



SPINAL COURIER

The spinal cord disability information source for Arkansans since 1989

Vol. 23 No. 2

January 2012

www.spinalcord.ar.gov

ASCF Receives Craig H. Neilsen Foundation Grant

The Arkansas Spinal Cord Foundation (ASCF) announced on December 16th that they had been awarded a \$100,000 grant from the Craig H. Neilsen Foundation to fund Project Access.

Project Access will assist 20 newly spinal cord injured individuals in accessing their homes and communities by providing case management, technical assistance, resource development and up to \$5,000 grants to increase their independence through the provision of home adaptations and assistive technology. These services will allow the individual to live as independently as he or she chooses.

Recipients of the grants will be Arkansas Spinal Cord Commission

clients who sustained a spinal cord injury in 2011 or 2012 and have need for adaptive services.

ASCC Case Managers will identify clients, conduct a home assessment to determine needs for home modifications, ramps, environmental controls or other assistive technology and develop a Project Access plan with the client and family.

After approval by the ASCF Board of Directors, the Case Manager will coordinate all aspects of implementation, including technical assistance, recruiting qualified providers, obtaining bids, overseeing implementation and final inspection. Projects will utilize all available resources and will be conducted in the most cost effective manner.

Recipients will complete a satisfaction survey within 30 days of completion and Case Manager will do home visits at 30 and 90 days to assure everything is working as planned. The quality of life of the participants and their families/caregivers will be improved through increased independence, access to home and community and control of their environments.

Craig H. Neilsen, who sustained a spinal cord injury in 1985, established the Craig H. Neilsen Foundation, in 2002. The Foundation is dedicated to supporting cutting edge research to find a cure for SCI and caring for those living with SCI by funding innovative rehabilitation programs throughout the United States and Canada.

See *Craig H. Neilsen Grant* on page 3

Don't Forget Your Spina Bifida Tax Credit

For most of us, January means we begin thinking about filing our taxes. For families with dependent children with Spina Bifida, a new tax credit will be available.

Act 68 of 2011 added the diagnosis of Spina Bifida to the definition of developmental disabilities in the Arkansas Code. This means that any state service provided to individuals with developmental disabilities are now available to those with Spina Bifida.

This includes the \$500 tax credit for dependent children with developmental disabilities. While the functional definition always

included those with impairments common to Spina Bifida, there was never a Spina Bifida box to check on the form.

This year, the box will be there, thanks to the efforts of State Representative Andy Mayberry who sponsored the bill in the 2011 legislative session. The Department of Finance and Administration will have the new form available on their website at:

www.dfa.arkansas.gov/offices/incomeTax/individual/Pages/Forms.aspx

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SPINAL COURIER

Published quarterly by
Arkansas Spinal Cord Commission

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www.spinalcord.ar.gov

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With Thanks

Donations this quarter from:

Diane Buck

Tanya Davis

Richard Genereau

In Memory of Buddy Murray

Annette and Bob Stacey

ASCC accepts tax-deductible donations. Contributions are used to assist our clients through purchases of equipment and educational resources.

To make a contribution, please contact ASCC at **501-296-1788** / **1-800-459-1517** (voice) / **501-296-1794** (TDD), or send your donation to:

AR Spinal Cord Commission
1501 N. University, Suite 470
Little Rock, AR 72207

From The Director

On vacation in November, I came across a wall of magnets in a little beach store. They were pretty, so I looked at them more closely. One had a saying from one of my heroes, Coach John Wooden, esteemed basketball coach at UCLA for many years. The magnet said:

Don't allow what you cannot do interfere with what you can do.

It made me think how often I say, 'well I can't do this' or 'I can't do that.' Needless to say, I bought the magnet and when I got back, I posted it on my refrigerator. After a couple weeks I realized I needed to see it more often. So, I put it on my computer, where I gaze for hours every day. It makes me think CAN.

There are many things I can't do, because of money, time, skills, rules... the list goes on. But, there are at least the same number of things I CAN do, things I can accomplish each day, month, year. I may not be able to lose 10 pounds this month, but I can lose one or two and that will help. I may not get to take a vacation out of state, but there are plenty of places I've not seen in Arkansas. We may not be able to provide the all the services that our clients need, but we can help a lot of folks. You see what I mean?

