



SPINAL COURIER

The spinal cord disability information source for Arkansans since 1989

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Tom Farley Retires from Commission

When Tom Farley came to the Arkansas Spinal Cord Commission as our first Director of Research and Statistics in December of 1988, he found that the Arkansas Spinal Cord Disability Registry consisted of a box of index cards with information about each client printed in pencil (so it could be changed). Cards were counted and sorted by hand to create the registry. Today, thanks to Tom's ingenuity and skills the Commission maintains one of the most comprehensive spinal cord disability registries in the Country, in a database of over 6,000 cases that collects nearly one hundred attributes about each person and allows reports to be created in seconds. The registry was just the beginning of Tom Farley's contributions to the Arkansas Spinal Cord Commission and our clients.



Cheryl Vines and Tom Farley.

Among his other accomplishments, Tom was the creator of the Spinal Courier newsletter in 1989 and had served as its editor for all 22 years that it has been published, writing, doing the layout, editing articles and serving as our key photographer. He has also served as editor

of our annual report each year and has overseen creation of most of our publications.

As the Commission's Research Director Tom has been responsible for managing millions of dollars in grant project funding from Centers for Disease Control and Prevention, Paralyzed Veterans of America, the National Highway and Traffic Safety Administration and the Christopher Reeve Foundation, among others for projects to prevent spinal cord injuries, prevent secondary conditions, develop health promotions and educational resources and conferences and describe personal care activities of

See **Tom Retires** on page 7

Mark Your Calendar

The Arkansas Spinal Cord Commission's statewide Living Well with Spinal Cord Disabilities conference is scheduled for Friday, May 20, 2011. The conference will again be held in the Campus Center at Pulaski Technical College in North Little Rock Arkansas.

ASCC clients, families, and care givers as well as Nurses, Case Managers, Physical, Occupational and Recreation Therapists, Rehabilitation and Independent Living Counselors and anyone interested in the latest in spinal cord injury services are urged to attend. In addition to a national keynote speaker, educational sessions will include topics, such as: cutting edge urological and orthopedic care, selecting the best wheelchair for you and making your home accessible. A full exhibit hall will feature the latest in wheelchairs, exercise equipment, medical supplies, assistive technology and demonstrations. The day will culminate with door prizes. This is a great opportunity to learn the latest about spinal cord injury with an opportunity to speak face to face with experts in many fields. More details will be available in the April 2011 Spinal Courier but mark you calendar now and plan to be there on May 20st.

In this issue . . .

Grant Marshall Honored	Page 2
ASCC Staff Have New Email Addresses	Page 3
Aging with SCI is not for Wimps	Page 4
Governor Establishes Employment First Initiative	Page 5
ASCC Develops Resources on Regeneration Medicine	Page 6
Shana Warren Joins ASCC	Page 7
Geron Initiates Clinical Trial of Human Embronic Stem Cell-Based Therapy	Page 8

SPINAL COURIER

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Donations this quarter from:

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Jenny Masullo

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).

From the Director

Do you know anyone who doesn't complain about accessible (handicapped) parking? Folks who need it complain that those who don't are always using the spaces. Those who don't need it complain that all the 'close spaces' are taken up. It seems a no win situation. Unfortunately, most misuse of accessible parking is by folks who have a disabled plate or placard. Too often, family members or others driving a vehicle with a disabled plate use accessible spaces, even though they do not need them. The biggest abuse is probably the van accessible spaces, where, state law allows *only* folks who use wheelchairs, or other mobility devices to park.

The Commission is working with a coalition to improve enforcement of Arkansas laws on accessible parking. We don't need more laws until we have compliance with the ones we have! We won't become the 'parking police,' but we will be working with everyone from users to law enforcement to judges on an educational campaign.

So, in 2011, I ask YOU to make these 4 resolutions and ask others to follow them too:

- Never allow anyone to use your disabled plate or placard to park in accessible parking unless you are in the vehicle. Not even 'just for a minute.'
- If you are in the vehicle, but do not plan to get out, do not park in accessible parking – it is reserved for those folks exiting their vehicles. You can easily sit and wait in a regular space.
- Never park in the lined area next to an accessible space. It is there to allow enough space for lifts or loading a wheelchair—you could block someone's ability to get in or out of their vehicle.
- Only vehicles that load or unload a wheelchair or other related mobility device may use those parking spaces designated as "van accessible."

Please make these resolutions and follow them this year! It will make a difference. As we develop additional efforts, we will be posting them on our website. Please help us spread the word.

Wishing you a healthy happy 2011!

