trying to wean Chris off the ventilator and strengthen his voice, while physical and occupational therapists attempted to undo the damage a year of lying in the ICU had done.

The team helped Chris build up the lung capacity to only need the vent at night. He was able to go fishing. After four months, Chris returned to Maine. He continues to fight the system to receive maximum benefits, while his mother serves as his primary caregiver.

"I don't know that I would have been able to make things happen without United Spinal Association," Carol says. "I was getting tired. I wasn't going to give up, but they came in and propped me up and gave me some courage and

some encouragement to keep going. They pointed me in some right directions and stood behind me, and that's all I needed to cross that finish line."

And that, says Wierbicky, is the essence of what the Resource Center strives to do. "Rehabilitation stays have decreased so dramatically over the years I've been involved in the field, and it can be so difficult for people to get all of the information they need in such a short time," she says. "It's very gratifying to talk with people to help them drill down to the information they need when they need it and hopefully feel supported and less overwhelmed."

"This is why the Resource Center is here: to fight for people and give them the support they need — on a personal and professional level — to attain the best quality of life possible," says Fertig.

"THEY'VE GOT MY BACK"

Shannon Cobb, a sociology student at McHenry County College in Illinois, says she is one of the Resource Center's most frequent users. "I've sent so many random questions to the Resource Center — it's hard to list all the things they've helped me with. Overall, it's nice to know someone has your back," says Cobb, a paraplegic who uses a manual wheelchair — often pulled by Princess, her Rottweiler-Shepherd service dog.

"I was having a lot of problems figuring out how to get things done when I was first injured [in 2018]," she says. "The Resource Center has helped with finding accessible housing, adapting a home to be more wheelchair-friendly and helping me find a wheelchair and getting grants."

Cobb participates in wheelchair lacrosse, searches for more adaptive

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sports in her location an hour-plus away from Chicago and is interested in extreme wheelchair sports. Fertig wrote a letter of recommendation to help Cobb with a grant to fund a wheelchair that stands up to the abuse of WCMX. The center also has helped the budding social worker with peer advice on how to stretch the paltry disability payment that she receives each month.

Lindsey Elliott, a social worker who serves as United Spinal's director of member initiatives and as an information specialist, invited Cobb to one of the Resource Center's new Zoom-based nationwide peer sessions. "Her participation led to resources and information from her peers who were on the call — United Spinal members from all over the country. She was on the call with notebook in hand, furiously taking notes on all the resources," says Elliott. "We started these calls to address the isolation born of COVID. They are a time to kick back and chit chat about all kinds of things. Lots of questions are asked and information is shared."

"I have learned to be very resilient. I cannot imagine how my journey would have been without the team of people at the Resource Center," says Cobb.

FAST, PERSONAL SOLUTIONS

Wes Holloway reached out to the Resource Center for help finding a personal care attendant when he moved to Washington, D.C., from Houston to pursue a Master of Fine Arts at George Washington University. An accomplished artist, Holloway took his first year of coursework via Zoom. But when in-person classes for his second year demanded a quick relocation adjacent to campus, the scramble was on.

Castagnino, who is based in D.C., remembers getting an email on a Friday afternoon that Holloway needed PCA help for the weekend. "Bill and I put all ideas to work and put all hands on deck at the last minute. I checked a Listserv for caregivers, CILs and agencies and showed Wes how to narrow a



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Congratulations to **United Spinal Association** on its 75th anniversary!





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search on Care.com,” says Castagnino.

Thanks to a combination of Castagnino’s personal knowledge, contacts at D.C.-based home-health agencies, a local center for independent living, department of disability services and the local United Spinal chapter, the team was able to help Holloway find a PCA and make the move.

“It is great to see that the Resource Center responds quickly in a personalized, thorough and individualized way. I didn’t get the call center, voicemail runaround,” says Holloway, who hopes to teach at the university level while continuing with socially-engaged art projects.

HACKS, IDEAS AND ANSWERS

Annie Mitchell reached out to the Resource Center for accessible gardening ideas two years after becoming a paraplegic. She ended up with several ideas for home modifications and other hacks that Fertig and his team came up with to enhance her quality of life.

“We try to phone people, rather than email,” Fertig said. “Rather than answering a quick question from a category on a form, it gives us the opportunity to chat and respond more fully and directly.

Hers was a typical case where we were able to identify so many areas of information that she could utilize comprehensively. When our information specialists make direct personal contact with people, very good things happen.”

On the gardening end, the team suggested a short-handled gardening rake for gardening from a wheelchair. The gardening chat let to simple home modifications such as:

- Spring hinge pins for exterior doors to simplify door opening/closing from a wheelchair.
- Adding a magnetic catch to the back of the door to keep the door open when needed.
- Fold-down kitchen cabinet rack choices for quick accessibility to upper kitchen cabinets.
- Vanity drain and trap options to facilitate roll-under bathroom vanity access.

CATHETER CONUNDRUM

Everyone should be able to go to the bathroom when they want and need to, but without the proper supplies, it can be a difficult and frustrating task for people with disabilities. Betty Sheril reached out to the Resource Center because she was not receiving enough catheters per month from Medicaid and didn’t know what to do.

“Centers for Medicare & Medicaid Services had hard ceilings on how many catheters they would provide to a CMS beneficiary,” Fertig says. “Supported by the Resource Center information specialists and the United Spinal policy department, Betty was eventually granted an exemption from CMS catheter limits and began to receive all of the monthly medical supplies that she required.” **NI**



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POLICY

Policy and advocacy touch every part of our members' lives, from what wheelchairs they can access to where they can go in those wheelchairs and how they'll get personal assistance, if needed, when they get there. United Spinal's dedicated advocates ensure that our members' voices are heard from city halls to the halls of Congress.

