



# ***United Spinal Association***

## ***Media Kit***



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[WWW.UNITEDSPINAL.ORG](http://WWW.UNITEDSPINAL.ORG)



# United Spinal Association

## MISSION & HISTORY

United Spinal Association's mission is to improve the quality of life of all people living with spinal cord injuries and disorders (SCI/D).

United Spinal was founded in 1946 by a determined group of paralyzed WWII veterans in New York City who advocated for greater civil rights and independence for themselves and their fellow veterans. Rejecting the poor treatment they received at their local VA hospital, they decided to form a support group. From these modest beginnings, United Spinal was born.

Since then, our core belief has remained unchanged. Despite living with SCI/D, a full, productive, and rewarding life is within the reach of anyone with the strength to believe it and the courage to make it happen.

United Spinal has built upon the strong foundation forged by our organization's founders—never losing sight of their grassroots efforts to provide a voice to the disability community and to transform the public's perception of wheelchair users.

Today, United Spinal is the largest non-profit organization dedicated to helping people living with SCI/D. We are committed to providing active-lifestyle information, peer support and advocacy that empower individuals to achieve their highest potential in all facets of life.

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## COMMUNITY

Each year, United Spinal helps thousands of wheelchair-users, veterans, and people with multiple sclerosis and other spinal cord disorders overcome the daily challenges of living with a disability. And we extend our support to those most important in their lives— their family members and caregivers.

United Spinal's 35,000 members include individuals of all ages and backgrounds who are driven, independent, and active participants in our society. They are paralympians, wounded warriors, talented artists, kids with big dreams, proud parents, empowered women, self-advocates, heroes, survivors, and accomplished professionals.

National Spinal Cord Injury Association (NSCIA), [www.spinalcord.org](http://www.spinalcord.org), is the membership arm of our organization. NSCIA has over 65 years of experience educating and empowering individuals with SCI/D to achieve and maintain the highest levels of independence, health and personal fulfillment. It has more than 60 local chapters and support groups nationwide, connecting people with SCI/D to their peers and fostering an expansive grassroots network that enriches lives.

Our membership program is a lifeline for many individuals that are focused on regaining their independence and improving their quality of life—whether they are leaving rehab after sustaining a spinal cord injury, learning to live with symptoms of a spinal cord disorder, or have spent years of frustration coping with disability.

NSCIA provides members guidance and resources on a variety of topics they are passionate about, such as employment, affordable housing, transportation, health care, home- and community-based independent living, education, peer support, and leisure and recreation.

Membership is also open to medical and nonmedical professionals, product and service providers, public policy makers and others who are interested in the issues affecting people with SCI/D.





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## PROGRAMS

United Spinal's programs and services enable people living with SCI/D to pursue rewarding careers. They give members the opportunity to discover new hobbies and get more involved in their communities—while others find motivation to challenge the status quo through self-advocacy.

### *Travel Made Easy*

In its effort to address the common headaches travelers with disabilities encounter when using travel agencies unfamiliar with booking accessible accommodations, United Spinal created its Able to Travel program ([www.abletotravel.org](http://www.abletotravel.org)). Able to Travel meets all the accessibility needs of business and leisure travelers with disabilities, including air travel, transportation, cruises, tours and excursions, hotel accommodations, and access to vital medical equipment.



### *Centralizing Resources*

One important component to our membership Web site ([www.spinalcord.org](http://www.spinalcord.org)) is Spinal Cord Central, which offers valuable resources and an extensive e-library of knowledge books for people with SCI/D, their families and friends, health care professionals, direct service providers, and businesses focused on serving this community. Our experienced information specialists understand all aspects of living with SCI/D. They are dedicated to helping visitors to the site find the resources and solutions that they're looking for, whether their intent is locating information on their own, seeking expert assistance, or finding a friendly port in a stormy situation.



### *Push for More!*

People with disabilities have had limited freedom when choosing equipment critical to their quality of life and independence due to government and health insurance company restrictions. One of United Spinal's newest programs, UsersFirst, advocates for improved access to seating and mobility equipment and denounces the long-established "one-size-fits-all" mentality when it comes to the selection of wheelchairs and other mobility devices. UsersFirst ensures people with disabilities nationwide have access to equipment that's right for them, so they can live the lives they choose.

### *Serving America's Veterans*

United Spinal is committed to serving our nation's veterans and their family members in obtaining the benefits and services they desperately need and deserve. Our VetsFirst program ([www.vetsfirst.org](http://www.vetsfirst.org)) advocates for all generations of veterans, including individuals living with post-traumatic stress disorder and traumatic brain injuries. VetsFirst's network of National Service Officers provides free assistance, resources, and representation for veterans struggling to navigate the intricate and often confusing VA claims process. The program connects with over 2,000 veterans annually.

through its call center and online help desk. Staff tackles each case individually, taking the time to discuss self-help tips and assist with questions on military separation, claims appeals, and state benefits.

