

Governor Appoints Annette Stacy to Commission

Governor Mike Beebe appointed Annette Smith Stacy to the Arkansas Spinal Cord Commission on May 24, 2010. Ms. Stacy will serve until January, 2015; she replaces Sandra Turner, who passed away in December.

Annette brings a strong medical background to her role on the Commission. Annette is Associate Professor in the School of Nursing at Arkansas State University and Director of the BSN Program. She holds a Bachelor of Science degree in nursing from Vanderbilt University and a Master of Science in Nursing from the University of Virginia.

Some would say that Annette comes naturally by her interest and involvement in spinal cord injury and the Commission. Her grandmother sustained a spinal cord



Annette Stacy

injury when Annette was a child. This led her mother, Jane Smith on an odyssey of advocacy for the needs of Arkansans with spinal cord disabilities, resulting in the establishment of our Commission. Mrs. Smith was the first chair of the Arkansas Spinal Cord Commission, making Annette a 'second generation' commission member.

"We are so lucky to have someone with Annette's strong medical background and personal interest on our Commission," noted Executive Director Cheryl Vines. "Her experience will be invaluable as we move forward in our efforts to develop educational resources on spinal cord disabilities for our clients and families, health care providers and our staff."

Annette and her husband Bob live in Wynne and have two sons Jake and Sam.

Please join our members and staff in welcoming Annette Stacy to the Arkansas Spinal Cord Commission.

Heat and Spinal Cord Injury

Summer and heat go together, at least in Arkansas. This is a potentially dangerous time for anyone with a spinal cord injury (SCI). Impairment of temperature regulation is a recognized problem in SCI. What makes it worse is that, if you have SCI, you may not be aware of the problem until it is too late. This makes it essential that you take precautionary and preventive measures to avoid becoming overheated and having a heat stroke.

Body temperature is maintained by balancing heat production and heat loss. Sensation of hot and cold is located peripherally in the skin and centrally in the brain. A person with a complete SCI and tetraplegia has the most impairment in temperature control and thus the highest risk of overheating. The big problem is that an individual with SCI does not sense the heat and cannot get rid of heat like the able-bodied individual. The skin is unable to feel the sensation of heat; the body's circulatory system is not able to dilate the blood vessels

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SPINAL COURIER

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With Thanks

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In memory of Sandy Turner
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In memory of Teresa Wagner
Rita Wagner

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

From the Director

Does it seem possible that it could be July? We're already half way through 2010. A lot has happened at the Commission in the past few months. As you see in this issue, we welcomed a new Commission Member, Annette Stacy and a new Case Manager Von Daniel – both hail from the eastern part of the state and are welcome additions to our ASCC family.

The Commission continues to work with the Trauma Advisory Council to develop a true continuum of care for Arkansans with spinal cord and other injuries, from the roadside to emergency and acute care through the rehabilitation process. Trauma system resources will include a 'hotline' for emergency medical technicians so they can find out exactly where to take a person based on their injury and available services – care in those first few hours can make a huge difference for the rest of one's life, so excellent decisions are important.

Five years ago, the members of the Arkansas Spinal Cord Commission got together to establish the Arkansas Spinal Cord Foundation, a not-for-profit organization that could raise funds and assist Arkansans with spinal cord injuries live independent healthy lives. To date the Foundation has partnered with the Christopher Reeve Foundation and the Craig H. Nielsen Foundation to make grants for home modifications and wheelchairs. They have also received donations from individuals to help support our efforts – many of those in honor or memory of a loved one with a spinal cord disability.

Last month, John Wyrick took the helm of the Foundation, when he was elected president. John and Mike Cranford, both ASCC Commission members are working to expand the membership of the Foundation Board of Directors and establish committees. Basically their plan is to GET IT DONE – raising funds for programs and services to accomplish the mission of the Foundation: to promote the health, well being and quality of life of Arkansans with spinal cord disabilities.

Two guys cannot do this alone – they are looking for others to help in the mission. The Foundation needs folks who can raise money, folks who can give money, folks with good ideas for fundraisers, folks who can serve on committees to make those things happen and folks to represent the Foundation around the state. YOU may be interested in helping or may know of someone who could or have an idea for a fundraiser.

John has asked me to ask you for your help. If you are interested or have ideas please drop me an email at cvines@arspinalcord.org or give me a call at **800-459-1517** and I will pass the information along to John and the Foundation Board. We can use your help!

Stay cool this summer!

