

## Josh Miller Rolls into the Arkansas Legislature



Josh Miller sustained his spinal cord injury in 2003, ten years later he will be the first person with a spinal cord injury to serve in the Arkansas House of Representatives. A native of Heber Springs, Josh will represent District 66 including parts of Cleburne, Van Buren and Faulkner counties. Josh has owned businesses in Heber Springs for several years and in 2008 was elected to the Heber Springs City Council. That

experience and the opportunity to give back to the community that had supported him, lead him to run for the state legislature. He won a primary election in May and took the seat in the general election in November with 65% of the vote. Now he is ready to come to Little Rock and represent his district and his conservative values.

During his first term as a state representative, Miller already knows he wants to help improve the state's healthcare system and help those who live with disabilities. Batesville Case Manager Bruce Kelley who has worked with Josh for a number of years was not surprised with the win, "Josh is one of the most positive clients I worked with. One of his most notable accomplishments was being named to the 2007 Chancellor's List at ASU Beebe. I was thrilled to learn he won the District 66

State Representative position. We face serious fiscal budget challenges but it brings comfort to me knowing representatives like Josh Miller will bring a common sense approach to finding solutions to our health care challenges."

Asked about wheelchair accessibility at the Capitol, Josh notes that he will have one of the coveted 'back row' seats in the House Chamber, usually reserved for senior statesmen, that best accommodates his power wheelchair. House staff have made minor modification to the desk and the voting buttons so that he can use them. He will serve on the Public Transportation and State Agencies Committees during the 2013 session. Josh plans to return to Heber Springs most evenings during the session to spend time with his wife Bethany and son Malachi.

## I Can! Dance

I Can! Dance groups from around the state took the stage for their 2012 Recital on December 1, 2012, performing to a full auditorium at Benton High School. Over 100 dancers with disabilities, including Katie Mayberry (l) and Emma Cordero (r) and their dance buddies performed.

I Can! Dance class is a free dance class includes, but is not limited to, children ages 4-17 with Spina

Bifida and other disabilities. The goal for the class is to not only give these children the opportunity to perform on the stage with bright lights and fancy costumes, but to show to as many spectators as possible that these children CAN dance and have the same dreams and desires as other children.

For more information go to [www.communityconnectionsar.org/icancenter](http://www.communityconnectionsar.org/icancenter) or call (501) 329-5459.



## SPINAL CONNECTION

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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

As a brand new ASCC Case Manager in the fall of 1987, I was determined to meet and communicate with all of my clients. I learned that at least one client had a hearing impairment would need a TTY (the old term for a communication device for those who can not hear), but ASCC did not have one. Someone suggested that the agency 'upstairs', Advocacy Services (now the Disability Rights Center) might have one. I went up to ask. In the first office I came to, I asked the woman there if one was available. She said 'certainly' and proceeded to find one for me, show me how to use it and said it was available anytime I needed it. I borrowed it many times.

It was sometime later that I learned that this person was the Director of the agency, Nan Ellen East. That was the first time she and I met and 'collaborated' to help someone with disability, but not the last. Over the past 25 years I have grown to know and respect Nan Ellen for her advocacy, leadership and commitment to Arkansans with disabilities. She was a pioneer in these efforts, and there are few disability efforts in our state that she has not touched. When our paths crossed at the Arkansas Disability Coalition conference this summer, I mentioned that I thought she was involved in the establishment of the group. She told me the story of the true grass roots efforts that she and other parents had undertaken to get it started.

When the American With Disabilities Act was passed in 1990, Nan Ellen called the meeting to start the ADA Roundtable. She and her staff have taken on the difficult job of protecting the rights of many Arkansans, especially those in institutions. In the past few years, she has advocated for Arkansans with traumatic brain injuries, serving as an advocate for this group of citizens with great needs. She has been a mentor and role model to me and many other disability leaders in our state and around the nation.