Cheryl L. Vines

Grant Marshall Honored

Grant Marshall of Magnolia was inducted into Southern Arkansas University's Mulerider Hall of Fame during homecoming celebration in October 2010. Mr. Marshall's selection was for meritorious service to the university's athletic program.

Grant served many years as the announcer for SAU men's and women's basketball, baseball and softball; he also worked the time clock for the football team. His work includes announcing at athletic events for Magnolia and Stamps high schools. He graduated from SAU in 1981 and served eight years on the Alumni Board.

ASCC Staff Have New Email Addresses

ASCC recently changed its email service provider. New email addresses and other contact information are listed below.

Little Rock Administrative Office

Cheryl Vines, Executive Director	501-296-1788	Cheryl.Vines@arkansas.gov
Patti Rogers, Client Services Administrator	501-296-1788	Patti.Rogers@arkansas.gov
Andy Hendricks, Fiscal Officer	501-683-1132	Andy.Hendricks@arkansas.gov
Mary Jo Stanton, Administrative Specialist	501-683-1120	Mary.Stanton@arkansas.gov
Cindy Baker, Administrative Specialist	501-296-1790	Cynthia.Baker@arkansas.gov

Little Rock Case Management Office

Gaylon Branch, Case Manager	501-296-1792	Gaylon.Branch@arkansas.gov
John Breen, Intake Coordinator	501-296-1792	John.Breen@arkansas.gov
Terra Patrom, Case Manager	501-296-1792	Terra.Patrom@arkansas.gov
Doug Fish, Case Manager	501-296-1792	Douglas.Fish@arkansas.gov
Christina Hopson-Allen, Case Manager	501-296-1792	Christina.Hopson-Allen@arkansas.gov
Marie Campbell, Administrative Specialist II	501-683-1127	Nettie.Campbell@arkansas.gov
Shalia Delph, Administrative Specialist II	501-683-1124	Shalia.Delph@arkansas.gov

Batesville Case Management Office

Leetha Wren, Case Manager	870-793-4153	Leetha.Wren@arkansas.gov
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Fayetteville Case Management Office

Maryanne Caldwell, Case Manager	479-521-1463	Maryanne.Caldwell@arkansas.gov
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Fort Smith Case Management Office

Craig LaRue, Case Manager	479-478-0504	Craig.LaRue@arkansas.gov
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Hot Springs Case Management Office

Kim Brown, Case Manager	501-701-6591	Kim.Brown@arkansas.gov
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Jonesboro Case Management Office

Russell Henry, Case Manager	870-268-0425	Russell.Henry@arkansas.gov
Shana Warren, Secretary	870-268-0425	Shana.Warren@arkansas.gov

Magnolia Case Management Office

Evelyn Wainwright, Case Manager	870-234-6219	Evelyn.Wainwright@arkansas.gov
Janet White, Case Manager	870-234-6219	Janet.White@arkansas.gov
Felicia Rufus, Secretary	870-234-6219	Felicia.Rufus@arkansas.gov

Pine Bluff Case Management Office

Bobby Johnson, Case Manager	870-534-2993	Bobby.Johnson@arkansas.gov
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Russellville Case Management Office

Toney LeQuieu, Case Manager	479-890-5751	Toney.LeQuieu@arkansas.gov
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West Memphis Case Management Office

Von Daniels, Case Manager	870-735-4725	Von.Daniels@arkansas.gov
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Aging with a Spinal Cord Injury is not for Wimps

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



ASCC Medical Director Tom Kiser, M.D.

The life span of someone with a spinal cord injury (SCI) has significantly improved since 1936 when Dr. Donald Munro started the first SCI service in the United States. Addressing the health rehabilitation issues facing someone with a SCI, especially skin, bowel and bladder issues, made a huge difference in the health and survival rates. Other huge factors were attention to psychological attitudes, the development of new technology, and the ability to discharge individuals with SCI back to the community. As a result of all this progress, aging, with all its ramifications, is becoming an important issue. As Bette Davis stated it: "Old age is no place for sissies." It takes forethought, intentionality, and preparation now, so that you and I can age with grace and die having accomplished our mission and goals in life.

The nervous system dysfunction caused by SCI may result in lasting impairment of many organ systems. Autonomic dysfunction must be addressed by managing your bladder and bowels well and avoiding prolonged pressure on your skin (i.e., always sitting on a good wheelchair cushion, doing frequent pressure reliefs, wearing appropriate shoes and checking the temperature before sticking your foot in hot water). Protect your shoulders by conducting good, safe transfers, planning your day to minimize the need for transfers, and having a good shoulder exercise program. Remember that life is a marathon that requires endurance, not a hundred-meter dash with no thought for tomorrow.