My guess is I'm not the only one that sometimes get stuck in the "can'ts". Living with spinal cord disabilities may throw a lot of can'ts in your way. But there are lots of cans too. We all have opportunities that present themselves to us. They may not be what we planned, but we can accomplish a lot if we let ourselves.

I'm working on being a Can Do person in 2012. I challenge you to join me – who knows what we might accomplish!

Here at the Commission we are working on lots of things we can do. Over the next several months our website and newsletter will be recreated to provide you with the best, timely, accurate information about life with spinal cord disabilities. I think you will like our new look.

Wishing you and your families a wonderful, productive 2012!

Cheryl L. Vines

Spina Bifida Tax Credit

Continued from page 1

When you complete your state tax return, be sure to include the AR-1000RC5 form, the Certificate for Developmentally Disabled Individual. Directions for completing the form are attached.

You must have a physician complete the form before submitting it. With the form, the head of household will be eligible for the \$500 tax credit for 2011.

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

**PARKING HERE FOR
JUST A MINUTE**
*...is 60 seconds
too long!*



It's the LAW.

**NEVER PARK IN A SPACE RESERVED
FOR PEOPLE WITH DISABILITIES**

UNLESS: The person to whom the permit, placard or handicapped parking plate was legally issued is using this parking spot—it's the courteous thing to do, and **IT'S THE LAW.**

REMEMBER: Do not park in the striped access aisles next to spaces reserved for people with disabilities, even if you have a permit or plate. Access aisles provide room for wheelchair users to transfer safely to and from their vehicles.

To learn more about the laws on reserved parking for people with disabilities contact:

Arkansas Dept of Finance and Administration
www.dfa.arkansas.gov/offices/motorVehicle/Pages/specialtyPlates.aspx



Arkansas Spinal Cord Commission
 800-459-1517 / 501-296-1788
www.spinalcord.ar.gov/resources.parking

Accessible Parking Initiative

The growing number of people illegally parking in accessible parking spots are making every day life for those with disabilities more challenging.

The Arkansas Spinal Cord Commission has developed a task force to address the issue of these offenders by increasing public involvement and awareness.

The first product of the task force is the accessible parking notice. These notices, stating "Parking here for just a minute ...is 60 seconds too long!", come in pads of 50 and are available to everyone by the Arkansas Spinal Cord Commission.

The idea behind the parking notices is to drive home the fact that it is not only is it discourteous to misuse an accessible parking spot, but it is also against the law.

In late October and early November the ASCC mailed over 1,800 letters to physicians in order to reinforce guidelines and improve awareness. The letters clearly state the disabilities, in accordance with Arkansas Code, that qualify a person to receive an accessible parking placard.

The task force is ever expanding and constantly coming up with ideas to address this issue but new ideas are always welcome.

ASCC will be performing a survey to gather more statistics about accessible parking violators. We are looking for volunteers to assist us by filling out an ASCC provided form while watching people using specific accessible parking spots.

If you believe that you can help with the survey or if you are willing to 'tag' those parked illegally and would like to receive a pad of accessible parking notices please speak with your local Case Manager or contact the Arkansas Spinal Cord Commission central office at 501-296-1788 or 800-459-1517.

Craig H. Neilsen Grant

Continued from page 1

Mr. Neilsen's vision has brought significant advances in the SCI community. His goal was to foster effective collaboration and cooperation among researchers and rehabilitation facilities across the country. In doing so, he hoped to accelerate research to improve the quality of life for those living with SCI that will eventually lead to a cure for paralysis. Though Mr. Nielsen died in 2006, his legacy continues through the Foundation and its Board of Directors.

The Arkansas Spinal Cord Foundation was established in 2004 with a mission to promote the health, well being and quality of life of Arkansans with spinal cord disabilities through promoting awareness and prevention of spinal cord disabilities in Arkansas. The Foundation is committed to providing education about spinal cord disabilities to consumers, their families, health care professionals and the general public and to provide resources and support to assist Arkansans with spinal cord disabilities to live independently in the community.

For additional information about Project Access, contact your local Case Manager or Project Director Cheryl Vines at **800-459-1517**.

Pain and Spinal Cord Injury

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

Pain due to a spinal cord injury is difficult to manage both for the patient and the health care provider. Spinal cord related pain is classified as above-level, at-level or below-level pain as it relates to the level of the spinal cord injury.

