



Spinal Connection

Quality of life publication for Arkansas wheelers living well.

www.ascc.arkansas.gov

WINTER 2015 • VOLUME 27 • ISSUE 2

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Save the Date

Client Primary Care Survey Results

The Arkansas Spinal Cord Foundation Advocates for Better Health Care Delivery in Rural Arkansas.

Client survey participation an important component in state study

This past year provided ASCC tremendous opportunities for our clients through collaboration to advocate for better health care delivery in Arkansas for people living with spinal cord injuries, especially in rural communities.

ASCC became a collaborating partner to participate in a three-year \$300,000 grant awarded to the Arkansas Spinal Cord Foundation (ASCF) from the Craig H. Neilsen Foundation. Other collaborating partnerships were developed with the University of Arkansas Medical Sciences (UAMS); College of Medicine; Centers for Distant Health; the Baptist Rehabilitation Institute, and the Baptist Health School of Nurses.

The grant is being implemented by ASCF to advance spinal cord injury healthcare delivery in rural Arkansas through provisions to provide an education platform not only for our new and existing clients, but with focus directly to primary care providers, first responders; emergency department physicians, and clinicians. One goal is to promote and achieve SCI care delivery through consultations with a SCI specialist and utilization of telemedicine.

Prior to implementation statewide the project began in a pilot area. ASCC was instrumental in selecting a strategic 25-county pilot area that represents a 85% ratio of clients living in rural areas of Arkansas.

Our appreciation to all clients that participated in the study.

Client Spotlight:



Meet Christie Hoffarth

It was after midnight, on a hot summer eve, when Christie Hoffarth dropped-off the last one of her friends. It had been a long day, and she was now regretting her offer to be Designated Driver for a Girls Night Out that carried over into morning. Christie was close to home, when she rounded a sharp curve, and lost control of her vehicle. The next thing she remembers is hanging upside down, seatbelt still buckled, both airbags deployed, and the car roof crushed into the top of her head.

Continued on page 3

85%
PEOPLE WITH SCI LIVE IN RURAL AREAS



CLIENT SURVEY VITAL TO STUDY: As part of this initiative, a consumer survey to examine utilization and satisfaction with primary care providers was mailed to 687 with a 40% return participation ratio.

In total, 86% of individuals reported having a family doctor; since injury 62% have seen an SCI specialist, and 46% have both a family doctor and SCI specialist. Of those surveyed, 84% felt primary care providers need more comprehensive information on caring for those with spinal cord injuries.

84% HEALTHCARE PROVIDERS NEED SCI CARE EDUCATION

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Spinal Connection

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An Official Publication of



Patti C. Rogers Executive Director
Jason Francis Editor

ARKANSAS SPINAL CORD COMMISSIONERS

Jon Wilkerson Chairman
Ronnie Wheeler Vice Chairman
Mike Cranford Commissioner
John Wyrick Commissioner
Jimmy Ashley Commissioner

CONTACT INFORMATION

(800) 459-1517

Email: ascc@arkansas.gov

Website: www.ascc.arkansas.gov

Donations

The Arkansas Spinal Cord Foundation accepts tax-deductible donations to support ASCC.

Send your donation to:

ASC Foundation

PO BOX 242103

Little Rock, AR 72223

Those to Remember

Dorothy Elger	Dec. 15, 2015
Darrell Chalk	Dec. 13, 2015
Roy Pugh	Dec. 11, 2015
Andrew Lee McMillian	Nov. 16, 2015
Miles Thompson Graham	Nov. 14, 2015
Lola Huyck	Nov. 12, 2015
Rickey Dale Eich	Nov. 10, 2015
Thomas Joseph Cunningham	Nov. 6, 2015
Cassandra Straka	Nov. 1, 2015
Chester Wayne Seats	Oct. 27, 2015
Jon Carlos Fuhrman	Oct. 26, 2015
Lorenzo Don Noiel	Oct. 11, 2015
Kylee Vignoe	Oct. 10, 2015
Julie Farmer	Oct. 2, 2015
David Ferrell	Oct. 1, 2015
Bobbie Jean Hudson	Sept. 27, 2015
Gertie King	Sept. 26, 2015
Cescily Nicole Porter	Sept. 23, 2015
Ferrall Reed Williams	Sept. 22, 2015
Justin Lee Tucker	Sept. 20, 2015
Russell E. Hooker	Sept. 19, 2015
Ricky Basham	Sept. 15, 2015
Tanya Deanne McCabe	Sept. 15, 2015

