

9800 Vinson Court, Little Rock, AR 72205
Phone: 501-223-3696
Web site: www.ardownsyndrome.org

ARKANSAS DOWN SYNDROME ASSOCIATION

Newsletter

Volume 2 Number 2

Spring 2009

ZOO DANCE—WE NEED HELP!!

Saturday, September 26th is the date set for "Gettin' Down for Down Syndrome", the 5th Annual Dance at the Little Rock Zoo.

The Arkansas Down Syndrome Association sponsors the dance to provide recreation and socialization for individuals with Down syndrome, as well as an opportunity for families and providers to network. Last year 700 people attended!!

We need sponsors and volunteers for the dance. If you can help, please call us at 501-223-3696. ☼

DOWN SYNDROME & SLEEP DISORDERS

Sleep disorders are extremely common in Down syndrome. These disorders are a group of conditions with many different causes but one thing in common: they all interfere with getting a good night's sleep. As a parent, you know that tired children can behave very differently from tired adults: they can become restless, whiny, and difficult to calm. People of all ages have difficulty focusing and learning new information when they are sleep deprived.

Sleep apnea, or short periods of not breathing during sleep, is especially common in people with Down syndrome. People with Down syndrome have small, often "floppy" airways. These small airways can sometimes be completely or partially blocked during sleep by large tonsils and adenoids, or by the floppy walls of the airway collapsing as air is exhaled. Regardless of the cause of obstruction, the sleeper must awaken briefly to resume breathing. Some patients with sleep apnea awaken hundreds of times per night without remembering it.

Symptoms associated with but not specific to sleep apnea include snoring, lots of "thrashing" while asleep, excessive daytime sleepiness, mouth breathing, and unusual sleep positions such as sleeping in a seated or hunched forward position.

Children suspected of having a sleep disorder should undergo a sleep study evaluation. ☼



In The Spotlight

LITTLE ROCK'S BRAD RAINES IS TAEKWONDO CHAMPION

Bradford Tillar Raines, age 33, has been involved in the American Taekwondo Association since the age of 17 when the founder of ATA, Eternal Grand Master Lee wanted to start training a group of individuals with varying disabilities and ages. Brad developed his taekwondo/karate skills through twice weekly classes and competes in state, regional, national and international tournaments throughout the year.

Brad has moved through the ranks of color belts to become a Blackbelt and won the World Championship Title in 2008 in Blackbelt Forms, Weapons, and Sparring. Prior to that time, he won many first and second place trophies in the Top Ten Competitors category at the World Tournament with 20,000 people attending.

After competing in tryouts with a Judges' Panel in Las Vegas, Brad was awarded a place on the ATA World Demonstration Team. The ATA members are given the distinction of the 25 World's Best. The World Demo Team has the honor of performing annually at Opening Ceremonies for the National Tournaments in Orlando and Las Vegas and the World Tournament in Little Rock.

Brad has learned focused discipline and has enjoyed fun exercise while he memorized and performed his 81 moves at the Blackbelt level in this ATA world of "doing your best". He has also made lifetime friendships with people of all ages, backgrounds and levels of accomplishment. In addition to his taekwondo activities, Brad worked a full-time job for Alltel in the Mail Room for nine years from the time he graduated from Hall High School. He has now been working full-time for UAMS Hospital for over a year in Patient and Guest Services. ☼



GROUP MEETINGS

4-States Down Syndrome Society

Support group, the Twin City Angels, meets 3rd Thursday, 6:00 p.m. @ Opportunities Inc., 6101 N. Stateline, Texarkana. Contact Kristy McKean-Meeker at 903-249-9533 or 903-249-9526 or email twincityangels@live.com. ♻️

River Valley Down Syndrome Network

Meeting on 3rd Saturdays of January and February @ McDonald's, Brooken Hill and Hwy. 71 in Ft. Smith
Contact Brandi Tanner at 479-295-2795 or email everybreathhasareason@centruytel.net ♻️

