



Arizona Spinal Cord  
Injury Association

# AZSCIA E-NEWS

February 2009

*"A monthly update  
on the happenings  
and upcoming  
events in the  
association."*

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Injury Association  
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We're on the Web!  
www.azspinal.org

## Volunteers Needed

We are looking for SCI Consumers to volunteer some hours at the swap meet by selling Sun Artisans candles. We feel that Consumers would create a better impact when dealing with the public.

We would like a couple of volunteers for Fridays and Saturdays from 9:00AM – 1:00PM at the Mesa Market Place Swap Meet, 10550 E Baseline Road, Mesa, AZ 85209. The cross streets are Signal Butte and Baseline. For more information, please contact Ken Coleman at 602-578-2404.

## Annual Program and Web Site Evaluations

The Association would like to invite you to participate in our annual evaluation of our Web Site and our programs. Please visit [www.azspinal.org](http://www.azspinal.org), and click on the Feedback Tab. The Program Evaluation contains 23 questions and approximately 15 minutes to complete. The Web Site Evaluation contains 16 questions and takes approximately 10 minutes to complete.

The evaluations will be on the web site only for the month of **February**. As a token of our appreciation, we will be giving you a \$5.00 discount toward any of our Sun Artisans candles. Visit [www.sunartisans.com](http://www.sunartisans.com) to see a list of candle fragrances that we have. To take advantage of the discount, leave your email address on Question 23 of the Program Evaluation and/or Question 16 of the Web Site Evaluation. A staff member will contact you shortly on your order.

## Disability Empowerment Center of Arizona Open House

Arizona Bridge to Independent Living is pleased to present the new Disability Empowerment Center (DEC) Open House. Event will be held on Friday, February 20, 2009, from 10:00AM – 4:00PM. The location is 5025 E Washington Street, Phoenix, AZ 85034.

The DEC is a 62,000 square foot center and is a universally, accessible, and transit-oriented non-profit resource to serve the disability community. It features fully accessible administrative office space, meeting rooms, event space, a cafeteria and kitchen, computer lab and resource center.

Food/Beverage will be available in the Nina Mason Pulliam Conference Center.

## Women's Support Group Meeting

For the months of February, March and April, the dates will be moved to the

second Monday of each month. The dates will be Monday, February 9<sup>th</sup>; Monday, March 9<sup>th</sup>; and Monday, April 13<sup>th</sup>. The Women's Support Group will meet at the Banner Good Samaritan Rehabilitation Institute, 1012 E Willetta St., Phoenix, AZ 85006 on the 2<sup>nd</sup> Floor. For more information, please contact Jill Greenlee Sclase, CTRS, at 480-363-5880.

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## Legislative Awareness Day 2009

Presented by The Governor's Council on Developmental Disabilities

Date: Tuesday, March 10, 2009

Location: Arizona Capitol Lawn, 1700 W. Washington Street in Phoenix

Time: 8:00AM - 2:00PM

Contact: Jason Geroux, Public Relations Director at toll free 1-866-771-9378 or e-mail [jason@azgcdd.org](mailto:jason@azgcdd.org).

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## Banner Wheelchair Suns Web Site

Please visit [www.bannerwheelchairsuns.org](http://www.bannerwheelchairsuns.org). If you have any questions or comments, please contact Gary Venjohn at 602-790-7909.

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## Junior Wheelchair Basketball Clinic

As part of NBA Cares All-Star 2009 Community Caravan, the NBA and NWBA are hosting a Junior Wheelchair Basketball Clinic. Join the NWBA All-Star Team, NBA Legends and WNBA Players for basketball fun!

Date: Wednesday, February 11, 2009

Location: St. Mary's High School, 2525 N 3<sup>rd</sup> St., Phoenix, AZ 85004

Time: 6:00PM – 8:00PM

Registration is limited to 50 participants so sign up today! Please contact Gary Venjohn at 602-790-7909 for registration information and more details.

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## Valley Adaptive Sports Meeting (Advocacy for those with physical disabilities in Arizona)

Wednesday, February 18, 2009 from 1:00PM - 2:30PM

Disability Empowerment Center (DEC), 2nd floor classroom  
5025 E. Washington Street, Phoenix, AZ 85034  
(Park on either level of the parking structure)

Disability Organizations, Therapists, Support Group Providers, Parks and Recreation Professionals, Teachers... come exchange ideas and opportunities that exist in the Valley!

