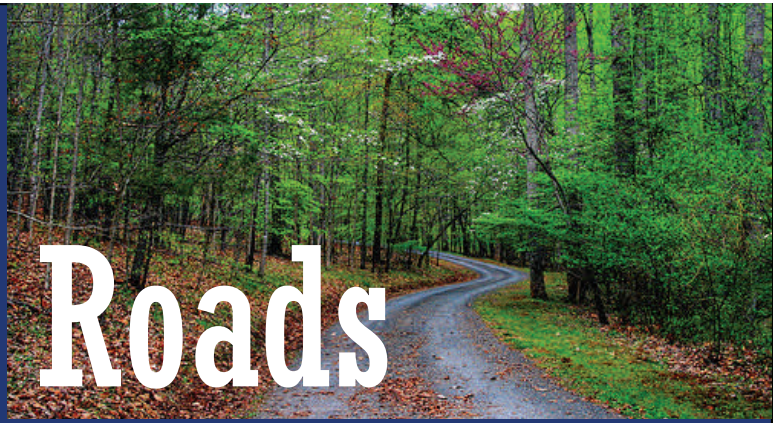


Country Roads

Volume 2, Issue 2

August 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.

Project CARAT Update—Walt Bower



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My name is Walt Bower and I was recently hired through the Kentucky Office of Vocational Rehabilitation as the Outreach Coordinator for Project CARAT. Along with Ryan Creech, a rehabilitation technologist from Corbin, we are blitzing Eastern Kentucky, getting the word out about Project CARAT. The vision and mission of Project CARAT is to improve the health and quality of life of individuals with disabilities who may not be able to afford the medical equipment they need to become independent. We are developing community partnerships at the Paint Lick Family Clinic in

Paint Lick, Premier Home Care in London, Sav-Rite Home Care in Corbin, Rockcastle County Regional Hospital in Mount Vernon, Medi Home Care in Harlan, and the White House Clinics in Appalachia. So far I have made presentations and answered questions regarding Project CARAT at the 10th Annual Summer Institute in Assistive Technology Conference in Frankfort and the Staff Meeting of the Bluegrass/Lexington Districts.

Donations are starting to arrive from medical practitioners and community members as a result of the Project CARAT initiative. While traveling throughout Eastern Kentucky, we have taken in over 85 donated medical items, including wheelchairs, walkers, abdominal braces, quad canes, crutches, and shower chairs. One community member donated a power chair and a hospital bed. Almost all the places we visit have medical items on hand they are willing to donate to Project CARAT. In addition, a member of the community in Western Kentucky has donated an adapted van!

We have assisted with the CARAT specialty electives for the Physical Therapy doctoral students at the UK Center for Excellence for Rural Health in Hazard. Carol Weber, Branch Manager for Rehabilitation Technology, and Ryan conducted a workshop discussing the many different types of assistive technology that are currently available to consumers. James Gensch, rehabilitation technologist, and Ryan led a workshop on disassembling and reassembling manual wheelchairs. A final meeting with the physical therapy students will include how to access the AT4ALL website and refurbishing medical equipment. We have recently completed interviews with outstanding candidates for the Occupational Therapist position at the Carl D. Perkins Vocational Rehabilitation Center in Thelma. Hopefully, we will have a new OT soon to coordinate CARAT activities and facilitate the refurbishing and storage of medical equipment at the Perkins Center in Eastern Kentucky.

In the upcoming weeks, we have appointments with the Christian Appalachian Project in Hagger Hill, the Director of Durable Medical Equipment for Hospice of the Bluegrass, and a presentation for the participants at the Rockcastle County Senior Citizens Center in Mount Vernon. You can visit us next month at our partner table at KARRN's annual conference in Richmond at Eastern Kentucky University's campus on September 25th. We will also have a table at the Kentucky Free Health Clinic Association annual meeting on September 26th and 27th at the downtown Lexington Hilton. In addition, I am also excited to be attending the Access to Care Peer Learning Seminar, sponsored by the Office of Rural Health Policy, on October 22nd-24th in Decatur, Georgia. Please feel free to contact me by telephone (859-246-2185, extension 275) or by email (walter.bower@ky.gov) anytime if you have input about the project, other agencies to contact, speaking opportunities, or just would like to make a donation to Project CARAT.