Down Syndrome Connection of Northwest AR

614 East Emma, suite M-403,
Springdale, AR 72764
Meetings 3rd Tuesday of each month at 6:30 p.m.
Programs subject to change
May-Pizza Party and McGruff the Crime Dog
June-Nutritionist from Children's Hospital
July-Behavioral psychologist
August-Summer party
October 17-Buddy Walk
Contact Kim Warren 479-443-1370,
kim@dscnwa.org or Stacy Reed 479-464-4272,
stacy@dscnwa.org.
Website: www.dscnwa.org ♻️

Down Syndrome Association of NE Arkansas

3rd Tuesday of each month @ 6:30 p.m.
Calvary Pentacostal Church, 5312 Caraway Road,
Jonesboro.
Buddy Walk-October 3
Website: www.dsaofnea.org ♻️

"Designer Genes" in Smackover

Contact Joede Fleming at 870-866-4060,
email—dg_ar@yahoo.com ♻️

Angels of Arkansas (Hot Springs/Benton)

Buddy Walk—October 24. Volunteers are needed to help with the Walk. Contact Leslie Faulkner at 501-620-4731, email lesliefskylar@yahoo.com
Web site—www.angelssofar Arkansas.org ♻️

North Central AR Down Syndrome Association

Mt. Home area. Contact Chris and Jenifer Willis at 870-435-2659
Web site: ncadsbuddywalk.yahoo.com ♻️

"New Mother's Brunch" will meet on Saturday, June 13th from 11:00 a.m.-1:00 p.m. The meeting will be at the home of Dawn Adams in Little Rock. Babies are welcome! For information contact Dawn at 501-219-2148. ♻️

INVESTITURE AT UAMS

Kent D. McKelvey, Jr., M.D. is the inaugural recipient of the Winthrop P. Rockefeller Chair in Clinical Genetics. The investiture on May 14 was held in the Fred W. Smith Conference Center at the University of Arkansas for Medical Sciences. Dr. McKelvey has been and will continue to see individuals with Down syndrome in the Adult Down Syndrome Clinic. ♻️

GINKGO, PROZAC AND FOCALIN AS "TREATMENTS" FOR DS

A group of healthcare professionals, scientists and support organizations have recently released an article about a proposed "treatment" for Down syndrome. The article reads: "We recognize that all parents wish to improve the lives of their children with Down syndrome and are interested in treatments, therapies and interventions that can help. We respect these wishes. At the same time, we are concerned that these "treatments" are potentially dangerous. We are all aware of the advances that have been made in the basic science of memory and cognition in animal models of Down syndrome and are hopeful that these studies may lead to new ways to improve the lives of people who live with the condition."

Physicians and biomedical scientists evaluate potential interventions on the basis of safety and benefits to patients. The "treatments" that the Changing Minds Foundation recommends have not passed either test: there is no information whether these compounds are safe for children, especially young children. Furthermore, there is no evidence to support the claims for benefits that have been made.

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Arkansas Down Syndrome Association Board of Directors

Dawn Adams	Elaine Cockmon	Suzie Hicks
Susie Keesling	Debbie Kern	Dana McClain
Fred Norman	Phyllis Watkins	

The newsletter is a free quarterly publication of Arkansas Down Syndrome Association, 9800 Vinson Court, Little Rock, AR 72205. It is sent to our mailing list and others by request. All material in the newsletter is offered as information to our readers. ADSA cannot endorse or recommend any program, person or product.

RESEARCH

Stem Cells Yield New Clues to Glut of Glial Cells in Down Syndrome

A newly identified molecular pathway that directs stem cells to produce glial cells yields insights into the neurobiology of Down syndrome and a number of central nervous system disorders characterized by too many glial cells, according to a recent study by researchers at the Salk Institute for Biological Studies. Their findings were published in the March 13 online edition of *Cell Death and Differentiation*.

