

## Terra Patrom Rejoins Commission

The old saying, “You can’t go home again,” isn’t always true. Terra Patrom rejoined the Arkansas Spinal Cord Commission Case Management staff the first week in October after an eight-year hiatus.

Terra obtained her Master’s in Rehabilitation Counseling from the University of Arkansas and began her association with ASCC in 1998 when she completed her Rehabilitation Counseling internship in the Russellville office. Terra worked as a Case Manager in the Little Rock office from 2000-2002. Over the past eight years Terra has worked as a Manufacturer Sales Representative with Pride Mobility, Advocate Medical Supply and most recently was employed as a Certified Vocational Rehabilitation



*Terra Patrom*

Counselor with DHS Services for the Blind.

Terra’s children Jade and Bailey were ages eight and four when she first began working for ASCC. They have grown up quite a bit

since then. Jade is now eighteen and is a college freshman at UCA. Bailey is fourteen and is a freshman at Mt. Vernon Middle School. Terra, her children, and husband Toby still live on their farm in Mt. Vernon.

“It is not often we are able to hire someone with SCI experience let alone someone who has worked with the Agency previously. We are fortunate in this aspect and look forward to Terra’s return,” commented Client Services Administrator, Patti Rogers. Please join the Commission members and staff in welcoming Terra Patrom.

## The ADA Turns 20

On July 26, 1990, there was a huge gathering on the White House lawn to watch President George H. W. Bush sign the Americans with Disabilities Act. The ADA was landmark civil rights legislation that, for the first time, prohibited discrimination on the basis of a disability. Coming three decades after the Civil Rights Act, which did not include disabilities, the ADA was an opportunity to right that omission to ‘level the playing field’.

It did not come easily. Disability advocates and legislators worked tirelessly for two decades to accomplish the task, from hearings and amendments to other legislation in Washington to wheelchair ‘sit-ins’ in Denver and San Francisco.

Finally, under the leadership of Senator Tom Harkin of Iowa, the concept became a bill and the bill became law. As Senator Harkins noted at a 20<sup>th</sup> anniversary commemoration of the ADA, “Twenty years ago, we heard testimony from Americans who had to crawl on their hands and knees to go up a flight of stairs; who couldn’t ride on a bus because there wasn’t a lift; who couldn’t even cross the street in their wheelchairs because there were no curb cuts ... The ADA has broken

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## SPINAL COURIER

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## With Thanks

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To make a contribution, please contact ASCC at **501-296-1788 / 1-800-459-1517** (voice) / **501-296-1794** (TDD).

## From the Director

We are often asked “Do you remember where you were when . . .?”. For some events, we know exactly, others don’t register with us. I remember exactly where I was when I learned that the Americans With Disabilities Act (ADA) had passed Congress and would be come law. On that July day in 1990, I was sitting in my office on Marshall Street, talking with staff from then Senator Dale Bumpers’ office, who had called with the good news. The ADA was the first legislation that I had really ever worked to help get passed. Many of us here in Arkansas worked closely with our Arkansas legislators and those from other states to push the legislation. More than that, folks with all different types of disabilities had come together to support one Act that offered civil rights to then 43 million Americans with disabilities. It was an exciting time.

Little did we know then that our work was just beginning! Though the landmark legislation became law in 1990, some of the regulations to carry it out took years to be established and then deadlines for compliance took even longer. Educating Arkansans to those regulations has been a monthly, weekly, daily activity for the past two decades. I don’t think a week goes by when I don’t get a call about some ADA related issue, or see an injustice that needs remedy.

The ADA has had a significant impact on the lives of Americans with disabilities in the areas of communication, transportation, employment and access to programs, services and buildings. There are dozens of good examples. But, noncompliance, ignorance and inactivity still abound. Unfortunately there are no ADA police, we are left to ‘police ourselves’ on these issues and as anyone who uses accessible parking can tell you, we aren’t doing a very good job! A few cases have made it to the Supreme Court, but not those day-to-day inconveniences that the ADA was established to help.