Center for Clinical and Translational Science (CCTS) - Supported Pilot Grants

Effects of Transvertebral Direct Current Stimulation in Humans—Lumy Sawaki, MD, PhD

According to the National Spinal Cord Injury Statistical Center, as many as 300,000 people in the United States are living with spinal cord injury (SCI). Approximately 12,000 new cases of SCI occur each year in the United States. It has not yet been discovered how to limit damage in early stages of SCI. Therefore, it is important to find ways to enhance motor recovery in SCI survivors over the long term. A considerable amount of evidence shows that noninvasive forms of brain stimulation can promote recovery of motor function in neurological populations, including SCI. Limited data exists regarding similar strategies to stimulate the spinal cord, but evidence in this regard is promising. To expand on this evidence, we will study transvertebral direct current stimulation, or tvDCS. In tvDCS, we apply mild, painless electrical stimulation to the spinal cord through electrodes placed on the back. Our experiment will help us determine if tvDCS makes the spinal cord more receptive to motor training and gait rehabilitation. We will study tvDCS in healthy subjects without SCI, and then, in subjects with SCI. This design will allow us to establish strong, basic science data prior to rapid clinical application of our findings. This unique, groundbreaking work represents the cutting edge of advanced technology-based strategies to restore function and enhance quality of life for SCI survivors.

Drug Dosing and Traumatic Brain Injury—Ed Hall, PhD

Cyclosporine A (CsA), an immunosuppressant drug, has been shown to diminish the amount of neurological loss or function in models with traumatic brain injury (TBI). Subsequently, CsA was the subject of a National Institutes of Health clinical trial involving a larger group of “severe” TBI patients; results showed the drug to be safe and it had some degree of effectiveness in protecting those neurons affected by the injury; investigators found that CsA produced a dosage-related neurological improvement. The CCTS is supporting a pilot project that supports additional clinical trials to explore potential biological characteristics of TBI that might serve as *diagnostic* indicators of the severity and timeline involved with posttraumatic brain damage. The study also seeks to identify potential *theranostic* indicators (or diagnostics and drug dosages unique to patients) of those that respond early to neuroprotective drug therapy, to include CsA dosing among other types of neuroprotective therapies.

Research

Living with Stroke: Lives Turned Upside Down

Stroke is one of the leading causes of long-term disability. The area in the United States that is hit the hardest with stroke is the Appalachian region of Kentucky. This is due to a number of factors, including reduced access to medical care, increased prevalence of chronic health problems, and reduced income and education. Stroke can result in decreased quality of life for the person with stroke, and caregivers can experience stress and depression. These are “lives turned up-side down” according to one person interviewed by Kentucky Appalachian Rural Rehabilitation Network (KARRN) researchers in their Needs Assessment of People with Stroke.

To better understand challenges faced by stroke survivors and their caregivers within Appalachia Kentucky, KARRN affiliates conducted interviews with thirteen stroke survivors and twelve caregivers living in rural Appalachia Kentucky. The interviews were broken into three categories: 1) Stroke Onset 2) Transition through the health care continuum (e.g. emergency room, to hospital, to rehabilitation units, to subacute care, to home health) 3) Reintegration into life in their rural communities.

For "Stroke Onset," participants interviewed described the initial event as unexpected and traumatic. Most did not recognize the warning signs and symptoms and had little to no knowledge of stroke prevention. While many spoke highly of their physicians, some noted concern about a lack of depth of knowledge or expertise among rural health providers in the area of stroke. As Larry, a stroke survivor, explained, "(The) challenge of a rural community (is)...gettin' medical help...somebody that can recognize it and know how to treat it...". Other challenges included the inability for paramedics to navigate to a person's home due to rural geography, lack of neurologists, and distrust in rural medical care. Of the people interviewed, 83% ultimately received their acute care from hospitals in urban communities. Unfortunately, the time it took to arrive at urban environments resulted in most missing the early windows for optimal care and prevention of expansion of the stroke.

