Calling all Roll on Capitol Hill Advocates for 2014

Alexandra Bennewith, MPA
VP Government Relations, United Spinal Association

Jenn Wolff, OT
Manager, UsersFirst, United Spinal Association

Thursday, June 5, 2014
Thank You To Our Sponsors
Webinar Archive/Upcoming Webinars

- **Advice for Parents and Caregivers of Children with Special Needs**
  Wed, Jun 11, 2014 1:00 PM – 2:00 PM EST

- **Raising a Child with Special Needs: A Mother’s Story**
  Thu, Jun 26, 2014 1:00 PM – 2:00 PM EST

- **Intro to Implanted Neural Prosthesis for People with SCI/D**
  Wed, Jul 9, 2014 3:00 PM – 4:00 PM EST

- **Fight to Improve Wheelchair Access in NYC and Its National Implications**
  Thu, Jul 24, 2014, 3:00PM – 4:00 PM EST
  24th Anniversary of the ADA

http://www.spinalcord.org/webinar-archive/
Introductions

Alexandra Bennewith, MPA
VP, Government Relations
United Spinal Association

Jenn Wolff, OT
VP, Community Initiatives, UsersFirst
To ask a question or make a comment, please type in the “Questions” box

abennewith@unitedspinal.org
jwolff@usersfirst.org
June 22-25, 2014

United Spinal Association’s Annual Legislative and Advocacy Conference

• United Spinal’s Public Policy department
• NSCIA – United Spinal’s Membership and Chapter division
• UsersFirst – United Spinal’s grassroots advocates division

You can find more information at:
http://www.unitedspinal.org/events/roll-on-capitol-hill/
United Spinal Association

- Parent company
- Consumer-run, nonprofit
- Began in 1946
- Authors of Title II of the ADA
- 60 years of policy experience in DC
- Over 40,000 members
- 46 chapters nationwide
- Over 170 support groups
- NSCIA – chapter network/UsersFirst – grassroots network
- Fields over 500 consumer calls/month
Who is United Spinal Association?
United Spinal Association

Mission: To improve the quality of life of all people living with spinal cord injuries and disorders (SCI/D). 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.

www.unitedspinal.org

UsersFirst

Mission: To empower and amplify the voice of wheelchair consumers and maximize our independence in the community. UsersFirst rejects the one-size-fits-all perception of wheelchairs. The right wheelchair is essential so we can live the lives we choose.

www.usersfirst.org
National Spinal Cord Injury Association

*Mission*: NSCIA chapters are vital partners in providing support, resources and opportunities right in your own community. Contact the NSCIA chapter nearest you to learn more about their programs.

[www.spinalcord.org](http://www.spinalcord.org)
Roll on Capitol Hill 2014
Program Agenda

Roll on Capitol Hill 2014 Schedule

• **Sunday June 22nd:**
  6:30pm – 7:30pm
  Welcome Reception

• **Monday, June 23rd:**
  9:00am – 5:00pm – Speaker Panels and Issue Briefings
  **Keynote Speaker: Claudia Gordon**, Special Assistant, Department of Labor Office of Federal Contract Compliance Programs

• **Tuesday, June 24th:**
  Capitol Hill Day
  Congressional Awards Reception, 5:00pm – 7:00pm

• **Wednesday, June 25th:**
  **United Spinal/NSCIA Recognition Breakfast**, 8:30am – 10:30am
ROCH 2014 Honorees

• **Sen. Bob Casey (D-PA)** will be honored with the 2014 Disability Rights Champion Award for his work to ensure every American has access to high-quality, affordable health care.

• **Rep. Al Green (D-TX 9th)** will receive the 2014 Vets First Congressional Bronze Star Award for his efforts to increase opportunities for veterans living with disabilities to reintegrate into their communities.

• **Rep. Cathy Morris Rodgers (R-WA 5th)** will be presented with the 2014 Outstanding Congressional Leadership Award for her extensive leadership and vocal support of disability issues.
ROCH Congressional Co-Chairs

- Sen. Thad Cochran (R-MS)
- Sen. Charles Schumer (D-NY)
- Rep. James Sensenbrenner (R-WI 5th)
- Rep. Joe Crowley (D-NY 14th)
Support HR 942/S 948, **Ensuring Access to Quality Complex Rehab Technology Act** which will create a separate benefit category for CRT and ensure access to critical medical equipment for people with disabilities.

