



Summary of Accomplishments

2009 to Present

Partnerships

2008-2009

Drs. Patrick Kitzman and Beth Hunter conducted **“THE STUDY”** (2008-2009) that focused on the supports and barriers to long-term health and health care for individuals with SCI living in rural communities. **It was through this study that the initial connections with many of our founding members were established.**

Founding Organizations: Appalachian Regional Healthcare System (ARH), Cardinal Hill Rehabilitation Hospital, Carl D. Perkins Vocational training Center, Kentucky AgrAbility Program, Kentucky HomePlace, Kentucky Office of Vocational Rehabilitation, PT Pros, UK Centers of Excellence in Rural Health, University of KY Physical Therapy Program and Rehabilitation Sciences Program, UK Spinal Cord and Brain Injury Research Center, Multiple community members including Helen Ascani, Joe Angle, Bob Patterson, Jason Jones, Cindy Goff.

2010-2011

Continued growth within the communities as well as with other organizations, such as: UK Human Development Institute • BIAK • Heart Disease and Stroke Prevention Program • Department of Aging and Independent Living • Department of Behavioral Health, Developmental and Intellectual Disabilities • UK-Commonwealth Center of Excellence in Stroke • Veterans Affairs SCI Program • National Guard Community and Medical Outreach • Kentucky Injury Prevention and Research Center • No Barriers USA • Grip Solutions in PA (Lou Gaston).

2012

Partnerships begin to develop with free clinics throughout eastern KY as part of the Project CARAT initiative.

Began development of the Inaugural Kentucky Congress on Spinal Cord injury to be held May 10, 2013 in downtown Lexington.

2013

The Inaugural KY Congress on Spinal Cord Injury held on May 10, 2013 (Lexington, KY). The Mission of the Kentucky Congress on Spinal Cord Injury (KCSCI) is 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. 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 the KCSCI wishes to build cohesion among this community of individuals throughout the Commonwealth by expansion into the more rural areas.



Members of the Inaugural Kentucky Congress on Spinal Cord Injury.

- 40 attendees
- Topics discussed: 1) *employment*, 2) *accessibility*, 3) *equipment*, and 4) *healthcare*.
- Follow-up meeting was held on October 29th.
- Sasha Rabchevsky and Jason Jones have taken on the unofficial leadership roles for this initiative.

Development

2009

- ✓ **Initial meeting that led to the formation of KARRN** was held on May 21, 2009 (Hazard, KY)
 - 27 attendees, across 11 organizations, plus nine community members.
 - Cheryl Vines, Director of the Arkansas Spinal Cord Commission, served as guest speaker.
 - Identified available resources within rural communities; this sets the tone for the KARRN mentality of determining what is available and leveraging the visibility of those resources to community members.
- ✓ KARRN website was **developed and officially launched**.
- ✓ Standing meetings were established to discuss network expansion and use of the ITV system for coordinated communication across remote sites was initiated.

2010

- ✓ The **community-based resource database** was developed as a means to provide a list of resources (healthcare and community support) for each county in eastern KY.
 - This collaboration involved many partners, especially Kentucky HomePlace and ARH.
- ✓ **Peer-mentoring program** was started through Cardinal Hill Rehabilitation Hospital funded in part through a grant from the Christopher Reeve Paralysis Foundation (PI Beth Hunter and Co-I Michelle Graybeal, Cardinal Hill). Additional collaborators were Dr. Sara Salles and Ashley Hudson at Cardinal Hill.
- ✓ First meeting was conducted using teleconferencing for inclusion of input from multiple sites.

2011

- ✓ Journal article on the development of the KARRN project was published:
Journal of Rural and Community Development (2011) 6(1):95-104.
- ✓ The 1st KARRN newsletter was completed, made available online and distributed throughout the network.
- ✓ Created a spinal cord injury community page for the website.
- ✓ SCI community flier was redeveloped for greater clarity.

2012

- ✓ The 4th KARRN newsletter was completed and made available online.