Most participants had a difficult time recalling their acute care experience, and any education that might have been provided was typically forgotten due to being overwhelmed by the initial trauma of their situation. One participant, Samuel, remembered his doctors in acute care being “insensitive”, bringing in students and other doctors to view his condition without any thought to his feelings on the matter. In addition, upon transfer to inpatient rehabilitation, he was shocked to discover the truth of his condition; while in acute care, he had believed he suffered a massive heart attack, not a stroke.

Anne Harrison, PT, PhD is a faculty member in the UK Division of Physical Therapy (College of Health Sciences)

-Megan Danzl
Bellarmine University

-Beth Hunter
Georgia Regent University

-Violet Sylvia
Appalachian Regional Healthcare System

-Sarah Campbell
UK SLP Program

-Katie Maddy
UK SLP Program

-Janice Kuperstein
UK-DPT program

To his recollection, no health care provider had explained what had actually happened to him.

In their transitions through the health care continuum, participants had mixed feelings about their experiences. All but one participant moved from acute care to inpatient rehabilitation. While many considered this another frustrating hurdle before returning home, in hindsight most appreciated the experience, which offered the tools to begin coping and adapting to their condition. Columbo considered the atmosphere, "the sunshine in the darkness," as he and other survivors were integrated into a support system that improved their sense of self, feelings of accomplishment, and perception of recovery. Most were very positive about the care received from therapists in inpatient rehabilitation. One participant, Columbo, described a deep connection with his speech therapist. "She reached into my soul...there was just a personality connection there." Caregivers also experienced varying levels of care and engagement, with some feeling well-informed of what they would need to do to care for their loved ones, and others feeling they remained uninformed, resulting in a sense of helplessness and frustration.

Language barriers proved to be one of the greater challenges, as providers would inadvertently use medical lingo outside the participants' understanding, or language the participants believed to be misleading. At least three of the participants were told they had experienced a "small stroke," leading them to believe they would make full recoveries. This caused difficulty coping and a sense that their loss and change was being trivialized. One participant's husband felt she was going crazy because she was having memory and speech problems due to the stroke. She was told her stroke was small and she never received rehabilitation after acute care. This gave her and her husband the message that she should not be having any problems, leading to serious problems and damage to their marriage.

Inpatient rehabilitation is a key environment for providing essential education to stroke survivors and caregivers. In one rehabilitation hospital, caregivers were invited to a "family teaching day" by inpatient rehabilitation staff; survivors worked with providers who within a specialized stroke unit and also had the ability to interact with peers undergoing similar therapy. Although these experiences provided essential information to participants, serious drawbacks were noted by those interviewed. "Family teaching day," which gave vital information to caregivers, was held just one day prior to their loved ones being discharged. Most information given by providers was offered verbally, many times through conversations with patients, not in a structured setting for demonstration of the education. In addition, participants often felt reluctant to ask questions or simply did not know what to ask when speaking with healthcare professionals.

Living with Stroke: Lives Turned Upside Down (continued)

Even with time in inpatient rehabilitation to prepare them for returning home, most participants felt ill-equipped when they left. Many sought out community-based rehabilitation (outpatient, home-based or long-term skilled nursing facilities), but could not find easy access to such services in or around their rural hometowns. One caregiver would drive his loved one three hours, three times a week, for six months to reach an urban outpatient therapy center. With limited access to healthcare within their communities, participants felt overwhelmed and isolated. Most considered the education they received in acute care and inpatient rehabilitation important but ultimately lacking, especially as they tried to reintegrate back into their lives and communities.

Upon returning home, problems included changed life roles, inadequate coping mechanisms and both positive and negative rural community support. As Larry explained, "People were...makin' fun of me, especially my family. [The home health nurse] said...they're just showin' their ignorance is all they're doin', they don't understand'...she gave me a bunch of literature to hand out". Many participants would not or could not use the written materials provided (if provided). They had difficulty recalling information they had received from providers, and new questions would arise from participants during day-to-day activities with no one there with answers.