Glial cells are brain cells that act as personal assistants to neurons. The research indicates that synaptojanin-1, a central component of the pathway, is essential to production of glia. Down syndrome, spinal cord injury, Alzheimer's disease, and stroke all are linked by an overproduction of glia. Understanding this molecular pathway may also have implications for the onset of glioblastoma, the most common and malignant type of brain tumor.

Down syndrome is the most frequent cause of mental retardation, with an incidence of 1 of every 800 births. Cognitive deficits, as well as changes in the basic composition of the brain, are observed soon after birth, reflecting problems in brain development. Although it is known that Down syndrome is caused by an extra copy of chromosome 21, the exact genetic details largely remain a mystery.

Among the established anomalies found in the brains of Down syndrome patients are a greater than normal number of glial cells and perhaps fewer nerve cells. The reason for these characteristics has been unclear, however. Using a new mass spectrometry technique and stem cells that can be made to produce either neurons or glia, researchers identified a molecular signaling pathway that is required for the production of glial cells. The team of Salk researchers led by first author Federico Herrera, Ph.D., a senior scientist in the Cellular Neurobiology Laboratory.

"Given the required balance between the numbers of neurons and glia in a normal brain, an excess of glia may contribute to the cognitive deficits that characterize Down syndrome," says Herrera.

The team also found that Synaptojanin-1 was not required for the production of neurons, and

they identified the particular part of the Synaptojanin-1 molecule that was responsible for generating glia. "This is a critical first step to identifying drugs that specifically block the excess proliferation of glial cells associated with Down syndrome and perhaps promote the production of more neurons," Herrera adds.

Increased production of glial cells is frequently seen in other conditions as well, including stroke and neurodegenerative disorders such as Alzheimer's disease, and may contribute to the brain damage associated with them. Interestingly, a large proportion of Down syndrome patients develop Alzheimer's disease at a young age, and Herrera believes that a higher proportion of glial cells could be a contributing factor. *

(From the Salk Institute for Biological Studies)

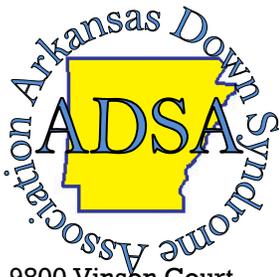
Down Syndrome "Treatment"

(Continued from page 2)

The 'treatment' includes regular doses of Fluoxetine (Prozac), Dexmethylphenidate (Focalin XR) and Ginkgo biloba, Phosphatidylcholine, 'Body Bio Balanced Oil' and folic acid. Some of these substances are associated with potential harmful side-effects. Some of these side-effects are of particular concern for people with Down syndrome and younger children.

Fluoxetine (Prozac) is used to treat depression, obsessive-compulsive disorder, bulimia nervosa and panic disorder. Dexmethylphenidate (Focalin XR) is used for the treatment of attention deficit and hyperactivity disorder (ADHD). Their use should be initiated and monitored by an appropriately qualified physician. It should be limited to applications and treatments formally reviewed and approved by appropriate governmental and medical drug regulatory agencies.

The complete article with a list of supporting physicians and organizations can be found at www.down-syndrome.org/statements/2106/?page=1. *



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The mission of the Arkansas Down Syndrome Association is to promote comprehensive community-based health care services for individuals in Arkansas who have Down syndrome.

**ARKANSAS DOWN SYNDROME ASSOCIATION
MAILING LIST APPLICATION
Listing is free**

Please include my name on the Arkansas Down Syndrome Association mailing list.

Name: _____ Home Phone: _____

Address: _____ Work Phone: _____

City: _____ State: _____ Zip: _____

E-mail: _____

Name of relative/dependent who has DS: _____ Birth date: _____

I am a provider or teacher at _____

I am interested in volunteering: Annual Conference Zoo Dance Development

Communications/publicity Board of Directors

I want to support ADSA by becoming a member, Enclosed is a check for my \$25.00 annual membership.

Mail to: Arkansas Down Syndrome Association, 9800 Vinson Court, Little Rock, AR 72205
For information call: 501-223-3696.