Cheryl L. Vines

Increasing Capabilities Access Network

By Eddie Schmeckenbecher

Increasing Capabilities Access Network (ICAN) is one of Arkansas' best-kept secrets. We are your connection to Assistive Technology (AT). AT is any type of device or tool that help people live, work, communicate and play more independently. In addition, ICAN maintains the *Assistive Technology for all people* (AT4ALL) database, which is our statewide AT program. Arkansans of all ages, families, schools, agencies, and businesses can find the appropriate AT, which will assist an individual with disabilities to become as independent as possible. There is no age or financial restriction. All that ICAN requires for a loan is a picture ID or Arkansas Driver's license. The AT4ALL database can be accessed at <https://equipment.ar-ican.org>.

ICAN/AT4ALL offers a loan program, recycled devices, device demonstration, technical assistance, training opportunities, presentation and exhibits, clearinghouse tours, and information and assistance to anyone in the state of Arkansas.

ICAN has a section full of AT equipment for individuals with limited movement in activities of daily living. This includes modified silverware, cups, reachers, writing utensils, door openers, and many other items. All of the equipment may be loaned out for a six-week period to see if it will meet the needs of the individual. If the AT equipment does meet their needs and they would like to purchase their own, ICAN will tell them where it can be purchased and how much it costs. If the AT is not a good fit, the individual can bring it back and exchange it for another equipment item. We also loan durable medical equipment like power chairs, shower chairs and other AT.

ICAN also accepts donated items that are in good shape. We clean and sterilize the equipment and then donate it back into the community at no charge to the individual. We're particularly proud of our recycle and reuse program! The accompanying photos indicate a small portion of the equipment we can demonstrate or loan out.

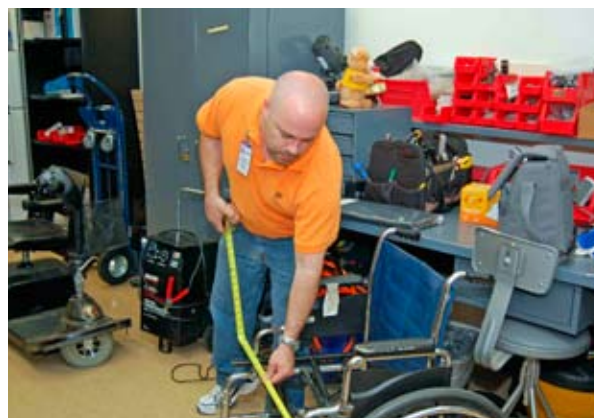
If you have any need, please go to our website at www.ar-ican.org and check out the equipment. If you have a question, please call us at: **501-666-8868** local, **888-828-2799** statewide, **501-666-5319** fax or visit us at: ICAN, 26 Corporate Hill, Little Rock, AR 72205.



Augmentative communication device.



Client at home in hoier lift.



Measuring a wheelchair.



Head tracking computer system.

Living Well with SCI: Numbers, 4 and 3

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



ASCC Medical Director Tom Kiser, M.D.

At the annual spinal cord injury conference in Little Rock last year, the focus was “Living Well with Spinal Cord Injury.” I was asked to give a brief presentation on my recommendations for “Living Well” from the medical and rehabilitation perspective, prior to a panel discussion on the same topic.

Many attendees requested a list of the ten items I presented, so we decided to publish the list, here, in the *Courier* and provide a more in-depth discussion of each recommendation. Due to *Courier* space constraints we’re presenting only one or two at a time in order to give justice to each recommendation. So here are numbers 4 and 3 of the “Ten things I encourage my patients to do!” I will be working toward number 1 in future *Courier* articles:

Number 4:

Spasticity Management

- Routine stretching program
- Appropriate use of antispasticity medication:
 - Baclofen – stable dose is most helpful; taper off and do not stop suddenly.
 - Tizanidine (Zanaflex®), do not use with ciprofloxin (Cipro®) or fluvoxamine (Luvox®); monitor liver function
 - Dantrolene (Dantrium®); monitor liver function
 - Consider botulinum toxin or intrathecal baclofen pump
 - avoid diazepam (Valium®)

If you have damage to the spinal cord, you have abnormal nerve input to the muscles of your body, which can result in spasticity. However, if the nerves are injured after they exit the spinal cord, i.e. herniated disc, cauda equina injury or brachial plexus injury, all signals to the muscles are lost and you may have a flaccid, atrophied muscle.