On-going and timely education and access to healthcare providers with in-depth knowledge about care of people with chronic stroke are two critical issues that need to be addressed within Kentucky's Appalachian communities. As healthcare providers attempt to tackle these problems, however, more questions surface. When is the best time to educate patients and their caregivers? What is the best method to deliver such information? Should this information be given repeatedly throughout the continuum of care and after returning home? And perhaps the most important question—who should be responsible to educate patients on what issues?

Having leaders in the interdisciplinary teams in each environment of care coordinate which providers are responsible for what essential information throughout the patient's treatment could greatly improve patient care. Verbal methods of education were described by participants as being overwhelming, and one study (Garrett and Cowdell, 2005) showed a preference for verbal communication accompanied with visual models such as pictures and videos. While research has shown that stroke survivors and caregivers have difficulty recalling written information, when that information is individualized and revisited multiple times, their recollection of written information greatly improves.

Typically, websites are not used as a source of information by participants, possibly due to lack of computer accessibility, reduced internet services in their communities, or the participants' inexperience with using a computer or looking up information on the internet. While this might be changing with time and improved accessibility, providers should develop educational strategies that include additional alternatives to online information.

In one study (Johnson and Pearson, 2000), the effects of a structured education course for stroke survivors living in the community (eight classes over one month) found participants had a greater sense of hope and decreased depression from the experience. Key factors of that education that must be addressed include: general stroke information (what is stroke, residual effects, causes of the stroke, prognosis), the role of therapy to facilitate recovery, how to assist functional mobility, information about the potential of the brain to recover, prevention of secondary complications and future strokes, and information about accessing financial resources.

In addition to the physical aspects of stroke, there are also the emotional aspects, such as depression, changing relationships, and coping strategies, that should be addressed for stroke survivors and caregivers. What is their support system? How do they manage stress? What support and resources do they have in their community?

The current healthcare system is not well designed to provide long-term support for stroke survivors and caregivers, particularly once they have returned to life in their rural communities. Yet the ultimate goal of people with stroke and caregivers is to return home and have a decent quality of life. All participants experienced a sharp decline in support once discharged from either acute care or inpatient rehabilitation, leaving them to fend for themselves after returning home. With better education methods, and improved community support, it may be possible to improve the lives of stroke survivors and caregivers as they learn to adapt to their new lives upon return to their rural communities.

The information from this study can be found in the publication: Danzl, M.; Hunter, E., Sylvia, V. Campbell, S. Maddy, K., Kuperstein, J. Harrison, AL. Living with a ball and chain: The lived experience of stroke for individuals and caregivers in rural Appalachian Kentucky. *The Journal of Rural Health*, Printed on-line ahead of print version May 23, 2013.

A Library for People with Stroke Now Available on the KARRN Web Site—Anne Harrison, PT, PhD

People who have suffered from a stroke and their caregivers and loved ones need ongoing support and education in order to adapt well once they return to life in their communities. In fact, according to people who have had this experience, there is often very little education and support once they leave inpatient acute care and rehabilitation hospitals. KARRN researchers completed an interview study of people with stroke and caregivers who live in rural Kentucky and named the study *Needs Assessment of People with Stroke (NAPS)*. The NAPS study provided a voice for people with stroke and caregivers who live in rural Kentucky to explain the challenges they faced once they returned home to their communities. KARRN researchers also interviewed and surveyed health care and rehabilitation practitioners who serve people in rural areas to determine their perspectives on the needs of people with stroke once they return home to rural areas. People report receiving good care in inpatient environments, but because of the overwhelming challenges of coping with “lives turned upside down” by stroke, they often are not able to remember the education they received when they return to their homes. The result is that at exactly the time they most need it (i.e. when they return home), the informational support is largely not present. This is particularly true in rural areas where health care and social support become more difficult to access due to distance and geography (Danzl, et al 2013). In spite of receiving information on these topics in the inpatient environment, questions arise upon returning home regarding proper use of assistive devices for walking, safe approaches for assistance with transfers, and strategies for getting up from a fall safely. As time progresses, concerns begin to grow regarding how to stay healthy both physically and emotionally. Many people voiced concerns regarding how to prevent future strokes.

