



9800 Vinson Court, Little Rock, AR 72205  
Phone: 501-223-DOWN (3696)  
www.ardownsyntax.org

## ARKANSAS DOWN SYNDROME ASSOCIATION

# Newsletter

Volume 4 Number 1

Winter 2012

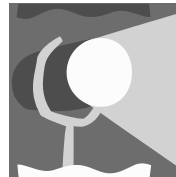
### PAISLEY AND HEATH WHITE IN LITTLE ROCK MARATHON

Four-year-old Paisley White has run in multiple marathons for a total of 312.7 miles. Well, actually her Dad, Heath, does the running while Paisley, who has Down syndrome, rides in a special stroller. Their most recent race was in late January when they ran the Miami Marathon along with one of Paisley's classmates who also has Down syndrome. When they finish with Little Rock Marathon on March 4, 2012, they will have accumulated 365.1 miles of races.

ESPN, who will be filming the Whites at the Little Rock Marathon, is looking at the significance in the number of miles. For example, 365 represents one mile for every day of that first year [of Paisley's life] that Heath says he didn't appreciate how special she was. By not counting the shorter races and only counting the marathons the total miles would be 306 at the start of the Little Rock race. That would mean they would be breaking 321 miles of marathons right about mile 15. The significance of this number is that it would represent the 3rd replication of the 21st chromosome.

Heath White joined the Air Force and was commissioned in 1998. He was a B-52 pilot with 18 combat missions in Afghanistan and was on the 3rd one to leave the country after 911. He was also an instructor pilot and instructed for 3 years at the Euro-NATO Joint Jet Pilot Training Base in Texas. He left active duty but remained in the reserves for a year while he—flew a 737 for Continental Airlines. Currently Heath is a Special Agent with the FBI.

**Arkansas Down Syndrome Association will be hosting a "Meet and Greet" at Professor Bowl in Little Rock on Saturday, March 3 from 11:00 a.m. – 12:30 p.m. All are welcome to join us to meet Paisley and Heath and wish them well. Refreshments will be served.** (See PAISLEY, Page 2)



### In The Spotlight

#### CENTRAL HIGH SCHOOL JUNIOR CIVITAN CLUB

Members of the Junior Civitan Club at Little Rock's Central High School are dedicated volunteers for Arkansas Down Syndrome Association. At the Zoo Dance they help to decorate, serve the burgers and clean up. In addition they are great dance partners for our guests.



Junior Civitan Club members visit Santa

At the annual Family Holiday Party, they help with crafts, read stories, serve refreshments and, of course, dance. ☸

### WORLD DOWN SYNDROME DAY

March 21, 2012 marks the 7th anniversary of World Down Syndrome Day and, for the first time, this day will be officially observed by the United Nations. This date, 3/21, represents the 3 copies of chromosome 21, which is unique to people with Down syndrome.

Each year the voice of people with Down syndrome, and those who live and work with them, grows louder. Down Syndrome International encourages people all over the world to help raise awareness of what Down syndrome is, what it means to have Down syndrome and how people with Down syndrome play a vital role in our lives and communities. ☸

## HAPPENINGS

In addition to their regular meetings, several groups are planning events. See page 4 of this newsletter for contact information.

### Down Syndrome Connection of Northwest AR

**February 11**—Valentine Party 10:00 a.m.-12:00 p.m. at St. Thomas Episcopal Church in Springdale.

**March 21**—World Down Syndrome Day at Mimi’s Café in Rogers from 5:00-10:00 p.m. 15% of purchases will be donated to DSCNWA with flyer presented upon cashing out.

**April 17**—Estate Planning with elder law attorney Collier Moore at St. Thomas Episcopal Church in Springdale.

### Angels of Arkansas

Special Olympics Gymnastics practice on Saturdays’ from 9:00-10:00 a.m. at Leah’s Gym in Benton. “I Can Dance” classes start on Monday afternoons in March.

### Down Syndrome Association of Northeast AR

Valentine Dance. Call for details. ☼

## PAISLEY (Continued from Page 1)

### HEATH WANTS A HAIRCUT

Heath says, “I would like to have a couple of the self-advocates give me a mohawk while I’m there. I’m going to be doing it anyway and it would mean more to me if they did it. Again it’s all about how I have to go to extremes to stand out as an individual but our children are born that way. And although I may run with a mohawk and “Down Syndrome” tattooed on my chest there is a lot more to me. Those physical characteristics don’t define me just like Downs doesn’t define them. It’s only one of many adjectives that define them. In fact it’s probably the only adjective you wouldn’t use to describe any child. You can make it a positive adjective, not a negative one. As humans we celebrate and strive for individuality. Nobody does that better than someone with an extra chromosome.” ☼

#### Arkansas Down Syndrome Association Board of Directors

Dawn Adams	Elaine Cockmon	Suzie Hicks
Susie Keesling	Debby Kern	Dana McClain
Donna Morey	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.

