

Arkansas Spinal Cord Foundation Implements \$300,000 Initiative to Benefit SCI Clients in Rural Arkansas

The Arkansas Spinal Cord Foundation (ASCF) announces a \$300,000 three-year grant initiative to advance spinal cord injury healthcare in rural Arkansas. The initiative, entitled "Operation Outreach: Advancing SCI Healthcare in Rural Communities," is funded by the Craig H. Neilsen Foundation.

ASCF will implement the initiative agenda through partnership and collaboration with five organizations: Arkansas Spinal Cord Commission; University of Arkansas Medical Sciences (UAMS); UAMS Center for Distance Health (CDH); The TRIUMPH Call Center, and Baptist Health School of Nursing. It is through our combined research, knowledge, strengths and capacity that we advance solutions to improve the quality

of life for those living with a spinal cord injury, and address strategies necessary to provide health and wellness.

Maintaining Health and Wellness

For an individual with SCI, maintaining overall health and wellness are necessary to maintaining quality of life. But ongoing health can only happen if there is ready and easy access to primary care for common and preventable health complications and an individual can incorporate a routine into their everyday activities. "Having to keep healthy is so important to patients with spinal cord injuries," says Thomas Kiser, MD, and Professor of Dept. of Physical Medicine and Rehabilitation at UAMS. "When you live well and exercise regularly, you

can definitely feel the difference - physically and emotionally."

Research looks at what is required in delivering optimal primary health care and wellness services for individuals with SCI in rural areas. ASCF and its partnering organizations are in a position to build that capacity in communities across Arkansas and evaluate its effectiveness.

Currently many individuals with SCI who do not have a family physician and some who have one are not satisfied with the services they receive. On the other hand, many family physicians either have never seen an SCI patient nor have few in their routine practice. This poses challenges for the physicians and patients. The geographic size of Arkansas, the

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Arkansas Spina Bifida Support Group Annual Christmas Party

Over 150 adults and children with Spina Bifida and their families attended the annual Christmas party held at Camp Aldersgate in December. Everyone enjoyed Santa and festivities. The event was sponsored by the Arkansas Spina Bifida Support Group.



Central Arkansas Corvette Club showcases Red Corvettes at event.

SPINAL CONNECTION

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With Thanks

Donations this quarter from:

Maxine Buchanan

ASCC accepts tax-deductible donations. To make a contribution send your donation to:

AR Spinal Cord Commission
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Little Rock, AR 72207

Gone But Not Forgotten

Mike Armbrust - November 30, 2014
Bobby J. Dennis - December 22, 2014
Danny French - August 4, 2013
Wayne Houghton, Jr. - November 20, 2014
Terry M. Kornas - December 8, 2014
Paul L. McCann - October 4, 2014
Destin E. Meadors - February 14, 2014
Stephen L. Meserve - July 30, 2014
Maria Miranda - November 12, 2014
Nita K. Moore - July 2, 2014
Delbert B. Phillips - October 3, 2014
John H. Quince - July 31, 2013
Renea D. Rushin - October 19, 2014
William J. Sherrill - December 19, 2014
Cindy Short - October 18, 2014
Timothy Summers - November 9, 2014
Darius Woolfolk - July 9, 2014



From the Desk of the Director

No one knows you better than yourself. Becoming a strong self-advocate will assist you when dealing with the health care system especially your own physician. Unless you have easy access to a spinal cord injury specialist, your primary care physician may be the only doctor available

in your area. Most primary care physicians do not have a lot of experience treating someone with a spinal cord disability. If this is the case, what do you do? The best expert, and the most consistent one, is often found within. After all, no one knows you better than yourself. Remember the old phrase, "today is the first day of the rest of your life." Take it to heart. You are never too young or too old to start communicating what's best for you. Learning to be your own self-advocate begins with learning about your disability and understanding what works and what doesn't work best for you. Speaking up and communicating is the first step in becoming a strong self-advocate.