From the Director

Patti C. Rogers



Looking Back, Moving Forward in 2016

The year 2015 marked ASCC 40th year!

As I began looking back over the ASCC accomplishments during 2015 I began thinking about the past history of the agency. It has taken many dedicated individuals to get us where we are today. 2015 marked the 40th year since the Arkansas Spinal Cord Commission was established.

The initial start of this quest actually began in 1973 and was spearheaded by Jane Smith with the initial support of then Governor Dale Bumpers and First Lady Betty Bumpers. First Lady Bumpers hosted a meeting to determine the needs of those with SCI, which resulted in establishing the Spinal Cord Injury Task force of the Arkansas League of Nursing. Governor Bumpers provided a grant of \$50,000 to conduct a survey to determine the number of SCI in Arkansas. Mrs. Bumpers also requested that Spina Bifida be included in the survey. A statewide door-to-door search began to determine the number of individuals with SCI and Spinal Bifida living in Arkansas. At that time 601 individuals with SCI and 284 individuals with Spina Bifida were identified.

With the results of the survey in hand and with the support of many others, Mrs. Smith determined to get the much-needed services for individuals with spinal cord disabilities headed to the State Capital. As a result of these efforts, in 1975 the Arkansas Legislature passed Act 311, which established the Commission. ASCC became the first State Agency in the United States to be solely responsible to individuals with spinal cord disabilities. In July of 1975 the first Arkansas State Spinal Cord Commission was given the oath of office by then Governor David Pryor. 1977 marked another historic milestone as Act 330 established the Arkansas Spinal Cord Disability Registry.

Over the years other milestones included: the establishment of Spina Bifida Camp in 1978; the ASCC Long Term Attendant Care program in 1981; the adoption of our medical criteria in 1987; implementation of our first annual conference and quarterly newsletter publication in 1990; agency's name changed to Arkansas Spinal Cord Commission in 1993; development of the ASCC website in 2003; formation of the Accessible Parking Taskforce in 2011; ASCC assumed the oversight of the Arkansas Trauma Rehabilitation Program in 2011; revision of the financial eligibility criteria guidelines in 2012; implementation of the ASCC Face book page in 2013, and development of a two-day healthcare professional SCI/D conference in 2015.

I am proud to have been a part of this successful agency since 1989 and realize that without our dedicated staff and Commission members to carry on the initial vision much of our history would have never happened.

As we move forward into 2016 we will continue to uphold and promote our vision so that the individuals we serve may live a better quality of life.

Continued from page 1 | **Client Primary Care Survey Results**

Consumers report anecdotally that they often cannot find a family physician in their community whose office and equipment are accessible, or who is willing to take them on due to lack of SCI expertise and time requirements. Further, they report *disappointment at the level of knowledge and experience with SCI disability in the medical community*. Current access to health services, usually refer to wait times or geographic distribution of services. However, for people with disabilities access issues also relates to additional types of barriers: physical inaccessibility, lack of expertise about SCI, attitudes toward disability and health system issues.

The mission the Arkansas Spinal Cord Foundation's initiative is to address gaps in service; 1) stimulate healthcare cost-savings through efficient around-the-clock support to advance timely SCI care delivery, 2) reduce repeated emergency department visits and hospitalizations, and to 3) develop a SCI Curriculum in medical and nursing schools.

