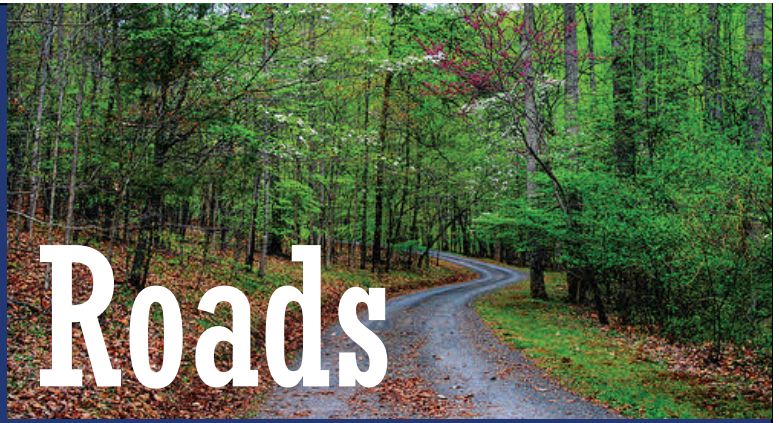


# Country Roads

June 2013



## **KARRN Mission:**

A collaborative team including individuals impacted by neurological conditions, providers who serve them, members of communities in which they live, advocates, and researchers who investigate these impairments will identify, develop and disseminate information and strategies, and maximize resources to improve outcomes and quality of life.

## **The Inaugural Kentucky Congress on Spinal Cord Injury**

### **Mission:**

The Mission of the Kentucky Congress on Spinal Cord Injury (SCI) is to hold an unprecedented one-day meeting (Summit) to gather individuals with SCI from around the Commonwealth to discuss the critical issues that are important to them and to draft an agenda to be used to legislate change in our Commonwealth for people with SCI.

### **Need:**

Organizations, outreach programs and specialized medical care providers for individuals with chronic SCI in the Commonwealth of Kentucky have traditionally been unorganized and without a common mission. Importantly, while current outreach efforts appear to have some impact for SCI individuals in urban areas, we wish to build cohesion among this community of individuals throughout the Commonwealth by expansion into the more rural areas. The Community of individuals with SCI and their support systems can be a strong advocacy group given the right organizational structure. It is time we brought our issues to the forefront to make all of Kentucky aware of the needs of this group.



# KYCSCI Continued



## How the day went!

Registration and Continental Breakfast was followed by a **welcome and open presentation by Mr. Jason Jones and Sasha Rabchevsky**. This



opening presentation was followed by instructions for goals for the breakout sessions.

### **Breakout sessions.**

There were 2 breakout sessions of approximately 50-60 min each. In each session the participants

were asked to discuss and prioritize issues that are important to them related to one topic per session. Based on the survey that was part of the registration form, the 4 specific topic areas of the greatest interest were: Healthcare, Accessibility, Equipment, Employment. For this inaugural congress, these will be the four topic areas that were discussed in the breakout sessions. Each participant had the opportunity to discuss each of these topics as the day progresses.

### **Lunch and socialization in the LCC atrium**

**Breakout Session #3 was followed by a final Wrap up session** in which the results of the breakout session were reviewed and the steps were discussed. These steps include: 1) Developing an actual agenda to be used to legislate change in our Commonwealth for people with SCI, 2) Develop work



groups from the participants to move this SCI agenda forward, 3) Develop an email list for anyone who would like to stay up to date on activities related to the SCI Congress.

Before ending, each participant was asked to sign up to participate on at least one work group.

## Kentucky Congress on Spinal Cord Injury Committees

The following committees were a result of the KY Congress on Spinal Cord Injury:

KYCSCI Continued

### Committee on Accessibility

- Angela Burden
- Ardetta Harrington
- Cassy Churchill
- Donnie Wittler
- Emily Coons
- Eva Cook
- Jagjit (John) Dade
- Heidi McKenzie
- Michelle Graybeal
- Rick Eisert
- Sasha Rabchevsky
- Terry Thorndale
- Twilla Parr
- Veronica Umeasiegbu

### Committee on Equipment

- Angela Burden
- Bob Jones
- Bob Patterson
- Cassy Churchill
- Claude Owen
- Emily Coons
- Jagjit (John) Dade
- Jeffery Mathews
- Keith Hensley
- Micah Jackson
- Michelle Graybeal



### Committee on Employment

#### Jason Jones (Chair)

- Amber Barnes
- Angela Burden
- Emily Coons
- Lee Gordon
- Michelle Graybeal
- Veronica Umeasiegbu

### Committee on Healthcare

#### Sasha Rabchevsky (Chair)

- Emily Coons
- George Cambron
- Michelle Graybeal
- Sara Salles
- Tony LoBianco
- Veronica Umeasiegbu





## Results from the Accessibility Breakout Sessions

In terms of **accessibility**, ADA compliance took the lead in votes, followed by parking, and transportation. Attendees discussed a need for education about basic ADA regulations and their weaknesses. There seems to be a lack of knowledge about the law, the ADA minimum is insufficient, interpretation of ADA rules varies, and there is a general lack of education for people with disabilities and their families. In terms of parking, attendees identified needs for education and enforcement of current parking rules, such as physician education on prescribing permits. Finally, there was an emphasis on the need to educate service providers, such as airline employees or bus drivers, on barriers to travel, perhaps via sensitivity training (accommodating passengers using wheelchairs, challenges of being able to use bathrooms, and mishandling of wheelchairs during travel). Also, the need for long term policy changes was deemed important with regards to transportation; currently, Medicaid is the sole means for those with disabilities to pay for medical transport.