Be prepared! It is often difficult to remember everything when you get to your appointment. In preparation for your appointment the following suggestions may assist you in getting the most out of your visit:

- Make a list of all the symptoms you are currently having or have recently experienced. Include anything that seems out of the ordinary, regardless of whether you think it has something to do with the exact problem for which you are seeing the doctor.
- Bring a comprehensive list of your medications including any over-the-counter medicines, vitamins, herbal treatments or anything else you take. Some medicines or supplements do not react well with others, so it is important your physician knows what you take.
- When you have an appointment with your physician make a list of the things you want to discuss and write down your questions prior to your visit.
- Bring a friend or family member with you to the appointment. Having another person in the room will help you remember what your physician says.
- Most importantly never be afraid to question what your doctor recommends, especially if you know from previous experience that it has not worked in the past.
- If you have information regarding your spinal cord injury or disability that you feel is important for your physician to know provide them with a copy.
- Communicate with your physician. If you do not understand an explanation or medical term ask for clarification.
- Whenever possible take notes or ask someone with you to take notes. After you leave the physician's office it is often difficult to remember everything that was discussed.
- Remember if you have any concerns express them to your physician.

Start the new year off right! Advocate for yourself since no one else can do it better than you!

Patti Rogers
Executive Director

Arkansas Spinal Cord Foundation Implements \$300,000 Initiative

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population distribution, and the concentration of SCI healthcare expertise in metropolitan Little Rock create substantial inequities in access to care and in opportunities for continuing SCI education for healthcare professionals.

How Can Existing Resources in Primary Care Be Used More Effectively?

ASCF's initiative supports effective primary care by integrating existing resources to better serve individuals with SCI and build capacity in Arkansas communities. ASCF plans to launch the first in a series of new e-learning resources (SCI primary care) in February 2015 through collaboration with UAMS Centers for Distance Health. Spinal cord injury evidence-based guidelines "Caring for Persons with Spinal Cord Injury" will be expanded to educational training webinars, telemedicine interactive-videos, and SCI rehabilitation educational curriculums. This platform provides information on specific SCI topics including identification of symptoms, treatment, and overall health management.

"An individual using a wheelchair has a laundry list of tests that have to be done at various times through the year, such as a bone density scan, ultrasound to monitor kidney health, a urodynamic

test for the bladder," explains Dr. Kiser. "It's all about preventative maintenance of health so issues don't get to a point where it's really bad. Having this kind of resource for persons with mobility issues and for the general primary care physician is so important."

To address barriers that rural patients face, the TRIUMPH Call Center will provide a 24/7 service linking primary care and emergence physicians, as well as the SCI patient to cutting edge clinical information and consults. Primary care providers will have access to phone-based or interactive-video-based, on-the-spot physician/nurse consultations to specialist, and 24/7 patient and family support. Individuals with SCI will have access to a triage nurse who can help them over the phone without ever having to leave home. The ultimate outcome is to provide patients and local physicians with immediate access to SCI specialists.

How do consumer voices broaden perspectives for better health care delivery outcomes?

For ASCF, listening to consumer voices means more than just representation on a board or committee where an individual observes. Health researchers tend to view issues from the provider side;

consumers experience treatment and care first hand. Determining priorities comes from broadening both perspectives. ASCF wants to hear what you need from your primary care providers. What are your experiences with primary care in your community? What does good healthcare maintenance mean to you? What does secondary condition preventive care mean to you?

ASCC Clients to Receive a Survey: Caring for Individuals with Spinal Cord Injury

Your feedback and opinions set the priorities to enhance learning and advance SCI primary care, especially in rural communities. In collaboration with the Arkansas Spinal Cord Commission a survey will be mailed to give consumers a voice. It is very important to complete the survey and return it in a timely manner. If you need assistance, your case manager is available to help you.

Help us to identify the quality of health care and rehabilitation sources currently accessed. Your voice is important to identify any healthcare needs or issues that you may face. Your response also serves to identify those primary care providers that excel in providing the appropriate care you require.