Another important component is to develop training and learning educational modules for physicians and clinicians, as well as interactive educational videos for those with SCI.

The focus is to improve the following:

1. Expertise in treating acute trauma in an emergency situation.
2. The importance of proper diagnosis and treatment of, sometime fatal, secondary conditions.
3. Enable access to a SCI specialist via phone consultations and telemedicine video assessments.
4. Comprehensive rehabilitation programs.
5. Vocational and psychological counseling to encourage community reintegration.

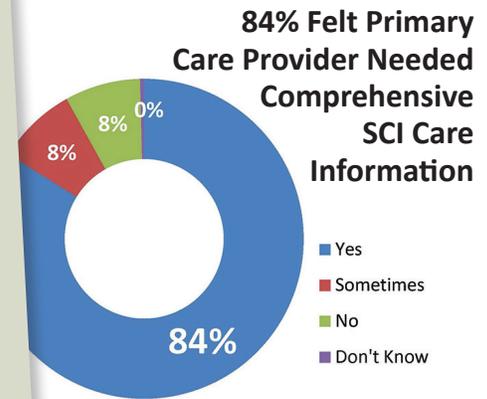
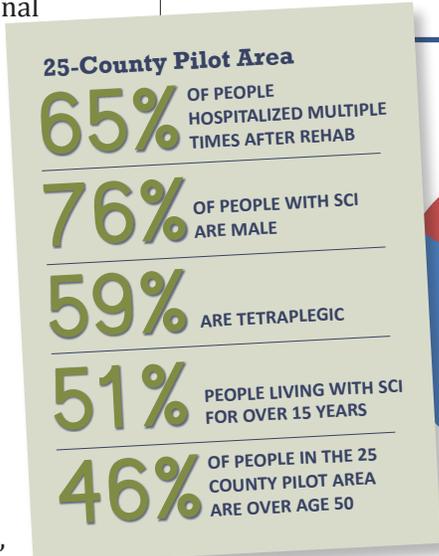
Led by Thomas S. Kiser, MD, at UAMS, BRI, and ASCC Medical Director, technical writing was developed using evidence-based guidelines to emphasize SCI education. Training presentations began in 2015 around the state; two of six educational webinars are produced to raise care standards and evolve quality patient-focused rehab and care. On-the-spot call center and telemedicine consultations with a SCI specialist for immediate diagnosis and treatment determinations are accelerating. Consumer and caregiver interactive video production continues.

Arkansas lawmakers approved legislation to support the use telemedicine in the state. As of January 1, 2016 insurance providers covers service.

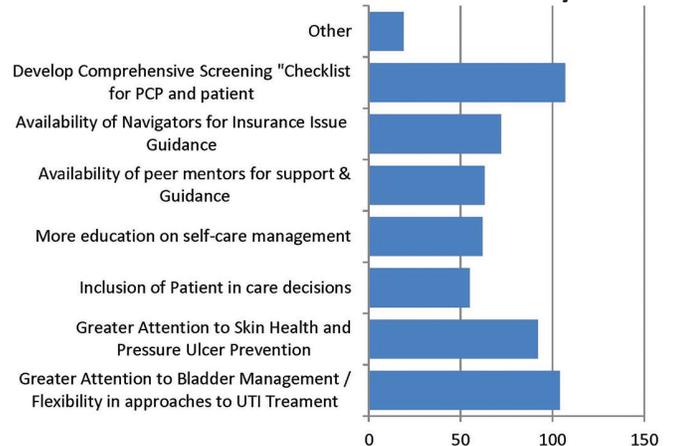


2015 Spina Bifida Christmas Party Brought Joy and Fun to All.

The 2015 annual Spina Bifida Christmas Party hosted by the Spina Bifida Support Group of Arkansas was held on December 13, 2015. Despite a stormy, rainy morning over 150 adults and children attended this year festivities. Lots of games. Door prizes and activities kept everyone busy until they heard rain deer hooves and a merry HO HO HO!! Much to everyone's delight Santa Claus dropped in to provide early Christmas presents to all! Special thanks to the Central Arkansas Corvette Club for their support and to Dave's Burgers for providing lunch for everyone.



