



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

ARKANSAS DOWN SYNDROME ASSOCIATION

Newsletter

Volume 3 Number 4

Fall 2010



Families who have a child or an adult with Down syndrome are invited to attend the

Family Holiday Party

Hosted by
Arkansas Down Syndrome Association

Saturday, December 4, 2010

11:00 a.m. – 1:00 p.m.

at
Genetics/Down Syndrome Clinic
Freeway Medical Center
6th Floor

Fun for all

Refreshments
(including gluten-free)



Performance of "Horton Hears a Who"

Visit with Santa

Crafts

Please RSVP by November 29 to
ARDownSyndrome@aol.com or call
501-223-DOWN (3696)



In The Spotlight

Saturday Bowling

Every Saturday morning, from September through April, a group of adults with Down syndrome meet for bowling at Professor West in Little Rock. Some of the bowlers have been bowling since they were five years old and students at the Francis Allen School for Exceptional Children. That original group traveled to Minneapolis, Minnesota for the International Special Olympics.



Elvis' Girls and Razorbabes are the names of some of the teams that now bowl on Saturday morning. The league is registered with the United States Bowling Congress (USBC), which allows all children under the age of 21 or authorized as mentally challenged as Youth Members.

In addition to the weekly social aspect of bowling with friends, holidays are also celebrated at the bowling alley. Families bring refreshments for Valentines Day, Halloween and Christmas. At the end of the season, trophies are awarded at the annual pizza party.

If asked, most of the bowlers would say that they bowl because it's fun. What their parents know is that it is good exercise. The game builds leg muscles as you approach the foul line. At the same time you are building your arm muscles by holding the bowling ball. It also stretches muscles and makes them more flexible. Swinging your arm to roll the ball down the lane exercises tendons, joints and ligaments. Bowling is also a fat burning form of exercise. Every time you walk down the approach lane, you are burning calories. By the time you bowl three games, you have a complete body workout.

Another health benefit is that this sport helps build friendships and relationships. The bowling alley is a great way to meet new people and socialize. When you have a social life, your heart muscles perform better. So, in the end, the bowlers are correct—it's fun! 🎳

RESEARCH

The Kennedy Krieger Institute in Baltimore, MD has been awarded an \$8.5 million grant from the National Institutes of Health (NIH). The grant will provide for the continuation of Kennedy Krieger's Aging and Dementia in Adults with Down syndrome program through May 31, 2015. Begun in 1987, this program has developed into one of the largest research efforts of its kind in the world. Its earlier studies showed that risk for dementia among adults with Down syndrome (DS) was lower than expected in their 30s and early 40s, but increased substantially thereafter. Earlier findings also revealed that some health-related factors influence whether a specific individual with DS will be at higher or lower risk. They also showed that risk of Alzheimer's disease for adults with intellectual disability who do not have DS seems to be similar to what it is in the general population.

The program will now undertake a variety of projects to extend the understanding of the onset and progression of Alzheimer's disease within the older population with DS to its earliest stage of clinical impact. These projects will:

- Conduct studies to determine if risk for Alzheimer's disease within the elderly population with DS is associated with insulin resistance;
- Develop empirically validated methods for identifying the presence of mild cognitive impairment (state of mind impairment that is intermediate between declines associated with lifespan brain aging and the deficits that occur in conjunction with dementia) in adults with DS, differentiating this condition from cognitive changes associated with developmentally appropriate aging;
- Determine the role of basic biological mechanisms that underlie Alzheimer's disease, including altered patterns of DNA methylation (a chemical modification in DNA) and other observed characteristics within this population, including aging-selected processes;
- Ascertain the contribution of genetic variants that may influence cognitive function, risk for Alzheimer's disease and age at onset of Alzheimer's disease in adults with DS. ☼

Help Us to Stay in Contact. Sometimes news happens fast! Sometimes we want to let you know about an upcoming event or conference. The best way for us to contact you quickly is via email. With that in mind, we are asking that you send us your email address. Just send it to ardownsyndrome@aol.com. ADSA will not share your address with any other organizations and will use the address only to contact you regarding information important to parents and providers for adults/children who have Down syndrome. ☼

WALTON FOUNDATION GRANT

Arkansas Down Syndrome Association was a recent recipient of a \$5,000 grant from the Walton Foundation. Jim Cargill, president of Arvest Bank, presented the check as a representative of the Foundation. We are grateful for this generous gift, which will be used to fund our programs such as the spring health conference and for our support of the Adult Genetics/Down Syndrome Clinic. ☼

RESOURCES

Down Syndrome Pregnancy, Inc. is a New Jersey non-profit corporation whose purpose is to provide information and support to expectant parents waiting for the birth of a baby with a diagnosis or increased chance of Down syndrome. The organization was created to help expectant parents, and also to help the Down syndrome community prepare for the increasing numbers of prenatally diagnosed parents as new, non-invasive diagnostic prenatal testing for Down syndrome becomes available next year. The www.downsyndromepregnancy.org includes a downloadable book titled Diagnosis to Delivery. ☼

New Report from the United States Government Accountability Office (GAO). A 47-page report titled "Children With Down Syndrome: Families Are More Likely to Receive Resources at Time of Diagnosis Than in Early Childhood" was released in October 2010. GAO examined (1) what is known about the extent to which children with Down syndrome receive medical care during early childhood and (2) what resources families of children with Down syndrome receive through their health care providers and what barriers families face to using these resources. The report can be accessed at from GAO at www.gao.gov/new.items/d1157.pdf.