2013

- ✓ Regularly scheduled KARRN newsletters have been completed and distributed throughout the growing network and online.
- ✓ Multiple state and national presentations were conducted to discuss our work and collaborations.

Education

2008-2009

- ✓ **Inaugural KARRN Conference** on spinal cord injury is held (Somerset, KY): Following our study on the supports and barriers to long-term health for people with SCI in rural communities and our initial meeting in Hazard it became apparent that some rural practitioners did not feel comfortable working with individuals

with complex neurological conditions and wanted additional education. But we didn't want the meetings to be for MD only, or PTs only, or just the community members. We wanted everyone together hearing the same material and talking with each other. We also wanted the OT students (EKU) and PT students (UK) who were getting ready to graduate to be involved since they will be working with these different groups.

- 223 attendees including persons with spinal cord injury and their caregivers, healthcare providers who serve them, future healthcare providers, community partners, educators and researchers.
- Topics included: 1) community integration and quality of life, 2) long-term care issues and prevention of secondary complications, 3) the importance of exercise and nutrition, and 4) the development of peer-mentoring and support systems.
- The presentations were videotaped and made available through CE Central.



Speakers from the 1st annual KARRN conference (2009). Dr. Gale Whiteneck from Craig Hospital in Englewood, CO presents on Community participation following SCI(left), Dr. David Gater from Virginia Commonwealth University presents on metabolic syndrome following SCI (middle), and Dr. Sara Salles from the University of Kentucky presents on the prevention of secondary complications following SCI (right).

- ✓ **Educational handouts** on wheelchair accessibility were created (extending beyond handicap accessibility). This project was a partnership between community partners Sasha Rabchevsky, Jason Jones, Bob Patterson, and Joe Angel and the UK PT students. The educational materials focused on Travel Tips for people traveling in wheelchair in general than travel Tips for those wishing to go to KY State Parks.

Travel Tips Handouts.

1. The first Travel Tips addresses questions a traveler in a wheelchair needs to ask to ensure accommodations are truly wheelchair accessible and not just handicap accessible. Getting the right information about the accessibility of a hotel can be difficult and sometimes frustrating. With so many places to choose from, travelers with disabilities need a quick way to compare hotels and find one that can accommodate their special needs. The original Travel Tips was developed to provide a list of tips to make traveling with a wheelchair, or other mobility disabilities, less frustrating.
2. The second Travel Tips kicked off a series of handouts that focus on wheelchair accessibility in KY State Parks. Many people love to enjoy the sights and sounds of our Kentucky State Parks and recreation areas. There is no difference in the wish to appreciate nature whether you are able bodied or require the use of a wheelchair. However, individuals who do require the use of a wheelchair many times are unable to fully enjoy our state parks and recreational areas due to multiple barriers. Often times park personnel are under the impression that an area being "handicap" accessible also makes it wheelchair (WC) accessi-



ble, when that is often not the case. Thus, the material compiled in these handouts were designed to aid persons traveling in a wheelchair on common barriers they may face, questions to ask prior to traveling to a location, and travel tips for combating some of the commonly encountered dilemmas once they reach their destination.

2010

- ✓ The KARRN website evolves several steps to include information focused on Stroke.
- ✓ **The 2nd Annual KARRN Conference** on SCI is held (Somerset, KY).
 - 176 attendees including individuals with SCI and caregivers, healthcare providers, PT and OT students, researchers, educators and community partners.
 - Topics included: 1) connecting pathology with expected functional outcomes and participation 2) Universal design and environmental modifications, 3) panel discussion for persons with SCI about living in rural KY, 4) practical (inexpensive) assistive technology and home modifications, 5) state-of-the-art innovation in assistive technology and environmental adaptations, and 6) recreational and sports opportunities for individuals with SCI.



Students from the University of Kentucky PT program participating in breakout sessions on adaptive sports and farming equipment during the 2nd Annual KARRN conference (top left and middle). Mr. Bob Patterson demonstrating his seat lift for his truck (top right). Ms. Susan Bachner presents on Universal Design (bottom left). SCI panelists Terry O'Brien, Ryan Creech and Ralph Profitt talk about living with SCI in rural communities.