SCI-Specific Healthcare Needs that Could Be Better Met in Primary Care



Spasticity and Cold Weather

Spasticity after spinal cord injury is the result of poor coordination between the upper motor neurons (UMN) located in the spinal cord and the lower motor neurons (LMN) that make the connection between the spinal cord and the muscle. The LMN is the last leg of the nervous system that provides the nerve signal to your muscles to make them move. In a spinal cord injury there is a loss of control signals and of positive and negative feedback signals from the spinal cord and the brain to the LMNs that are located below the spinal cord injury. There are also feedback effects on the LMNs from sensory inputs from muscle spindles implanted within the muscle fibers. The muscle spindles sense the stiffness of the muscle and send a signal to the LMN making it either more or less sensitive to other signals that are feeding into the LMN. That is one reason that a stretching program which stretches and loosens the muscles and tendons reduces the muscle spindle tension and thus decreases the input of the signal into the LMN and decreases spasticity. Heat has a similar effect of relaxing the muscle and the tension on the muscle spindle and cold has the opposite effect. Cold stiffens the muscle and thus the muscle spindle, therefore increasing the sensitivity of the LMN to any stimulation which causes spasticity.

In winter months as the temperature drops, the muscles tighten up and therefore the muscle spindle stiffens and becomes more sensitive to any rapid movement or painful stimulation below the spinal cord injury level. This can increase the spasticity and tone



ASCC
Medical
Director



to a higher level than is usual for a patient. This hampers a person's ability to manage their spasticity as effectively and impedes their movement and transfers. At this time of year a lot of my patients increase their stretching routine and spasticity medication or increase the rate of their baclofen pump to better control their spasticity. Other treatment strategies are to maintain the temperature in the home at a warmer level, dress warmer than usual, or head south to a warmer climate for the winter if that is an option. If you live in Arkansas, you are already in better shape than your northern friends.

The medications that are most effective in decreasing spasticity are baclofen (Lioresal), tizanidine (Zanaflex) and dantrolene (Dantrium). Baclofen is similar to an inhibitory neurotransmitter called GABA and slows the nerves' responses to stimulation. It is the most frequently used medication for spasticity in spinal cord injury. Baclofen's biggest drawback is sudden withdrawal symptoms, such as hallucinations and seizures, if it is stopped suddenly, so always taper off if you are stopping or running low on baclofen. Tizanidine slows the communication between nerves in the spinal cord and the LMN, but it can affect liver function so lab tests need to be checked periodically. Dantrolene works at the muscle level and decreases the muscles' response to nerve signals from the LMN. Liver function tests also need to be followed with dantrolene. These medications

can be combined as they work at different points in the interaction between the UMN, the LMN and the muscle. Other options are muscle relaxants such as cyclobenzaprine (Flexeril), carisoprodol (Soma), and metaxalone (Skelaxin) which all depress the central nervous system and mainly lead to drowsiness. These medications have minimal effect on the LMN to muscle interaction, so are rarely used in spinal cord injury.

As we move into colder weather this year, do not be surprised by increased spasticity and tone. Be proactive with medication management, stretching and maintaining a warm and comfortable environment for you and your family.

Continued from page 1

Meet Christie Hoffarth

On August 3, 1995 at age 21, Christie was diagnosed with C5 Tetraplegia.

In 2011, Christie partnered with Greg Alderson (*a Certified SCI Recovery Trainer*) to create Destination Walk: a non-profit, neurological recovery center located in Springdale, AR, offering personalized training for people with SCI and neurological injury/disease. Christie also offers education and advocacy for local schools to help communities of NW Arkansas better understand the valuable role people with disabilities play in our society today.