So, twenty years later, we keep working. Will America ever be truly accessible? I hope so, the President is making efforts to continue the work and disability advocates, like you and me continue to do everything we can to keep the dream alive!

*Cheryl L. Vines*

## Project Eli

Julie and Andy Mayberry were excited to welcome their second child in 2001. About half way through the pregnancy, they learned that their daughter Katie would be born with Spina Bifida. They received a lot of medical information, all very clinical. As Julie recalls, “I wanted to meet children with spina bifida and talk to parents.” However, there weren’t a lot of resources available about life with spina bifida. To fill this need, Julie began a project to develop a

resource about the birth and life of the child with spina bifida; she has been working on it since Katie was born.

In 2009, she met the McGinley family, who were expecting a baby with spina bifida. Working together, the two families have produced *Project Eli—Every Life Inspires*, a DVD to help families learn about raising a child with spina bifida. The powerful DVD is available from Project Eli at [www.communityconnectionsar.org](http://www.communityconnectionsar.org). For more information contact Julie Mayberry at **501-888-8222**.

# Research Update: Electrical Stimulation in Persons with SCI

Kennedy Krieger's International Center for Spinal Cord Injury ([www.spinalcordrecovery.org](http://www.spinalcordrecovery.org)) has released its latest research update, which includes information from two recent studies looking at electrical stimulation to promote central nervous system (CNS) repair.

Electrical stimulation is currently used to promote recovery of function and control following nervous-system injury or disease, but researchers now are investigating it and the birth of endogenous neural progenitor cells in white matter tracts of the spinal cord. The birth of these cells is thought to be CNS's attempt to repair itself in response to injury.

Both studies investigate the fate of these progenitor cells and reportedly provide evidence that a percentage of these cells become myelinating cells of the CNS, or oligodendrocytes. By restoring these oligodendrocytes, scientists hope people with multiple sclerosis (MS) or spinal cord injury (SCI) will regain lost myelin and subsequently sensation, movement, cognition, and other functions impaired by these conditions.

As a therapeutic tool, electrical stimulation is being used in innovative ways to promote recovery of function following nervous-system injury or disease. It can restore control and offset atrophy to muscles after injury and has a variety of therapeutic applications in the clinical setting. The International Center for Spinal Cord Injury (ICSCI) at Kennedy Krieger Institute is one of the first facilities in the world to combine innovative research with a unique focus on restoration and rehabilitation for children and adults with chronic paralysis.

Founded in 2005 by neurologist, John McDonald, MD, PhD, an expert on the treatment of paralysis, ICSCI researchers are conducting numerous studies in the field of paralysis treatment.

## Study Number One

Published in *Neuroscience Letters* ("Electrical Stimulation of the Medullary Pyramid Promotes Proliferation and Differentiation of Oligodendrocyte Progenitor Cells in the Corticospinal Tract of the Adult Rat"[online May 2010]), this study provided the first in vivo demonstration in the adult CNS showing that electrical stimulation can selectively promote proliferation or rapid increase, and development of myelinating cells.

Researchers stimulated the corticospinal tract in adult rats and injected a stain to identify proliferating cells. Upon stimulation, an increase was noted in cell birth around the axons along the corticospinal tract. Findings showed that electrical stimulation selectively increased the proliferation and differentiation of oligodendrocyte progenitor cells (OPCs) in the corticospinal tract, compared to the unstimulated side. OPCs are critically important, as they mature into oligodendrocytes that wrap and insulate bundles of axons (a process known as myelination) and secure the communication signals along the spinal cord.

"This is the first published research examining activity-dependent development of OPCs in the adult CNS, and there are currently no therapies that specifically target remyelination. We predict that these newborn OPCs, after maturation, will contribute to the remyelination in demyelination events," says Dr. McDonald,

lead author of the study and director of ICSCI. "Our findings have important implications for explaining the mechanism of myelin formation, harnessing activity to promote remyelination, and devising new approaches for the treatment of MS and SCI."

