

Country Roads

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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.

Save the Date: May 10, 2013

The Inaugural Kentucky Congress on Spinal Cord Injury

The Kentucky Congress on Spinal Cord Injury (SCI) will be an unprecedented one-day meeting gathering 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.

Organizations, outreach programs and specialized medical care providers for individuals with chronic SCI in 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.

Topics to be discussed will include healthcare, transportation, technology, and employment. Expected outcomes will be the establishment of a unified SCI community, and to develop an agenda and work groups to create legislative change in Kentucky.

This event is FREE and open to anyone living with an SCI in the Commonwealth of Kentucky. Online registration will open in February 2013. If you have any questions, contact KARRN Director Patrick Kitzman at phkitz1@email.uky.edu or Assistant Director Beth Hunter at egh1@cardinalhill.org.

Inside this issue:

KARRN Conference	2
Being a Dad with SCI	4
TBI Research	5
Community Photos	5



4th Annual KARRN Conference A Success

The 4th annual Kentucky Appalachian Rural Rehabilitation Network conference on September 19th featured four speakers and two panel discussions that focused these main topics: 1) discuss special issues related to spinal cord injury and stroke in the pediatric population, 2) discuss the long-term issues related to aging in the spinal cord injured population, 3) discuss communication difficulties after stroke, 4) demonstrate wheelchair set up, positioning and pressure mapping, and 5) discuss technology that is available to enhance patient/client communication in stroke rehabilitation.

Over 215 attendees from across Kentucky and the U.S. took part in this event. The conference welcomed individuals from the community, particularly those personally affected by spinal cord injury (SCI) or stroke and their caregivers. Many healthcare professionals were also in attendance, along with physical therapy students from the University of Kentucky and occupational therapy students from Eastern Kentucky University, who attended to network and learn about their future clients .

Left: A panel discusses life with spinal cord injury.

Right: Conference attendees listen to Dr. Jicha's keynote presentation.

Dr. Therese Johnston PT, PhD from the University of the Sciences in Philadelphia opened the conference with a keynote presentation about SCI rehabilitation in the pediatric population. Dr. Greg Jicha M.D., Ph.D. from the University of Kentucky's Department of Neurology presented on vascular dementia and the use of telehealth to reach rural communities. *(cont. on next page)*



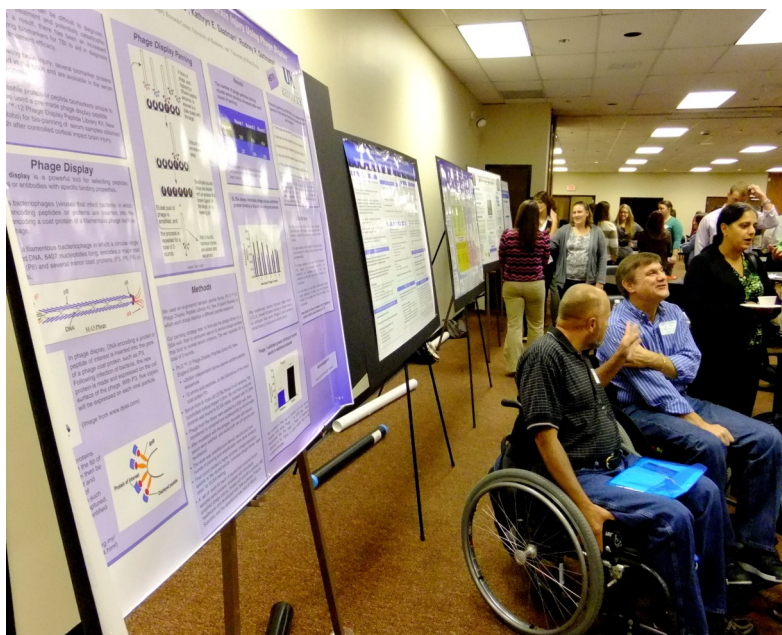
KARRN Conference, cont.

During the extended lunch break, attendees had the chance to view research posters covering a diverse array of topics including adaptive farming equipment and crafting for ventilator-dependent patients. Several vendors in attendance displayed their unique services and adaptive equipment. In the afternoon, two breakout sessions focused on either stroke or SCI. The SCI breakout session began with a presentation from Dr. Susan Charlifue of Craig Hospital in Englewood, CO regarding aging in individuals with SCI, who was followed by a demonstration of the use of pressure mapping to ensure proper wheelchair setup. The stroke breakout session began with Dr. Bob Marshall of the University of Kentucky, who discussed ways to reveal the competence of individuals who have communication difficulties following a stroke. Therapists from Cardinal Hill Rehabilitation Hospital shared cutting-edge technology, such as computer programs and mobile apps, being used to help people who have had a stroke with communication difficulties.