Roll for Rights



1946:
Founded as Eastern Paralyzed Veterans of America, United Spinal Association has always advocated for paralyzed veterans and always will.



1979-1983:
One of United Spinal Association's earliest and most enduring policy wins was ensuring accessible public transportation.

Photo courtesy of MTA

Shaping an Accessible World

ONE POLICY AT A TIME

BY SETH MCBRIDE

United Spinal Association understands that policy is about people. At the heart of our mission is a commitment to advance government policies that directly improve the lives of disabled Americans.

United Spinal's policy team, led by Alexandra Bennewith, is based out of Washington, D.C., where it successfully advocates for members of Congress to support important disability legislation and reject laws and policies that would harm our community. The policy team also organizes the annual Roll on Capitol Hill to bring United Spinal members from across the country to the nation's capital — virtually in 2021 — to tell their stories and advocate directly with legislators, thus strengthening the team's efforts.

HERE ARE FIVE OF UNITED SPINAL'S TOP NATIONAL POLICY WINS:

1. Increased Funding for Home and Community-Based Services

Anyone who requires personal assistance understands how woefully inadequate home and community-based services in the United States are. Finding and retaining quality caregivers is perennially challenging, and the pandemic further stressed the system. United Spinal advocated for increased federal HCBS funding as part of the pandemic relief bills and succeeded in getting significant, though temporary, funding that states could use to pay for caregivers included in the American Rescue Plan of 2021.

Thanks to sustained advocacy from

the disability community, President Biden pledged some \$400 billion in sustained HCBS funding. Securing that vital “human infrastructure” boost is one of United Spinal's top policy priorities.

“The pandemic shone a light on the horrendous choices members of our community have always had to make around obtaining personal assistance services from family members, friends or employees alike,” says Bennewith. “How many times have any of us heard about a husband, wife or sibling forgoing their employment income and staying home to assist a loved one?” The pandemic further exacerbated an already unsustainable caregiving crisis with nationwide caregiving shortages. “Having to ‘choose’ between work and personal assistance



1994-2019: United Spinal successfully fought for curb cuts throughout NYC.



2015: Thanks to United Spinal, wheelchair users have the right to hail a cab or call an Uber.



2017: When Medicare was under attack, United Spinal stepped into the breach to protect health care.

Photo by Don Emmert/AFP via Getty Images



2018: United Spinal successfully improved air travel protections for wheelchair users.



2021: United Spinal fights for more home and community-based care funding.

Photo by Education Images/Universal Images Group via Getty Images

services is a false choice, and it is way past time to fix this,” she says.

2. Saved the Affordable Care Act, 2017

The most potentially impactful national story of 2017 was the Republican effort to repeal the Affordable Care Act. United Spinal and other disability organizations fought to preserve this vital piece of health care legislation, which, among other things, guaranteed insurance regardless of preexisting conditions and provided increased funding for Medicaid. As ADAPT activists stormed the halls of Congress, and United Spinal’s members met with their legislators during ROCH, United Spinal staff lobbied lawmakers to reject all repeal efforts.

The full-court press succeeded, and the efforts to repeal the ACA ultimately failed — albeit in nail-biting fashion. Disability advocates fought to preserve the ACA like our lives depended on it because they did. As United Spinal’s then-president and CEO James Weisman summed up, “People with disabilities shouldn’t be sicker than everybody else just because we don’t have access to health care.”

3. Protected the ADA’s Physical Access Provisions, 2017

2017 also saw one of the most significant attacks on the Americans with Disabilities Act ever when Representative Ted Poe of Texas introduced a bill

to make it significantly harder to remedy access violations at businesses and other public places. Proponents claimed the ADA Education and Reform Act, as it was mislead-

“These important reforms are now locked in, thanks to the efforts of our advocates.”

ingly named, was intended to stop so-called “drive-by lawsuits” by giving businesses 180 days after a complaint to start making progress toward removing an access barrier. But disability activists saw the law as an unnecessary piece of legislation that prioritized businesses over disabled Americans. Fortunately, Congress agreed, and the bill was ultimately defeated.