## RESOURCES

### The Girls’ Guide to Growing Up now available.

As announced in last summer’s newsletter, Terri Couwenhoven’s newest book is titled The Girls’ Guide to Growing Up. Now available from [www.woodbinehouse.com](http://www.woodbinehouse.com), the book is an easy-to-follow guide for girls with intellectual disabilities. It serves as is an introduction to the physical and emotional changes young girls encounter during puberty. Written on a third-grade reading level for preteens or young teenaged girls to read by themselves or with a parent, it’s filled with age-appropriate facts, as well as realistic illustrations and photos. The 54-page book is currently on sale at Woodbine for \$13.56. ☼

Speaking of Apraxia is a parents’ guide to understanding, treating and living with childhood apraxia of speech (CAS). Characterized by difficulties with planning and producing the complex set of movements necessary for intelligible speech, CAS can be a child’s only diagnosis or can be accompanied by other special needs such as learning disabilities, Down syndrome or autism. Parents and professionals will appreciate the author’s clear explanations of everything from diagnosing CAS and working with speech-language pathologists, to understanding how to distinguish it from other speech disorders, and getting appropriate early intervention and special education support. Written by Leslie Lindsey, the book will be available from Woodbine in March for \$19.95. ☼

**Communication Book.** Newly revised and updated, Early Communication Skills for Children with Down Syndrome is an authoritative guide, based on Libby Kumin’s more than thirty years’ experience working with children and adolescents with Down syndrome and their families. This third edition of the book is expected in May. ☼

**Video About Down Syndrome.** There have been over 96,000 hits on this video of Maddox, who has Down syndrome, and her mother. The hope of the family is to bring about awareness and to teach others about the hopes and dreams of those with Down syndrome, as well as combat the use of old school words such as retarded. Find the video at: <http://www.youtube.com/watch?v=hkNzRjXK3hc>. For more of Maddox’s adventures, you can check out [www.mcclinticfamily.com](http://www.mcclinticfamily.com). ☼

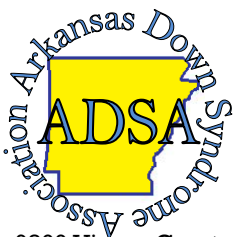
## RESEARCH BRIEFS

**Memantine Ineffective Treatment.** Though commonly used to treat patients with moderate-to-severe Alzheimer's disease (AD), the anti-dementia drug memantine--trade name *Namenda*--has been labeled as ineffective for treating AD patients with Down syndrome (DS) over the age of 40. The finding comes from a publication by *The Lancet* written by Professor Clive Ballard, Wolfson Centre for Age-Related Diseases at King's College London, UK, and colleagues. Pathological features similar to those found among AD patients are evident in all DS patients above the age of 40. As a key clinical challenge, dementia has become increasingly common in individuals with DS - as they are living longer than before - with dementia being diagnosed in over 40% of such patients over 60. The 52 week-long study involved two groups of patients, a group of 88 taking memantine and another group of 85 taking the placebo. Selection of the participants across the two groups was balanced in accordance to memory, sex, age group, executive function scales [DAMES] score, dementia and DS attention. Assessment was based on evaluating the change in cognition and function. They did so by measuring DAMES scores and using a standard assessment tool called the adaptive behavior scale (ABS). Cognition and function dropped for both groups with little disparity between the two rates. ☸

**The Down Syndrome Cognition Project (DSCP)** benefits from a 'Virtual Network' which includes investigators at Johns Hopkins University, Emory University, University of Arizona, University of Wisconsin, National Children's Medical Center in Washington, DC and the Oregon Health and Science University. The formally networked group is investigating the genetic reasons for the high degree of variability in the cognitive ability of different persons with Down syndrome. The project utilizes the new Arizona Cognitive Test Battery. In addition, the collection of DNA samples and cognitive profiles from individuals with Down syndrome and their parents will provide the basis for genetic analyses to identify targets for therapeutic interventions. The study is funded by the Down Syndrome Research Foundation. ☸