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 the Certificate for Developmentally Disabled Individual form (AR1000RC5).

You can find the form at: www.dfa.arkansas.gov/offices/incomeTax/individual/Documents/AR1000RC5_2014_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 2014.

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

Arkansas Energy Bill and Utility Assistance

Low-income Arkansas customers can get assistance paying utility bills. There are assistance programs and resources available throughout the state. Utility companies that operate in the state offer several of these programs and others are provided by non-profits, charities, and government programs. Examples of assistance programs are listed below:

American Electric Power runs the Neighbor-to-Neighbor program. Funds are offered that may be able to help qualified low-income customers in the region pay their bills. For information call 318-862-2954.

Arkansas Energy Network is a regional fuel fund. The non-profit organization focuses on providing information about churches, charities and places to go in order to apply for utility assistance. Information on programs that are offered directly by energy providers is available.

Arkansas Western Gas, now known as Source Gas, has a program known as The Heart Warming Homes Assistance Program. This service provides heating bill assistance to customers who live in Northwest, North Central and Northeast Arkansas. The financial assistance program will operate from November to April each year and offer assistance and cash grants based on need and not strict income guidelines. If you are interested in more information, call 1-800-563-0012 for the address and phone number of the nearest Arkansas Salvation Army office.

Center Point Energy administers the Good Neighbor Fuel Fund. The Good Neighbor Fuel Fund coordinates with the federal government Low Income Home Entergy Assistance Program (LIHEAP) by supplementing LIHEAP dollars after the assistance program has ended or when benefits are insufficient to meet the household's energy and heating bill needs. LIHEAP provides money to help individuals with energy bills and other energy related expenses. LIHEAP is funded through the fed-

eral government and works with community action agencies to help customers pay for and keep electric service in their home. A person who participates or has a family member who participate in certain other benefit programs, such as Supplemental Nutrition Assistance Program (SNAP), Supplemental Security Income (SSI), Temporary Assistance for Needy Families (TANF) or certain needs-tested Veteran benefits may be automatically eligible. Call 1-800-563-0012.

Protections against Extreme Temperatures - Entergy will not disconnect registered elderly or disabled customers when temperature is projected to be 95 degrees or greater, or 32 degrees or lower.

Special Cases-Sale Tax Exemption Registered customers with an annual household income of less than 12,000 are exempted from the sale tax on the first 500 kWh each month. To qualify, a customer will need to fill out a registration form and mail to: Entergy Customer Relations - Arkansas P.O. Box 551, Little Rock, AR 72203. This form is also available at local Arkansas Revenue Offices or by request from the Customer Service Center at 1-800-Entergy.

Landlord/Tenant Agreement - This option is for the protection of customers whose electric service is included with their rental payment. The agreement protects the tenant from disconnect because of the landlord's action.

Essential Service Credit - This program provides a reduced rate for customers who use electric service for only basic, essential services. Basic service is defined as annual electricity consumption of no more than 6000 kWh or an average of 500 kWh per month. The other restriction is that the customer's maximum summer consumption is not more than 1.2 times their maximum winter month's consumption.

Certified Medical Emergency - This

program allows for the electric service to be continued for up to thirty days for any qualifying customer whose disconnection would cause a medical emergency. To qualify for this benefit, the customer must furnish Entergy with a medical certificate from a physician.

Life Support Identity Program

Entergy recognizes that loss of electric service can be especially difficult for customers with certain medical problems. If a customer or a permanent resident in a customer's home is on life sustaining, electrically operated equipment, or needs life-sustaining medical treatment that requires electricity, please call 1-800-ENTERGY (1-800-368-3749). You may be eligible for special payment arrangements based on the receipt of a statement from your physician or health care provider.

Protected Customer - This program is available to residential customers age 65 or older and customers with severe mental or physical disabilities that substantially limit their ability to manage their energy cost. For qualified customers registered with this status, Entergy will attempt to make contact and explain payment and assistance options in an attempt to avoid service disconnection.

