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Roll On Capitol Hill

The first annual Roll on Capitol Hill was held on June 25th and 26th in Washington, D.C. It was held to address issues that will directly impact the health, independence and quality of life of individuals living with spinal cord injury or disease.

The first day was a conference that gave more background on the issues that needed to be discussed with the legislators and well as prepare for the meeting. The position papers on those issues described below and can be found at http://www.unitedspinal.org/position-papers/.

Congressional Bipartisan Disabilities Caucus
We urge members of Congress to join the Bipartisan Disabilities Caucus and demonstrate their support for the rights of individuals living with disabilities.

Medicare Coverage of Intermittent Catheters for the SCI/D Community
We believe Medicare’s catheter policy has broken the physician-patient relationship and put the care at stake. The policy’s original flexible language must be restored.

UN Convention on the Rights of Persons with Disabilities (CRPD)
We support ratification of the CRPD to continue to advance the rights of people with disabilities throughout the world.

A New Medicare Complex Rehabilitation Technology Benefit is Needed
We support the passage of HR 4378. Ensuring Access to Quality Complex Rehabilitation Technology Act of 2012—that will create a separate benefit category for complex rehab technology.

How the Government Can Do More for You: Expanding Employment Opportunities
The government must do more to stimulate employment opportunities and improved income security for people with disabilities and take a transformational approach to promoting self-sufficiency and independent living via meaningful work opportunities, income generation, asset-building and community integration and engagement.

My Medicaid Matters: Fighting Serious Threats from Capitol Hill
We urge members of Congress to take a more balanced approach to financing Medicaid, one that is policy-driven and involves both expense savings and revenue enhancements to strengthen rather than diminish health care access, coordination and quality.

Provide Exceptions to Medicare Beneficiaries for High-cost Prescription Drugs
We support the passage of HR 3613, Part D Beneficiary Appeal Fairness Act and support implementation of a fair and reasonable exceptions and appeals process under Medicare Part D coverage for seniors and people with disabilities that depend on ‘specialty tier’ drugs to improve or maintain their health status and function.

Eliminate the Cap on Rehab Payments for Medicare Beneficiaries
We support the passage of HR 1546 and S 829, the Medicare Access to Rehabilitation Services Act which eliminates Medicare Part B’s arbitrary and unfair outpatient rehab therapy payment caps.

On Tuesday, wheelchair users and other advocates visited over 80 offices in the Representative and Senate buildings, sharing personal stories and leaving information on all the issues that can affect our ability to fully participate in our lives. Overall, it was a GREAT success!

The event came to a close with a reception to honor legislators who have truly helped our community. The Honorable John Carter (R-31st TX) was given the VetsFirst Congressional Bronze Star Award. The Honorable James Langevin (D-2nd RI), who is also a wheelchair users was recognized with the Junius A. Kellogg Award for Outstanding Congressional Leadership on Behalf of People with Disabilities. The last award, I had the honor of helping present the Honorable Tom Harkin (D-IA) with the James J. Peters Disability Rights Champion Award.

It was an amazing event. To be in the presence other wheelchair users and advocates who “get” the struggles/stigma that is hard to understand unless you use a chair or know someone who does, was just empowering and re-energizing. Then to be able to talk to the United Spinal Association leadership, who some of them have been fighting for disability rights for over 30 years, was truly a humbling experience.

I encourage any of you who have had difficulties with any of the issues addressed above, to share your stories – even with your Representatives and/or Senators. Policies will not be changed unless they hear from us, the constituents they are supposed to be working for. If you have any questions on how to do this or are interested in doing more advocacy work, please feel free to contact me, Jennifer Wolff, jdw071@hotmail.com

Celebrating Senator Harkin’s Award.
From Left: Jim Weisman (United Spinal, General Counselor), Senator Harkin, me and Paul Tobin (President and CEO of United Spinal)
8th Annual Adaptive Sports & Recreation Clinic

SCIA of Iowa Board Members wish to THANK each of you who participated, volunteered, or contributed in any way, to the 8th Annual Adaptive Sports & Recreation Clinic!!! We had a record turn out! We love to see familiar faces in attendance, and are excited to see new faces as well! The day started out a little brisk but turned out beautiful, sunny, and not too hot. As we were on our way home, it began to sprinkle rain drops….our timing was impeccable!