As you read this, Nan Ellen has moved to the next chapter of her life, retirement! On behalf of the members, staff and clients of the Arkansas Spinal Cord Commission I offer our sincere thanks for her long career in advocacy, education and service development for Arkansans with disabilities. Arkansas is a better place thanks to Nan Ellen East.

Enjoy the new year!

*Cheryl L. Vines*

# SCI Research: An Update

Information regarding research related to spinal cord injuries can be difficult to find and often good sources of information can be difficult to discriminate from sources that are less than reliable (to put it mildly). However, exciting and credible research is ongoing on several fronts. This is the first half of a two part article and will focus on research at the cellular level.

## Cell Transplants

Most people are familiar with some of the issues surrounding cell transplants, specifically those involving embryonic stem cells. Federal funds were freed up to expand the field of embryonic stem cell research in 2011. Since then this field of research in the United States has experienced some ups and downs.

Geron, a powerful biomedical organization that helped crack the human genome and the primary benefactor of stem cell research in the spinal cord, announced last November that it would no longer pursue spinal cord research. They abandoned their current phase I study on embryonic stem cell transplantation into people with acute spinal cord injuries in favor of focusing on cancer research. This was concerning to all of the

stakeholders in the field of spinal cord injury because of a lack of a legitimate and well leveraged successor.

Fortunately, one has emerged in the form of another biomedical company, Neuralstem (<http://www.neuralstem.com/neuralstem-in-the-news>). Most notably since picking up the mantle, researchers at Neuralstem published a paper in the journal Cell (<http://www.sciencedaily.com/releases/2012/09/120913122834.htm>) demonstrating human embryonic stem cell transplants restoring lower extremity function and sensation in mice who's spinal cords had been recently transected. This is a very exciting finding that may have substantial implications in the human model.

Meaningful research is also being performed into the use of adult stem cells, the less controversial type of stem cell that does not require the destruction of a human embryo. Currently, StemCells, Inc. is conducting a phase I/II study in Zurich, Switzerland involving the transplantation of adult stem cells on three incomplete paraplegics (the study's plan will involve 12 subjects total). Preliminarily, this study shows no adverse effects on its

participants, is well tolerated and two of the subjects have actually experienced increased sensation below the level of injury, which is not related to the placebo effect (<http://investor.stemcellsinc.com/phoenix.zhtml?c=86230&p=irol-news&nyo=0>).

Ongoing research continues on non-embryonic cell transplant technologies at programs like the Miami Project (<http://www.miamiproject.miami.edu/page.aspx?pid=895>) which studies specialized neural tissue called Schwann cells that are hoped to foster neural regrowth after injury. The University College of London (<http://www.ucl.ac.uk/ion/departments/repair/themes/spinal-repair>) is studying olfactory ensheathing cells which are harvested from the nose and have been shown to regenerate neural tissue in culture and in the mouse model.

## Other Technologies

Next, a number of other emerging technologies will be discussed that attempt to bridge the gap, so to speak, of the injured part of the spinal cord without actually trying to repair the damage at the point of injury. These technologies are generally bionic in nature. Yes, think the Six-Million-Dollar Man.

## Don't Forget Your Spina Bifida Tax Credit

For most of us, January means we begin to think about filing our taxes.

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

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 2012.

You can find the form at [http://www.dfa.arkansas.gov/offices/incomeTax/Documents/AR1000RC5\\_2012.pdf](http://www.dfa.arkansas.gov/offices/incomeTax/Documents/AR1000RC5_2012.pdf) If you have questions about the form, contact the AR Department of Finance and Administration, Individual Income Tax Section at 501-682-1100.

## Essie Morgan Award

ASCC Executive Director Cheryl Vines was honored by the Academy of Spinal Cord Injury Professionals at their national meeting in September with the Essie Morgan award for her service in providing psychosocial services to individuals with spinal cord injuries. In addition to the award, Ms. Vines was asked to give the Morgan Lecture. Her lecture, entitled "A View From the Trenches: Life After Spinal Cord Injury", featured the legislative mandates and services provided by ASCC.