If you do have spasms, there are things you can do to decrease them. Spasms are increased if you have any condition causing increased signals to the spinal cord, such as pain, bladder infection, bowel impaction, rapid movement, or even a sudden loud noise. To decrease spasticity you need to decrease the signals from all five of your senses to the spinal cord. By treating pain, managing the bowel and bladder well, avoiding sudden movements and moving more gently and slowly you can often manage spasticity without medication. By incorporating a stretching program into your daily routine you lengthen the resting length of the joints, tendons and muscles, so that when you move

years, and there is minimal need to routinely check blood for any bad side effects. However, baclofen can make you drowsy at high doses, and it cannot be stopped suddenly. Stopping it too abruptly can cause seizures, hallucinations, and severe spasticity. Tizanidine is a newer medication which works in the central part of your brain to decrease spasticity, it can make you even drowsier than baclofen, so we often start it at bedtime. It can also damage your liver, so we periodically need to check blood work. Another side effect of tizanidine that can be dangerous is that it can affect your heart rhythm if you take it with ciprofloxin for an infection, or if you use fluvoxamine for depression; so if you need either of these medications you need to stop tizanidine while you are on it. Dantrolene works at the muscle level by decreasing the release of calcium, and therefore decreases muscle movement. It is effective, but liver functions have to be moni-

Life is a marathon not a . . .

the signal to the spinal cord is reduced, and thus your spasticity is decreased.

If the above measures do not work, we then resort to medication: baclofen., tizanidine, dantrolene, and diazepam has been used successfully. Baclofen is the mainstay of spasticity treatment, because it is effective, it has been around for

tored closely because liver failure has occurred in a small number of patients taking this medication. Finally, I do not use diazepam for the management of spasticity, except in patients, who have already been on it for years and years. Its major drawback is, that, it is extremely addictive and very difficult to get off of it. We have better medica-
See **Living Well** on page 5

Living Well

Continued from page 4

tions now, and diazepam is not required.

If all the above measures fail to control your spasms, we can then use botulinum toxin, which is a neurotoxin that prevents the release of nerve signals to the muscle injected. It can help with localized spasticity, but usually only lasts for about three months. Urologists are using botulinum toxin in the bladder to decrease bladder spasms, and it appears to last 6 months in that setting. The final big gun treatment we have in our arsenal of management tools is an intrathecal baclofen pump. The baclofen can be delivered to the spinal fluid directly, and needs to be refilled about every 6 months in an out-patient clinic setting. It is usually quite helpful in spinal cord injury patients.

Number 3: Routine Exercise

- A strength program, especially shoulder strengthening
- Aerobic endurance program: arm cycle, wheelchair activity, an exercise class at a wheelchair level, pool activity, Wii fit, or use of a functional electrical stimulation cycle
- Standing frame or stretching program daily

I have often told my patients that if exercise came in a pill form, I would prescribe it to almost everyone. "Use it or lose it" would be a good motto; however, you have to be smart about how you exercise.

Life is a marathon not a hundred meter dash, so you have to plan for the long term. In my previous recommendations, I stressed the need to protect your shoulders, and I do the same here. You need a good core strengthening program for your shoulders, to give you a good

Clinical Practice Guideline for Sexuality and Reproductive Health Now Available

The Paralyzed Veterans of America (PVA) has published a new volume in their clinical practice guideline series titled, *Sexuality and Reproductive Health in Adults with Spinal Cord Injury: A Clinical Practice Guideline for Health-Care Professionals*.

This guideline addresses a wide range of topics related to sexuality. It includes recommendations that address physical, interpersonal, emotional and medical concerns. It also addresses the importance of privacy and individuality as well as the practical needs of individuals with spinal cord injuries. The PVA hopes that the availability of this guideline will help ensure that an increasing number of knowledgeable professionals are available to support people reclaiming their sexuality after injury.

After a spinal cord injury, people often have questions about their attractiveness, relationships, and their ability to conceive and have children. Life does not end after a spinal cord injury and neither does the ability to have fulfilling intimate relationships and a satisfying sexual life. It is important that people with SCI and their partners are able to have open dialogue regarding sexuality with a knowledgeable and supportive health care provider.

Printed copies of new guideline are free with the payment of shipping and handling. However, an electronic (PDF) version may be downloaded at no cost. See details at their website:

<http://www.pva.org/site/News2?page=NewsArticle&id=14639>

DVD Highlights the Effects of Smoking on Conditions Secondary to SCI

The University of Alabama (UA) has produced a new DVD titled *Smoking Effects on Secondary Complications of SCI*.

The video may be viewed for free on their website at www.spinalcord.uab.edu/smoking or you may order a copy of the DVD from their website for \$5.00. The UA website also has links to educational information and research abstracts related to smoking and spinal cord injury.