It is recommended that anyone who is struggling should call his or her utility company first. Many have some form of customer assistance program that can give help to people entering into a payment plan or give people a few more days to make a payment on their account. However, you need to call the provider right away. Do not wait until your bill is past due as by then it may be too late.

The Arkansas Entergy Network and its partners strive to make a difference meeting the needs of the less fortunate, seniors, working poor, and Arkansans who are elderly or disabled. For a list of application sites for Arkansas Entergy Network programs please visit: www.needhelpayingbills.com

Amyotrophic Lateral Sclerosis (ALS) is a degeneration of nerve cells that control the muscles. These nerve cells die and the person becomes unable to move on their own. "Many say that ALS is a rare disease and I disagree. It's not rare when you have a loved one diagnosed with it," states Lara Blume-McGee, Founder and 'ALS in Wonderland' Director. "People can live if they are paralyzed but the disease is fatal for individuals with ALS because it affects the patient's ability to breath."

About 30,000 patients in the US have ALS disease and about 5,000 are diagnosed with ALS every year. ALS tends to strike in midlife between the ages of 40 and 60, but others can develop the disease. Men are about 1 1/2 times more likely to have the disease than women. In most cases, it occurs at random with no family history of the disease. ALS attacks nerve cells and pathways in the brain and spinal cord, causing the body's motor neurons to waste away. The result is progressive



muscle weakness. It causes difficulty with mobility, speaking, swallowing and breathing. Proper medication and physical therapy, however, can help control symptoms and allow patients to lead more independent lives.

The ALS in Wonderland Foundation was created for persons with ALS (PALS) in the state of Arkansas because of the need and lack of awareness, education and funding for PALS. The mission of the foundation is to promote awareness and provide funding directly to benefit Arkansans with ALS. The objective is to provide assistance immediately without a long drawn out process. "Once registered in our system then we send them ongoing financial help. Since the inception of PALS gifting program in April 2014, we

have granted \$30,000 in gift check donations and equipment to local PALS," states Blume-McGee. The ALS in Wonderland Foundation is in place to help each ALS family while they are dealing with the biggest challenge of their life. It is essential for the ALS patient and their caregivers to understand this disease and its physical, emotional, mental, and financial implications.

ALS in Wonderland hosts their marquee fundraiser every May during ALS awareness month. This year the ALS in Wonderland fashion show will be held May 16th at the Villa Marre. The production consists of an over the top eccentric fashion show, paired with live music and talented performers to create a magical experience for all. This May we will be honoring our friend and PAL Kevin Thompson whose sister passed away from ALS.

To learn more about ALS in Wonderland or to get involved please visit our website at: www.alsinwonderland.com.

ASCC's Accessible Parking Task Force Pushes Law Statewide

January marks an important year for ASCC Accessible Parking Task Force members to stand up and fight for the rights, under law, for all Arkansans with disabilities.

It is a serious offense when citizens unlawfully park in an accessible parking space reserved for individuals with disabilities without displaying an accessible parking placard or plate. A conviction could result in fines from \$100 to \$500 for

the first offense, and up to \$1,000 for the second offense.

We strongly urge you to join the task force and help defend your rights! Meetings are held monthly. Those participating from around the state can conveniently call-in to the meeting via conference call access, at no cost to you.

The laws are clear. Help us help you by getting involved. Work

with other state agencies and disability organizations, law enforcement agencies, concerned citizens and other individuals with SCI/D that have already joined in this initiative to help stop those violating the law.

For more information contact Joy Wier, Task Force Chair, at 501-779-2162 or connect to accessible parking information by visiting ASCC's website at: ascc.arkansas.gov.

Resolve to Be Ready in 2015

Arkansans may not have to deal with full blown hurricanes or nor'easters, but we have our fair share of disasters to contend with. If you search FEMA's website, you'll find five major disaster declarations for the Natural State in just two years, spanning from Christmas of 2012 to April of 2014. Those declarations include severe winter storms, severe storms, tornadoes, and flooding; and those are just the natural disasters that have blessed our state, not emergencies caused by humans. If you haven't been touched personally by one of these unfortunate events, I imagine it's safe to say that you probably know someone who has.