This research study was supported by grants from the Hugo W. Moser Research Institute at Kennedy Krieger, the National Institutes of Health (NIH), and the New York State Spinal Injury Research Program.

## Second Study

Published in *Experimental Neurology* ("Functional Electrical Stimulation Helps Replenish Progenitor Cells in the Injured Spinal Cord of Adult Rats [in print, April 2010]), this study examined whether FES-induced patterned activity in the chronically injury spinal cord can enhance CNS repair.

Researchers provided patterned activity to the spinal cords of chronically-injured rats through electrical stimulation to the peroneal nerve and monitored the birth and survival of neural progenitor cells.

Functional electrical stimulation (FES) induced a selective increase in cell birth that was confined to the lower lumbar spinal cord, an area researchers predicted would experience increased activity from the nerve stimulation. Overall results showed FES induced an approximately 85% increase in cell birth in the lumbar spinal cord.

"This study provides the first demonstration that FES can enhance cell generation in the injured adult CNS," says Daniel Becker, MD, lead study author and head of pediatric restoration therapy at ICSCI. "These results raise the exciting possibility that in addition to its physical  
See **Research Update** on page 8

# Living Well with SCI: Numbers, 2 and 1

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. Here are the last two of my top 10 recommendations for “living well with a spinal cord injury” from the medical and rehabilitation perspective.

## Number 2: Good

### Bladder Management

- Use in/out catheterization to keep your bladder volume below 600 cc (~20 ounces).
- Change your Foley catheter at least monthly (if you have problems with bladder stones; change it more frequently - every 1 to 2 weeks).
- If you have recurrent bladder infections, consider modifying your bladder management technique.
- Undergo a renal ultrasound exam to assess your kidneys’ anatomy at least every five years.

One of the most common reasons for an admission to the hospital is a bladder infection. If you manage your bladder with good technique by proactively using either a clean or sterile technique when in-and-out catheterizing or when changing your Foley catheter, you can reduce your risk of a bladder infection. Do not let your bladder volumes get greater than 600 cc’s or 20 ounces routinely (normal bladder volume is around 400 to 500 cc’s), because excessive volume will overstretch your bladder and make it easier for bacteria to invade your bladder wall.

A clean technique (i.e. washing hands and using a clean catheter) is often all you need to avoid bladder infections. If you use either a Foley

assess for bladder stones. Bladder stones can hide bacteria from antibiotics; so that once the antibiotic is stopped the infection will return with a vengeance. Bladder stones can occur with a Foley catheter if it is left in the bladder long enough for a crust to form on the balloon. This crust will flake off when the balloon is deflated, so if you have had recurrent bladder stones consider changing your Foley catheter before it can form a crust on the balloon, (i.e. every 1 to 2 weeks).

A renal ultrasound is a noninvasive, easy way to check your kidneys without the need for intravenous

*You need to be obsessive and . . .*

catheter or an in-and-out catheter, you will have bacteria in your urine (called “bacteriuria”). This is normal and expected. You only need antibiotics if you have white blood cells in your urine and have symptoms of an infection, such as fever, chills, and/or increased fatigue. Overuse of antibiotics can lead to resistant bacteria or fungal infections and the eventual need for intravenous antibiotics. If you have recurrent bladder infections, you need to reassess your bladder management technique. I often ask my patients to go to a sterile technique and use betadine to clean the urethral opening prior to introducing the catheter. This often makes a big difference. Sometimes a cystoscope of your bladder is needed to

dyes or ionizing radiation. An ultrasound can screen for kidney stones and bladder reflux and should be done every 5 years if everything is going well. A cystoscope exam should be done as you age due to the risk of bladder cancer, because the best way to screen for cancer is to actually look in the bladder through a scope.