THANK YOU…..
To over 50 volunteers
To over 37 participants,
To over 28 sponsors and exhibitors
……ALL contributing to 1 fantastic event!

We look forward to seeing each of you next year at the 9th Annual Event! Please send us your suggestions and ideas. Planning the next event has already begun! We want to serve you!

THANK YOU to ALL of you who volunteered your time and talents, this day would not have been possible without you!

Volunteers include, but not limited to:
-Students from DMU Doctorate of Physical Medicine, Iowa State University, Simpson College, University of Iowa
-SCIA of Iowa Board Members

WE APPRECIATE EACH ONE OF YOU!!!
Enjoying Cycling Clinic!

Craig Hospital recently launched the Spinal Cord Injury Nursing Advice Line to address health related phone calls. It is designed to address health information needs of people living with spinal cord injury in the community in a comprehensive, standardized, evidence based practice, and programmatic approach. Resources for over 150 health issues have been compiled in a database of Craig nursing staff and doctors to answer questions from callers.

Examples of when a person may call the Nursing Advice Line:

- A non-emergent medical question arises that does not warrant a trip to the doctor’s office, yet needs answered.
- Experiencing changes in care and wondering whether it is “normal?”.
- A new caregiver arrives and needs education materials to help in the transition.

The Spinal Cord Injury Association of Iowa participated in the State Fair’s Building Bridges day on Friday August 17, 2012. This event is typically held on the second Friday of the Iowa State Fair from 9am to 4pm on the main concourse. The goal of this program is to educate fairgoers on programs, services, and support groups in Iowa to assist Iowans with disabilities. There were more than 20 tables highlighting programs such as Iowa Vocational Rehabilitation, Brain Injury Alliance, Paralyzed Veterans of America and Very Special Arts. Our table was next to our friends at Adaptive Sports Iowa. Fairgoers enjoyed watching the wheelchair basketball demonstrations, and received information on various programs in their communities in Iowa.

Iowa State Fair Building Bridges Day

Written by Joyce Ellens

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Easter Seals Lending Library: Part 3 of 3

Easter Seals has an Assistive Technology Center with a Resource Lending Library available for free to any Iowan. Located at the Camp Sunnyside location in Des Moines, a person can check out up to five items for up to 30 days at a time. The Lending Library has many daily living devices. These devices are available to help make daily activities easier for anyone. The dressing aids available include button hooks, shoe horns, sock darners, extra wide slippers, and clothing protectors. We also have several other daily living devices that include medication organizers, voice recorders, built-up handled silverware, universal jar openers, and playing card holders.

The Assistive Technology Center also contains a Durable Medical Equipment Loan Program for people who are unable to purchase brand new equipment. Some equipment available is manual and electric wheelchairs, shower chairs, canes, walkers, hospital beds, and hoist lifts. With a prescription from a medical professional and a one-time equipment fee a person can keep these items for as long as they are needed. Our Durable Medical Equipment Loan Program is based entirely on donations. If you would like to donate a piece of equipment, you can bring it to our Camp Sunnyside location to be refurbished and loaned to someone who can benefit from it.

If you would like to learn more, please visit our website at www.eastersealsia.org or if you would like to set up an appointment to tour the Lending Library or to check out equipment, please contact us by phone at (515) 309-2395 or by email at info@eastersealsia.org.

You have previously read two articles on this subject, in prior newsletters. If you wish to learn more, or take advantage of this great resource, please contact them directly.

We have had several members benefit from this service, and organization.

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