The following are key principles that have been suggested in a nice review on aging with SCI by Susan Charlifue, et al:

- The effects of aging appear more quickly in the individual with a SCI, so it is important to be proactive with preventative strategies to minimize the effects of aging.
- Individuals with SCI who have a higher neurologic level of injury, complete SCI, or who are older at time of injury have an accelerated mortality rate.
- Aging has an effect on medication metabolism, and a good review of medication used and slowly tapering of the dosage

it is important to be proactive . . .

and frequency of administration must be done at each clinic visit.

- Depression is common among individuals with SCI and is greater in those who have been injured for a long time and in those who are older.
- Nevertheless, individuals with SCI have a relatively good and stable life satisfaction over time, even after many years living with a SCI.

I would make the following suggestions:

- Plan to have routine medical and rehabilitation follow-up to address issues as they come up,

and do not put off getting the opinion and help of experts in the field. A good review of systems is important to mitigate the myriad of secondary complications that can develop with aging and SCI.

- Pay attention to your body's complaints, and do not accept a decline in function just because you are getting older. Technology and advances in equipment and medication have given us some new management options, so try to stay abreast of what is available.
- If at all possible, avoid the

chronic use of narcotics, because one of their side-effects is inhibition of the gastrointestinal tract and respiratory system. In addition, there is a risk of habituation, and thus the need to go to higher doses over time. If unable to avoid narcotics, use the lowest dose possible, try not to increase the dose with time, and try to space out the dosing to avoid habituation. Finally, the risk of medication diversion in those who have caretakers should be considered.

- Avoid the chronic use of benzodiazepines, such as valium for spasticity. They tend to slow cognition and response time

See **Aging** on page 5

Aging

Continued from page 4

even in patients who deny this side effect, and it is difficult to wean patients from them after they have used them chronically for years. There are better medications for the treatment of spasticity now than in years gone by.

- If at all possible, as you get older, avoid medication on the “do not use” medication list from the geriatric literature (Darvocet, soma, valium, etc.). I would recommend discussing these medications with the prescribing physician. See the following web sites for more information about this list of medications: <http://archinte.ama-assn.org/cgi/content/full/163/22/2716> and www.dcri.org/trial-participation/the-beers-list/.

Suggested Readings:

Charlifue S, Jha A, Lammertse D. Aging with Spinal Cord Injury. *Phys Med Rehabil Clin N Am*. 2009;21:383-402.

Tom Retires

Continued from page 1

people with spinal cord injuries and spina bifida. He has done research into the causes of spinal bifida.

Tom served as the Commission’s Information Technology Manager, before the job had a name — managed all of the agency’s hardware, software and technology, including our email system, he has been our webmaster, creating and managing the ASCC website.

Finally, as a member of the ASCC management team, Tom has served as acting director often over the past two decades and assisted in developing the agencies strategic plans and special projects.

The list goes on. Tom Farley has been integral to the mission of the

Governor Establishes Employment First Initiative

On October 21st, 2010, Governor Mike Beebe issued an Executive Order to establish the Arkansas Employment First Initiative to Increase State Employment of Arkansans with Disabilities.

Arkansas has the 4th highest rate of disability in the nation. One in ten working age (18 to 64) Arkansans have disabilities and receive either SSI or SSDI. The number of disability recipients has increased by nearly 24% in the past 5 years. While these benefits are helpful and often include healthcare benefits, a large percentage of these recipients continue to live at the poverty level. Within the spinal cord disability population in Arkansas, only about 20 percent work.

In the Executive order the Governor stated, “Many Arkansans with disabilities want to work and become more self sufficient. These citizens should be supported and encouraged by state government agencies to find employment in the competitive job market. Such employment furthers important public policy objectives of advancing individual well being and reduces the demand on public resources. State Government should do all that it can to demonstrate leadership in facilitating the availability of employment of our citizens with disabilities, including those with the most significant disabilities.”

The Governor directed state agencies to coordinate efforts to increase employment of Arkansans with disabilities. To that end he ordered the Department of Human Services convene an Employment First Task Force that would include representatives from disability service, education and vocational agencies as well as consumer advocates. Krista Hughes, director of Aging and Adult Services in the Department of Human Services is heading the Task Force. Cheryl Vines represents ASCC on the Task Force.

Governor Beebe charged the group with several objectives including developing a staff training curriculum on disability employment for state agencies, reduce or eliminate barriers to employment for people with disabilities and create a mechanism to measure employment of people with disabilities. The Task force is to create a final report of recommendations by October 31, 2011. In addition, he charged state agencies that provide services to individuals with disabilities to make employment a priority.