Contact Susan Rossi, City of Mesa Parks, Recreation & Commercial Facilities at 480-644-5702 Desk or visit [www.arizonadisabledsports.com](http://www.arizonadisabledsports.com)

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## ABIL's February 2009 Advocacy Presentations

*Accommodations: No fragrances please. To accommodate those with allergies, breathing conditions or multiple chemical sensitivities please do not smoke or wear scented products when attending ABIL events. ABIL's events are accessible in compliance with ADA guidelines. We provide sign language interpreters and materials in alternate formats upon request. To participate via teleconference, please contact David – (Local Calls Free)*

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## **Arizona Center for Disability Law – Client Assistance Program (CAP)**

The Coordinator of the Client Assistance Program (CAP) will be providing a training on your rights as a client or applicant of a program funded under the Rehabilitation Act. Do you have questions or concerns about the Vocational Rehabilitation (VR) program? Or do you have questions or concerns

regarding the Independent Living Centers and the services they provide for you? If so, come join us for an in-depth training on your rights as a Vocational Rehabilitation client or applicant. Issues to be discussed will include, services and benefits under the Rehabilitation Act, how to negotiate and resolve problems with VR and your appeal rights as a client of VR.

Guest Speaker: John Gutierrez - Coordinator of the Client Assistance Program (CAP)

**Date/Time: Monday, February 23, 2009 - 10:30AM – 12:30PM**

Location: Disability Empowerment Center (DEC), 5025 E Washington St., Phoenix, AZ 85034 – Classroom B

Teleconference: Interested individuals can attend this presentation in person or via teleconference call. In order to attend via conference call, please call David no later than Friday, February 20, 2009.

### **Social Security Work Incentives Planning and Assistance Presentation for Service Providers**

Learn how ABIL's Work Incentives Planning and Assistance Outreach program, granted through the Social Security administration, can help people on SSI and/or SSDI understand how employment affects their cash and medical benefits. Over the last few years, several new work incentives have been created through Social Security and other public programs. Our trained and certified Work Incentives Coordinators are also happy to provide presentations at your agency location.

Guest Speaker: Erik Jensen - Community Work Incentives Coordinator

**Date/Time: Tuesday, February 24, 2009 - 10:00AM – 12:00PM**

Location: Gilbert Career Center, 735 N Gilbert Rd #134, Gilbert, AZ 85234

Teleconference: Not Available

### **Social Security Work Incentives Planning and Assistance Presentations for Consumers**

Consumers come and learn how employment will affect your cash and medical benefits. Please sign up for the workshop that matches the kind of Social Security you receive. If you are unsure which kind you receive, David can help you figure that out when you call to RSVP. From now on, we will be having separate workshops for each type of benefit: Social Security Disability Insurance (SSDI) or Supplemental Security Income (SSI) because each program has different rules and different work incentives. If you receive both, let David know and he will help you get an appointment with a Work Incentives Coordinator. Family members and/or support person are welcome.

### **Work Incentives & SSDI**

Guest Speaker: Rhonda Webb - Community Work Incentives Coordinator

**Date/Time: Tuesday, February 3, 2009 - 10:30AM – 12:30PM**

Location: City of Phoenix One-Stop, 9801 N 7th St. Phoenix, AZ 85020

Teleconference: Not Available

Guest Speaker: Erik Jensen - Community Work Incentives Coordinator

**Date/Time: Tuesday, February 10, 2009 - 10:00AM – 12:00PM**

Location: Gilbert Career Center, 735 N Gilbert Rd #134, Gilbert, AZ 85234

Teleconference: Not Available

### **Work Incentives & SSI**

Guest Speaker: Erik Jensen - Community Work Incentives Coordinator

**Date/Time: Tuesday, February 10, 2009 - 1:30PM – 3:30PM**

Location: Gilbert Career Center, 735 N Gilbert Rd #134, Gilbert, AZ 85234

Teleconference: Not Available

Guest Speaker: Rhonda Webb - Community Work Incentives Coordinator

Date/Time: Tuesday, February 17, 2009 - 10:30AM – 12:30PM

Location: City of Phoenix One-Stop, 9801 N 7th St. Phoenix, AZ 85020

Teleconference: Not Available

Call David Carey to RSVP for presentations/workshops at 602-443-0723. Trainings are subject to cancellation unless a minimum of 4 people register.

