

May 2016



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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.

Advocacy Award

Nominations due August 1

A new award is being developed by the Kentucky Congress on Spinal Cord Injury. This award recognizes an individual who has had an exemplary effect on the Spinal Cord Injury community's wellbeing. The first award will be publicly presented at the annual meeting of the Congress in September. *(continued on page 2)*

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*2015 Annual Meeting of Kentucky Congress
on Spinal Cord Injury*

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Individuals eligible for nomination include those with spinal cord injuries, caregivers, family members, policy makers, neighbors, educators, employers, local business owners, other community members, etc.

Advocacy is broadly defined, and self-nominations are accepted. Please consider nominating someone, and encourage others to do the same.

For more information and to obtain an award nomination form, contact Patrick Kitzman at phkitz1@uky.edu or (859) 218-0580.

Kentucky Congress on Spinal Cord Injury Update by Jason Jones

It is an exciting time to be a member of the Kentucky Congress on Spinal Cord Injury (KCSCI). The advisory committee is working on the 4th Annual KCSCI. Mark your calendars for Thursday, September 15. The agenda is coming together and should be even better than last year. The KCSCI will be held for the first time at the Cardinal Hill Rehabilitation Hospital's Center for Learning in Lexington. If you have never been to the congress, keep that day open and join us. You will leave with a great deal of information and a day of networking with others in the SCI community. You will also be treated to good food and a free t-shirt. The KCSCI is free to anyone interested in advocating for people with SCI and any other disability group. We would like to thank Superior Van & Mobility and their partners Braun and Bruno for their continued support of the KCSCI. We would not be able to hold our conference without them. *(continued on page 3)*

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In addition to planning the next congress, the KCSCI has upped its presence on social media with what we call “Guest Webhosts.” Every two weeks for the next year, a different member of the KCSCI will post a short bio about themselves, as well as various content about SCI and other relevant disability information. See what is up from our current webhost and join the Facebook group at <https://www.facebook.com/groups/KCSCI>.

The advisory group will have met by the time this goes to print. We need everyone’s help to formalize a platform for the next year. In the past we have tackled snow removal, legislative agendas, parking, accessible playgrounds and several other disability related issues. If you have a suggestion for something we can advocate for on behalf of people with disabilities, please send an e-mail to jpjones@twc.com.

The most important item for members of the KCSCI is mentoring. KCSCI continues to fill the need when called by medical practitioners, family or friends of people with SCI. Over the past year, dozens of newly injured Kentuckians have been provided with a mentor to guide them through the ends and outs of dealing with a spinal cord injury. Please get in touch with any member of the KCSCI if you know someone that could benefit from our group. The best way to do that is through the above Facebook link or e-mail address.

Finally, the SCI community lost one of its giants at the end of 2015 with the passing of Tom Gravitt. Tom was one, if not the first, true advocate for people with SCI. Tom raised thousands of dollars for research and patient care. He spent countless days in Washington D.C. and Frankfort pushing legislation that greatly enhanced the quality of lives for all people with disabilities. He spoke his mind and used every resource at his disposal to change the world around him. Even more important than the advocacy was the mentoring he did for so many people who came through Cardinal Hill. He never avoided a question, no matter how personal, if a newly injured person needed an answer. The legacy of Tom carries on in so many of us who believe in an equal playing field for people with disabilities. He will be missed and never equaled.

Project CARAT Update by Sheila Levy

A news story on WDRB (the Louisville FOX affiliate) aired on April 15th and the phones and Google emails have surged as a result of this increased exposure.

Outreach Coordinator Sheila Levy was invited to provide the Public Health Nursing ITV Update to Kentucky Department for Public Health and Local Health Departments on April 21st to tell the health departments across the state about project CARAT. Project CARAT will be doing more outreach

through the Department of Public Health.

Some of the remaining HRSA funds are being used to purchase power wheelchair batteries in order to make donated power wheelchairs operable and available to give away to those in need.

Project CARAT has an abundance of donated items at this point in time. To date, Project CARAT had provided 1,091 pieces of equipment to 512 Kentuckians at a cost savings of \$414,675 .

One of CARAT's consumers with his mother



Kentucky Care Coordination for Community Transitions—Update

The Stroke Navigator program has been featured in three news outlets recently:

- On January 29, 2016, *UKNOW (University of Kentucky News)* highlighted the program, focusing on the medically complicated nature of stroke (especially when other chronic diseases are present) and the effect of hope and function that the navigator program has provided. The article emphasized the partnerships that this program has with other organizations in the area, and the multitude of services that the navigator is able to refer to, coordinate, and help the patients ultimately self-manage their follow-up care needs. The *UKNOW* article is available at: <http://uknow.uky.edu/content/community-transition-program-supports-stroke-survivors-eastern-kentucky>
- On February 2, 2016, the *Hazard-Herald* ran a feature article on the contributors to stroke and the reasons for high incidence in Perry County, and the positive results that navigator Keisha Hudson has had on the individuals who have participated in the program. Local community involvement and trust are key components, and Keisha's ability to individualize each patient's experience and services has been beneficial. The article is available online at <http://hazard-herald.com/news/2051/local-program-helps-stroke-patients>
- On February 8, 2016, The Kentucky Office of Rural Health's weekly newsletter showcased the hospital readmissions data. When patients received navigator services, they did not need readmission to hospitals for medical problems in the initial 30 days after discharge, which is typically a vulnerable time for patients as they return home and have many questions and face complications. The navigator is able to proactively address difficulties and connect the patient with needed resources.

