

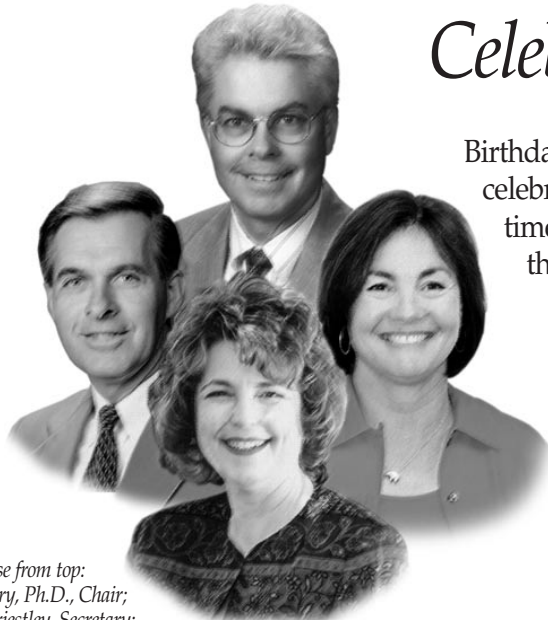
# VISTAS

A NEWSLETTER OF THE ARIZONA GOVERNOR'S COUNCIL  
ON SPINAL AND HEAD INJURIES

Spring 2003

Department of Economic Security, Rehabilitation Services Administration

Volume 5, Number 1



Clockwise from top:  
Phil Barry, Ph.D., Chair;  
Mimi Priestley, Secretary;  
Chrystal Snyder, Executive Director;  
and Roger Schuler, Vice Chairperson.

## *Celebrating our Accomplishments*

Birthdays are a time for celebration and also a time for reflection. As the Governor's Council on Spinal and Head Injuries marked its 10th birthday last month, we had the opportunity to do a little of both.

With five past Chairpeople in attendance, it was easy to see how far we have come. Growing out of community concern about the unmet needs of individuals with spinal and head injuries, the Council was signed into law by Governor Fife Symington as a result of the passage of the Spinal and Head Injury Bill (A.R.S. §41-3201-3203).

Our mission – then, as now – was to enhance the health, safety and quality of life for children and adults with spinal cord and brain injuries, their families, and communities. Given the fragmentation of Arizona's service system, the paucity of resources, and the general public's limited knowledge about spinal and head

injuries, we knew from the start that it was an ambitious undertaking.

To tackle this challenge, Council members have worked to develop comprehensive systems for the prevention and treatment of spinal cord injuries and traumatic brain injuries. We realized early on that our work is too complex and the needs we address are too great for any organization to succeed alone.

Much of our energy over the past 10 years, therefore, has been channeled into development of rich and meaningful partnerships. With our partners, we have taken important steps to ensure that individuals with spinal and head injuries can access appropriate services during the acute and post-acute phases of care.

But as we celebrate our accomplishments, we know there is great deal more to do – and with the current uncertainty in the economy, there are no guarantees. We head into our second decade with tremendous gratitude towards the people and organizations that have contributed to our success and with a renewed commitment to continue our efforts.

— Phil Barry, Chair

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## USING DATA FOR DECISION MAKING: *Targeting Resources for People with TBI*

“WE’RE FORTUNATE TO HAVE WONDERFUL, RICH SOURCES OF DATA THAT WE CAN USE. THE DATA GIVE US A PLACE TO START, BUT ALSO SEND US ON A SEARCH.”

“Every person with a traumatic brain injury has a unique story and unique needs,” says Chrystal Snyder, Executive Director of the Governor’s Council on Spinal and Head Injuries. “But the key to developing a service system that meets the needs of these individuals often lies in our ability to collect and analyze data – to look at the numbers and find the meaning behind them.”

In Arizona, the hub of data collection efforts is the Traumatic Brain Injury Surveillance Program, a unit of the Arizona Department of Health Services’ Bureau of Public Health Statistics. Dr. Timothy Flood serves as Medical Director and Principal Investigator for the project; Ardis Decker, M.P.H. is TBI Program Manager.