While the efforts of the Task Force will not produce results immediately, it is a first effort on behalf of all state agencies to promote employment in for Arkansans with disabilities that choose to work. For more information about the Task Force, contact Scott Holladay at the Employability Project, Scott.Holladay@arkansas.gov or **501-682-8510**.

Arkansas Spinal Cord Commission. But, on December 31, 2011, Tom retired from his duties at the Commission. How do you replace someone who has ‘done everything’? You don’t! It will likely take several people to carry out all of Tom’s duties and responsibilities.

All we can do is THANK Tom for his dedication, his insights and commitment to making life better for Arkansans with Spinal Cord disabilities.

Please join the Commission members and staff in wishing Tom well in his retirement!

ASCC Develops Resources on Regeneration Medicine

In 2010, ASCC Executive Director Cheryl Vines convened a Task Force to consider an ASCC position statement related to President Obama's lifting of the ban on stem cell research. Over the course of the year, the issue ended up in court and has yet to be decided, but the Task Force continued to meet to consider issues related to stem cells and other regeneration therapy. With the recent start of stem cell clinical trials on human subjects with spinal cord injuries in the United States as well as the ever increasing offers for a variety of treatments abroad, the Task Force had a primary goal of identifying or creating cutting edge, useful resources to assist ASCC clients and their families in considering these treatments.

The Task Force included:

Jon Wilkerson, MS, PT
Tom Kiser, MD
Maryanne Caldwell, MS, CRC
Russell Henry, MRC, CRC
Micah Hester, PhD
Cheryl Vines, MS

Task Force members created two documents including the Arkansas Spinal Cord Commission Regenerative Medicine Glossary by Jon Wilkerson M.S., P.T. and Predicting Outcomes (Prognosis) in Spinal Cord Injury fact sheet by Thomas S. Kiser, M.D., M.P.H.

In addition, they reviewed literally hundreds of resources, articles and websites to select those that were most useful and credible. The Task Force created this list to assist individuals in making good decisions in determining whether to participate in regeneration clinical trials or treatments. The resources are also posted on the ASCC website at spinalcord.ar.gov.

Arkansas Spinal Cord Commission Stem Cell and Medical Regeneration Resources

Internet Links:

[HTTP://STEMCELLS.NIH.GOV/INFO/BASICS/](http://stemcells.nih.gov/info/basics/)

National Institute of Health Resource for Stem Cell Research, Bethesda, Maryland.

An informational website about stem cell research, including spinal cord. Has definitions, glossary, basic information, current research updates, frequently asked questions and federal policy statements. Frequently updated.

<http://sci.rutgers.edu>

WH Keck Center on Collaborative NeuroScience, The Spinal Cord Injury Project, Rutgers University, Rutgers, New Jersey.

This project hosts the CareCure Community, a forum for individuals with spinal cord injuries, families and healthcare providers to interact. Includes forums on care and treatment of SCI as well as SCI research. Wise Young, M.D., PhD a world renowned expert in spinal cord injury research who is committed to responding to questions from those living with spinal cord injuries moderates the research section. Users should understand that while some posts are directly by Dr. Young and other medical professionals, posts by others might not actually be based on medical experience or training, but share personal experience and information.

<http://christopherreeve.org>

Christopher and Dana Reeve Paralysis Foundation, Short Hills, New Jersey.

A Center founded by the late Christopher Reeve and his wife Dana to help individuals with spinal cord injury and other paralysis to learn about and obtain resources as well as to support SCI research and quality of life endeavors. Website provides a Paralysis Resource Center with information regarding research, treatment and other resources. The Research area provides information on the basics of SCI medicine research, clinical trials, and reports on projects funded by the Foundation.

<http://icord.org>

International Collaboration on Repair Discoveries (ICORD), Vancouver, British Columbia, Canada.

ICORD is an interdisciplinary research center for the development of effective strategies to promote functional recovery after spinal cord injury. Working in collaboration with SCI research organizations around the world, they have developed *Experimental Treatments for Spinal Cord Injuries: What you should know if you are considering participation in a clinical trial, 2007*, a resource to help those in considering participation in a clinical trial to understand what a clinical trial really means. In addition, the website includes other documents about SCI research and rehabilitation.

Arkansas Spinal Cord Commission Stem Cell and Medical Regeneration Resources *Continued*

Documents:

Arkansas Spinal Cord Commission Regenerative Medicine Glossary, Arkansas Spinal Cord Commission, 2010.

A glossary with definitions of frequently used terms related to stem cell research and activity based therapy, to provide readers with a basic understanding of these terms to help in reviewing articles, web information and treatment options.