4. Improved Air Travel Protections, 2018

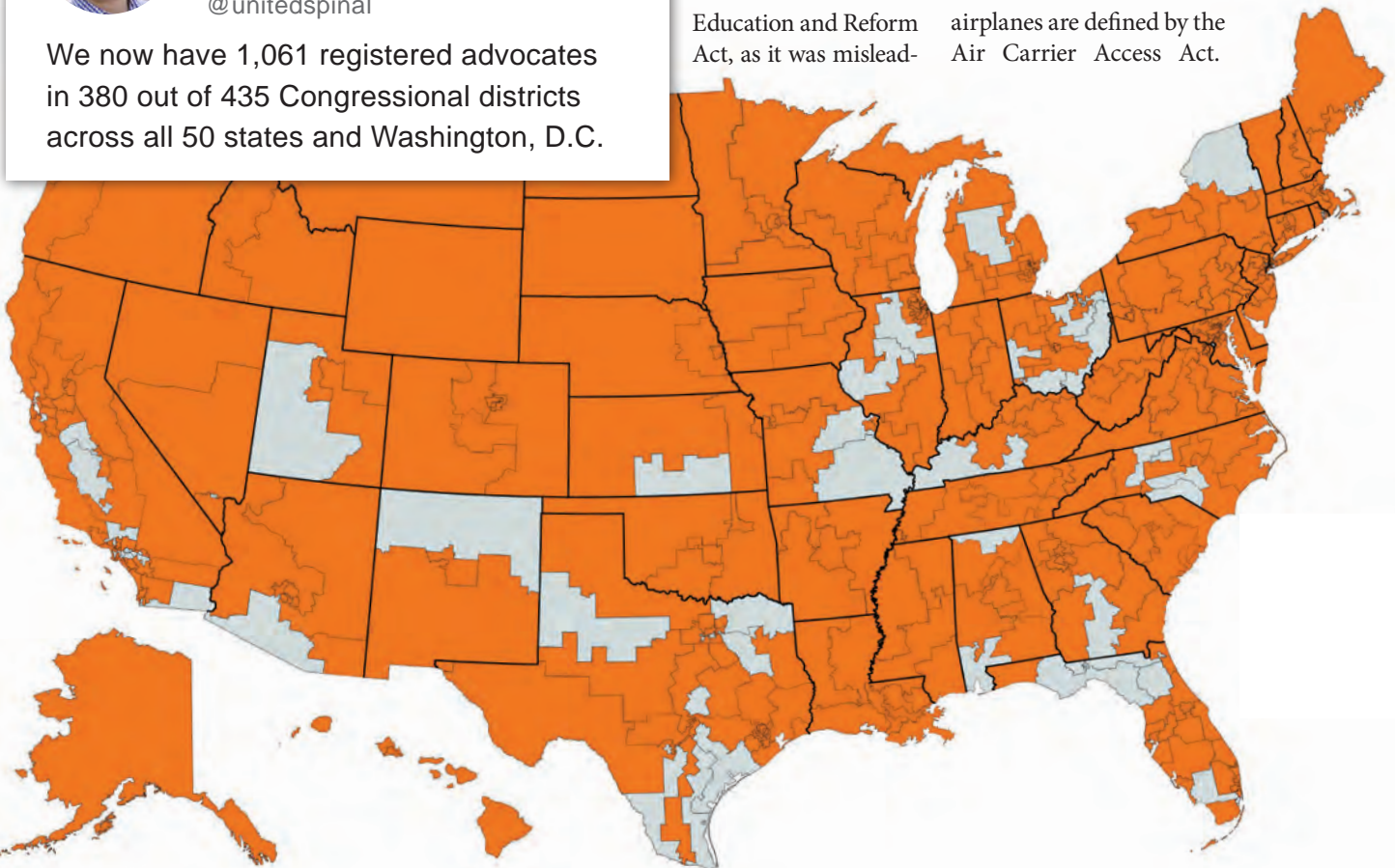
One of the quirks of disability law in the U.S. is that the Americans with Disabilities Act does not cover air travel. The rights of people with disabilities to travel on commercial airplanes are defined by the Air Carrier Access Act.



Stephen Leiberman

Director, Policy & Advocacy at
United Spinal Association
@unitedspinal

We now have 1,061 registered advocates in 380 out of 435 Congressional districts across all 50 states and Washington, D.C.





Passed in 1986, the ACAA was in desperate need of updating, and, in 2018, United Spinal members and staff rolled onto Capitol Hill, shared their personal stories of broken wheelchairs and ruined travel and advocated for amendments to the four-decade-old law.

By the fall, new regulations passed that required the Department of Transportation to draft a “Passengers with Disabilities Bill of Rights,” track the number of mishandled and damaged wheelchairs, and increase civil penal-

ties for bodily harm to a passenger with a disability and damage to wheelchairs or other mobility aids. “It’s a big win,” says Bennewith. “These important reforms are now locked in, thanks to the efforts of all the advocates who shared their experiences and highlighted the importance of equal access to air travel.”

5. Strengthened Veterans Health Care and Housing Access, 2018 and 2020

Improving health care and access to accessible housing for veterans has been

a priority of United Spinal’s ever since our founding members’ first protest in 1946. The fight is just as important today as it was then. In 2018, United Spinal helped secure passage of the VA MISSION Act, which gives veterans greater access to health care in VA facilities and the community, expands benefits for caregivers and improves VA’s ability to recruit and retain the best medical providers.

In 2020, VetsFirst successfully advocated for the passage of the Ryan Kules and Paul Benne Specially Adaptive Housing Improvement Act of 2019, signed into law in August 2020. It provides grants to veterans with certain service-connected disabilities to help them construct, purchase or remodel a home to meet their access needs.

RAMPING THE BIG APPLE

Many of United Spinal’s earliest wins

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came in New York City, and these access victories often serve as models for cities and states across the country. Doing anything in New York — an old, tightly packed metropolis — is complicated, expensive and a massive undertaking. As Weisman, United Spinal's longtime legal counsel and former president, likes to say, "If you can do access here, you can do it anywhere."

HERE ARE UNITED SPINAL'S TOP FIVE ACCESS WINS AND HOW THEY CHANGED AMERICA:

1. United Spinal's Landmark MTA Settlement, 1979

The Americans with Disabilities Act's transportation section might not exist if United Spinal hadn't sued MTA over 40 years ago.

ity," says Weisman, who was then legal counsel for United Spinal. For the MTA, mobility meant paratransit services — something the New York disability community immediately saw for what it was: a separate and unequal solution that would continue to segregate the city's disabled citizens.

Weisman and United Spinal [then the Eastern Paralyzed Veterans Association] sued the MTA using two New York State laws. One prohibited discrimination based on disability, and the other required all newly built or renovated municipal buildings to be accessible. The legal battle took five years. When it was finally settled in 1984, the MTA was required to make all its buses wheelchair accessible, install elevators into 50 subway stations, and set up a paratransit service. It was a landmark settlement, the

ties Act in 1990, the law set a deadline of 1995 for cities and towns across the country to have their sidewalks fully ramped. By 1994, it was clear that nowhere, including the United States' largest city, would meet this deadline. So United Spinal sued New York City to force the installation of curb cuts.