## ***Bringing You Up to Code***

United Spinal's Accessibility-Services program ([www.accessibility-services.com](http://www.accessibility-services.com)) ensures that the built environment is accessible to all people with disabilities, from wheelchair-users to those who use canes, walkers, and scooters. Our certified specialists, plan examiners, attorneys, architects and code enforcement officials maintain the highest accessibility standards as key consultants on projects big and small, including arenas, sports venues, museums, residential projects, and concert halls.



## ***We're Mobile, So You Can Be Too***

Many of United Spinal's members pursue active lifestyles. Over 30 years ago, we established our Wheelchair Medic program ([www.wheelchairmedic.com](http://www.wheelchairmedic.com)) to keep our members' wheelchairs and other mobility equipment functioning as good as new. One of the largest mobility equipment repair programs in the nation, Wheelchair Medic operates a fleet of repair vehicles that provides door-to-door service in the Greater New York City area, taking the hassle out of transporting broken equipment to repair shops.

## ***It's All About Choices***

USA Techguide ([www.usatechguide.org](http://www.usatechguide.org)), United Spinal's Web hub exclusively dedicated to sharing information on the latest wheelchairs, mobility scooters, and assistive technology choices receives over 50,000 visitors per month. It's the first place many people with disabilities stop before purchasing new gear. Visitors can read and submit reviews on wheelchairs, mobility scooters, cushions and standing devices, as well as search for all types of assistive equipment.

## ***Ask Us***

"Ask Us" is a direct service delivery tool used by many of our programs to increase United Spinal's public outreach efforts. It offers members and other people with disabilities an opportunity to submit their questions through a fast and easy online form. Serving over 5,500 individuals annually, Ask Us makes it convenient to obtain information and guidance without having to search the Web or make phone calls. Unlike other online support desks that offer automated, canned replies, Ask Us takes a much more unconventional and personal approach in responding to all inquiries. Knowledgeable staff members are the driving force behind the program, offering timely feedback on a multitude of disability-related issues.



# **United Spinal Association**

## **QUICK FACTS**

Two years after its founding, 70 of United Spinal's members rolled into Grand Central Station in New York City in 1948 and collected signatures supporting an accessible housing bill. Days later, President Truman signs the legislation into law.

Our former executive director and U.S. Army veteran James J. Peters convinced Life magazine in 1970 to run a cover story exposing the deplorable conditions facing Vietnam veterans with spinal cord injuries at the Bronx VA Medical Center. The story sparked a national outrage and convinced Congress to raze the facility and build a brand new hospital with special attention to SCI. In 2005, the hospital was renamed in honor of Peters and his work to ensure all veterans receive quality health care.

United Spinal has written federal legislation critical to the livelihood of people with disabilities, including portions of the Americans with Disabilities Act—the landmark civil rights law that prohibits discrimination based on disability. Since it was enacted in 1990, we have strived to ensure that the promise of the ADA becomes a reality to all it protects.

We have donated over \$52 million for spinal cord research and helped launch Yale University Medical School's Center for Neuroscience and Regeneration Research—one of the most respected spinal cord research facilities in the country. Led by a dedicated staff of scientists from around the world, the Yale Center continues to make an impact on the treatment, and ultimately the cure, of SCI/D.

NSCIA, United Spinal's membership program is committed to providing life-long resources for people with SCI/D. It actively develops and implements initiatives that allow direct contact with newly injured/diagnosed individuals and their families, within the first few days of injury.

In 1996, United Spinal was instrumental in getting New York City to create sidewalk curb ramps so that wheelchair users could navigate the City's streets. We also initiated a major advocacy campaign to make every bus and many of the subway stations in the City accessible. Each month, more than 90,000 people with disabilities ride New York City's lift-equipped buses and the program has become a blueprint for other US cities.

Paul J. Tobin, United Spinal's President and Chief Executive Officer is a United States Navy veteran and wheelchair user who worked his way up the ranks at our organization since 1995.

Lex Frieden, United Spinal's Chairman of the Board is one of America's pre-eminent disability activists and leaders of the Independent Living Movement. He was one of the major figures that oversaw the writing of the first draft of the Americans with Disabilities Act in 1990. From 2002 to 2006, he served as Chairman of the National Council on Disability (NCD), a presidentially appointed body.

In the aftermath of Hurricane Katrina, United Spinal staff stocked an accessible bus with 32 wheelchairs, two hospital beds, a Hoyer lift, and other mobility equipment -- drove to New Orleans -- and donated it to a local independent living center that was out of supplies and in need of transportation for its members.

Our Disability Etiquette booklet -- which offers tips on interacting with people with various disabilities -- has been distributed nationwide to thousands of businesses, schools, and organizations to help increase awareness of the importance of disability etiquette. United Spinal regularly hosts disability etiquette training sessions and webinars focusing on increasing sensitivity in the workplace and marketplace to issues affecting people with disabilities.