“The data tell us who is being injured, how and where,” says Ms. Snyder. “It’s up to us to look at the bigger picture – how can we use this information to make sure that we provide as many people as possible with the resources they need?”

In many cases, the answer to that question involves a type of data-driven

“detective work,” says Ms. Snyder. “For example, we knew from our surveillance data that for the past 10 years, approximately 1100 school-aged children per year were released from hospitals with new traumatic brain injuries. Yet when we looked at the state’s special education census, we saw only 85 children who were identified as having TBIs.”

Working closely with the Arizona



Department of Education, the Council set out to understand the incongruities in the numbers. Analysis indicated that special education funding formulas often encouraged administrators to identify children with TBIs by other injuries they may have experienced concurrently, such as orthopedic injuries.

The result was that schools were unaware of the number of children with TBI that

they were serving and that these children were less likely to receive the specialized services they required.

“Once we recognized the disparity, we were able to make some changes that encouraged better identification of these children,” says Ms. Snyder. “And as schools grew to understand the prevalence of children with TBI, they were receptive to providing increased training for teachers in working with this population.”

This understanding led to a joint initiative by the Council and the Arizona Department of Education to provide Master’s level training for teachers who work with children with traumatic brain injury. In addition, the Council is now in the first year of a multi-year effort to build community mentor teams to support teachers who work with children with TBI.

In other cases, data analysis is used to identify clusters of injuries and determine strategies for prevention. “By combining our surveillance data with data from the state’s Child Fatality Review Team, for example, we were able to better understand the impact and causes of car crashes among young drivers. This effort led to development of a creative alternative sentencing program for young alcohol abusers.”

Arizona’s use of multiple data sources to drive policy and program decision making has achieved national recognition. Last month, Ms. Snyder was invited to make a national presentation on uses of data at the Centers for Disease Control and Prevention in Atlanta.

“We’re fortunate to have wonderful, rich sources of data that we can use,” says Ms. Snyder. “The data give us a place to start but also send us on a search – a search that drives us to ask questions that help us determine what kinds of services people need, what we can do to prevent injuries, and how we can reduce disabling conditions.”

## *TBI by the Numbers*

Each year over 5,000 Arizona residents sustain a TBI severe enough to result in hospitalization or death. This equates to 14 TBIs per day or one TBI every two hours.

Each year, approximately 1,000 Arizona residents die of a TBI-related injury.

Males are two times more likely to sustain a TBI and three times more likely to die of a TBI than females.

The leading cause of all TBIs in Arizona is motor vehicle crashes (42.7%), followed by falls (20.5%) and firearms (12.3%).

Falls are the leading cause of TBI in infants and children from birth to 4 years of age and in the elderly, ages 75 and older. Motor vehicle crashes are the leading cause of TBIs in young males, ages 15-34. Firearms are the second leading cause for this group.

Over half the Arizona residents who survive an acute TBI are under the age of 35.

The age-adjusted incidence of TBI is highest in Native American males and second highest in Hispanic males. Among females, age-adjusted incidence rates are highest in Native American females and second highest in White, non-Hispanic females.

From 1995-1998, gross hospital charges for TBIs totaled over \$433 million. This does not include the cost of follow-up care, rehabilitation, outpatient care or physician charges.

From *Startling Stats: Traumatic Brain Injury in Arizona*, compiled by the Arizona Traumatic Brain Injury Surveillance Program, Arizona Department of Health Services for Barrow Neurological Institute of St. Joseph’s Hospital and Medical Center. Unless otherwise stated, all data are from 1998, the most recent year for which information is available.

For more information or a copy of *Traumatic Brain Injury and Spinal Cord Injury in Arizona, 1995-1998*, contact the Arizona Traumatic Brain Injury Surveillance Program, Arizona Department of Health Services, at (602) 542-1125.