The above-level pain is the result of wear and tear on the muscles and joints that have normal sensation and is similar to pain experienced by anyone without a spinal cord injury. However, the at-level and below-level pain are different. These pains are due to the injury to the spinal cord and the way the nervous system processes and interprets the sensation or lack of sensation in the area at- or below- the injury. This type of pain is generally hard to describe and explain, and just as difficult to manage and treat.

Prevention is the best way to avoid, or at least minimize, above-level pain, which is usually due to the wear and tear of many transfers, using a wheelchair, and performing activities of daily living (i.e. dressing, bathing and household tasks). It is important to minimize a lot of overhead reaching, difficult transfers, and awkward positioning of the shoulder and hands when lifting, tugging or pushing. A theraband strengthening routine and a good stretching program can prevent numerous problems that can occur with aging. Treatment for muscle soreness, joint inflammation, and pain is rest and ice (to treat the pain). If swelling and edema occur, they can be minimized with elevation and/or compression of the area. Acetaminophen and/or a NSAID (Non-steroidal anti-inflammatory drug), such as ibuprofen (Advil), can help decrease the pain and manage the inflammation. If there is concern about a pinched nerve, an EMG (electromyography)

and nerve conduction study can be ordered to diagnose and guide the treatment.

At-level pain is often described as a band of hyper-sensation or pressure. For someone with C5 or C6 injury it is experienced as shoulder pain, but for someone with paraplegia, as a tight belt or band about the chest or abdomen. Desensitization by rubbing or manipulating the area can decrease the pain and help re-train or re-educate the malfunctioning nervous system. A topical agent such as lidocaine ointment or a lidocaine patch can decrease the pain by causing some numbness. Capsaicin cream to the area has been shown to decrease substance P, a pain neurotransmitter. For some patients it may initially increase the pain sensation, but the pay-off comes with repeated treatments, which will eventually deplete the substance P and thus the feeling of pain.

Below-level pain is not well understood and seems like a mean joke to someone who has no sensation to touch, pressure or pin-prick awareness in the area of the pain. The pain is often described as a feeling of electrical shocks, burning, or pins and needles. Some patients describe it as the sensation of sitting in a tub of scalding water, or a feeling that the area of pain is sitting in a camp fire. The pain is usually constant in nature, but for a few persons can have a spasmodic course as the pain waxes and wanes in intensity. This type of pain can be decreased, but usually the sensation of pain never entirely goes away. Medications which can be helpful are tricyclic antidepressants such as amitriptyline (Elavil), and/or an antiseizure medication such as gabapentin (Neurontin) or pregabalin (Lyrica). Some antidepressants with a norepinephrine



ASCC Medical Director Tom Kiser, M.D.

effect such as venafaxine (Effexor) or duloxetine (Cymbalta) can be helpful. The pain is usually more of a problem when you are trying to go to sleep, because you can no longer use activity and distraction to manage the pain. Therefore, a sleeping agent such as trazodone (Oleptro) or zolpidem (Ambien) can be helpful.

The best advice I can give someone dealing with one of these types of pain is to stay active, use distraction and desensitization, and learn to live with the pain by using appropriate medications, adjustment of expectations, and exercise.

If you take narcotic medication with the expectation of getting rid of the pain, you will eventually have to resort to stronger and stronger narcotic medication to achieve the same pain relief, the end result is a decline in function and sadly, a paradoxical worsening of the pain. With the use of narcotic medication there is also a guaranteed worsening of the bowel program with constipation and, most of the time, a need for a chronic laxative use. I recommend the pragmatic management approach, because the alternative, the aggressive narcotic approach, is not pretty. Most of my patients, who have chosen the narcotic route, do poorly in the long run. They end up dealing with addiction and habituation to narcotics, multiple medical problems, and numerous pressure sores. Some of them have even died due to the results of all or some of these complications.

Welcome New Employees to the ASCC



Kyle Deen

The backbone of any agency is its fiscal management. The Arkansas Spinal Cord Commission is no exception. We were pleased to welcome a strong fiscal administrator to our staff in October. Kyle Deen joined our staff as Agency Fiscal Manager on October 31st. He comes to our agency from the Office of Budget at the Arkansas Department of Finance and Administration where he managed budgets for colleges and universities. In addition to his state experience, Kyle also brings a strong business background, working in the insurance industry and private business.