At age 41, Christie is the prime example of someone taking a life-altering experience and turning it into the greater good for others. This past year, she collaborated with the ASCC to start a Disabilities Connection Group, which is held on the 2nd Tuesday of every month at Destination Walk. Their website is under development, but more information can be found on Facebook.

<https://www.facebook.com/Destination-Walk-Neurological-Recovery-Education-Center-296653900346314/>

Ronnie Brown Named 2015 Recipient of the Phil Stinebuck Courage Award

The Arkansas State Independent Living Council (ARSILC) recently recognized Ronnie Brown, of North Little Rock, as the recipient of the prestigious *Phil Stinebuck Courage Award*, named in honor of the late Phil “Buck” Stinebuck.

Phil Steinbuck was a pioneer in this movement, who served as a chartering board member of the ARSILC and championed the cause for independent living in Arkansas. Despite his own physical disability, Phil worked tireless hours to advocate for the rights of all individuals with disabilities. His family, to this day, continues his legacy by operating and maintaining the Spa Area Independent Living Services center in Hot Springs, Arkansas.



Ronnie Brown

The *Phil Stinebuck Courage Award* recipient embodies this same spirit of advocacy, activism, and self-determination. We are proud to congratulate Mr. Ronnie Brown, of North Little Rock, on being the 2015 award-winner.

Brown has worked with the Baptist Health System since 1990. Most recently he has worked as a Prospective Payment System Analyst and a Nurse Educator. He and his wife, Suzette, have been married for 32 years; they enjoy two grown children and two granddaughters.

Prior to his injury, Ronnie worked as a cardiac nurse- it is worth noting that he still maintains his status as a certified rehabilitation nurse. Ronnie was injured on June 19, 1993, in a car accident. He sustained a spinal cord injury at the C6 level, but reports that he was only off for seven months before returning back to the Baptist Health System- such was his determination to continue working in spite of his disability. Ronnie is also the state chapter director of the Think First Program, which is a spinal cord injury prevention program.

What is especially remarkable about Ronnie is that his sense of motivation and passion for his work has prevailed for over 22 years, which is an inspiring example to us all. Well done and congratulations, Ronnie!

Don't Forget Your Spina Bifida TAX CREDIT

We want to remind parents of children with Spina Bifida that they may qualify for a \$500 tax credit. When you complete your state tax return, be sure to include the Certificate for Developmentally Disabled Individual form (AR1000RC5).

You can find the form at: www.dfa.arkansas.gov/offices/incomeTax/individual/Documents/AR1000RC5_2015_RE.pdf

You must have a physician complete the form before submitting it. With the form, the head of household will be eligible for a \$500 tax credit for 2015.

If you have questions, contact the AR Department of Finance and Administration, Individual Income Tax Section at 501-682-1100.

Have a medical question?

Experiencing issues and need immediate answers?

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ASCF initiative made possible through grant funding provided by the Craig H. Neilsen Foundation.

Winter Health and Wellness

Now that the holidays are over, you may find yourself searching for your most forgiving clothes as your body deals with the effects of a little too much food. Then there's the guilt, that mental wince when you remember that extra piece of pie or that giant glass of eggnog you wish you could take back in the cold light of day. Unfortunately, there's no way to un-eat what you ate, but you can do some damage control and get back on track for the new year; and you can do it without punishing yourself.

GUIDELINES FOR HEALTHY EATING



There are some basic guidelines for healthy eating:

- Eat a variety of foods and Maintain ideal weight,
- Avoid too much fat, saturated fat, trans fat and cholesterol,
- Eat foods with adequate complex carbohydrates and fiber,
- Avoid too many sweets, Avoid too much sodium.
- If you drink alcoholic beverages, do so in moderation.

If you're too heavy, you'll have a much greater chance of developing a chronic disorder. Obesity is associated with diabetes, high blood pressure and high levels of fats in your blood, which can lead to heart disease and hardening of the arteries and can increase your risk of having a heart attack or a stroke. Obesity can also increase your risk of developing pressure ulcers and can impair your mobility.