ASCC has copies of the DVD in the McCluer Resource Library that you may loan for home viewing. Call **501-296-1792** to request this DVD.

base from which to exercise. Once you have good shoulder strength, you can then move on to an aerobic endurance program to improve your heart and lung reserve and muscle efficiency. You need an exercise you can enjoy, do consistently, and work in to your daily routine. Twenty to thirty minutes daily is ideal, and I have listed some of the options above. The important

thing is to choose a routine that works for you and does not cause pain or overuse problems. A standing frame and a stretching program to supplement your program and maintain good joint range will put you in good position to decrease spasticity and participate in any upcoming research trials that may be coming in the future.

Chris Ashley - Physical Therapist

By Eddie Still

I read in a recent issue of the Spinal Courier about the appointment of Jimmy Ashley to the Spinal Cord Commission. The article spoke briefly about his wife Chris. It is about her that I wish to write.

I was a student at the Hot Springs Rehabilitation Center at the time Jimmy and Chris first met. Chris was my physical therapist in those days as I was beginning the process of rehabilitating from a spinal cord injury. Being of strong will, I set the unrealistic goals of walking out of that place within the next few months.

As I think back about those days it almost seems unreal that it has now been twenty-seven plus years since the accident that brought me to the center, where I first met Chris Lex, now known as Chris Ashley.

For the first six weeks or so I was assigned to an intern, mostly work-

ing on range-of-motion and endurance. When I became physically ready to begin learning how to live with a SCI, Chris became my therapist.

She played many roles in helping me learn how to make the best of the situation I had put myself in. Chris was compassionate when compassion was needed, tough when discipline was in order and always allowed me my dreams of the “miracle cure” while reminding me that in the meantime I would still need to know how to take care of myself until they found the cure that would save me from a life in a wheelchair.

The day finally came for when I needed to learn about pressure sores and how to prevent breakdown of my skin. She also taught me it was my responsibility to take care of myself and if I did not care enough to prevent sores then it was

my own fault. Reflecting back now I have a renewed appreciation for all she did teach me.

I have now had my injury twenty-seven plus years without even one bedsore on my rear end. The techniques taught me to swing my elbows caused a few problems but not anything that made me stay in bed.

I am very proud of not ever allowing my skin to breakdown and will always know in my head and in my heart that having Chris as my therapist and her method of teaching is the reason my health is as good as it is.

Of all the horrible things that come with a spinal cord injury, meeting Chris is one of the very few things I look back on with fond memories. With in-house rehab being limited as it is now, I believe that a “Readers Digest” version or a crash-course of Chris Ashley’s material could benefit both people with injuries and the funding sources that pay hospital bills.

Heat

Continued from page 1

of the skin; and sweating below the level of the SCI is severely impaired. The most important mechanisms of heat loss are dilation of peripheral blood vessels, sweating and behavioral changes (moving to a cooler environment, changing body position, changing amount of clothing). Therefore, if you were in a hot environment, you may be unable to sense the heat until the central core temperature had risen significantly. By the time you start feeling hot it may be too late to cool off, or your first signs might be symptoms of heat stroke. Symptoms of heat stroke range from: headache, increased respiration rate, dizziness, and confusion; to loss of consciousness. Complications include: breakdown of the muscle tissue, electrolyte

disturbances, acute renal failure and possibly death.

If you or somebody you know experiences this problem, medical attention should be sought promptly. Heat stroke is a medical emergency. Until help arrives, attempt to cool the person off as much as possible. Place the person in an air-conditioned environment, remove excessive clothing, use spray bottles of water to cool the skin, and massage the skin above the level of the SCI to stimulate peripheral dilation of blood vessels.

To prevent you from having trouble with heat this summer, please follow these simple measures.

1. Stay in an air-conditioned environment if the temperature is above 90° F. Have an accessible air-conditioned automobile or

trailer nearby if you have to be outside and away from your home.

2. Avoid alcohol—it suppresses the central brain temperature sensor; thus, decreasing your awareness of the heat.

3. Wear light and removable clothing and stay in a shady area if possible.

4. Drink plenty of water and have a water spray bottle available if you have to be out in the heat.

5. Limit the duration and intensity of activities on a hot day.

6. If other people are sweating, you are likely to develop heat stroke unless you move to a cooler environment.

Enjoy the summer and stay cool.