Kyle holds a bachelors degree in Political Science and a Masters degree in Business Administration from HSU. “We are pleased to have a Fiscal Manager with Kyle’s experience and enthusiasm on our staff” noted Executive Director Cheryl Vines, “In his short tenure, he has demonstrated that he uses sound fiscal practices and gets things done”.

In his free time, Kyle is a strong Razorback fan, plays golf and guitar and spends time on his computer. He, his wife Tisha and daughter Anika (age 3) live in Little Rock.



Zakeyieh Dissi Filat

ASCC is also excited to announce the promotion of Zakeyieh Dissi Filat to Case Manager. Previously Zakeyieh performed Administrative duties in the Little Rock office. “Her degree and experience made her the perfect choice when the Little Rock Case Manager’s position became available,” stated Client Services Administrator Patti Rogers.

Zakeyieh holds a bachelors degree in Criminal Justice from Northeastern State University. Her knowledge and previous experience working in a private school system and as a paralegal will assist her with her new duties as Case Manager. Zakeyieh began her Case Management duties on November 28, 2011. She will be providing services to the clients in Conway, Perry and Saline counties, the Maumelle area and part of Little Rock. She is looking forward to meeting clients in her area.

Zakeyieh, husband Eddie and son Malik (age 8) live in the West Little Rock area. She enjoys reading, jogging and is active in volunteer work in her community.

Kristin Elam joined the ASCC staff on October 3, 2011. She is the new Administrative Specialist in the Jonesboro field office replacing Shana Warren who returned to college to obtain her nursing degree. Kristin brings a strong background in customer relations and accounting and has excellent computer skills. She holds a bachelors degree in business with an emphasis in accounting from ASU.

“We are very fortunate to find someone with Kristin’s excellent qualifications and experience to work with Case Manager Russell Henry in serving our clients in Northeast Arkansas, said Client Services Administrator Patti Rogers. “We are happy to have Kristin on our ASCC team.”

Kristin, her daughter Katlynn (age 6) and son Jacob (age 3) live in Jonesboro. When asked what her hobbies and interests were, Kristin stated she loved to read but with a 3 and 6 year old the opportunities were few and far between.



Kristin Elam

Preventing Skin Complications and Pressure Sores

By Stephen Yerkovich, M.D.

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Perhaps the most common complication that occurs in individuals with spinal-cord injury or disease (SCI/D) involves the skin.

The skin below the level of injury is cut off from the nerve supply and thus has no sensitivity. The perception to change body position to relieve pressure that exists in those with intact sensation is absent. Moreover, practicing pressure-relief maneuvers without any sensory stimulus is difficult. Making matters worse, the skin below the level of injury undergoes physiological changes that make it more susceptible to breakdown. All these elements conspire to create a high incidence of pressure ulcers in the SCI/D population. In fact, the incidence of people with SCI having pressure ulcer sometime in their lifetime is greater than 50%.

A Big Challenge

Pressure ulcers and skin breakdown may affect any part of the body sustaining stress that is unrelieved. They range from very minor reversible changes in the superficial skin to deep penetrating wounds that extend through muscles and bone. The management of pressure ulcers is one of the most common and difficult challenges facing SCI/D physicians and nurses. The cost in human suffering, lost productivity and money caused by these wounds is massive. Studies done in the late 1980s and early 1990s estimate the average cost of treatment for a single pressure ulcer is \$30,000-\$120,000, with the total annual cost of pressure ulcer treatment in the United States exceeding \$6.5 billion. Obviously, the cost today is much greater – and a major national problem.

Pressure ulcers are classified into

four stages:

Stage I wounds consist of redness (nonblanchable erythema) of the skin. In those with darker skin they appear as areas of discoloration, warmth, and swelling.

Stage II ulcers have partial thickness skin loss involving the epidermis and/or dermis (the first two skin layers). They appear as a skin abrasion or shallow ulcer.

Stage III wounds are full thickness in depth extending through the skin to the underlying tissue. They appear as deep craters that extend to but not through the underlying supporting structures.

Stage IV ulcers extend all the way through the skin to penetrate muscles, tendons and bone.