## Promoting Exercise for Well-Being



“THE BENEFITS OF EXERCISE ARE NOT JUST PHYSICAL, BUT EMOTIONAL AND SOCIAL AS WELL. AND WHEN WE COMBINE THESE ELEMENTS, WE HAVE A SOUND FOUNDATION FOR OPTIMAL WELL-BEING.”

“Exercise is an important component of total well-being,” says Michelle Lindsey. “And that doesn’t change when a person has a spinal cord injury.”

For that reason, Michelle, owner of Rising Star Therapy Specialists, is committed to assisting people with disabilities achieve the benefits that come with physical activity. It’s a commitment that drives her work as a physical therapist and personal trainer.

“Exercise produces endorphins, a hormone that’s related to feeling good and fighting depression,” she explains. “That boost can give people the energy they need to tackle challenges and achieve their goals.”

The benefits, she believes, are “not just physical, but emotional and social as well. When we combine these elements, we have a sound foundation for optimal well-being.”

A professional inline speed skater and elite marathoner, Michelle has experienced the benefits of exercise first hand. Her own experience with injuries led to her professional interest in promoting the benefits of exercise for people with disabilities.

In many cases, she notes, people with spinal cord injuries are hesitant to become involved in an exercise program. “It’s all about motivation,” says Michelle. “Often people with spinal cord injuries believe that exercise is no longer possible for

them. Or they simply don’t know how to get started.”

To help her clients and others get started, Michelle offers these tips:

**1. Start with an assessment.** If you haven’t exercised regularly since your injury, begin by getting a medical release from your physician, followed by an assessment by a trained physical therapist. To help you plan your exercise program, he or she should consider your coordination, balance, range of motion, reflex and sensory issues, respiration, muscle testing, proprioception and activities of daily living.

**2. Set goals.** “Setting goals helps to keep you motivated,” says Michelle. “Break long-term goals down into manageable steps, so you can see success and stay motivated.”

**3. Find an exercise that fits your interests and your lifestyle.** If you weren’t an athlete before your injury, you may need to experiment to find an activity that interests you. “If you’re doing something you enjoy, you’ll do it more often,” says Michelle. “Exercise shouldn’t be boring. It should be something that you look forward to.”

**4. Don’t overlook the benefits of everyday activities.** You don’t need to join a gym to exercise. Gardening, housework and laps around the mall can contribute to a more active way of life. And exercises that you can do at home –

perhaps using a pool, exercise balls, weights or therabands – can provide tremendous benefits as well.

**5. Consider joining a group or a team.** For many people, being part of a group increases motivation. Many local Parks and Recreation departments offer exercise programs for people who use wheelchairs. Michelle also recommends checking out programs offered by the U.S. Tennis Association ([www.usta.org](http://www.usta.org)), the Wheelchair Basketball Association ([www.nwba.org](http://www.nwba.org)) and the Arizona Spinal Cord Injury Association ([www.azspinal.org](http://www.azspinal.org)).

**6. Celebrate small victories.** “The best thing about my work is seeing people succeed,” says Michelle. “Every time you do something that you couldn’t do before, that’s a victory.”

While getting started may be difficult, Michelle believes that the benefits of exercise far outweigh the challenges. “For many of the people I work with, the confidence they get from exercising helps them tackle other areas of

their life, such as jobs and social relationships” she says. “The best part of my job is seeing people say ‘I can and I will.’ Just trying a new activity is a success in itself.”

For more information, call Michelle at Rising Star Therapy Specialists in Phoenix, (602) 531-6306.



## Wheelchair Sports Abound in Arizona

Looking for world-class action in wheelchair sports? Then Arizona is the place to be. In the past few weeks, the City of Phoenix has hosted two of the world’s top sporting events for wheelchair athletes.

The National **Wheelchair Basketball** Association’s 55th Annual Championship Games took place March 26-29 at Arizona State University. Hosted by the Paralyzed Veterans of America, Arizona Chapter, and the Arizona Spinal Cord Injury Association (AzSCIA), the games drew 13 teams from the United States and Canada.

When the dust had settled, the Dallas Mavericks captured the Division I title, while the Lakeshore Storm of Birmingham, Alabama, reigned in Division 2.