It took decades of legal wrangling, but by 2016 over 97% of New York's streets had been ramped. Three years later, in 2019, United Spinal secured a victory — with NYC required to spend \$1.55 billion to survey, repair and install curb ramps at all of the city's 162,000 street corners — that should keep the city's sidewalks rollable for decades to come. "I'm glad they put in the stipulation that they have to maintain them because often trucks will damage ramps. In the past, even if you filed a complaint, who knew when the city would get around to fixing it," says José Hernandez, advocacy coordinator and president of United Spinal's

New York City chapter.

United Spinal's curb ramp lawsuits serve as a model for other disability rights organizations around the country. The settlements serve as important precedent as judges have settled similar

cases in cities from Los Angeles to Cedar Rapids to Portland.

3. Taxis for All, 1996-Present

United Spinal and other disability rights advocates formed Taxis for All campaign in 1996, but by 2011, New York City's Taxi and Limousine Commission required just 231 ramp-equipped yellow cabs out of a fleet of 13,237. The campaign sued the city for discrimination, and just two years later, in 2013, the TLC adopted new rules that mandated 50% of NYC's taxis be accessible by 2020. The two-decade campaign to force better access for the city's taxis had made significant progress by 2018 when the TLC expanded its Accessible Dispatch program.



"United Spinal is moving beyond physical access and is working toward equal inclusion"

first of its kind in the United States. It also provided a model for other cities across the country and the transportation provisions in the upcoming Americans with Disabilities Act.

2. United Spinal Wins Full Accessibility for New York's Curb Cuts and Sidewalks, 1994-2019

Nearly every sidewalk in New York City now has a curb cut and getting them installed has been one of United Spinal's biggest battles of the past 30 years. When President George H.W. Bush signed the Americans with Disabili-

In 1979, very little that was under the purview of the Metropolitan Transit Authority — the agency that manages subways, rail lines, buses, sidewalks, bridges and tunnels in New York City — was accessible to people with disabilities. And the MTA had dug into its stance that its facilities and services didn't need to be accessible. "They were arguing that [people with disabilities] don't need access, they need mobil-

Advocate Andrea Dalzell speaks to a staff member of one of her representatives.

“With dispatch, the waits are down to less than 15 minutes, and some of them are as low as three minutes in Manhattan. When it first started, it would be an hour, or never,” says Weisman. “So, it’s gotten dramatically better.”

At the same time, the rise of transportation network providers like Uber and Lyft threatened to render many of those taxi concessions obsolete. Thanks to its decades of experience fighting for accessible taxis, United Spinal successfully lobbied New York City to create some of the toughest accessibility regulations for TNCs in the country. One rule requires TNCs to provide at least 80% of requests for wheelchair accessible vehicle service in under 10 minutes and 90% in under 15 minutes. United Spinal continues to work directly with Uber and Lyft to improve their WAV services and to facilitate nationwide access.

4. Disability Rights are Human Rights, 1974

New York was the first state in the country to pass a human rights law banning discrimination based on race, creed, color and national origin in 1945. Disability rights advocates, including United Spinal Association, succeeded in getting New York to amend that law to recognize disability as a protected class in 1974.

This type of legal recognition provided the framework for the disability rights movement’s push to advance the civil rights of people with disabilities over the past four decades, especially as organizations like United Spinal look to move beyond physical access and work toward the equal inclusion of people with disabilities into all aspects of society.

5. Paralyzed Veterans Access Essential Services, 1948

The modern disability rights movement

has its origins in a group of paralyzed WWII veterans who began organizing in 1946, demanding the essential services they needed to live independently. In 1948, 70 members of this new organization that would eventually become United Spinal held a demonstration in New York’s Grand Central Station to gather signatures supporting the nation’s first accessible housing bill. The bill provided federal funds to build accessible homes for paralyzed veterans.

Other significant wins from those early years include improving health care and rehab services available to paralyzed veterans, securing access to job training and adaptive vehicle grants. The services and funding secured for paralyzed veterans would form the building blocks for many federal programs that provide essential services to the broader disability community. ■



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Roll on Capitol Hill

The Roll on Capitol Hill is United Spinal's signature annual policy event. It supports key advocacy priorities for its membership and the broader disability community to ensure that legislators include wheelchair users and all people with disabilities in policy debates on Capitol Hill.

Since the inaugural Roll on Capitol Hill in 2012, hundreds of United Spinal members have attended thousands of meetings with their congressional representatives to fight for greater access to quality affordable healthcare, community integration, disability rights, and much more. Whether in person in Washington, D.C., or online, the multi-day event has played a formative role in securing numerous policies critical to the SCI/D community and developing the next generation of leaders and advocates.

Georgia member Kim Harrison explained how attending transformed her from a nervous outsider to a fierce advocate. "I was very intimidated the first time I came, and I wondered what someone like me was doing here," she says. "Now it's not 'who am I?' but 'watch out for who I am.'"

"We need events like Roll on Capitol Hill more than ever," says Vincenzo Piscopo, United Spinal president and CEO. "The stories we tell about being able to land our dream job, move to our dream cities, and live truly independent lives, or proudly roll across the stage at graduation continue to be matched by those who remain underserved by our society. There's so much work to be done."



(Top-Bottom) Advocates meet in the lobby of Hart Senate Building before a meeting; Sen. John McCain speaks at the 2013 event; attendees soak up a full day of speakers and education. United Spinal's CEO Vincenzo Piscopo hitches a ride at the 2018 ROCH (far right).



(Top-Bottom): Arkansas member Kesha Pilot meets with Sen. John Boozman; Daniela Castagnino cruises the capitol with partner, Matt, in tow; participants take a moment to rest from a busy day.