Our membership site, [www.spinalcord.org](http://www.spinalcord.org), has grown to be a leading source of news and information for the SCI/D community, and the larger disability community.

United Spinal's New Mobility magazine ([www.newmobility.com](http://www.newmobility.com)) reaches 24,000 active wheelchair users each month. The publication encourages the integration of active-lifestyle wheelchair users into mainstream society, while simultaneously reflecting the innovative world of disability related arts, media, advocacy and philosophy.

We are vigilant in our efforts to challenge those who evade compliance with the ADA in transportation, housing and employment. In 2011, United Spinal filed a class action lawsuit against the New York City Taxi and Limousine Commission (TLC) for violating the law by failing to provide yellow taxis that wheelchair-users can access.

Our Accessibility Services program was a consultant for accessibility of the New Yankee Stadium. Our staff met with the team to review plans for compliance with the ADA and local access codes, conducted community outreach meetings, and performed as-built inspections to ensure that the facility was built according to the architectural plan.

United Spinal hosts unique events every year that attract thousands of consumers, advocates, community leaders, and disability organizations. Our conferences and expos help people discover new paths to independence and celebrate all of our individual abilities and talents.



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## WHAT IS SPINAL CORD INJURY/DISORDER (SCI/D)

### Spinal Cord Injury

Spinal cord injury can result in paralysis of the muscles used for breathing; paralysis and/or loss of feeling in all or some of the trunk, arms, and legs; weakness; numbness; loss of bowel and bladder control; and numerous secondary conditions including respiratory problems, pressure sores, and sometimes fatal spikes in blood pressure. Approximately 12,000 new spinal cord injuries occur in the U.S. each year. A majority of injuries occur from motor vehicle accidents, falls, work-related accidents, sports injuries, and penetrations such as stab or gunshot wounds.

### Spinal Cord Disorders

There are many different disorders of the spinal cord, below are a few common ones:

#### Amyotrophic Lateral Sclerosis (ALS)

ALS, sometimes called Lou Gehrig's disease, is a rapidly progressive, invariably fatal neurological disease that attacks the nerve cells (neurons) responsible for controlling voluntary muscles. One or two out of 100,000 people develop ALS each year.

#### Multiple Sclerosis (MS)

MS is a chronic, progressive, degenerative disorder that affects nerve fibers in the brain and spinal cord. MS symptoms often worsen, improve, and develop in different areas of the body. Early symptoms of the disorder may include vision changes (blurred vision, blind spots) and muscle weakness. MS affects about 500,000 people in the U.S.

#### Post-Polio

Polio—also known as poliomyelitis—is a contagious viral disease that attacks the central nervous system and can cause temporary or permanent paralysis and weakness. While the disease has been virtually conquered in many areas of the world through vaccines, some survivors of childhood polio have been experiencing a new syndrome called “post-polio” that typically emerges 25 to 30 years after the initial attack. Post-polio occurs in approximately 25–50 percent of people who survive a poliomyelitis infection.

#### Spina Bifida

Spina bifida is the most common neural tube defect. In the developing vertebrate nervous system, the neural tube is the precursor of the central nervous system. Neural tube defects result from the failure of the spine to close properly during the first month of pregnancy. Worldwide incidence of spina bifida is 1–2 cases per 1,000 births, but certain populations have a significantly greater risk.

## PUBLIC POLICY

United Spinal Association is committed to advancing public policies that lead to greater civil rights and independence for people with disabilities.

Throughout our history, we have advocated on behalf of individuals living with SCI/D through state and federal legislation and accessibility litigation in the courts. Our members know that we are on their side, and will remain there until our support is no longer needed.

By leveraging all of our resources, we have stronger involvement in community affairs and more opportunities to advance public policies. This allows us to form key alliances that expand the reach of our mission.

Our public policy initiatives focus on expanding education and employment, improving enforcement of the Americans with Disabilities Act (ADA), ensuring adequate access to public transportation and taxi services, and amending Medicare rules that restrict many individuals to their homes and nursing facilities.

## Education and Awareness

Disability awareness has always been an integral part of United Spinal's mission and culture. Our aim is to raise public awareness on the often-overlooked disability issues that affect our community. Throughout the year, we share news and information on our key initiatives, life-enhancing events and our inspirational members with print and web media outlets nationwide.

Maintaining the highest quality communications, we promote our mission through our websites; social media pages; press releases; magazines and informative publications; participatory events and instructional sessions; public service announcements; and e-mail alerts. But the greatest asset in spreading our message has always been our members and supporters who believe in the work we do.

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# United Spinal Association



Disability  
Leadership & Policy  
Summit

THE ANNUAL  
**FROM WITHIN**  
CONFERENCE