## Living Well With A Disability

Do you ...

- ✓ Have a physical disability or experience chronic health problems?
- ✓ Have trouble sleeping or get tired easily after exertion?
- ✓ Have nagging pain or muscle spasms that interfere with life?
- ✓ Get the "blues", feel depressed or cut-off from friends?
- ✓ Want to start getting more pleasure out of life, mix with new friends?

Research shows that secondary conditions such as muscle weakness, pain, fatigue, depression, social isolation, and other chronic problems can be reduced when you learn the steps to Living Well. By investing a few hours each week you can realize an important personal goal and create a better quality of life. Many who complete Living Well report fewer problems with their secondary conditions and reduced use of costly medical services.

**ACT NOW!** There is **NO CHARGE** to join. You'll get an easy-to-follow workbook to guide you through goal-setting and problem-solving exercises. A peer facilitator will help cover other vital topics such as healthy communications, beating the 'blues', physical activity, nutrition, advocacy and more. Expect, each week, to stimulate mind, body and lift your spirits. Enjoy the snacks, have fun and make new friends.

Living Well at the Disability Empowerment Center

- Fridays February 6 through April 10, 2009
- 10:00 a.m. - 12:00 p.m.
- 5025 East Washington Street, Phoenix AZ 85034

**Seating is limited. PLEASE PRE-REGISTER to reserve your place.**

Please contact Kathryn Robins, Director, Living Well with Disability Valley of the Sun YMCA, Community Initiatives YMCA at 602-252-2963 Ext. 102 or 602-509-2455 [krobins@vosymca.org](mailto:krobins@vosymca.org).

You may also contact Pam Allan, Prevention Specialist, Arizona Bridge to Independent Living at 602-256-2245 Ext. 732 or 602-296-0591 (TTY) [pama@abil.org](mailto:pama@abil.org).

## FDA Approves Stem Cell Study for Spinal Injuries

**Stem Cell Therapy Worked on Injured Rats; Humans Next Test**

**By SHARYN ALFONSI and LEE FERRAN**

Jan. 23, 2009

The Food and Drug Administration approved the first clinical trial today that will use human embryonic stem cells to potentially draw recent paraplegics out of the wheelchair and back on their feet.

Scientists hope the stem cell therapy will prevent permanent paralysis caused by acute spinal cord injuries and even return feeling and movement in patients who suffered the paralyzing injury two weeks before treatment. The treatment showed positive results when tested in rats.

"In animal models, this restores the animal's ability to walk," Dr. Tom

Okarma, president and CEO of Geron Corp., the company putting on the trial, told "Good Morning America" today. "And that's what we hope to achieve in the first trial with patients with spinal cord injury."

A group of eight to 10 paraplegics who still have use of their arms but not legs will be injected with cells derived from embryonic cells, Okarma told The Associated Press.

Although the aim of the study is to test the procedure's safety, doctors will be on the lookout for much more.

"The focus of this trial is safety," Sean Morrison, director at the University of Michigan Center for Stem Cell Biology, told "GMA."

"And if Geron can show it's safe to derive stem cells into patients, that will be an important precedence to enhance future trials for all diseases that could benefit from this work from juvenile diabetes to other types of neurological disorders."

Doctors will also be on the lookout for potentially hazardous side effects. The cells could create benign tumors and there is a danger the patient's immune system could attempt to reject the injections, "thereby increasing the inflammation in the spinal cord instead of decreasing it," Morrison said.

In response, doctors plan to provide the patients with anti-rejection drugs for two months after the initial injection, the AP reported.

If successful, supporters see nearly endless potential for the treatment.

"This is vast," said Peter Kiernan, chairman of the board of directors of the Christopher and Dana Reeve Foundation. "This is like the dawn. It's not a comet across our sky; it's the beginning."

### **Treatment Requires Patience**

Christopher Reeve, the actor who famously portrayed Superman on the big screen before a fall off a horse caused paralysis from the neck down, championed the cause of those with spinal cord injuries until he died in 2004. Kiernan said the Man of Steel would have taken hope in the news.