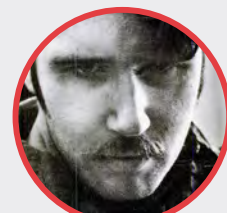
HISTORY

**Curb cuts. Lifts on buses.
Accessible businesses.
SCI healthcare specialists.**

We hardly have to think about these things anymore since they're an accepted part of modern life. Today's disability access that we take for granted happened because of the leadership of paralyzed veterans who no one even thought would survive. Their story is our story.



1946-50s:
This is one of the earliest photos of EPVA's founders.



1969-70:
Marine Mark Dumpert tells Life Magazine about the conditions at the Bronx VA.

How We Became UNITED SPINAL ASSOCIATION

BY JOSIE BYZEK

Today, United Spinal Association is the largest disability membership organization in the world, with 59,000 members, 49 chapters, close to 200 support groups and over 100 rehab and hospital partners.

We're vibrant, diverse, active and energetic. In many ways, we are a young, up-and-coming disability network. Yet, our roots go back to the paralyzed World War II vets who came home to an inaccessible nation and founded our predecessor, Eastern Paralyzed Veterans of America. Much has changed since then, but aspects of their stories sound all too familiar.

1944-1968: OUT OF WAR AND INTO THE BATTLE FOR ACCESS

The outlook for paralyzed soldiers re-

turning from World War II was dire. Since their life expectancy was one to five years, they were written off as lost causes.

"The situation in the treatment of spinal cord injury at that hospital was typical of most places," said George Hohmann, who was injured in 1944 and sent to Bushnell Military Hospital in Utah. "And that was almost total neglect except for the care of the nurses and especially the volunteers from the communities around. Medical staff knew nothing about what could be done for us and made short and sweet of the fact that there wasn't a damn thing that could be done for us but keep us alive until we died. And this is a quote that I was told one day: 'And that wouldn't be very damn long.' The prognosis was about two years." That

was for paraplegics. Quadriplegics didn't last even that long.

The East Coast situation was similar, with just a glimmer of hope. "We had 300 paraplegics at England General Hospital, Atlantic City," recounted Bill Green, former national president and national service director of Paralyzed Veterans of America. "Dr. Glen Spurling came up from the surgeon general's office, and he was asked what they were going to do with the paraplegics. His remark was, 'We'll put them in a corner of the hospital. They're going to be dead in a year anyway.' Well, at that point, we blew our stacks. Because we knew that there was a doctor in Boston who had treated paraplegics successfully since 1935, Dr.

Donald Munro.



1983:
EPVA Executive Director James J. Peters looks on as the historic MTA settlement is announced.



1990s:
Terry Moakley proudly poses in front of a lift-equipped city bus.



2004:
EPVA expanded its mission and changed its name to United Spinal Association.



2017:
United Spinal members protest for Uber and Lyft to offer accessible rides.



2019:
United Spinal staff and members march in the New York City Disability Pride Parade.

We felt that if he could, why couldn't the Army set up programs? We didn't even have OT. And they looked upon PT as being a means of amusing the patients. This was the Army hospital. The veterans' hospitals were even worse."

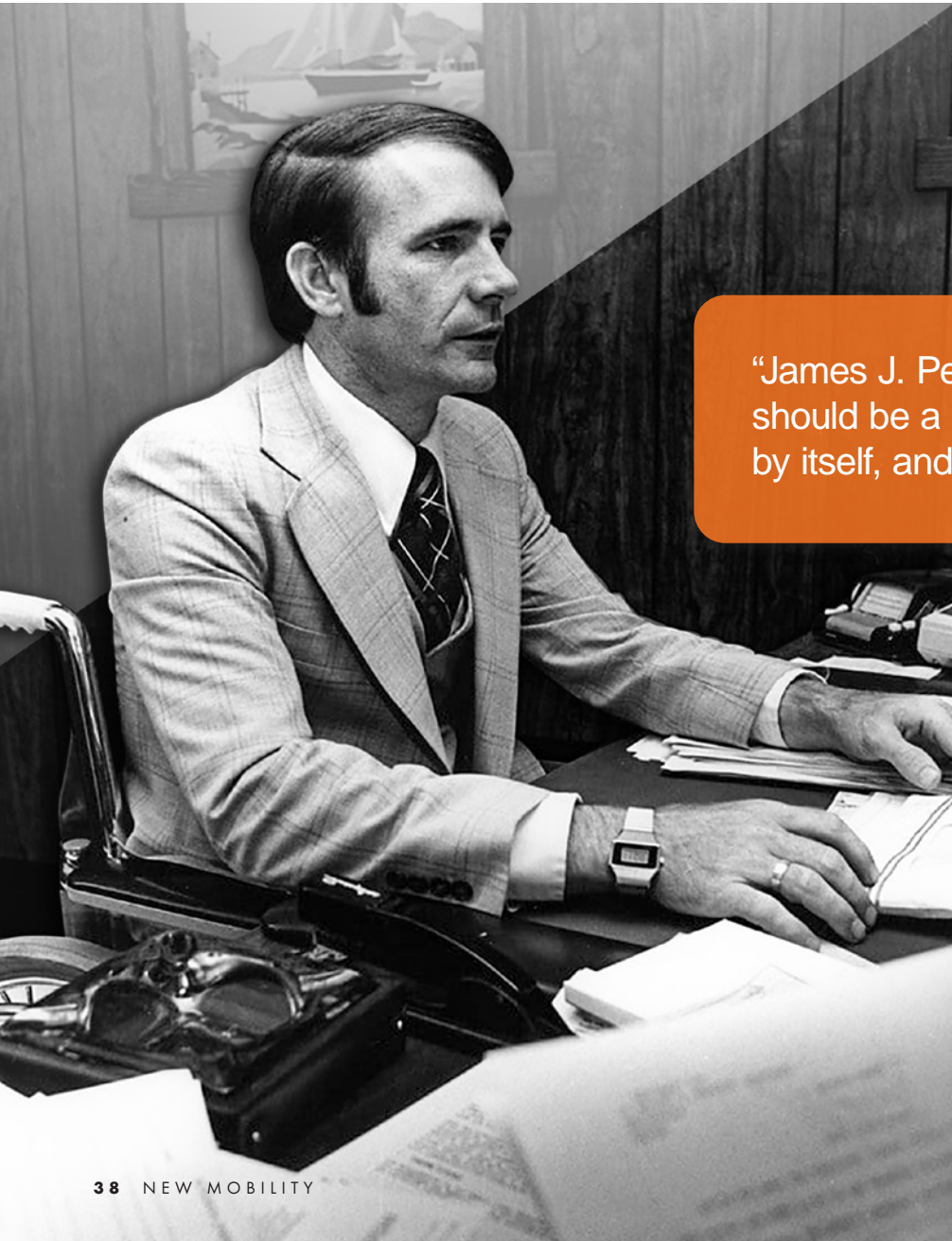
Veterans like Hohmann and Green found each other over the next few years, began forming groups and got busy writing bylaws and organizational charters for their new associations.