## Results from the Employment Breakout Sessions

Results of top concerns related to **employment** include employee barriers, accessibility/workplace accommodations, employer barriers, and job seeking barriers. In terms of employee barriers, attendees identified a need for education and training related to employment for people with SCI. This need results from a lack of clear expectations at work, financial disincentives to work, hospitalizations and medical supplies related to health issues. There is also a need for training related to specific SCI accessibility and adaptation issues (i.e. employer willingness to make work place modifications, restrooms, heavy doors, steps, etc.). On the employer side, there is a need for education about hiring people with SCI (in terms of accommodation, job adaptation, etc.). Some barriers include: employers see a disability (i.e. chair) rather than person, the perception that disabled is less qualified, and fear to hire. Finally, with regards to job seeking barriers, peer mentoring and education related to employment, skill, and resources exploration are needed. Some specific concerns discussed include lack of knowledge about job opportunities, having a job versus career, and networking issues.

## Results from the Healthcare Breakout Sessions

**Healthcare** results include training/in-service of medical personnel, insurance barriers, coordination of services, and self-advocacy. In terms of training and in-service of medical personnel, attendees discussed the lack of SCI knowledge among healthcare professionals, an incomplete view of “health” among practitioners, urban versus rural quality of care (statewide), knowledge and research about aging with SCI. and the ability to find SCI specialists. In terms of insurance barriers, a long-term policy change goal is necessary. Insurance does not cover sufficient rehabilitation, the gap between leaving intensive care and then going to Cardinal Hill is too short, “medical necessity” needs to be redefined, payment as a driver of service and support, a “minimum of care” guideline should not become the ceiling of practice, and affordable care remains an issue. In terms of coordination of care, there is a need to educate hospital administrators, social workers, and other members of the medical team to ensure coordination of care and medical records. Other issues include shortage of medical social workers, physiatrists without hospital privileges, benefits planning is not incorporated into the rehabilitation process, and a need for all member of a medical team (urologist, neurologist, etc.) to get together and coordinate care. Finally, for the self-advocacy issue, there needs to be peer mentoring or support and health history management. This may take the form of information sharing about best practices and resources, knowledge of one’s own medical regimen (as a physician may not), and understanding “fine print” within health insurance policies.

## Results from the Technology/Equipment Breakouts Sessions

In terms of **technology and equipment**, the following were the top issues identified: affordability, education and information, and bureaucracy. With regards to affordability issues, needs to assess current resources for accessing equipment and identifying gas for long-term policy change were identified. Specific matters discussed include inappropriate billing of medical equipment, unequal access, insurance coverage, enrollment in trials for assistive technology (AT), and cost of equipment modifications and repairs. There is also a need to educate service providers (i.e. physiatrists, vendors) and people with SCI on current best practices and what technology and equipment is available. Finally, with regards to bureaucratic issues, attendees identified a need to assess problems related to accessing and maintaining repairs for future long-term policy change (e.g. “jumping through hoops” to get needed items, lengthy time to receive equipment after insurance approval, and lengthy time to repair).

KYCSGI Continued



## Comments from the Participants

I think this congress was very effective in identifying problem issues. I think the team is very motivated and I enjoyed working with everyone. -Emily Coons

I was privileged to attend the inaugural Kentucky Spinal cord Injury Congress and encouraged by what I saw. The attendees I interacted with were excited and ready to act to make changes. I'm very excited to keep working with like-minded individuals. I will note that I was disappointed more paras didn't make it to the meeting. -Micah Jackson

It was great to meet some new people. It was good to hear that I'm not the only one with frustrations with many things that makes our life harder. I was sad of the turn out cause I know there are so many more of us out there. It is way past time for change in this world and we can be apart of it. -Terry Thorndale

I feel that we are a group that benefits from interacting more with each other, but that such interactions don't naturally occur very often... I particularly liked, and learned from, the different perspectives that participants shared regarding how factors related to SCI have changed over the years – some in positive ways, some in not so positive ways. I also really like to complain, so in that sense it was definitely my kind of event. -Tony LoBianco

I had a wonderful experience – it was energizing and challenging...I think that we can draw more people in the future, once they see that we are tackling issues and effecting change. I encourage us to not be overwhelmed by all the “challenges” but to realize that Rome was not built in a day and we can make a difference if we work together and keep each other going. I felt privileged to be invited and to have the chance to meet and work with so many interested (and interesting!) individuals. -Michelle Graybeal

I was impressed with individuals I met. I was disappointed that so few people in a wheel chair attended the meeting. Since my accident I have encountered so many things that needs change. Then I was confused, There were so many thoughts and problems that needs a solution. I hope working as a group we can find a solution. -Bob Patterson

Who would have thought that the inaugural KY Congress on SCI would be held here in Lexington and that we are leading an important and vital effort for our voices to be heard throughout the commonwealth?! - Sasha Rabchevsky

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