Do you have a plan? If you don't, you aren't alone, but you do need to get one. Being prepared is extremely important for everyone, but particularly for those of us living with SCI/D. If you are like me, you probably rely on a wheelchair to get around in this world. You may have certain medications and supplies that you need to fully function and stay healthy; so it makes sense for us to plan ahead and take extra care in preparing for a disaster. A website that really helps make this whole planning and preparedness thing easy, and is helpful in making personalized information in your

emergency/safety profile accessible to first responders is www.smart911.com. This secure website allows you to store important personalized information for everyone, including evacuation routes and pictures of family members, your home, pets, and service animals.

It's vital to know what type of emergencies you are likely to experience in your area of the state; many live in areas prone to flooding, while others in the northern part of the state probably experience more winter weather. Prepare to adapt information about the types of emergencies for your personal situation and be aware of the news and communication going on around you. For information about specific types of emergencies, go to www.Ready.gov/be-informed. Remember to stay calm and act rationally.

Will you need assistance during a disaster? If so, you should create a personal support network of people in your life you can count on, such as family, friends, neighbors, or caretakers. Create a plan to seek. Keep record of any medical treatment or providers you may need to contact in an emergency, and be sure that someone in your network can get into your home in case you need them to

access your emergency supplies and devices. Make sure those in your network have instructions on how to work your devices or equipment if they need to, administer any medicine, or use lifesaving equipment. Be sure to practice your plan regularly.

Build a basic kit of emergency supplies that will help you survive for at least three days; you can find the list here at www.ready.gov/kit. Clean air, water, and food are the most important things on the list, but if you live with a disability, there are other things you'll need to consider. Inventory the things you use every day that you need to live independently and include those items in the kit; these may include prescription medications, durable medical equipment, batteries, etc. If you have a service dog, prepare for your animal to survive for at least three days as well.

Preparedness doesn't have to be scary, and if you need additional guidance, resources, or information on this topic, please be sure to contact Erin Gildner at egildner@uark.edu or 501-920-1432. I'm a Program Specialist for the Arkansas Disability & Health Program and I'd love to help you resolve to be ready in 2015.

Arkansas Spinal Cord Commission Support Groups

An ongoing Support Group for ASCC clients in Northwest Arkansas has been established! The focus of this gathering is for members to share their knowledge of community resources, relate personal experiences, and establish much needed social networks in

the NWA area. This support group currently meets on the second Thursday of each month. Please contact ASCC Case Manager Susie Hook at (479) 521-1463 if you are interested in participating.

Support groups also meet in

Searcy on the first Tuesday of each month and in Sherwood on the third Thursday of each month.

If you are interested in these support groups please contact Doug Fish (Sherwood) or Sara Stevens (Searcy) at (501) 296-1792.



Enhancing Health Care Delivery to the Spinal Cord Community

Have you ever wished you could reach your doctor late at night or on the weekend when you are struggling with a health problem, such as autonomic dysreflexia, a bladder infection, or a new pressure sore? Sometimes getting an appointment or getting a refill on your medication can be difficult.

Many primary care doctors and nurses are not familiar with the medical problems that are faced by individuals with spinal cord injuries. The University of Arkansas for Medical Sciences (UAMS) and the Arkansas Spinal Cord Commission (ASCC) are attempting to address these issues with several new programs. These programs are designed to help people with spinal cord injuries stay healthy and active by improving their ability to get questions answered and to access health care promptly.