Available from Woodbine. The Guide to Good Health for Teens and Adults With Down Syndrome by Brian Chicoine, M.D. & Dennis McGuire, Ph.D. of the Adult Down Syndrome Center of Lutheran General Hospital in Chicago. Order from www.woodbinehouse.com. ☼

Arkansas Down Syndrome Association Board of Directors

Dawn Adams	Elaine Cockmon	Suzie Hicks
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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.

ADSA ANNUAL DANCE AT THE ZOO

The annual “Gettin’ Down For Down Syndrome” dance at the Little Rock Zoo was attended by 625 people. The group of fun-loving people included adults and children with Down syndrome, parent and guardians, providers and professionals. Elvis (Butch Dicus) was a hit as the headliner, but also receiving an enthusiastic reception was the Zumba instructor. That dance is good exercise!



We are grateful to all of our volunteers including those from the Little Rock Civitan Club, Jr. Civitan from Central High, Parkview High School Mime



Troupe, photographer Rusty Gartrell and the UAMS Genetics Department. Also many thanks to our sponsors: Staley’s, Inc., Superior Paint & Body Service, Inc., Coca-Cola & Dr. Pepper Bottling, Lamb & Associates Packaging, Inc., Saline Audiology Associates, Karen Flake & Associates and Lamar Outdoor Advertising. ☼



WEIGHT GAIN & DOWN SYNDROME

Research suggests that children with Down syndrome have a lower basal metabolic rate (BMR) than their same-aged peers. BMR is the rate a person burns calories for fuel when completely at rest—or sleeping. As a result, a child with Down syndrome uses fewer calories. In addition, adults with Down syndrome have finished growing and require fewer calories than they did as a child.

If your child is gaining weight consistently, visit with your doctor to rule out any medical causes of weight gain such as hypothyroidism. Ask if there are any physical limitations to be considered with an increase in physical activity. With the physician’s permission, your child and you can begin to create a plan for a healthy lifestyle.

To slow or stop weight gain, focus on beginning healthful habits that your child is willing to do. Some areas to consider are: increasing activities such as walking and using stairs (try swimming or bowling or join Special Olympics or the Miracle League); confining eating to designated areas; balancing meals; planning snacks rather than eating without control and menu planning. ☼

----- Cut Here -----

ARKANSAS DOWN SYNDROME HEALTH CONFERENCE SURVEY

Our goal for our spring health conference is to meet your needs. We would appreciate your answering the following questions to help us in our planning.

- 1) I have attended the conference. Yes No
- 2) If yes, was the information you received useful? Yes No

The conference has always been on Saturday. However, last year, we had very poor attendance even though we had outstanding presenters and a delicious lunch.

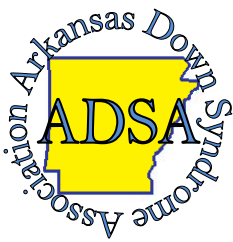
- 3) If you did NOT attend, was there a specific reason? _____
(e.g. day was inconvenient, didn't have child care, presentations didn't interest me, etc.)
- 4) Would you be more likely to attend if the conference was on a weekday? Yes No
- 5) Would you be more likely to attend if the conference was on Saturday? Yes No
- 6) Day doesn't matter.
- 7) What topics would you like to hear about? _____

Additional comments: _____

I am a parent Age of child _____ Professional/provider Other _____

I am interested in receiving Continuing Education Credits when I attend the conference.

Please return this survey to ADSA, 9800 Vinson Court, Little Rock, AR 72205



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Little Rock, AR 72205

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Special thanks to
Horton Brothers Printing
for printing our newsletter

ADSA MAILING LIST APPLICATION

(Fall 2010)

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: 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

Combining with the Autism Group. For information contact Stephanie Young at 479-295-2795 or everybreathhasareason@centruytel.net

Down Syndrome Connection of Northwest AR

Meets 3rd Tuesday of each month at 6:30 p.m. 614 East Emma, Suite M-403, Springdale
Contact: Kim Warren at 479-443-1370 or kim@dscnwa.org; www.dscnwa.com

Down Syndrome Association of NE Arkansas

Meets 3rd Tuesday of each month @ 6:30 p.m. Calvary Pentecostal Church, 5312 Caraway Rd. Jonesboro. Contact: Vickie Speaks @ 870-273-6997. Web site: www.dsaofnea.org

Trisomy 21 of South Central Arkansas

(Formerly Designer Genes of Smackover)
Contact Joede Fleming at 870-866-4060 or dg_ar@yahoo.com

Angels of Arkansas (Hot Springs/Benton)

No longer has a leader. Anyone interested in taking charge of the group, please contact Leslie Faulkner at 501-620-4731 or leslietfkylar@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.ar downs syndrome.org.

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