**Celiac Disease and Depression.** Individuals who have Down syndrome are at increased risk for celiac disease. For those with celiac disease, consuming gluten -- a protein found in wheat, barley and rye -- triggers a reaction in the intestines that decreases the body's ability to absorb certain nutrients. Celiac disease can cause diarrhea, bloating, weight loss, anemia and vitamin deficiencies. Several studies have linked celiac disease with depression. A large Swedish study compared more than 13,000 people with celiac disease to the general population and concluded that those with celiac disease were 80 percent more likely to experience depression. Several factors may contribute to depression if you have celiac disease. First is an inability to sufficiently absorb certain critical nutrients. The amino acid tryptophan, for example, is often deficient in people with celiac disease. Tryptophan is converted by the body into serotonin, a neurotransmitter believed to regulate mood and anxiety, including depression. In addition, deficiencies in folate and vitamin B6, also found in celiac disease patients, are associated with neurological problems, such as tingling and numbness, lack of coordination and seizures. Depression could be yet another neurological problem tied to these deficiencies. It's also possible that the gluten sensitivity of celiac disease may affect the nervous system directly. ☸

**A prenatal blood test** to detect Down syndrome is now available in 20 major cities. The test, developed by California-based Sequenom, accurately identified Trisomy 21—the most common form of Down syndrome—in 98.6 percent of cases, according to a study published October 10, 2011 in the journal *Genetics in Medicine*. The research indicates that there is a false-positive rate of 0.2 percent. Officials with Sequenom say the new blood test is intended for the estimated 750,000 pregnant women each year who are at high risk for having a baby with Down syndrome. The test can be performed as early as 10 weeks into a pregnancy. Previously available testing methods such as amniocentesis are far more invasive and present a risk of miscarriage. However, the availability of a noninvasive test has also been met with concern by many of those affected by Down syndrome. They are worried that easier screening could lead to fewer children with the chromosomal disorder and ultimately prompt reduced supports and services for the population. ☸



9800 Vinson Court  
Little Rock, AR 72205

Nonprofit Org.  
U. S. Postage  
PAID  
Permit # 277  
Little Rock  
Arkansas

ADDRESS SERVICE REQUESTED

Please let us know if your address changes. The Post Office does not forward the newsletter.

**Special thanks to**  
*Horton Brothers Printing*  
for printing our newsletter

**ADSA MAILING LIST APPLICATION** (Winter 2012)

Listing is free

Name: \_\_\_\_\_ Phone: \_\_\_\_\_

Address: \_\_\_\_\_

City: \_\_\_\_\_ State: \_\_\_\_\_ Zip: \_\_\_\_\_

Email: \_\_\_\_\_

Name of relative/dependent who has DS: \_\_\_\_\_ Birth date: \_\_\_\_\_

I am a provider or teacher at: \_\_\_\_\_

I want to volunteer: Circle Dance, Board of Directors, Conference, Publicity, Development

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

ADSA has my permission to share my mailing information with the Down Syndrome Clinic. Yes  No

Mail to: Arkansas Down Syndrome Association, 9800 Vinson Court, Little Rock, AR 72205

**PARENT GROUP MEETINGS**

**River Valley Down Syndrome Network**  
For information contact Stephanie Young at 479-295-2795 or everybreathhasareason@centurytel.net

**Down Syndrome Connection of Northwest AR**  
Support Group meets 3rd Tuesday of each month at 6:30 p.m. @ St. Thomas Episcopal Church, 2898 S. 48th St. in Springdale.  
Contact: Jennifer McWhorter @ 479-936-2149  
Web site: www.dscnwa.com

**Down Syndrome Association of NE Arkansas**  
Meets 3rd Tuesday of each month @ 6:30 p.m. Calvary Pentecostal Church, 5312 Caraway Jonesboro. Contact: Vickie Speaks @ 870-273- 6997.  
Web site: www.dsaofoea.org

**Southern Angels**  
Contact Joede Fleming at 870-866-4060 or dg\_ar@yahoo.com

**Angels of Arkansas (Hot Springs/Benton)**  
Contact Leslie Faulkner at 501-282-8281 or leslieskylar@yahoo.com.

**Arkansas Down Syndrome Association**  
Board Meeting—First Monday of every month @ 12:30 p.m. Contact Suzie Hicks @ 501-223-DOWN (3696) or www.ardownsyntax.org.

*If you know of a group that isn't listed or if your group information changes, please email phyllis.watkins@alzark.org*