## Number 1: Protect Your Skin!

- Every 15 minutes do a pressure relief in your wheelchair.
- Change positions in bed frequently - at least every 2-3

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## Living Well

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hours.

- Check your skin routinely at the end of day.
- Avoid sitting on hard surfaces and always use an appropriate wheelchair cushion.
- If stool or urine frequently contaminates your skin, talk with your physician.

The other common reason for admission to the hospital is a pressure sore. Frequent pressure reliefs with wheelchair push-ups, side-to-side leans, or a forward lean are the most effect method to prevent pressure sores. This frequent weight shift technique has to become a habit or pattern of your life. My patients who check their skin daily and call me at the first sign of a problem tend to do very well. Do not put up with areas of redness or a small sore; these areas only tend to become problems down the road as you get older. If you have any signs of problems, something must be changed in your pressure relief technique or your sitting surface. I have had patients who have done well for years and then all of a sudden (or so it seems) they have a large pressure sore. What has really happened is that they have been living on the edge of disaster for too long. You need to be obsessive and compulsive about your skin.

Make sure your wheelchair cushion is properly maintained and in the wheelchair appropriately. Check your skin every day for any problem areas and take action to correct any problems. Only sit on soft surfaces, and if at all possible, make sure you always are sitting on a wheelchair cushion. Car seats are often a big problem, and I recommend some type of wheelchair cushion on your car seat.

If you have an episode of bladder or bowel incontinences, clean your

## Bladder Management Following Spinal Cord Injury: What You Should Know

The Consortium for Spinal Cord Medicine has developed a new consumer guide to explain bladder management options for people with spinal cord injuries (SCI). It is distributed by Paralyzed Veterans of America. Written by medical experts, this publication offers guidance on successful methods of bladder management which best suits your life style and health care.

The consumer guide provides an overview of the Urinary Tract System, discusses common bladder issues and concerns, bladder-emptying techniques, and medications. The guide also describes different surgical procedures to assist with gaining more control over poorly functioning bladders and provides advice to those who are considering a bladder management program. This guide is an excellent resource but you should talk with your physician before trying new procedures or making decisions regarding your bladder management routine.

The Arkansas Spinal Cord Commission has obtained copies of the consumer guide and will mail one copy to ASCC clients. Anyone interested in receiving a copy should contact your Case Manager or call Mary Jo Stanton at 1-800-459-1517. Other individuals who are interested may request a copy from the PVA website at [www.pva.org/site/PageServer?pagename=pubs](http://www.pva.org/site/PageServer?pagename=pubs)

### Governor's Commission to Award Scholarships

The Arkansas Governor's Commission on People with Disabilities will award several student scholarships. Applications are graded on financial need, academic achievement, community involvement, your goals and the specific challenges you face due to your disability. Scholarship recipients will be recognized at a reception in Little Rock in July, 2011. Applications must be postmarked by February 28, 2011.

Applications are available at [www.spinalcord.ar.gov](http://www.spinalcord.ar.gov) or may be obtained by calling Leonard Boyle at 501-296-1637.

skin and change your clothes as soon as possible. If this is a frequent problem you need to talk to your physician about a better way to manage your bladder and/or bowel program.



Luke and Rozene Whitby.

### Rozene Whitby—New Author

ASCC client, Rozene Whitby, has written and published a children's book titled *Luke and Nana*. The book tells the true story about a small boy and the bond between him and his grandmother. He calls her Nana. Nana pushed him around in a stroller when he was a baby. Later, Nana was in an accident and unable to walk. The only way she could get around was in a wheelchair. Luke, although a very young boy, started taking his Nana for rides, just as she had done for him years earlier. *Luke and Nana* is available at [www.publishamerica.net/product91171.html](http://www.publishamerica.net/product91171.html) or from the ASCC library.

# Money Talks

By Daniels C. Jones

## Putting Your Affairs in Order

In the event of your death, have you considered the choices that must be made concerning your final affairs? How can you ensure these decisions will be consistent with your wishes? Did you know if you die without executing a will, your affairs will be settled based on one drafted by the government?