As always, the most popular sessions of the afternoon were the panel discussions. A group of individuals with SCI offered a candid discussion about their experiences aging with SCI, and a panel of caregivers discussed strategies they have used to facilitate communication with their loved ones with aphasia. The conference provided a friendly, open forum for all interested individuals to learn and connect with the stroke and SCI communities of eastern and central Kentucky. ♿

Left: Scientific posters on display during the lunch break

Right: Students learn about special equipment from a vendor



The Uncertainties of Parenting by Jason Jones

Chaos! Absolute chaos! It is 30 minutes until bedtime and the madness has begun. First it's a bath, but wait. One boy is missing and the other just opened a Capri Sun and has discovered the geyser-like affect the straw creates when a good squeeze is applied sharply to both sides. The dog gets let out and somehow gets back in and tracks mud on the carpet. Several minutes have passed and we are no closer to the joyful bliss of two sleeping children and a few fleeting moments of tranquility before my wife and I shut down for the day. At this moment, we have a carpet full of muddy dog prints, a puddle of Pacific Cooler Capri Sun in the floor of the pantry and a missing person report to file.

I look around at times like this and I see the house in shambles and my wife starting a nervous breakdown and then it happens. I hear two laughing children. And better than that, I hear MY laughing children. At that moment chaos is replaced with the sheer joy of being a father. And what a joy it is.

When you have a spinal cord injury, your mind instantly becomes packed with so many uncertainties. Take the fact that my injury occurred at age 15 and those uncertainties dealt much more with whether or not I would ever get to drive a car or date another cheerleader. Having a wife and family weren't really in the forefront of my considerations for what I might be losing. However, as days turn into years, the uncertainties unfortunately start to become certainties. I never drove that car and until I met my wife, I hadn't dated a cheerleader either.

When you are young and have good parents like I did that hold you to a high standard, your natural path sort of becomes a given. I always expected to graduate from high school, go to college, get a good job, get married and eventually have children because that is what the Jones children were destined to do. Unfortunately, the first three happened quickly and the last two took much longer to come to fruition, almost to the point that I really had accepted the last two probably weren't going to happen.

Then I met Jess and the world changed in a flash. Within a six-year period, I went from being single and wrapped up in my job, to being married with two sons. The uncertainties of my youth were replaced with the normal uncertainties every parent has for their children. It quickly became about them and a lot less about me. Yes, I have a spinal cord injury. And yes, there are a plethora of things we never considered before having children. But the uncertainties are gone for me because I got everything thing I wanted out of life in spite of a significant disability.

The Uncertainties of Parenting cont.

Micah is four and Bryce is 17-months and they are all boy. In addition, we are raising my 14-year-old niece as a last wish of my older sister who passed away last year after battling cervical cancer. Our lives are crazy with all the things you have to do as parents. But, that is ok because it is normal. Anyone with a spinal cord injury would agree that normal can be the greatest feeling of all. We are a normal family and that means more to me than anything.

The messes got cleaned up, the kids got a bath and put to bed and my wife and I finally slept. It is just another typical night at the Jones house. With the laughter still lingering in the air, what a wonderful night it is indeed.



KARRN Meeting and Holiday Get Together 2012




A few images of our KARRN members after a delicious meal provided by Personal Chef and Catering of London. While the faces may seem serious, a lot of laughter was had by all.

KARRN Researchers Reaching Out to Individuals with Traumatic Brain Injury

The Needs Assessment for People with Traumatic Brain Injury (NAP-TBI), living in rural Kentucky, has begun! We have started our interviews to determine what the assets and needs are of people with TBI and caregivers, living in rural Kentucky.

This research study aims to learn about the problems and challenges of individuals who have suffered traumatic brain injury and live in rural Appalachian communities. Researchers hope to learn more about the long-term health care for these individuals, and how well they have been able to find needed community resources such as transportation and medical equipment. The information collected will help to better understand where additional services and education are needed to improve the quality of life of individuals who have suffered a TBI and return to their homes in rural Appalachia.

Several initial interviews have already uncovered many issues faced by individuals with TBI. If you know of anyone interested in participating, or would like to learn more about the study, please contact Patrick Kitzman at phkitz1@email.uky.edu or 859-218-0580, or Anne Harrison at anne.harrison@uky.edu 

Research

In order to help people with their return home after a traumatic brain injury the NAP-TBI project is currently interviewing individuals about their lived experiences in Appalachian Kentucky



Community Photos



Happy Holidays from KARRN!

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