# Tele-Rehabilitation: Digital Doctoring

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



I am an old school doctor in a new school world, and technology is constantly pushing the envelope and changing how I manage and treat patients. Sometimes it's for the better, but often I think it is for the worse.

I spend more time at the computer than seeing patients, and even when I am in an exam room technically "seeing" a patient, I still have to spend most of the time working at the computer entering data.

I am being asked to text my colleagues and do a lot more work from home. Now that I can do my progress notes from any available computer, I have to be more disciplined with my time or I could work 24 hours a day, 7 days a week.

Thus technology and government regulations often come between me and my patients and can be very disruptive. However, there are positive changes as well as negative changes and, neither you nor I can put the genie back in the bottle,

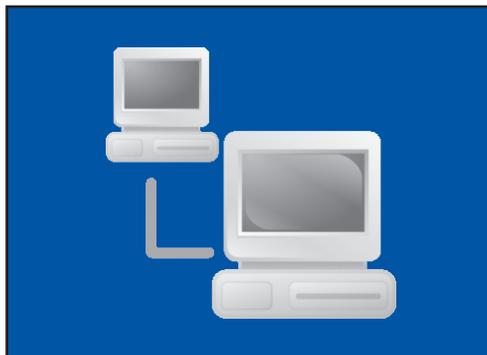
One positive aspect that I want to focus on in this article is the ability to see patients via a video link between my office and outlying Area Health Education Centers (AHECs) throughout the state. "Tele-Rehabilitation" (TR) provides rehabilitation consultation and support through interactive video, connecting distant patients with rehabilitative specialists for real-time services.

Patients who need to see me or some other health professional can simply visit their nearest Area Health Education Center (AHEC) to attend a video appointment. This allows the health care provider to

interact with a patient anywhere in the state as long as they can get to a local AHEC.

This is the perfect scenario for discussing issues with bowel, bladder, spasticity and equipment, and the video link allows me to assess function, evaluate equipment, order therapy, and prescribe or renew medications as needed.

The difficulties are the mild delay in the video link, which is usually a little disconcerting at first but rapidly becomes less noticeable and does not hamper the clinic visit. A specialized video camera



is available if a pressure sore or a skin rash is the issue. I can assess the skin as long as the staff at the AHEC is able to transfer the patient to an exam table for me to assess a pressure sore, if it is underneath clothing.

It is, however, more difficult to assess sensation and motor strength or perform the dreaded pinprick or rectal exams if they are needed. In my opinion, it is not quite as good as a face-to-face clinic visit, because I enjoy the clinical interaction and the ability to examine an area of interest without the barriers of technology.

On the first clinic visit, a good



ASCC Medical Director Tom Kiser, M.D.

physical exam is essential to establish the exact level of injury and whether the injury is complete or incomplete. The tele-rehabilitation visit, however, can be an excellent setting for established patients and for follow-up clinic visits to discuss the results of testing, medication or therapy. For those who simply cannot come to Little Rock, then a tele-rehabilitation clinic definitely beats no clinic visit.

At the present time, I am not aware of other rehabilitation clinics offering this service, but I am sure that it will become more available as technology and the push of the government and health care payors becomes more insistent.

If you or your loved one would benefit from this service, the contact information to be scheduled for a visit is listed below. If you need help and are not sure tele-rehabilitation is for you, discuss this option with your Arkansas Spinal Cord Commission Case Manager.

At the present time I am setting up a monthly clinic specifically for tele-rehabilitation on the second Thursday of each month.

To discuss if you or your loved one is a candidate for tele-rehabilitation, please contact:

Ellen Lowery, R.N.  
Phone: 501-526-7656  
Email: emlowery@uams.edu

# New Employees at ASCC



*Cathy Shipley*

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.

Cathy Shipley joined our staff as Agency Fiscal Manager on October 29st. She is a strong fiscal manager with extensive state experience including previous experience at Department of Human Services, UAMS and Public Employees Retirement System as well as in the private sector.