Death is a topic most people are uncomfortable talking about. Unfortunately, statistics state those of us with certain disabilities do not live as long as average men or women. But, with a little planning, you can maintain control and ensure your estate will be settled consistent with your wishes.

It's the type of topic we'd rather not think about – too reminiscent of our own mortality. No one wants to contemplate the possibility of a spouse's death. And no one wants to talk about how the survivor will sort out the final details. Did you know that three of four Americans die without a will, and financial planners estimate at least half of us are underinsured or not insured at all?

The death of a spouse or a loved one is horrific enough, yet during this period of emotional upheaval we make some of our most important financial arrangements. You're expected to make important decisions at the worst time of life. No matter how relaxed you feel or how much you think it's not going to happen to you, you still should sit down and talk about it.

Unfortunately, planning often necessitates asking hard questions. Do not be afraid. Consult professionals who can help. Have faith, and rely on your religious leader of choice as well as your

trusted advisor in troubled times.

However, before all of the above, take care of yourself. If we perform some physical exercise and listen to our doctors, occupational and physical therapists, and our other health professionals, we all can have long and productive lives.

## Vital Documents

Back to the business at hand in this article. Consider the following documents:

**A will** tells how you want your estate distributed upon your death. It is the foundation in determining how personal and real property in an estate is divided. The document also can name a guardian to care for minor children, in the event both parents die. Hiring an attorney to write your will is relatively inexpensive – usually \$100 to \$300 if you do not have a complicated or large estate. A trust can offer greater flexibility but is more complex. To determine which one could best suit your needs, consult your financial advisor. Remember to update these documents after any change in circumstance such as a death or divorce to avoid an adverse situation later on.

**A letter of instruction** can make the settling of your estate much easier for your heirs. It is not legally binding but can provide all the information necessary regarding accounts, arrangements, advisors, etc. *This is not a legal document.* It is a list of everything the deceased person owns and owes and where it is located. It should list the location and policy numbers of life insurance, mortgage insurance, checking and savings accounts, investments, real estate titles, stock certificates, safe deposit boxes, credit cards, motor

vehicle titles, employee benefits, debts, and other personal property.

This document can also include the names, addresses and phone numbers of your trusted advisors.

**A durable power of attorney** authorizes a person to conduct your legal or financial affairs if you become incapacitated. This is a *very* important document. Without this, it can be extremely difficult for a loved one/caregiver to access and retrieve financials, documents, medical information, etc.

**A living will** states your wishes regarding medical actions to keep you alive. These medical actions are often an area of contention among loved ones when not clearly spelled out in writing prior to individuals becoming medically incapacitated.

**A durable power of attorney for healthcare**, sometimes referred to as a healthcare surrogacy, designates a person to make certain your living will's instructions are followed. This document helps to carry out your decisions, or those of a sick loved one, during a very rough time in a family's life.

## Additional Advice

Purchase enough life insurance to ensure your family will be taken care of. Just because you have a disability does not mean you cannot acquire life insurance. You may have to look a little harder, but in many cases you can get coverage. Often, you may have to pay a bit more for the coverage, but inquire – and after an offer is made, you will be in a better position to make an educated decision regarding your situation. It does not cost you anything to apply.

How much you need depends on your age, your assets, how many years you want to provide for your family, and your current lifestyle. It

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## Money Talks

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is best to consult a financial advisor or insurance agent to determine the proper coverage for your particular situation.

Disability insurance is a different story and *very* difficult to get after you are disabled. But, if you are lucky enough to work for a large employer with large group-insurance plans, you can be covered for disability insurance for other than pre-existing conditions.

Maintain a relationship with a lawyer, an accountant, and a financial advisor. It's much easier to deal with unexpected problems when a professional knows your situation ahead of time. Experts can also provide you with timely advice, such as whether you need a trust to protect your assets from taxes.