Everyday Health

Treatment of pressure ulcers occupies a large percentage of an SCI/D caregiver's time. The first order of business is to improve the individual's general health. This involves aggressive nutritional support and hydration. It's recommended that a person with a pressure ulcer eat 25-30 calories per kilogram of body weight per day, including 1.25-1.50 grams of protein per kilogram of body weight. Supplements including vitamins C, K, and zinc are also recommended.

Any conditions that affect wound healing such as anemia or heart or lung disease need to be identified and corrected. Also, all mechanical forces that apply pressure to the wound need to be eliminated. Unfortunately, this causes some lack of independence and daily enjoyment, as the person is often confined to bed and unable to use

wheelchairs or sit for meals.

Specific Care

Aside from those general measures, specific therapies are tailored to the individual and the stage of the wound. These are performed by wound care certified nurses and doctors who specialize in wound treatment. Ulcers are cleaned and debrided (removal of dead tissue), and dressings are applied on a regular basis. A recent advance is the use of Platlet Rich Plasma (PRP) dressings, which show great promise in the nonsurgical healing of wounds. Wound vacuums are also frequently applied to keep the areas clean and promote healing.

Higher stage wounds often will not heal with this type of treatment. They need surgery to close them. Plastic surgeons specializing in wound care create flaps of skin from adjacent sites and use them to close large stage III and IV ulcers. The surgery is complicated, and the recovery time for the patient is long. Patient selection and pre-surgical preparation, particularly ensuring proper protein levels, are important in ensuring a successful outcome of flap surgery.

Checkup

The best treatment, however, is prevention. It's not reasonable to expect to prevent all stages of skin wounds, even among the most diligent of individuals. Rather, the goal of a workable prevention program is early detection and quick response to avoid ulcers from progressing to stage III or IV. The foundation of such a program is the twice daily inspection of skin in areas at risk. Depending on circumstances, this can be performed by

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Skin Complications

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the individual, a family member, or caregiver. This examination includes visual inspection and physical contact to detect swelling and warmth, since skin breakdown can occur in deeper layers and not have any visual changes.

Pressure reliefs accomplished by “wheelchair pushups” and other maneuvers every 15 minutes are extremely important. Meticulous skin care with daily bathing and avoidance of excessive moisture on skin surfaces is mandatory. Proper routine maintenance of seat cushions and other equipment that interfaces with the skin is vital. Also, the importance of proper diet and avoidance of smoking and excessive drinking can't be overstated.

Contact: PVA Medical Services, 800-424-8200.

Project ELI (Every Life Inspires)

Project: ELI is a video that will be distributed to ob/gyns, pregnancy crisis centers, hospitals and other organizations to give to families who are expecting a child with spina bifida. The purpose is to give these couples hope, encouragement and advice from families who have been in their shoes.

The video provides insights as well as interviews with parents, individuals and healthcare providers.

Project ELI will be televised for the first time in the next few weeks. Check the ASCC or Community Connections websites for exact dates and times.

If you would like a copy of the DVD, please contact Community Connections at 501-329-5459 or visit their website at www.communityconnectionsar.org.

Arkansas Governors Scholarship

Each year the Arkansas Governor's Commission on People with Disabilities awards scholarships to students with disabilities to attend the college of their choice. Last year, 2011, the Commission awarded 39 scholarships, 37 at \$750.00 each, and 2 book scholarships for \$500.00 each, to Arkansans with disabilities to help offset the escalating cost of a college education.

The Scholarship Program is funded from the fines levied against the accessible parking violators.

Applications for 2012 scholarships are available now and must be postmarked by February 28, 2012.

To get an application or for more information please contact the Arkansas Governor's Commission on People with Disabilities at 501-682-5317.



Children playing Christmas bingo at the annual Christmas party hosted by the Spina Bifida Support Group of Arkansas

Spina Bifida Christmas Party

The Spina Bifida Support Group of Arkansas hosted its annual Christmas party on December 11, 2011.

The children in the photo to the left are playing Christmas Bingo which always proves to be one of the favorite games enjoyed by the children attending the party.

Dillard's Department Store employees are Santa's helpers and provide gifts each year.

Approximately 125 children and family members attended the Christmas party this year.

For more information about the Spina Bifida Support Group of Arkansas, contact Vicki Rucker at 501-978-7222.

The ASCC Case Management Team



ASCC Case Managers pose for a team photo at the fall Case Managers Meeting

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