Predicting Outcomes (Prognosis) in Spinal Cord Injury, fact sheet, Thomas S. Kiser, M.D., M.P.H, Medical Director, Arkansas Spinal Cord Commission, 2010.

A fact sheet developed for newly injured individuals and their families to help them understand spinal cord injury, concepts of complete and incomplete injuries, and realistic expectations of predicting recovery. Provides timely references for additional information.

Patient Handbook on Stem Cell Therapies, Appendix 1 of the Guidelines for Clinical Translation of Stem Cells, 2008. International Society for Stem Cell Research, Deerfield, IL.

A must read for individuals with spinal cord injuries and other disabilities considering stem cell treatment or clinical trial. Provides questions and answers on topics including what are stem cells and stem cell therapies, clinical trials and experimental treatments and considerations for both, including informed consent, how to learn more about stem cell research. The ISSCR is a professional stem cell research organization with a commitment to ensure the promise of stem research is delivered to patients in a safe, effective manner.

Experimental Treatments for Spinal Cord Injuries: What you should know if you are considering participation in a clinical trial. International Collaboration on Repair Discoveries (ICORD), Vancouver, British Columbia, Canada.

A 40-page booklet or 10-page summary in pdf format. (See ICORD above.)

Position Statement on Sale of Unproven Cellular Therapies for Spinal Cord Injury, Spinal Cord, 2009, 47, 713-14. A brief article penned by directors of the International Campaign for Cures of Spinal Cord Injury Paralysis regarding the impact of participation in unfounded treatments including stem cells.

Cellular Transplants in China: Observational Study from the Largest Human Experiment in Chronic Spinal Cord Injury, Neural Rehabilitation and Neural Repair, 2006, 20:5.

Report of a study conducted on 7 subjects with chronic spinal cord injuries who underwent fetal brain cell transplantation in China to determine the effects and improvements after the transplantation.



Shana Warren.

Shana Warren Joins ASCC Staff

Shana Warren joined the ASCC staff on November 29, 2010. She is the new Administrative Specialist in the Jonesboro field office replacing RoseMary Agee who has moved to another state agency. Shana brings a strong background in providing administrative support in physicians' offices, therapy and mental health programs as well as experience at Arkansas State University (ASU) and the Red Cross. She holds a bachelors degree in public relations and management from ASU.

“ We are very lucky to find someone with Shana’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 look forward to having Shana on our ASCC team.”

Shana, her husband Nick, sons Caleb (19) and Zander (6) live in Jonesboro. In her free time she enjoys reading, sewing and shopping. Please join us in welcoming Shana to the Commission.

Geron Initiates Clinical Trial of Human Embryonic Stem Cell-Based Therapy

First Patient Treated at Shepherd Center in Atlanta

Geron Corp., a biopharmaceutical company based in Menlo Park, CA announced on October 11, 2010 the enrollment of the first patient in the company's clinical trial of human embryonic stem cell (hESC)-derived oligodendrocyte progenitor cells, GRNOPC1. The primary objective of this Phase I study is to assess the safety and tolerability of GRNOPC1 in patients with complete American Spinal Injury Association (ASIA) Impairment Scale grade A thoracic spinal cord injuries. Participants in the study must be newly injured and receive GRNOPC1 within 14 days of the injury.

The first patient was enrolled at Shepherd Center, a spinal cord and brain injury rehabilitation hospital and clinical research center in Atlanta, GA. Shepherd Center is one of seven potential sites in

the United States that may enroll patients in the clinical trial.

"Initiating the GRNOPC1 clinical trial is a milestone for the field of human embryonic stem cell-based therapies," said Thomas B. Okarma, Ph.D., M.D., Geron's president and CEO. "When we started working with hESCs in 1999, many predicted that it would be a number of decades before a cell therapy would be approved for human clinical trials. This accomplishment results from extensive research and development and a succession of inventive steps to enable production of cGMP master cell banks and preclinical studies in vitro and in animal models of spinal cord injury, leading to concurrence by the FDA to initiate the clinical trial."

"We are pleased to have our patients participating in this exciting research," said Donald Peck Leslie, M.D., medical director, Shepherd Center. "Our medical staff will evaluate the patients' progress as part of this study. We look forward to participating in clinical trials that may help people with spinal cord injury."

In addition to Shepherd Center, Northwestern Medicine in Chicago, IL is also open for patient enrollment. As additional trial sites come online and are ready to enroll patients, they will be listed on the Patient Information pages of Geron's website and on the NIH clinical trials registry, **ClinicalTrials.gov**. Further information on the criteria for patient eligibility is also available on **ClinicalTrials.gov**.

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