The purpose of our 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 developed a “Stroke Library” of resources designed to be easy to access, easy to understand, and culturally competent. Our project was formulated based on what we learned from the NAPS study. A desire for resources within their own community was expressed by people with stroke, their caregivers, and respective family members. The results of this study highlighted the need for a compilation of resources, available in varying forms, which were easily understood and accessible to people living in rural Kentucky.

Such resources could also be used by health care providers for education, and then the resources could travel home with the patient.

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.

Whether you are a person with stroke, a family member or loved one, a professional, or just an interested community member, we would like your feedback on the library. When you visit the library at www.karrn.org, you will find a link to the Stroke Library on then home page. Once you are in the library, you will find a link to a brief survey. We would like to continue to enhance our materials using your feedback.

No Barriers Summit—Sasha Rabchevsky

Four representatives from our newly formed Kentucky Congress on Spinal Cord Injury attended the No Barriers Summit that took place in Telluride, CO August 8-11, 2013; Sasha Rabchevsky, Bob Patterson, Micah Jackson and Myles Cope (picture below).

This amazing event brought together a community of participants who



engaged their barriers and learned to harness them for their own good and the good of the community. Participants experienced the No Barriers Mindset, focusing on developing several key characteristics: 1) Curiosity for exploration & innovation, 2) Participation in strong teams, 3) Harnessing adversity 4) Service to others.

The No Barriers Summit provided technological, physical and emotional support for participants with a wide variety of abilities and disabilities to start or continue down the path of embracing the No Barriers Mindset in unique ways over the course of the 4-day event. It is a combination of innovation and community building as a solution for overcoming challenges.

The No Barriers Summit embodies the philosophy of pushing yourself beyond a comfort zone, by learning and embracing innovative assistive technology designed to afford greater expansion of one's ultimate capabilities; this extends to participants who do not necessarily have a physical disability since they witness firsthand how seemingly insurmountable obstacles are overcome when innovation and motivation are combined in such a unique, inspiring venue.

The event structure was centered around 3 days of outdoor adventure and arts clinics that allowed participants to try new physical activities with a community of volunteer supporters to help make the activities accessible to their many different ability levels. These clinics included (but were not limited to) rock climbing, off-road wheelchair racing, adaptive hiking, biking, photography, filmography, painting a mural, tennis, golf, etc.



Then each evening session consisted of scientific presentations by innovative experts as well as extraordinary disabled end-users of innovative adaptive equipment who shared stories of success and showcasing leading technological solutions to barriers.

Whether or not participants had a disability or were loved ones and/or care providers, everyone at the Summit was immersed in the company of pioneering, innovative individuals who either develop assistive technologies to overcome barriers or are courageous trial users of such innovations designed to overcome obstacles that prevent engagement in physical activities that may otherwise appear infeasible.

Unfortunately, Micah Jackson was seriously injured during his downhill 4-cross cycling and broke his clavicle and shoulder blade the 2nd day of the summit. However, with the support of the No Barriers staff and board, including Soldiers to Summit participants, Micah was well taken care of and was even escorted to the airport in a wheelchair and van donated by the Telluride Adaptive Sports Program to get him to his rearranged flights back to Lexington. He was also accompanied during his entire flight exchanges by a wonderful volunteer and newfound friend from Soldiers to Summits, Karen Diener!!! Micah is now recovering comfortably at home in Lexington.



Highlights of Speakers/Performers:

Mandy Harvey is a deaf American jazz singer and songwriter. A Vocal Music Education major at Colorado State University, Mandy lost her hearing in 2006-2007 at age eighteen and left. She pursued several career options, including education, but returned to music in 2008. She is now an acclaimed performer and has maintained perfect pitch despite her hearing loss. Her singing was truly inspirational, knowing that she cannot hear her own voice!?

Bob Woodruff was the keynote speaker. He is an award-winning television journalist whose noted career with ABC News began in 1996. His intrepid reporting has taken him from the Afghanistan and Iraq wars to the unrest in Middle East/North Africa, to North Korea during its 2010 celebration of the 65th Anniversary of the Workers Party. In January of 2006, while reporting on U.S. and Iraqi security forces, Woodruff was seriously injured by a roadside bomb that struck his vehicle near Taji, Iraq. In an instant, his life was altered forever. He suffered a severe brain injury and was in a coma for over a month.