Several of these presentations were videotaped and posted on CE Central covering the following topics:

- Connecting Pathology with Expected Functional Outcomes and Participation (Deborah Backus, PhD, PT)
- Use of Universal Design and other Environmental Modifications to Improve Comfort, Safety and Independence for People with SCI (Susan Bachner, MA, OTR/L, FAOTA).

2011

- ✓ The **3rd Annual KARRN conference** held in Somerset, KY.
 - Topics expanded beyond SCI, to include stroke.
 - Over 200 attendees including individuals with SCI and stroke and caregivers, healthcare providers, PT and OT students, researchers, educators and community partners.
 - Topics included: 1) state-of-the-art research in stroke and spinal cord injury rehabilitation, 2) dissemination of health-related information into rural communities, 3) reproduction and parenting issues following SCI, 4) panel discussion with person with SCI, 5) long-term medical issues following stroke, and 6) panel discussion with stroke survivors and caregivers.



SCI panelist discusses the real life experiences and challenges of having children and being parents in wheelchairs.

- ✓ Supported **Mark Wellman's visit** and presentation at Cardinal Hill Rehabilitation Hospital. The image to the left shows Mark (in wheelchair) assisting a patient from Cardinal Hill up a climbing wall set up in Cardinal Hill's parking lot.



- ✓ Several KARRN members attended the **No Barriers Summit** in Colorado.
- ✓ **Multiple presentations** were conducted at local, state and national conferences by our members.

2012

- ✓ The **4th Annual KARRN Conference** is held at Eastern Kentucky University's Perkins Center (Richmond, KY)
 - Due to success in the previous year, both SCI and stroke tracks were included.
 - 218 attendees including individuals with SCI and stroke and caregivers, healthcare providers, PT and OT students, researchers, educators and community partners.
 - Topics included: 1) understanding spinal cord injury in the pediatric population, 2) understanding pediatric stroke, 3) long-term issues related to aging in the SCI population, 4) panel discussion of aging with SCI from the clients point of view, 5) wheelchair set up, positioning and pressure mapping, 6) stroke and issues unique to this condition, 7) panel discussion- caregivers experiences in communicating with stroke survivors, 8) technology in stroke rehabilitation.



Dr. Gregory Jicha from the University of Kentucky presents on the use of telehealth in the rural community. (left). Audience attends a talk on wheelchair seating by Mr. Glen Alden and Mr. Keith Grewe from Cardinal Hill.



Mr. Keith Grewe demonstrates some wheelchair set up (left). Dr. Susan Charlifue from Craig Hospital in Englewood, CO discusses issues related to aging with SCI (right)



SCI panelists discuss the realities of aging with SCI (left). Panel of caregivers of people who have had a stroke discuss the supports and barriers to caring for someone with a stroke in rural communities.



Dr. Robert Marshall from the University of Kentucky discusses the long-term issues related to stroke.

- ✓ **Basic wheel chair transfer videos** were completed and made available online. This project focused on issues concerning persons with mobility issues (whether because of a SCI, stroke, Multiple Sclerosis, etc) involving wheelchairs. The project also focused on a variety of wheelchair transfers; from basic transfers to more advanced “real world” type of transfers and problem solving.
 - Basic skills topics included wheelchair transfers to a level surface, on and off the floor, to a bed or couch.
 - Collaborators included community partners Ryan Creech (KY Office of Vocational Rehabilitation), Kara Lee DPT (Cardinal Hill), Heather Watts DPT (PT Pros and UK PT Program), and UK Physical Therapy students
 - Real world transfers included tractors, skid loaders, mowers, fishing boats etc. were completed and uploaded to YOU tube. Collaborators on these videos included John Hancock from Kentucky AgrAbility, Bob Patterson, Cindy Goff and UK Physical Therapy students.

- Videos were uploaded to You Tube and KARRN website. Hits were tracked and several videos were viewed in at least 20 different countries.
- **This project was funded through and Educational grant from the University of Kentucky College of Health Sciences.**

- ✓ **Assessed KY state parks** and recreational areas for wheelchair accessibility.
 - 50 parks and recreational areas were assessed in total.
 - The Parks Travel Tips handouts numbers 3 and 4 were completed and are online.