“We are pleased to have a Fiscal Manager with Cathy’s experience and commitment on our staff” noted Executive Director Cheryl Vines, “she brings great experience, including in grants management and is already a great asset to our agency.”.

Cathy holds Bachelors degree in Accounting and a Masters degree in Business Management from UALR. She lives in Sherwood with her two dogs. In her free time, she looks forward to spending time with her three young grand daughters.

A new voice will be answering the phones in the Jonesboro Case Management office. Kim Phillips began her Administrative Specialist duties in the Jonesboro office at the end of November providing support to Case Manager Russell Henry.

Kim holds a Bachelor’s degree in education with a major in English from the University of Saskatchewan in Canada. She

has an excellent background in customer service and computers.

Having managed her own computer/web design business in Paragould for twelve years, Kim will be an great asset to the Commission. “We are very fortunate to have found someone with such an excellent background”, commented Client Services Administrator Patti Rogers.

Please join the Commission and staff in welcoming Cathy and Kim aboard!



*Kim Phillips*

## Salt of the Earth

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Good health is vital for people with spinal cord injuries (SCI) who are at risk for complications that many individuals never have to worry about.

One of the biggest obstacles in our diet is table salt, which contains sodium and chloride. Too much sodium is a hazard for people with high blood pressure or heart disease. It also can cause swelling due to water retention.

Just one teaspoon of table salt has 2,325 milligrams (mg) of sodium. Yet the Dietary Guidelines for Americans, 2010 recommends limiting sodium to less than 2,300 mg daily – 1,500 mg if you’re 51 or older or have high blood pressure, diabetes, or chronic kidney disease.

Do you know what the leading salty food is? Bread and rolls! A single slice of white bread could contain as much as 230 mg of salt, according to the Center for Disease Control and Prevention.

Have a couple of sandwiches filled with cheese and processed meat, add some condiments, grab a bag of chips – and voila! Your sodium meter reads “tilt!”

There are also plenty of other places where salt is lurking: Certain processed foods, soft drinks, sauces, cured meats, baking sodax baking powder many medications, and pizza

So, how do you avoid too much sodium in your diet? Learn to

enjoy the unsalted flavors of foods, add small amounts of salt when cooking, add little or no salt to food at the table, limit your intake of salty foods, read food labels carefully to determine which foods contain sodium, and use herbs, spices and hot sauces to season what you eat.

Also watch those food labels. If a label says “light in sodium,” it means 50% less sodium per serving than you find in regular food. One claiming “lightly salted” has 50% less sodium than normal. And foods that are considered “low sodium” have 140 mg or less per serving.

For more information, visit [www.cdc.gov/mmwr/preview/mmwrhtml/mm6041a1.htm](http://www.cdc.gov/mmwr/preview/mmwrhtml/mm6041a1.htm)

# Financial Planning for Children With Special Needs

by David C. Ferrell

Families of children with special needs or disabilities routinely face complex issues and unique challenges when it comes to financial planning.

For them, wise investment for the future is not only critical but also much more complicated than for other families. The goal is to create an integrated financial and life strategy that allows a special needs child to maintain a sense of security, dignity and autonomy.

Planning carefully for the future will help alleviate some of the stress and anxiety parents of children with special needs may feel. Knowing their child will be cared for in the event of their demise is comforting.

## Limited Conservatorship

It's essential for parents planning for a child with special needs preserve and protect public benefits such as disability, Supplemental Security Income (SSI) and Medicaid.

These government benefits are available to provide food, shelter, healthcare and other living expenses. A Limited Conservatorship, established at age 18, will help protect the child from possible fraud and embezzlement.

## Trust Fund

A Special Needs Trust will fund a child's specific needs, including special therapies and interventions, educational programs, caregivers, equipment, and so on. Critically, a Special Needs Trust will ensure the child remains eligible for government benefits, federal as well as state. Its assets can be managed according to the parent's wishes. Like any trust, it can be funded with stock, real estate, or other assets but is generally most easily managed with cash or liquid

assets. Life insurance is also a good way to fund the trust. A Special Needs Trust is protected from creditors and litigation. An estate planning attorney is required to set up a Special Needs Trust.