Erik Weihenmayer, co-founder of No Barriers, has become a celebrated and accomplished athlete despite losing his vision at the age of 13. Redefining what it means to be blind, Erik has transformed the image of blindness and opened up the minds of people around the world. On May 25, 2001, Erik became the first blind climber in history to reach the summit of the world's highest mountain, Mount Everest. At the age of 33, he became one of less

than 100 individuals to climb all of the Seven Summits – the highest peaks on each of the seven continents.

No Barriers presented for the first time two exoskeleton users on the same stage! Exoskeleton technology has been referred to as a “wearable robot.” This powerful external skeleton is bringing the brink of modern technology to the lives of those affected by paralysis. It is redefining what is possible for many users. In this exciting presentation, moderator Sasha Rabchevsky, Ph.D. and exoskeleton expert Russ Angold helped the audience to better understand the history, present and future of this exciting technology.



Everyday users, Amanda Boxtel and Mitch Brogen each shared their personal journeys from the wheelchair to the exoskeleton and demonstrated the affect it has had on them as they showcase the technology. Amanda Boxtel, a paraplegic in a wheelchair for 21 years, demonstrated the Ekso exoskeleton which enables her to walk upright. Importantly, the existing technology is rapidly advancing. Speakers equated its progress to the once bulky cell phones which today are miniaturized with many applications. It was quite emotional when Amanda looked down at her audience, many in wheelchairs, and said, "For those of you in wheelchairs get ready to walk." How powerful is that? They were available for one-on-one Q&A immediately following the NBU presentation in the Innovation Village Bazaar.

Kyle Maynard, born with no limbs, who had tried climbing for the first time at our 2011 Summit, later perfected a technique that worked for him, and then went on to climb Kilimanjaro last year, along with winning the ESPY award for disabled athlete of the year. He gave us his thoughts about perseverance. "If you're not dead, keep going!"

Dr. Hugh Herr, a double-leg amputee himself, co-founder of No Barriers and a professor at Harvard/MIT, has developed the most sophisticated knee and ankle prostheses in the world. Hugh predicted at No Barriers University that most disabilities would be eliminated by technology by the end of this century. Pretty bold statement...and exciting....he received the No Barriers

Lifetime Achievement award!

Jen French is a quadriplegic and a competitive sailing athlete who recently medaled at the 2012 Paralympics Games in London. Ms. French is the

Executive Director of Neurotech Network and author of the book, *On My Feet Again: My Journey Out of the Wheelchair Using Neurotechnology*. She was a participant in a clinical trial of a neuroprosthetic



system that enables her to stand up outside of her wheelchair to move around on her own two feet using her own muscles, stimulated by 24 surgically implanted electrodes. In 2012, Jen became the first woman with a disability to be awarded the U.S. Sailing's Rolex Yachtswoman of the Year.

Of course, solutions require pioneering and a No Barriers mindset, but they also require money. We are very proud to report that Erik Weihenmayer completed his \$1 million pledge to No Barriers from his speaking engagements, which prompted an existing supporter to make a \$1 million donation which only needs to be matched with new gifts to No Barriers USA. What a finale!



5th Annual KARRN Conference Agenda

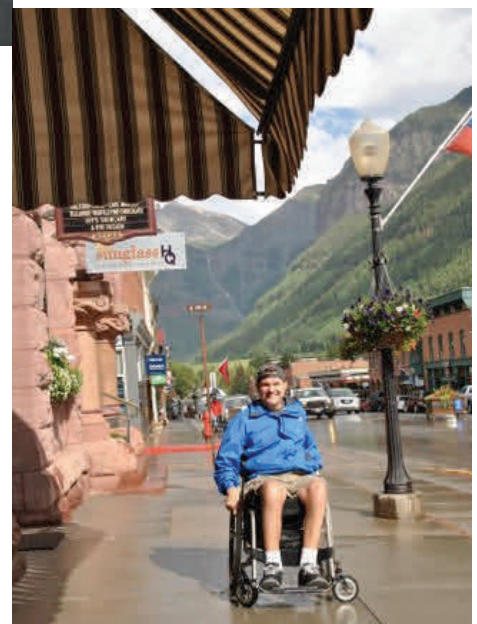
September 25, 2013, Perkins Center at EKU