Arizona’s entry, the Phoenix Banner Wheelchair Suns, ranked second in the Regional competition. The team is coached by Gary Venjohn and captained by Jim Miller.

In addition to approximately 200 athletes, the games drew a crowd of approximately 300 spectators, according to Dominic Corradin of AzSCIA.

AzSCIA and the Paralyzed Veteran’s Association teamed up in April to host the United States **Quad Rugby** Association’s National Finals. From April 11-13, 16 teams from across the United States battled for supremacy.

“This is an amazing sport,” says Mr. Corridan. “It’s played on a basketball court using a volleyball. It’s as rugged as full-on rugby.” The winning team was not known at press time. Last year, however, the Phoenix Heat took second place in the Nationals.

For those inclined to less robust activities, AzSCIA is sponsoring Wheeling in Nature, a day in a local park. A car show and golf outing are in the works. For more information, call (602) 239-5929 or visit [www.azspinal.org](http://www.azspinal.org).

## Mark your calendar!

The Arizona Center for Disability Law and the Governor's Council on Spinal and Head Injuries are sponsoring "Heads Up: TBI Trends and Transitions," a conference for individuals with traumatic brain injury, family members and professionals.

The event will take place Friday, June 13, from 9:00 a.m.-1:00 p.m. at the Sheraton Crescent Hotel in Phoenix.

If you need additional information, call Judy Fox at the Arizona Center for Disability Law, (602) 274-6287.

## On the Web...

The Internet is a rich source of information on traumatic brain injury and spinal cord injury. Here are a few sites you might want to visit:

**Information and Resource Center on Brain Injury in Children and Adults Lash and Associates Publishing/Training**  
[www.lapublishing.com](http://www.lapublishing.com)

This North Carolina-based company focuses on the neurological, psychological, communicative and educational impacts of brain injuries on children, youth and young adults. Their Web site features forums for survivors, families and children, where you can read others' stories or submit your own. The site also provides practical information on living with brain injuries and sells a wide variety of books, tip cards and tools targeted at survivors, family members and professionals.

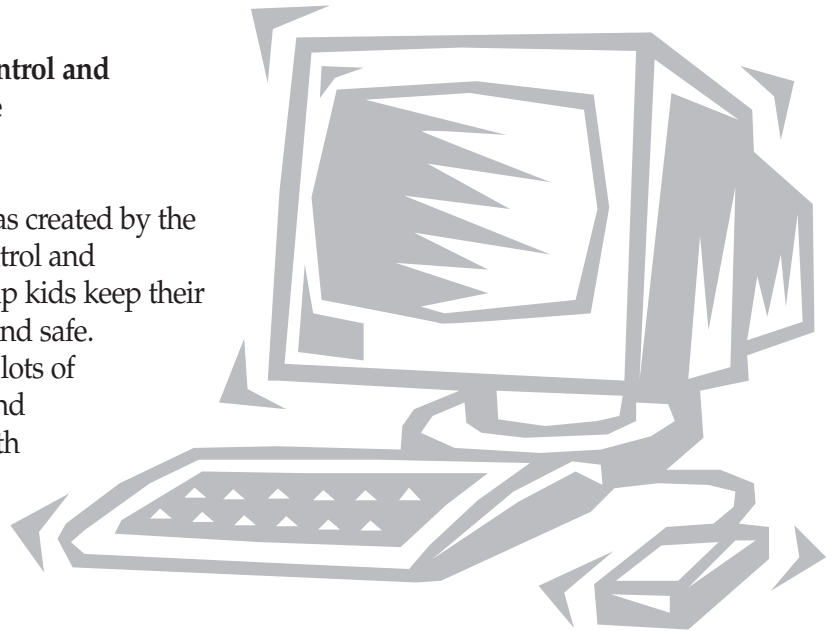
**BAM!**  
**Centers for Disease Control and Prevention's Kids' Page**  
[www.bam.gov](http://www.bam.gov)

This high-energy site was created by the Centers for Disease Control and Prevention (CDC) to help kids keep their bodies healthy, strong, and safe. Young readers will find lots of information on sports and fitness, intermingled with important safety tips. The site provides solid information on helmet

use and as well as sections on selecting the right equipment for each sport. Links to Health Topics for Kids provide additional information on violence prevention, living with disabilities, and other topics. BAM! also features a special section for teachers, providing interactive activities to support health and science curricula.