**CRT**
- Adjustable
- Durable
- Unique fit

**NOT CRT**
Non adjustable, basic
My Medicaid Matters

- Protect and increase essential home and community-based services to enable people with disabilities to remain in their homes and contribute to their community.
  - Medicaid funding is often at risk of being cut.
  - Many states are transitioning from Medicaid fee-for-service (providers are paid for each service) to managed care models with managed care organizations (MCOs).

- Ensure adequate funding for all Medicaid services.
- Oppose restructuring of Medicaid funding through block grants or per capita caps.
- Support and expand state participation in Medicaid programs that increase funding for HCBS.
- Promote state adoption of the Consortium for Citizens with Disabilities (CCD) and National Disability Leadership Alliance (NDLA) managed care principles. Adoption of the principles would ensure consumers transitioning to managed care have access to: consumer-directed care, dedicated state ombudsman advocates, and the specialized and supportive services they need to improve their quality of life and to remain in the community.
- Support and fund quality measures (i.e. data collection) that track how well Medicaid programs allow for: person-centered and consumer-directed services; timely provision of care; access to necessary services such as housing and employment; and, consumer satisfaction with those services.
A Path to an Improved Quality of Life: 
Support the ABLE Act

We support the Achieving a Better Life Experience Act (ABLE Act) of 2013, HR 647/S.313 which will help individuals and families save private funds to support people with disabilities for the purpose of maintaining their health, independence and quality of life.

- Education
- Housing
- Transportation
- Employment Support
- Health, Prevention and Wellness
- Assistive Technology/Personal Support Services
Ensuring Patient Safety, Access and Choice of Biologic Medicines

Why do we need to have protections in place?

• The ACA permits manufacturers of biosimilars to rely on clinical trial data from the original biologic as long as several conditions are met. However:

  • biologic medicines are unique and complex proteins that are made from highly specialized and purified living cells.

  • biosimilars are not identical “generic” versions of the innovator biologic medicines they seek to copy because they are made from different cell lines and different manufacturing processes.

  • biosimilars may provoke immune responses that differ from biologic medicines that can only be understood with adequate human clinical trials.
Ensure Access to Urological Supplies

• Recognize that individuals require access to specific catheter supplies that meet their specific medical needs, and that such products are not generic, one-type-fits-all commodities.

• Ensure Medicare, Medicaid, and private insurers within state/federal health care exchange marketplaces cover the full-range of prescribed catheter supplies, and do so in a manner that is not economically burdensome for the consumer.

• Ensure fair Medicare and Medicaid coding and coverage processes that recognize the function of urological medical supplies and will permit new innovative urological technologies to come to market.
Transportation Equity

We believe people with disabilities should have access to traditional and alternative modes of participation so that they can participate in society as fully as they wish and live independently in the setting they choose.

• **Support HR 3978, New Opportunities for Bicycle and Pedestrian Infrastructure Financing Act (NOBPIFA),** sponsored by Rep. Albio Sires (D-NJ 8th). The bill includes funding for achieving compliance with the ADA, improving public transit, biking and pedestrian infrastructure.

• **Support HR 3494/S 1708, the Bicycle and Pedestrian Safety Act,** sponsored by Rep. Earl Blumenauer (D-OR 3rd) and Rep. Howard Coble (R-NC 6th), and Sen. Jeff Merkley (D-OR) and Sen. Kelly Ayotte (R-NH). The bills would require the DOT to set a non-motorized safety performance measure.

• **Pass a long-term surface transportation bill with adequate funding measures.** Any bill should incentivize solutions to ensuring an accessible, affordable, reliable and safe transportation system in urban, suburban, and rural settings.
Convention on the Rights of Persons with Disabilities

• The UN Convention on the Rights of Persons with Disabilities (CRPD) is a human rights treaty that sets out the obligations of countries that ratify it to promote, protect, fulfill, and ensure the rights of people with disabilities.

• The CRPD is the first treaty to address disability rights globally. Like the Americans with Disabilities Act, the CRPD embodies the traditional American ideals of empowering people with disabilities to be independent, to claim personal responsibility for their own lives, and to be able to make their own choices.
Congressional Bipartisan Disabilities Caucus

Urge your Representatives to join the Disabilities Caucus in the United States House of Representatives to support the rights of people with disabilities.
A Successful Congressional Visit

- About 30 minutes
- Tell your story
- Use our talking points
- Be respectful
- Stay in touch
Advocating in Washington, D.C.
From grassroots to Washington, DC
Logistics – Getting around D.C.