On April 29, 1947, the New York City-based Eastern Paralyzed Veterans of America voted in its first slate of officers, which included Robert Moss as recording and executive secretary.

The previous year, 1946, Moss and fellow veterans rolled into Grand Central Terminal to gather signatures in support of the nation's first accessible housing legislation. This protest is considered EPVA's founding event. Moss' efforts were successful as Pub-

lic Law 702 passed in 1948. "We were faced with a group of young men with a physical handicap that had virtually no survivor prior to then," said Moss. "There was no way of coping with society as society was then constituted. There were no programs for survival, there were no care programs, there was certainly no such thing as elimination of architectural barriers — there was no legislation for it. The needs were tremendous."

The '50s to '60s were quieter, with a significant exemption being when EPVA joined with other advocacy groups to push for the passage of what became the Architectural Barriers Act of 1968. "I wanted it to be simple. I wanted accessibility to be one of the items on the checklist of designers and builders," said Hugh Gallagher, who wrote the law. He was a legislative aide



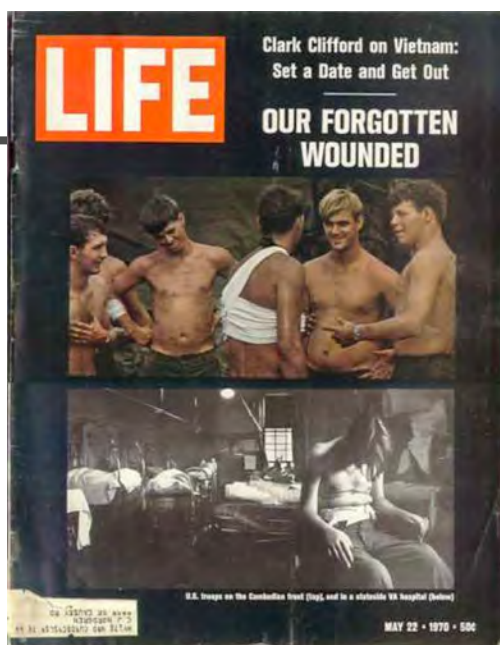
"James J. Peters believed SCI should be a medical specialty all by itself, and he made it happen."

to Sen. Bartlett of Alaska and used a wheelchair due to polio.

The law requires federally-funded buildings and facilities to be accessible for wheelchair users — thus setting the stage for more comprehensive, future legislation such as Section 504 of the Rehab Act and the Americans with Disabilities Act.

1970-1990: REBIRTH, REJUVENATION AND REDEDICATION TO THE CAUSE

PVA and EPVA might have quietly disappeared if not for the energy and organizational know-how of James J. Peters, an Army civil engineer who



Life Magazine's article on the deplorable conditions at the Bronx VA helped change conditions in America's military hospitals.

The article, published May 22, 1970, highlighted how Vietnam War vets with SCI lived longer than their counterparts in WWII and the Korean War, and this time around, quadriplegics were surviving.

But they had nowhere to go.

Marine Marke Dumpert told *Life* how he was blasted into the air at Khesanh, Vietnam, by a 6-foot Russian-made rocket and sustained quadriplegia. "The day they moved me into that gloomy 30C ward, I knew I was back at the battlefield," he said. "It was the misery of Khesanh all over again. I spent over a month and a half in an 8-by-21-foot bunker in Khesanh. I remember the smell of four other guys plus myself, when we had to use water to drink, not to wash with, when we lived with garbage rather than dump it and get hit by

a sniper. But at least in Khesanh, you could joke and be lighthearted. Death was around you, but there was still the possibility of getting out. Here in this ward, living with the misery of six neglected guys who can't wash themselves, can't even get a glass of water for themselves, who are left unattended for hours ... it's sickening."

The urine bags of Dumpert and other quads in the VA spilled over because there weren't enough attendants to empty them. "It smells and cakes something awful," said Dumpert, of the waste. Another Bronx VA inmate was anti-war activist Ron Kovic, who wrote the book, *Born on the Fourth of July*.

The vets' efforts led to the hospital being razed to the ground and rebuilt. In 2002 it was renamed after James J. Peters.