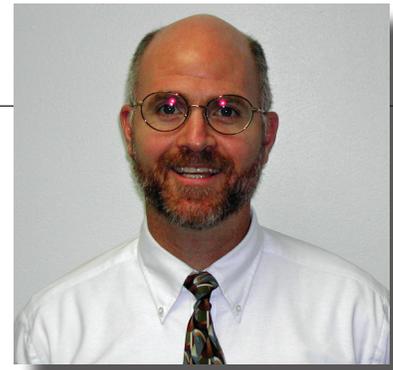
Over the last two years, two new programs have been started and a third has begun development: 1) UAMS tele-rehabilitation spinal cord injury clinic that meets once a month; 2) the TRIUMPH (Tele-Rehabilitation Interventions through University-based Medicine for Promotion of Healing) Call Center, and 3) "Operation Outreach: Advancing SCI Healthcare in Rural Arkansas Communities" to improve spinal cord medicine education of both nurses and doctors in Arkansas and specifically in the rural areas of Arkansas.

The tele-rehabilitation SCI clinic is designed to provide a spinal cord medicine clinic to patients who find it difficult or impossible to travel to Little Rock to attend the UAMS SCI Clinic in person. If you can make it to a local Area

Health Education Center (AHEC) or near-by hospital, a face-to-face evaluation can be set up through an internet connection. This can often help address bowel and bladder issues, medication management and even pressure sores through a specialized up-close video connection which can be used to assess the skin.

The Triumph Call Center is a collaboration of the UAMS Center for Distance Health and the UAMS Department of Physical Medicine and Rehabilitation (PM&R) and is funded by the Arkansas Trauma Rehabilitation Program. A triage nurse is available 24 hours a day, 7 days a week to provide: telemedicine consultation to you, a doctor, a nurse or a care-giver; emergency department services to you if you find yourself in an emergency room by providing the health care provider taking care of you access to a specialist in spinal cord injury medicine; and call center services to answer your health questions and address any health problems you have developed.

When you or your health care provider call the center at 1-855-PMR-MYTE (1-855-767-6983) the nurse at the call center will walk the caller through a series of questions designed to determine the medical problem and the best way to address it in a timely manner. If they are unable to address your problems, they will then forward the call to a rehabilitation doctor to assist you directly. The call center can also help if you are in the hospital or emergency department and your doctor wants to talk to a spinal cord medicine specialist about your condition. The call center



*ASCC Medical Director
Tom Kiser, M.D.*

can get them in direct contact with me or someone in the UAMS Department of PM&R if they have questions. As an SCI specialist I encourage anyone with a spinal cord injury to utilize the TRIUMPH Call Center and provide this information to your primary care physician.

The "Operation Outreach: Advancing SCI Healthcare in Rural Arkansas Communities" is being administered by the Arkansas Spinal Cord Foundation with new grant funding from the Craig H. Neilsen Foundation. The initiative is designed to improve access to telemedicine for rural counties and to address the deficiency in knowledge and improve the ability of Arkansas health care professionals to care for spinal cord injured patients. It is especially designed to educate health care providers in the rural counties of Arkansas to provide basic spinal cord medicine care. The plan is to develop training modules for both health care providers and patients, which can be accessed easily by the internet or with a DVD. We also hope to develop an SCI curriculum for nursing schools and the Medical School at UAMS to train professionals early in their career to be comfortable and proficient with managing individuals who have a spinal cord injury.

Arkansas Spinal Cord Foundation Donates Accessible Van



April Bates, an ASCC client in Batesville, and her mother Jody receives the keys to the van donated to her from the Arkansas Spinal Cord Foundation. Joy Wier, ASCF vice president, made the presentation.

*Don't Forget!
A new service
Just For You!*

TRIUMPH

Call 1-855-PMR-MYTE
(1-855-767-6983)

The TRIUMPH Call Center is a 24/7 resource to serve Arkansans who have sustained a Spinal Cord Injury and their healthcare providers through:

- TELEMEDICINE CONSULTATIONS
- PROVIDER EDUCATION
- EMERGENCY DEPARTMENT SERVICES
- CALL CENTER SERVICES

UAMS

UNIVERSITY OF ARKANSAS
FOR MEDICAL SCIENCES



For more information: call 501-526-7656

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