SAILS DeGray PlayDay

Spa Area Independent Living Services, (SAILS), in Hot Springs invites all people with disabilities and their families to join us for our DeGray PlayDay. The event will be held at the Caddo Bend Swimming Area on DeGray Lake on Saturday, **August 28, 2010** from 10:00 A.M. to 3:00 P.M. Activities include jet-ski rides, guided party-barge tours, games, prizes, and a picnic lunch. Participants will also receive a SAILS DeGray PlayDay tee shirt.

DeGray Lake Resort State Park is located 7 miles north of Arkadelphia, Arkansas on Highway 7. Turn off of Highway 7 at the DeGray Lake Resort State Park sign, and then in the Park, follow the signs to the Caddo Bend Swimming Area. For more information call SAILS toll-free at **1-800-255-7549**, or **624-7710** in Hot Springs.

Hope to see you there.

Fort Smith Area Support Group Meets

Under the leadership of ASCC Case Manager Craig LaRue, a support group for persons with spinal cord injury has been organized in the Fort Smith area. The group meets at the Ft. Smith public library at 3201 Rogers Ave. Meetings begin at 3:30 p.m. and are scheduled for August 7th, September 18th and November 20th.

The group also has a Facebook page, so if you can't attend in person you may stay in touch through their Facebook page.

For more information, contact Craig at clarue@arspinalcord.org or at **1-479-478-0504**. Come out and share your experiences with this exciting new group!

New West Memphis Case Manager

Von Daniels began his duties in April as the new Case Manager in the West Memphis Office replacing long-time employee Sharon McCoy. Von has completed the major portion of his orientation and training and has begun meeting the clients on his caseload. He will be providing services to clients in Crittenden, Cross, Woodruff, St. Francis, Prairie, Lee, Monroe and Phillips counties.

Von received his Bachelor's degree in Sociology from UCA and is currently working on his Masters in Counseling. He is scheduled to complete his degree this year. Von has a strong counseling background and several of his ASCC clients will recognize him from his previous job as an Alternatives Waiver Counselor. "Von is a highly motivated and dedicated individual and we are very fortunate to have him



Von Daniels

on our staff," said Client Services Administrator, Patti Rogers.

He is also a Pastor at a Baptist church in Marvell. Even though preaching takes up a lot of his time on weekends, Von does manage to spend time in the backyard doing some serious BBQing. Rumor has it he makes a mean BBQ sauce! Von and his wife, Nicole currently live in the Marion area.

Please join the Commission Members and staff in welcoming Von!

Research Study Investigates Mental Health Adjustment Following SCI

Spinal cord injury (SCI) is a life-changing event affecting the physical, social and mental health of persons sustaining such an injury. A research project at the University of Oklahoma is investigating the mental health attitudes and adjustments that take place after spinal cord injury. The goal of the research is to help develop better counseling treatment plans that would allow persons with SCI to be served more appropriately during their recovery following such a disabling injury.

The research project is being lead by Donald Ranallo who sustained a SCI in 1988 as a result of a rodeo accident. Mr. Ranallo is currently finishing up his requirements for a Doctorate degree in Counseling Psychology. For more information about this research or to participate as a subject in this research, please go to the website listed below:

SPINAL CORD INJURY RESEARCH OPPORTUNITY

For details and a chance to win 1 of 5
\$100.00 Wal-Mart gift cards

Go to: <http://students.ou.edu/R/Donald.L.Ranallo.Jr-1/>

For more information
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Camp Aldersgate Executive Director Sarah Wacaster presents Ben Wells with the Super Joe leadership award .

Ben Wells Named "Super Joe" at Award Ceremony

Another year of camp has ended and 35 campers, ages 6 to 16, had a fun-filled week. This year Ben Wells of West Memphis was honored with the Super Joe award for outstanding camper.

If you want to attend camp next year, look for details in our January 2011 newsletter, talk with your Case Manager, or contact Mary Jo Stanton at **501-296-1788** or **800-459-1517** or by e-mail at **mjstanton@arspinalcord.org**.

Southern Sportsman Foundation Hunt Applications Now Available

2010 is the seventh year that the Southern Sportsman Foundation will host their annual whitetail deer hunt for youth and adults who have a severe disability or a life-threatening illness. Interested parties must submit a completed application no later than August 15, 2010. Applicants who are drawn to participate in the hunt will be notified no later than September 15, 2010.

Applications can be downloaded at **www.sharingtheoutdoors.com** or obtained directly from Mike Cranford at **mcranford@whiti.net** or call **1-903-826-3318**.

The Southern Sportsman Foundation is a 501c3 nonprofit corporation.

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