2013

- ✓ **The 5th Annual KARRN Conference** was held at EKU's Perkins Center
 - Over 210 attendees including individuals with SCI, stroke, TBI and caregivers, healthcare providers, PT and OT students, researchers, educators and community partners.
 - Topics included: 1) connecting clients and clinicians with services/resources, 2) treatment options related to aging in SCI, 3) Evidence based care for individuals with stroke, 4) Best practices to facilitate community integration following TBI, and 5) polypharmacy management for individuals with neurological conditions.
 - 3 panel discussions covering SCI, stroke, and traumatic brain injury (TBI).
 - Poster presentations covered a variety of topics.



Audience listening to a presentation by Dr. Michael Dobbs of the University of Kentucky discussing acute and long-term care for individuals who have had a stroke.



Participants listened to speaker (left) and displays from the KARRN community partners (right).



Panel of survivors of TBI and caregivers discussing their real life experiences

✓ **Support provided to the Brain Injury University**, run by Cardinal Hill Rehabilitation Hospital. Workbooks for each of participant were provided.

✓ **A Library for People with Stroke** Now Available on the KARRN Web Site.

This project was formulated based on what we learned from the Needs Assessment for People with Stroke (NAPS) study. The purpose of this project is to provide additional educational resources that can be accessed as videos on the internet, as DVDs for home use, and in the form of paper copies. UK DPT students and faculty collaborated with the UK College of Agriculture Cooperative Extension Office faculty and staff to develop a “Stroke Library” of resources designed to be easy to access, easy to understand, and culturally competent. The KARRN Stroke Library can be accessed by visiting the KARRN web site at www.karrn.org. The materials include hard copy and internet PDFs addressing Stroke info, Transient Ischemic strokes, Fall Prevention at Home, Depression, Fatigue, Nutrition, Pneumonia & Dysphagia, Risk Factors and Prevention, Urinary Tract Infection, a Home Hazard Checklist, Caregiver Information, Respite Care, Sexual Problems, and Rehabilitation. There are also media resources available on the KARRN website. These are short video excerpts with audio and visual instructions on various topics including transfers & caregiving, bed mobility, and donning a gait belt. This library was designed for persons with stroke, family members or loved ones, healthcare professionals, and interested community members.

Educational videos are produced on the following topics:

- Falls
 - Falls prevention (www.nofalls.org)
- Transfers
 - Safe transfers for people who need minimal or moderate to maximum assistance
 - Helping people move in bed
- Mobility
 - Walker-related
 - Cane-related

Educational handouts are completed on the following topics:

- Preventing Future Strokes
 - Risk factors, red flags and prevention
 - TIAs (Transient Ischemic Attacks): red flags
- Emotional Health
 - Caregiver information
 - Coping with depression
 - Coping with fatigue
 - Sexual problems
- Preventing Illness and Injury
 - Preventing pneumonia
 - Preventing urinary tract infection
 - Nutrition: Guide to eating right
- Getting Support
 - Rehabilitation information & Kentucky resources

✓ **The TBI resource flow chart** is developed and available online. Common problems that patients with traumatic brain injury experience following their injury include mood and personality changes and neurological deficits such as weakness, loss of balance, or even paresis/plegia. Family members and friends must deal with the impact of their loved one’s injury as well which can be stressful, especially if they don’t

know where to go for answers or help. The purpose of this project was to research the resources available in Kentucky for patients who have suffered a TBI and format a handout that will provide important contact information for each stage of the recovery process.