If that were all Peters was known for,

sustained a spinal cord injury in 1967. Similar to the WWII vets, Peters found himself trapped in deplorable conditions in the Bronx Veterans Administration hospital. Two years later, in 1969, while still an inpatient, Peters managed to get *Life Magazine* to do an exposé called "Our Forgotten Wounded" on the conditions in the Bronx VA.



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United Spinal Association and members of its Arizona chapter gathered for an inaugural 'Roll on Arizona's Capitol' at the Arizona State Capitol Rose Gardens on January 22, 2018, to advocate for progressive legislation that benefits wheelchair users and all people living with disabilities



"We went from being a local vets' group to a national SCI/D organization and gained chapters nationwide."

it'd be enough. But it was just the start.

Peters was named executive director of EPVA, a small organization that housed the even smaller PVA.

For a while, the two associations joined to form the PVA/EPVA, supported by a direct mail operation. "Since its inception, PVA/EPVA, Inc., has raised more than \$1 billion in donations for programs that serve veterans with SCIs throughout the nation," wrote Terry Moakley in his 2002 obit for Peters. Moakley was also a well-known advocate who served as president of EPVA.

Peters' vision went beyond serving veterans. In 1977, he revitalized the

became today's ASCIPs," says Weisman, referring to the Academy of Spinal Cord Injury Professionals. "He believed SCI should be a medical specialty all by itself, and this was the way to do that."

His tenure was a fruitful time for policy work since he recognized good health is only one part of quality of life. He and Moakley famously recruited Weisman to be EPVA's general counsel in a men's restroom after they saw Weisman take it on the chin from his boss in the New York Governor's office for defending disability rights. Weisman's policy wins are legendary, spanning from successful lawsuits for accessible transportation to passage of the Americans with

Disabilities Act in 1990. You can read about some of them in the Policy section beginning on page 29.

ward enforcing it. Some post-ADA wins include helping to ensure all NYC buses had lifts and all sidewalks had curb cuts. Its Taxis for All campaign finally won agreements for wheelchair users to be able to hail cabs — and ride-share vehicles from companies like Uber and Lyft.

In 2004, EPVA expanded its mission to officially include all people with spinal cord injuries and disorders, regardless of military service. To reflect this new direction, it changed its name to United Spinal Association. The organization will always be there for wounded veterans, and in 2005 it successfully lobbied Congress to pass traumatic injury insurance legislation to provide between \$25,000 and \$100,000 for active-duty soldiers who sustained severe injuries.

But the real success story of this era began in 2010 when United Spinal Association acquired the National Spinal Cord Injury Association and New MOBILITY. "For us, it was amazing," says Weisman. "First of all, having New MOBILITY as our house publication is a huge benefit as it unites our members. People with disabilities live all over the place, rural to urban, many are iso-



James Weisman

former president and CEO of United Spinal Association
@unitedspinal

"We believe wheelchair users should be involved in creating disability policies. We're not just here to fight for a seat at the table. We're here to fight for a seat at the head of the table."

American Paraplegia Society, the national organization for physicians who specialized in caring for people with SCI. Then during the early '80s, he founded the American Association of Spinal Cord Injury and the American Association of Spinal Cord Injury Psychologists and Social Workers. "They

1991-2021: POST-ADA OR PRE-INCLUSION?

After successfully shepherding the ADA into law, EPVA turned its attention to-

lated, and we show them what life can be like. We always thought it was the perfect portrayal of members. And the merger with NSCIA was very similar. We went from being a local vets' group to a national SCI/D organization and instantly gained chapters nationwide. Our motives were pure, and I think people got it."

Today there are United Spinal chapters in most major cities and many smaller ones, and there are United Spinal advocates in practically every legislative district. Together, our members represent all aspects of American life, and under the leadership of our new President and CEO Vincenzo Piscopo, we continuously become more vibrant and diverse.

"I see diversity and inclusion as a painting. If it were just a plain canvas, it would be boring. It would not attract anybody, and it would not communicate anything. As you start adding colors, shapes and textures, it starts to become beautiful, and you want to see it and hang it in your room and all of that," says Piscopo. "When you have a diverse team, you add different points of view and experiences, making the work more beautiful. You can engage with more people, and they are proud to have you in their lives."

Our earlier leaders learned their organizational skills while serving in the armed forces. Piscopo comes to us from the global corporation Coca-Cola. He served as a vice president and developed a similar, yet different, set of organizational skills that promise to move us forward in new, exciting directions.

An old black and white photo shows Robert Moss leading his group of fellow veterans in a protest. They just wanted to be welcomed back home from war. They wanted a place to live, the means to travel and decent medical care. Moss carries a sign that says, "Don't Let Us Down,"

meant for nondisabled Americans to remember the men who sustained SCIs while fighting for them. But as a member of the organization that he and those vets started, I feel it as a charge for us to con-

tinue the work they began.

We have not let them down. We've built a vibrant, diverse community whose achievements they would marvel at. And we're just getting started. **MM**

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Meet New Member Malea Remele

Age 19, from Lisbon, Connecticut

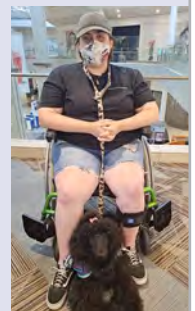
Spinal Stenosis, Spondylolisthesis, Congenital Anterolisthesis

Owner of Malea.Made, an online storefront featuring self-made crochet items

Why I joined United Spinal: I learned of United Spinal Association while recovering from two major spinal surgeries. I decided to join so that I could make a difference in our community.

What is the one disability-related product you couldn't live without? I cannot live without my reacher. Because I can't bend, this small product makes a big difference. Also, my wonderful service dog, Grazie, helps me open and shut doors.