## Write a Letter

A Letter of Intent will help clarify parental wishes for a child's future care and living arrangements.

This letter can detail characteristics of the child, including preferences for everything from food to environment. It is the vehicle through which parents can pass on their legacy. A Letter of Intent is typically not legally binding, but it can certainly help guide conservators or other types of guardians.

A Licensed Professional Fiduciary or Independent Trustee can be hired to ensure the provisions of any trust are carried out as intended. This person can also provide assistance with tax returns, court filings, trust distributions and other budgeting issues.

Parents can transfer life insurance policies to a Special Needs Trust and designate the trust as owner of the policy; thus, the death benefit of the policy is removed from the parents' estate. For the policy to be permanently removed from the estate, the parents have to outlive the transfer by three years.

A Succession Plan can be included in the Special Needs Trust for any assets remaining after death of the child.

## Care & Comfort

A comprehensive financial plan will help ensure all the above points are met and fulfilled over

time.

It will detail strategies that work together to provide all the heirs – not just the special-needs beneficiary – with the inheritance the parents intend.

Many people assume a direct gift bequest to their child is sufficient. While it's certainly a simple route, a child with special needs may be incapable of managing the gifted assets. Such a gift, because of income limitations, could also render the child ineligible for government benefits.

Similarly, a direct gift or bequest to the child's siblings has its drawbacks: It requires a long-term commitment by the sibling to provide for the child. And, such assets may be at risk if the sibling faces litigation or divorce or simply decides the money is best spent elsewhere.

While a Special Needs Trust may help avoid family conflicts, direct gifts and bequests may foster disagreements among the heirs.

Approached thoughtfully and comprehensively, financial planning for children with special needs can provide for a lifetime of care and comfort.

Knowing that the best intentions of the parents will be carried out – and the other siblings are not alienated – will leave parents more time to enjoy their children.

*David C. Ferrell is a financial advisor and planning specialist with Morgan Stanley.  
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# Exercise and Physical Activity

For many people, getting started on a regular exercise program is a psychological challenge within itself. However, before beginning any exercise program, it is vital that you consult your health care provider. If you're taking medications, ask your health care professional how they may affect your body's response. For example, some drugs may decrease the body's ability to sweat, so you may overheat more easily than the next person.

A person with a spinal cord disability (SCD) often has a variety of challenges to deal with on a daily basis. From preparing meals to maintaining a regular exercise routine, a spinal cord disability can make a simple task challenging. Spinal cord disabilities cause paralysis, so you have fewer muscles that you can control, and some of those that remain have limited function.

Exercise builds strength and endurance so you can do as much for yourself as possible. Lifelong exercise will help you keep your muscles strong and conditioned, maximize your function, reduce your risk of injury and help you stay healthy.

To benefit from exercise, you have to do it at an intensity that's greater than your everyday activities. You must progressively increase the intensity over time so the exercise continues to be challenging. You can modify the frequency (how often), intensity (how much), and duration (how long) of any exercise to make it more challenging. A general rule is to increase the intensity of an exercise every two weeks.

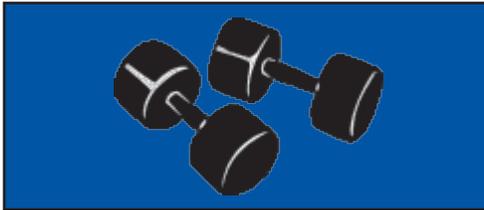
Your body reacts to an exercise on the basis of what that exercise is intended to do, with little carryover in other areas. For example, lifting weights will increase your strength

but will have little effect on your cardiovascular fitness.

We've all heard the phrase "Use it or lose it". The positive effects of exercise will keep coming as long as you continue exercising. As soon as you stop exercising, your body may get weaker and you will lose all the hard work you've put into it. Unfortunately, we lose fitness at a much faster rate than we gain it. It's important to stick with your exercise program so you don't have to start over from scratch.