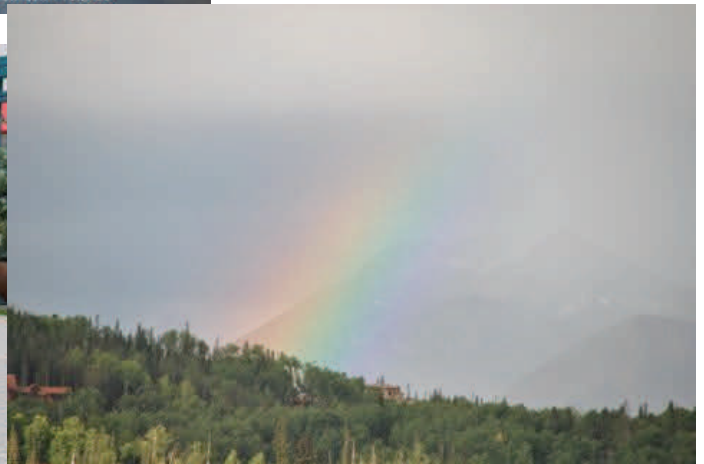
1. Connecting clients and clinicians with services and resources that will assist individuals with neurological condition. (Tonia Wells: KY Department on Ageing and Independent Living and the KY Traumatic Brain Injury Trust)
2. Long-term health and healthcare issues following spinal cord Injury. (Dr. Sara Salles : UK PM&R and Cardinal Hill Rehabilitation Hospital)
3. Spinal Cord Injury Panel discussion: Health and wellness living with SCI (weight, nutrition, joint care, energy, chronic illnesses like diabetes and high blood pressure, etc.).

LUNCH. There will be time for poster presentations and time to meet with the vendors and community partners.

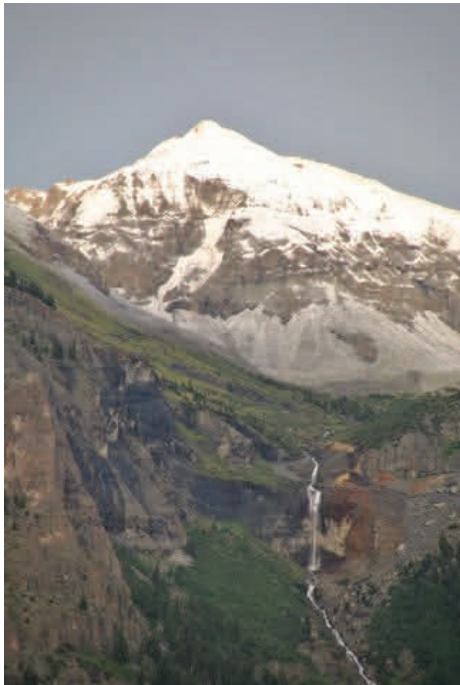
4. Long-term health and healthcare issues following stroke. (Dr. Michael Dobbs, UK Department of Neurology).
5. Stroke Panel discussion: The panel could talk about to the topic areas such as: 1) Issues with mobility issues and safety existed, 2) Right time and Right Type of Education for Community Re-Entry, 3) Support Systems available in community or development needed.
6. Best practices to facilitate community integration following TBI. (Stacy Grinder, OTR/L Cardinal Hill Rehabilitation Hospital).
7. Traumatic Brain Injury Panel discussion: Life after TBI
8. The possible interaction between poly-pharmacy and long-term health and healthcare for individuals with neurological conditions. (Dr. Jimmi

Community Photos





Community Photos



**For more information about KARRN
you can check out our website at
www.karrn.org**

OR

**Patrick Kitzman at
phkitz1@email.uky.edu**

859-218-0580