Kentucky AgrAbility Update by Linda Bokros

KY AgrAbility Has been on the road for the last few months attending the National AgrAbility Workshop in Fort Collins, CO, the American Occupational Therapist Association conference in Chicago, IL and the three-part series of workshops for veteran farmers “Farm Foundations”. The addition of the Growing Warrior program has expanded the client base into the veteran group of farmers with their unique problems and disabilities.

A few new pieces of demonstration items have been added to the arsenal of assistive technology. A Powerhorse is an adapted piece of equipment that allows a person to travel over uneven ground driving from their wheel chair that is rolled into a cart behind the power unit. This would be good for gardening and to go from house to out buildings. Also, KY AgrAbility has obtained an aging simulation suit. This will allow healthcare workers, care givers and others experience different aspects of aging. This not only simulates arthritis but hearing impairments, visual problems and *(continued on page 7)*



At left: Our KARRN partner Heidi McKenzie presented her Alter Ur Ego clothing line during the National AgrAbility Workshop in Ft. Collins, CO.

AgrAbility

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some restrictions after strokes and other diseases or accidents. Beth Hunter is working on a presentation that will be available to interested educators and therapists.

KY AgrAbility is heading into the third year of the four year grant cycle and looks forward to sharing some innovative new assistive technology with others.

Upcoming Events:

Summer Institute in Assistive Technology: This annual conference at Kentucky State University will be on June 14 & 15, 2016. Registration is free, and the innovative conference sessions have general and practitioner-specific topics. Three of our KARRN member organizations are co-sponsoring this event: Kentucky Office of Vocational Rehabilitation,

Kentucky Assistive Technology Service (KATS) Network, and Kentucky AgrAbility.

Register online at <http://www.katsnet.org/atconference/>

Farm Foundations: Planning for Success

Three-part workshop series for military veterans and beginning farmers and ranchers

Workshop 1: May 21, 2016 St. Catharine, Kentucky

The first workshop in this FREE series will focus on:

- Whole-farm planning
- Business management
- Starting a sustainable farming operation

Activities will include a hands-on component at a developing farming site. Dates for the second and third workshops in the series will be announced soon.

Space is limited! Register today to reserve your spot in each of the three workshops: <https://www.ncat.org/events>.

For more information please call 479-442-9824 or email margoh@ncat.org.

This workshop series is for military veteran and socially disadvantaged farmers in Kentucky. For a list of other available events, visit <http://www.ncat.org/events>.



This project is supported by the Outreach and Assistance to Socially-Disadvantaged and Veteran Farmer and Rancher Program of the Office of Advocacy and Outreach, USDA, Grant #59-2501-15-026.



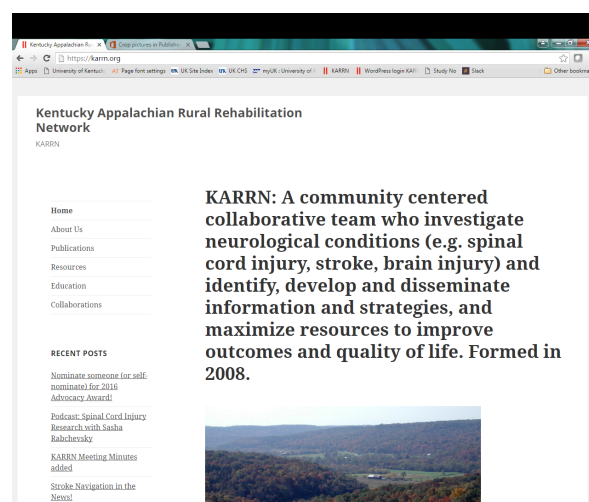
Patient-Centered Outcomes Research Institute (PCORI) Supports KARRN

The Patient-Centered Outcomes Research Institute graciously awarded a \$248,000 grant to the KARRN. This two-year grant will help to identify what sources of information are most helpful to patients making healthcare decisions. So far in the first year of the grant, interviews have been conducted by Patrick Kitzman and Beth Hunter with members of the spinal cord injury, traumatic brain injury and stroke populations. The results of these interviews will inform future focus group topics. The second year will be spent fine-tuning a research module for patients and will culminate in a half-day event to formulate a research question.

We are grateful to PCORI for their support of our work. PCORI's projects emphasize ways of improving patient care by engaging patients and other stakeholders in the research questions that are the most meaningful to them.

Visit Our Website: www.karrn.org

We have made some updates to our website lately, and would love your input. Bookmark it, and visit often! You can submit comments on the pages, and we are eager to promote any events, announcements or items of interest that you, our members, would like to publicize. One feature that we are especially interested in addressing is the overall accessibility of the site—we have chosen a template that has been reviewed as “accessible-ready” and have provided a link for further assistive technology features (the AT Bar), if needed. Give it a try and let us know what you think.



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