**Spanish language resources**  
**Brain Injury Association of America**  
[www.biausa.org](http://www.biausa.org)

Want detailed information on traumatic brain injury, presented in Spanish? The Brain Injury Association offers one of the most complete Spanish-language sites on the Web. You'll find information about traumatic brain injury as well as a host of downloadable resources. The site also includes samples of Spanish-language brochures and posters that can be ordered from the Association.



## Donna Sturgis

**EDITOR'S NOTE:** *This is the third of a series of profiles of Arizona professionals who work with individuals with spinal and head injuries. Donna Sturgis is director of Adam's House, a group home for adults with traumatic brain injuries.*

### **How did Adam's House come to be?**

*Our son, Adam, was injured in November 1991. Against all odds, he survived a gunshot to the head. He spent a year in hospitals and rehabilitation facilities. I cared for him at home for over a year until I became so physically and mentally exhausted that my husband and I had to look for other alternatives.*

*There were few residential choices for Adam. We moved him to a group home for developmentally disabled residents. We were so unhappy with his placement that we set about to open our own group home, specializing in young adults with traumatic brain injury.*

### **It's grown a lot since then, right?**

*We opened Adam's House in Phoenix in 1996. Because the need was so great, we opened a second Adam's House in 1997. We moved to Prescott Valley last year, and we are almost ready to open a third Adam's House here.*

*Our daughter, Amy, supervises the two homes in Phoenix. That is a tremendous help to us, because I know she has the same personal interest as we do in making the homes successful.*

### **What aspect of your work do you find most rewarding?**

*It is very rewarding to know that we have given some of these young men and women a better alternative than nursing homes or psychiatric hospitals. We want the best for Adam, and that helps us in making decisions for all the residents.*

### **What's your greatest challenge?**

*This was an unexpected career for us, and we have had to learn as we go. I think our greatest challenge is to achieve the quality of care that we want for Adam and the other young adults. It's not easy to find dedicated caregivers, those special people who truly want to make a difference and be a positive influence in the lives of these young survivors.*

### **What keeps you going?**

*When we first started, I worked long hours at the homes as a caregiver and I know that "burnout" happens when you put so much of yourself into your work. I finally learned that I have to take time for myself. I have started painting again, taking guitar lessons, exercising more, and spending time with my grandchildren – my best therapy!*

*Like all parents, we wanted Adam to have a happy life, challenging and rewarding, a good marriage, children...all those things. I know that he will never have that life and nothing I can do will change that. But he does have a family that loves and supports him. Out of this tragedy, some good things can come for him and others.*



# Council Welcomes New Staff

**Martha J. Dennler** has joined the staff of the Governor's Council on Spinal and Head Injuries as a Project Manager.

Martha will be assuming leadership of a number of projects, including the Maricopa County Continuum of Care Project, the Needs Assessment Workgroup, Web site development and the Council's new E-Newsletter.

In addition, she will be providing training to ALTCS Case Managers and DDD Support Coordinators in traumatic brain injury, working with the Arizona Center for Disability Law to coordinate the June TBI conference, and assisting the TBI Surveillance Program in developing materials for the Arizona data book.

Martha has worked with the Arizona Department of Economic Security for the past 15 years.

**Do you know someone who would like to be added to our mailing list? If so (or you would like to be removed from the list), please call (602) 863-0484 or e-mail: [nshcolnik@mail.de.state.az.us](mailto:nshcolnik@mail.de.state.az.us) It is our policy to not sell or transfer our mailing list to either public or private entities.**

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A publication of the Arizona Governor's Council  
on Spinal and Head Injuries.

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