These are important considerations for exercising with SCI:

**Range of Motion:** With aging, joint capsules tighten and muscles lose elasticity. This can reduce the range of motion in your joints,



especially if you experience spasticity. Even a minor loss of range can prevent you from performing simple tasks like pushing, dressing and transferring. It's important to have a regular program for stretching your arms and legs to prevent loss of range and maintain your independence. Your therapist can evaluate the range of your upper and lower limbs and give you some exercises to improve range of motion. Even if you need assistance with stretching, it's very important to make it part of your daily routine.

**Skin protection:** Don't forget to do your pressure releases during exercise. Avoid staying in one position for a long time, as this can damage your skin. If you're using fitness or sports equipment, make sure you have an appropriate cushion to reduce the risk of skin breakdown.

**Bone density:** People with SCD often develop osteoporosis, which weakens your bones. To minimize the risk of a broken bone, take care lifting heavy weights and stretching too hard.

**Temperature regulations:** Your body's ability to regulate temperature may be impaired by your SCI. Be especially cautious when you're exercising in very warm environments.

**Hydration:** Drink plenty of water before, during and after exercise. Balance your water intake with bladder management.

**Bladder and Bowel:** Empty your bladder or leg bag before you begin exercise. Maintain a consistent bowel maintenance program to avoid autonomic dysreflexia or accidents during exercise.

**Body stabilization and hand supports:** If your trunk muscles are paralyzed, you may need to use special straps or belts to stabilize your body while you exercise. If your hand strength is impaired, you may need to use gloves or wraps.

**Illness:** If you're sick, take a break from your exercise program until you feel better.

**Low Blood pressure (hypotension):** Blood pressure often drops in people with SCD when exercising, so stop if you feel light headed or dizzy.

**High blood pressure (hypertension):** Some exercises can raise your blood pressure or cause autonomic dysreflexia in those with SCD above T6. If you get a headache or feel flushed, stop.

Finally, choose activities you like. You're more likely to continue a program that's fun.

# CLIENT SPOTLIGHT



**Joseph Harrod of Monticello, AR**

**What is your level of injury or diagnosis?**  
*C-6 cervical fracture with SCI and paraplegia.*

**Where do you work?**  
*War Eagle Boats - Monticello, AR.*

**What type of job do you have?**  
*I do materials management - job title is Purchasing Agent*

**How long have you worked at this job?**  
*I have been at War Eagle Boats for almost 8 years.*

**Did you use any resources or agencies to find this job?**  
*No*

**What type of state/federal benefits have you maintained?**  
*None, they say I am over their pay scale a few dollars to receive any type of help.*

**What do you enjoy most about the job?**  
*Knowing that I am still very good at what I do even though I am physically disabled. I still make a difference.*

**What do you enjoy least about the job?**  
*It is very hard work on my care giver, because she has to get me to and from work and has a job to go to also. I do not have full use of my fingers and hands and this is frustrating at times because my job involves a lot of computer work.*

**What accommodations does your employer provide?**  
*Standard wheel chair access into office, and raised my desk. I was provided with some voice recognition software, but this is not the atmosphere to use it in.*

**How do you benefit by being employed?**  
*It is supposed to be my best physical therapy. I have health insurance. Puts food on the table, keeps a roof over my head, and pays never ending medical bills.*

**What made you decide to go back to work?**  
*I told a lot of people while I was still in ICU that it was my goal to return to work. Some of those people laughed at me thinking I had lost my mind. I proved those people wrong.*

**How much support do your coworkers provide?**  
*A lot from some, none from others.*

**What are your future goals?**  
*I would like to be an advocate for people like me who are not getting state or federal help that deserve it. I have truly seen first hand now how messed up the system is on who gets help and who does not.*

**What is the most positive benefit since starting work?**  
*Can't say. I was only away from work for about two months.*

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