Meet other members or join United Spinal at unitedspinal.org





THERE ARE ANNIVERSARIES, AND THEN THERE ARE ANNIVERSARIES

This month we're celebrating the 75th anniversary of United Spinal Association. Four years ago, we published a story about a different type of anniversary — how people commemorate the day they were injured. "SCI Anniversaries: Why Do We Celebrate Them?" looked at the experiences of 10 people who mark that date each year. Resoundingly, they noted they're not celebrating their injury — they're celebrating life and resilience and adaptation and moving forward.

"When I woke up 40 days after being run over, my daughter's photo was on the wall," said John Casey. "She was wearing the same dress she wore that day. I knew I had so much to live for, for my beautiful wife, Christina, and our wonderful twins, Marlana and Johnny. Now I celebrate life every July 11. I am a very fortunate person."



NM LIVE VIDEO SERIES with Teal Sherer

OCTOBER: UNITED SPINAL PRESIDENT AND CEO VINCENZO PISCOPO

"I'd rather be naïve and dream big than be realistic and stuck on the status quo."

— United Spinal President and CEO Vincenzo Piscopo

In this month's NM Live, Piscopo explains his quote and the underlying philosophy that guides him and tells Teal why this way of thinking is essential for the disability community.

Piscopo shares his excitement over United Spinal's 75th Anniversary Virtual Gala on November 10. He invites everyone to attend (it's free!) for a chance to celebrate United Spinal with celebrities Lin-Manuel Miranda and Ali Stroker, a performance by Carina Ho, and appearances by elected officials like Senator Tammy Duckworth.

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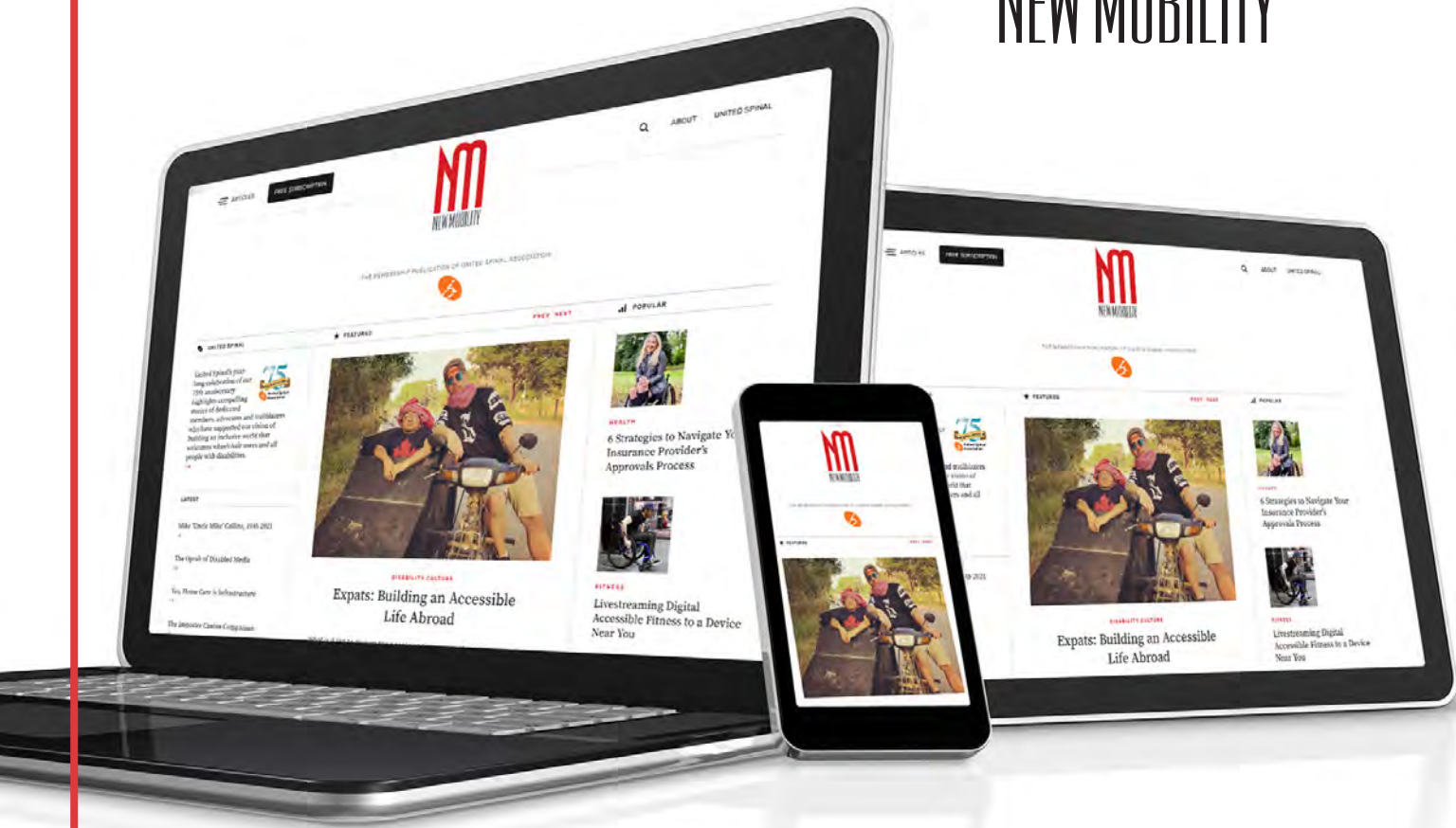
Toronto
Nov. 12-13, 2021

Dallas
Dec. 3-5, 2021

Chicago
June 24-26, 2022

Miami
Nov. 4-6, 2022

Houston
August 5-7, 2022



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