- This was a collaboration between Tonia Wells from the Kentucky Traumatic Brain Injury Trust in the Kentucky Cabinet of Health and Family Services, UK Physical Therapy students, and Carolyn Wallace.
 - They developed an easy-to-follow 2 page flow chart of the available state resources and waiver programs (including contact information) that is available online and in hardcopy. This handout was designed to be used by both clients and healthcare providers for convenience and quick reference. Input was received from clients and healthcare providers during its development. This handout also indicates when, during the continuum of care, these resources should be accessed.
- ✓ **Continuing education opportunities are initiated** in eastern Kentucky in the areas of multiple sclerosis and Parkinson's disease with our developing collaboration with Dana Lykins, DPT (Baptist Health, Lexington, KY). The first courses are scheduled to be offered in 2014 and will be a partnership with ARH (Violet Sylvia) and Carl D. Perkins Vocational Training Center (Barb Pugh). Additional educational offerings will be developed in 2014 that will focus around the topics of SCI, Stroke and TBI.

Research

2008-2009

- ✓ ***Planning Grant for Establishing a Collaborative Team to Investigate: Health and quality of life related challenges for individuals with spinal cord injury, living in medically underserved areas of Kentucky, receiving rehabilitation services.*** Funded through the Kentucky Experimental Program to Stimulate Competitive Research (EPSCoR; through the National Science Foundation). PIs: Patrick Kitzman (UK College of Health Sciences) and Beth Hunter (Cardinal Hill Rehabilitation Hospital). Funding Period: 6/16/08-6/14/09. **This is the project that started it all.**

2010

- ✓ ***Enhancing the Capacity of the Kentucky Appalachian Rural Rehabilitation Network.*** Funded through the grant from the National Institutes of Health, National Center for Minority Health and Health Disparities. PIs: Patrick Kitzman (UK College of Health Sciences), Anne Harrison (UK College of Health Sciences), and Julia Costich (UK College of Public Health). Funding Period: 2010-2013. This grant was funded to develop the infrastructure needed to conduct translational research within Appalachian rural communities as well as translate research results into services to improve long-term healthcare service and quality of life for persons with neurological conditions living in those rural communities. This funding allowed us to purchase a portable video conferencing system for Cardinal Hill and allowed us to setup our distance site for our monthly meetings.
- ✓ ***Training a community based spinal cord injury peer mentoring network in Kentucky's Appalachian Region.*** Funded through a Christopher and Dana Reeve Foundation Quality of Life Grant. PI: Beth Hunter. Funding Period: 2010-2011. This project was designed to begin the process of creating a community based peer mentoring program for people with SCI who live in Appalachia. This grant provided funds to recruit and train potential peer mentors. Once the training is complete the mentors will be paired with SCI patients receiving treatment at the Cardinal Hill Rehabilitation Hospital inpatient SCI program.

2011

✓ Research projects that were initiated:

- **Needs Assessment for People with Stroke (NAPS) study** was initiated and focused on the supports and barriers to long-term health and healthcare of people with stroke in rural communities.
 - This was part of the NIH infrastructure grant and included a collaboration between members of the UK College of Health Sciences, Cardinal Hill Rehabilitation Hospital, and Appalachian Regional Healthcare System. The NAPS team includes Danzl, M.; Hunter, EG; Campbell, S.; Sylvia, V.; Kuperstein, J.; Maddy, K.; Harrison, AL.
- **Research 101 project** was developed to help demystify limited notions that research (i.e. only in laboratory or University settings or by those with PhDs) in order to engage the community in this process
 - The first 3 modules are completed and the final 2 modules to be finished in early Jan (2012)
 - The Research 101 modules help illustrate that research does have a real and practical impact on their lives
 - This was a collaborative effort between Drs. Anne Harrison, Beth Hunter, and Patrick Kitzman with significant input from our community partners, especially Violet Sylvia (ARH), Ralph Fugate (KY HomePlace) and EJ Brucal (ARH).

2012

✓ Research projects underway:

- **The Needs Assessment for people with Stroke (NAPS)** study reaches final analyses stage
 - Multiple presentations were made and several publications are developed
- **The Needs Assessment for People with TBI (NAPTBI)** study was initiated and focused on the supports and barriers to long-term health and healthcare of people with traumatic brain injury in rural communities. The NAPTBI team includes: Anne Harrison, Beth Hunter (in the beginning), Erin Stokes, Paige Bordy, Heather Thomas
- Research 101: Everyone Can Do It. The final two training modules are completed and made available online.