As always, please do not hesitate to contact me with any questions you may have.

*This material was prepared by Raymond James and Dan Jones, Branch Manager and Vice President, Investments of Raymond James & Associates, Member New York Stock Exchange/SIPC. Changes in new laws may occur at any time and could have a substantial impact on your situation. While we are familiar with the tax provisions of the issues presented here, as financial advisors of Raymond James & Associates we are not qualified to render advice on tax or legal matters.*

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## First Mock Senate on Full Participation

The first Mock Senate on Full Participation was held August 18 and 19, 2010 in the state Senate Chamber at the Capitol. Senator Tracy Steele of North Little Rock sponsored legislation to establish the event.

Arkansans with disabilities served as Senators representing organizations and interests from around the state. Commissioner Mike Cranford (first row, second

from left) represented ASCC.

Senators served on committees the first day and then met in legislative session the second day to pass mock legislation including development of an Arkansas Civil Rights Commission, establishment of a pilot program for a transportation voucher system and to prohibit denial of insurance coverage for preexisting conditions.

## ADA

Continued from page 1

down barriers, created opportunities and transformed lives." Many Arkansans were integral in the ADA, from those who wrote letters, called and visited their legislators to those who took part in demonstrations, to Senator Dale Bumpers, who was integral in getting the bill passed in the Senate.

Fast forward: twenty years later, July 26, 2010, another President Barack Obama speaks to a group of advocates on the White House lawn. Over the two decades in between, the ADA has faced numerous court decisions and in the minds of many been 'watered down' to be less effective. President Obama recognizes the basic concepts of the ADA - equal access, equal opportunity and independence.

More important, he announces two new rules published by the Department of Justice to protect against disability-based discrimination. The first, prohibiting disability-based discrimination by any state or local government, which went into effect immediately. The second goes into effect in 2012, to require all new buildings, public and private, must be compliant with the 2010 federal standards for design. These rules expand the scope of entities covered by the ADA to recreational facilities, amusement parks, marina, gyms, golf courses and swimming pools. Other initiatives are underway to ensure access to telecommunications.

These new rules, continued education and advocacy at the grass roots level will all help prevent discrimination based on disability.

For more information about the ADA go to [www.ada.gov](http://www.ada.gov).

## Research Update

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rehabilitative benefits, FES may contribute to spontaneous repair and perhaps recovery of neurological function.”

This research study was supported by grants from the Barnes-Jewish Hospital and the Barnes-Jewish Hospital Auxiliary Foundations, the Sam Schmidt Paralysis Foundation, the Jack Orchard and ALS Hope foundations, NIH, the State of Maryland Department of Health and Mental Hygiene, and the Johnson & Johnson Focused Giving Program.

### About ICSCI

The center, located in Baltimore, is dedicated to restoration recovery

of chronic SCI and paralysis in children and adults. The interdisciplinary team at ICSCI is committed to the philosophy that with the right combination of therapies, recovery is possible – even many months or years after an injury.

The center’s therapy programs follow techniques that have shown promise in helping individuals with chronic SCI recover sensation, movement, and independence and achieve improved health and quality of life.

#### Contact:

[www.spinalcordrecovery.org](http://www.spinalcordrecovery.org)

[www.kennedykrieger.org](http://www.kennedykrieger.org)

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## Spina Bifida Christmas Party

Mark your calendars now for the Spina Bifida Support Group of Arkansas Annual Christmas Party. Persons who live with spina bifida and their families are welcome.

The party will be held at Camp Aldersgate, 2000 Aldersgate Rd., Little Rock, AR. This year’s party is scheduled for **Sunday, December 12<sup>th</sup> from 2:00 to 4:00 p.m.** Activities will include music, games, fellowship, Chef Garry’s great cooking and a visit from You Know Who!

Additional information will be sent out in November. If you have questions, contact Vicki Rucker at **501- 978-7222.**

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