Host Hotel:
Marriott Wardman Park
2600 Woodley Rd., NW
Washington, DC 20008

Additional Hotel:
Omni Shoreham Hotel
2500 Calvert St., NW
Washington, DC 20008
Go to http://www.wmata.com and click on the ‘Rail’ tab
Transportation to Capitol Hill
DC Metro
Transportation to and from Capitol Hill - DC Metro
Transportation

- Battle Transportation will be providing vans and buses Tuesday, June 24th from the hotel to Capitol Hill in the morning and from the Awards Reception back to the hotel in the evening.

- United Spinal has arranged discounted transportation through SuperShuttle to and from the airport and your hotel. Go to [www.supershuttle.com](http://www.supershuttle.com) to make your reservation, enter **United Spinal** under the company, and **SPINA** in the discount code box.
Additional Transportation

• DC Buses — www.wmata.com
• DC Circulator bus — www.dccirculator.com
• DC Accessible Taxis —
  – Royal Taxi, 202-398-0500 www.dctaxionline.com
  – Yellow Paratransit, 202-544-1213 www.orderyellowcab.com
• Contact Carol Tyson ctyson@unitedspinal.org (202) 556-2076, x7104
Capitol Complex Map

Areas of Interest

1. Russell Senate Office Building
2. Dirksen Senate Office Building
3. Hart Senate Office Building
4. U.S. Supreme Court
7. Cannon House Office Building
8. Longworth House Office Building
9. Rayburn House Office Building
10. Ford House Office Building
11. U.S. Botanic Garden & the National Garden

Red arrow indicates Capital Visitor Center* First Street Entrance & Exit (East Front)

*The Capital Visitor Center is the new entrance to the U.S. Capitol.
Security Screening on Capitol Hill

You must:

- bring a photo ID to enter Congressional buildings for Capitol Hill visits and Congressional receptions.
- pass through security screening. All bags are subject to thorough search and security screening.

Prohibited items include:
- Mace and pepper spray
- Any sharp or pointed objects
- Any bag larger than 14” wide x 13” high x 4” deep (per security discretion)
- Knives of any size (including pocket knives)
- Weapons of any kind
- Non-aerosol sprays
- Aerosol containers
- Cans and bottles (water bottles)
- Food

If it is raining or is likely to rain, bring along an umbrella and a plastic bag to protect the joystick on your power mobility device.
Accessible Entrances

**Capitol Visitor Center (CVC)** - main entrance at First and East Capitol streets.

**U.S. Capitol** - Public tours enter through the CVC official House business enters on the south side of the Capitol; official Senate business enters on the north side of the Capitol.

**Cannon House Office Building**
Entrance on New Jersey Avenue, SE, south of the terrace at the intersection with Independence Ave.

**Longworth House Office Building**
Main entrance, Independence & New Jersey Aves.

**Rayburn House Office Building**
Main entrance, horseshoe drive off S. Capitol St.

**Russell Senate Office Building** – Delaware entrance on ground level closest to Constitution Ave.

**Dirksen Senate Office Building** – 1st St. & C St. entrance.

**Hart Senate Office Building** - Second St. entrance.
Accessible Entrances
Capitol Hill Visits – All Shapes and Sizes
Capitol Hill Visits – All Shapes and Sizes
Get Involved and Make a Difference

• Become a member of United Spinal Association
  www.unitedspinal.org

• Join United Spinal Association’s Team Advocacy www.unitedspinal.org – visit our Advocacy Action Center
  http://www.unitedspinal.org/action-center/

• Join a chapter/support group or
• be the policy advisor for the chapter
  www.spinalcord.org

• Be a grassroots advocate
  http://www.usersfirst.org
More Ways to Get Involved

• Attend a town hall hearing/meeting in your state

• Find your Senator at www.senate.gov and your Representative at www.house.gov

• Call U.S. Capitol Switchboard: (202) 224-3121

• Or you can
To ask a question or make a comment, please type in the “Questions” box

abennewith@unitedspinal.org

jwolff@usersfirst.org