✓ **Research 101: Pilot Grant Program is created.** Three pilot studies are awarded through the Research 101 portion of our NIH Infrastructure grant to the following recipients: EJ Brucal (ARH), Megan Danzl (CHRH and the UK RHB program), and Ryan Creech (OVR).

✓ **Project CARAT (*Coordinating and Assisting the Reuse of Assistive Technology*)** was funded through a grant from the Health Resources and Services Administration (HRSA) PI: Carol Weber of the Kentucky Office of Vocational Rehabilitation. Funding Period: 2012-2015. Project CARAT is a collaborative project with the goal of improving the health and quality of life of individuals with disabilities in the Appalachian region of Kentucky through the provision and redistribution of assistive technology and durable medical equipment (DME: i.e. walkers, wheelchairs, hospital beds) and provide to those in need, at no cost. This project strives to improve the health and quality of life of individuals with disabilities by providing access to this equipment at no charge in order to improve independence and quality of life

- This is a collaboration between the Kentucky State Office of Vocational Rehabilitation, the Carl D. Perkins Vocational Training Center, the Bluegrass Technology Center, KARRN and the UK DPT program at the Center of Excellence in Rural Health in Hazard.

- ✓ **A Community-Based Appalachian Caregiver Peer Mentor Program** was funded through a pilot grant from the University of Kentucky Center for Clinical and Translational Science (CCTS) Community Engagement Core. PI: Beth Hunter of Cardinal Hill Rehabilitation Hospital. Funding period: 2012-2013. This project expanded the current spinal cord injury peer program at Cardinal Hill to include caregivers from Appalachian Kentucky, whose loved ones have received inpatient care at Cardinal Hill and have or will transition home to an Appalachian Kentucky community. A proposed Caregiver peer mentor network was designed to provide appropriate mentors for this population.
- ✓ **Needs Assessment for an adaptive sports equipment loan locker system** in Kentucky was started.
 - This is a collaboration between Cindy Jacobelli (CHRH), Cody Stanger (National Guard medical Outreach) and the UK Physical therapy students.
- ✓ Multiple presentations by members are conducted at local, state and national conferences.

2013

- ✓ **The Needs Assessment for People with Traumatic Brain Injury** study is ongoing.
- ✓ **The Needs Assessment for People with Stroke (NAPS)** study is completed. Several articles and presentations are in development.
- ✓ **Project CARAT** continues to expand at a phenomenal rate.
 - The number of equipment donations received has skyrocketed and the number of linking partners as increased in no small part to the efforts of Walt Bower and Ryan Creech (both with KY OVR).
- ✓ **Awarded a special pilot grant from the UK Center for Clinical and Translational Sciences (CCTS)** to look at the effectiveness of linking individuals who have had a stroke with a community health navigator (Kentucky HomePlace) to improve community integration and decrease poor health outcomes (PI: Patrick Kitzman).
 - Collaborators will include UK (Kitzman, Darrin Cecil, Jennifer Wycoff), Kentucky HomePlace, ARH (Violet Sylvia), and Cardinal Hill.
- ✓ **Continued work on the wheelchair accessibility project.** The Lexington Convention Center and Lexington City Hall have been assessed for wheelchair accessibility. More government buildings will be assessed for this project in 2014. This project is a collaboration of the UK PT students and Ms. Carla Johnson.
- ✓ **Appalachian Patient Stroke Recovery and Research Registry.** The purpose of this database/registry is to maintain quality data for analysis to meet stroke system quality improvement and research to improve the long-term health and healthcare of individuals with stroke in Kentucky and the Appalachian region.
 - This is a collaboration between KARRN (Darrin Cecil), the UK College of Health Sciences (Patrick Kitzman), The Kentucky Stroke Network (Dr. Michael Dobbs), the UK Office of the Executive Vice President for Health Affairs (Robert Edwards), and the UK CCTS ATRN (Kitzman) and BMI (Jeffery Talbert and Tammy Harper) cores.