If you transfer independently, the extra weight can lead to shoulder problems. If you require assistance for transfers and bed mobility, the extra weight makes the job that much harder for your caregivers. If you're underweight, you may be less able to fight infections and may tire easily. If your bones stick out, you may be more likely to get pressure ulcers. Being underweight is also associated with a shorter lifespan.

So the goal is to maintain your ideal weight. How do you determine what's ideal for you? There is no absolute answer for this. Paralyzed muscles often become much smaller, so body weight usually drops 10 pounds for people with paraplegia and 20 pounds for people with tetraplegia. Ask your health-care provider or a dietitian what your ideal weight should be.

Do you need to lose weight? If so, you have to take in fewer calories than you burn. You either have to select foods that have fewer calories or increase your activities-or both. Here are some ways to lose weight: Limit the size of your portions, don't have seconds, Eat slowly, allowing at least 20 minutes per meal, Enjoy every bite, Make eating a separate activity {for example, don't watch TV while you eat}. Try not to skip breakfast or lunch and avoid overeating at dinner. Don't use food as a way of dealing with boredom, anger, fatigue, or anxiety. Consciously choose food for its nutritive value. Avoid keeping high-calorie, low nutrient snacks around the house. Eat less fat and fatty foods. Eat less sugar and sweets. Eat only when you're hungry. Be active. Target exercise early in your rehabilitation helps you activate all the muscles that are still working and use them to their greatest potential. SCI causes muscle paralysis, so you have fewer muscles that you can control and some of those that remain have limited function. Exercise builds strength and endurance in those muscles so you can do as much for yourself as possible. Life long exercise will help you keep your muscles strong and conditioned, maximize your function, reduce your risk of injury and help you stay healthy.

Exercise is also important to manage body weight. Many persons with SCI have too much body fat. Paralyzed muscles don't burn as many calories as contracting muscles and people with SCI are typically less active than the general population, which results in a tendency to gain weight in the form of fat. Exercise and an active lifestyle are critical to prevent weight gain. Not only does exercise directly burn calories, it also increases your resting metabolism, which means that the body will burn more calories throughout the day.

Source: PVA Yes, You Can! Guide; Staying Healthy after SCI, section 4.b nutrition and weight.





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2
DAYS
**Thursday & Friday
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Packed with Empowering Information!

Watch for Exciting Details!
www.ascc.arkansas.gov
(501) 296-1788 / (800) 459-1517

- ① **National Speakers**
- ② **SCI/D Sessions**
- ③ **Exhibition Hall**
National, state and local vendors display their latest – Meet with vendors, disability related organizations, foundations, hospitals, rehabilitation facilities, and gather resources from statewide agencies.
- ④ **Demonstrations**
See and learn about state-of-the-art adaptive mobility devices, new assistive technology, pressure mapping, and more.
- ⑤ **Door Prize Drawings!**

**Attention SCI/D Clients:
BREAKOUT SESSIONS
ARE BACK THIS YEAR!**

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**Educational Sessions For
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BENTON EVENT CENTER: 17322 I-30, Benton, AR / Exit 118 (stay on access road)

New Administrative Specialist Joins Jonesboro Office.

Please join the Arkansas Spinal Cord Commission in welcoming Janie May to the staff in our Jonesboro office. Janie fills the position as administrative specialist helping to serve our clients living in the Jonesboro region.



Janie May
Administrative Specialist
Jonesboro office

Janie is a resident of Jonesboro and holds a bachelors degree in Special Education/Elementary Education from ASU-Jonesboro, as well as, a Masters in School Guidance Counseling from John Brown University. Janie retired from Special Education teaching a few years ago. She has always had a passion for working with individuals with disabilities. In her spare time, she enjoys cross-stitching, bible studies, and reads extensively.

Shooting For a Cause!

Watch For more Details!

Or Call
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