"You know Chris was an impatient man," he said. "He would say 'Why have we waited so long? Let's get to work.' Today, the hard work starts."

Even if the treatment is successful, Okarma warned that patients might have to show a little more patience.

They will not "get up and dance the next day," he told the AP, but the movement the treatment hopes to provide could be improved with physical therapy.

Michigan's Morrison said that almost any amount of movement would be a tremendous breakthrough.

"It may not be realistic to hope that this kind of therapy will allow patients with severe injuries to walk again," he said. "Even if you would restore lateral function in a subset of patients, that would be a real important advance and the trial would be a huge success."

### **Ethics, Politics and Controversy**

Though the approval for the trial is new, the ferocious ethical debate surrounding the use of stem cell therapy is anything but.

Geron is using discarded embryos from in-vitro fertilization procedures that were destined to be destroyed but that has not derailed some critics.

"The current lines of human embryonic stem cells are derived from living human embryos," David Prentice of the Family Research Council told "GMA."

"There is a concern that you're cannibalizing human lives for potential treatments."

Former President George W. Bush banned federally supported embryonic stem cell research during his administration.

Newly inaugurated President Obama has said he would relax such restrictions but the FDA's decision was not influenced by political timing, Okarma told the AP.

### **More Diverse Treatments**

The slightly less controversial use of adult stem cells has been tested in humans but embryonic cells have better potential for more diverse treatments, Kiernan said.

"When you're dealing with a problem as vexing as spinal cord injury, you don't want to enter the arena with one hand tied behind your back," he said. "This liberates the scientists to go where science can take them. It takes the politics out of science and enables them to do their job."

For Kiernan, the FDA's approval marks a significant shift that's been years in the making.

"I think the parade has started and the FDA took its rightful place at the head of the parade," he said. "We've gone through eight years of fighting to get this kind of approval. That's why we're so elated to be on our way. That's the exciting part."

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## **Fishing With Friends – The Anglers Adventures**

Joni and Friends Pro Bass Team in partnership with Joni and Friends Arizona, Arizona Bass Federation, Arizona Game & Fish and local area churches would like to invite you to:

Date: Saturday, February 7, 2009  
Tempe Town Lake Beach Park  
Time: 10:00AM – 4:00PM

If someone you know has a disability, then COME ON DOWN and bring the family for a fun-filled day. Other Activities Include: Bass Fishing Boat Rides, Pontoon Boat Rides, Fishing Competitions, The Hallelujah Blues Band, Hamburgers, Hot Dogs, Cookies, Crafts and Games, Face Painting, Prizes, and much more! This is a free event!

Special thanks to Desert Mini-Storage, KLOVE Radio, Local Area Churches, Community Partners, and many more...

For more information, contact 602-275-2568

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## **Winter Sportsline Newsletter**

<http://www.arizonadisabledsports.com/pdf/2008-09%20Winter%20Sportsline.pdf>

**Reminder: Registration for SkiAble Adaptive Alpine Experience at Sunrise Ski Park** is open until Friday, February 13th. Spots still available on Monday, February 23rd and Tuesday, February 24th with transportation an option on Tuesday. Volunteers needed as well!

<http://www.arizonadisabledsports.com/pdf/Athlete%20flyer%2009.pdf>. For more information, contact Susan Rossi, City of Mesa Parks, Recreation & Commercial Facilities at 480-644-5702 Desk or visit their web site at [www.arizonadisabledsports.com](http://www.arizonadisabledsports.com).

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## Looking for a Used Van

A family is looking for a large accessible vehicle with either a ramp or lift for under \$11,000.00. Please contact Lamar Lumpkin at 928-376-7503 (Yuma area).

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## For Sale

Brand new Standing Frame for sale. How can I go about this? The base price is \$3,000, not including all of the options (tool sac, straps, foot plates, etc). Asking for \$1,500 or best offer. If interested, contact Annabel at 928-649-3038.

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## Upcoming e-news information.....

If there is anything that you would like to share with your fellow members, please contact Vangie Mortenson at 602-507-4209 or [vangie@azspinal.org](mailto:vangie@azspinal.org). She will ensure that the information will be posted on the e-news.

**THANK YOU!**