

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

ARKANSAS DOWN SYNDROME ASSOCIATION

Newsletter

Volume 2 Number 3

Summer 2009

Q & A : THYROID DISEASE

Q: Why is it important for children and adults with Down syndrome to have their thyroid hormone levels checked on a periodic basis?

A: In all children, thyroid hormone is essential for growth, brain development, and other important functions in the body. In the newborn period, children with Down syndrome are 28 times more likely to have hypothyroidism (low thyroid hormone). The reason for this is not clear, but many experts believe that there is an immaturity in the development and communication between the brain and thyroid gland. In the brain, the pituitary gland makes thyroid stimulating hormone (TSH) which tells the thyroid to make thyroid hormone (T4).
(See "Thyroid" continued on page 3)



**Arkansas Down Syndrome Association
Presents**

**"Gettin' Down For
Down Syndrome"**

**5th Annual Dance at the
Little Rock Zoo**

September 26, 2009

**Registration 10 a.m. — 12 noon
Dance 11a.m. — 2 p.m.**

**Admission for individuals who have
Down syndrome is FREE
(including zoo entry, lunch and t-shirt)**

All others pay \$10.00 for zoo entry and lunch

**Please Pre-Register
Day of event the cost is \$12.00**



In The Spotlight

KENT McKELVEY, JR., M.D. HEAD OF UAMS DIVISION OF GENETICS

Alongside members of the Arkansas Down Syndrome Association, Kent D. McKelvey, Jr., M.D. has been instrumental in the creation of an adult genetics clinic at the University of Arkansas for Medical Sciences (UAMS). The clinic is designed to care for adolescents and adults with Down syndrome, as well as other genetic conditions.



As a founding member of the new UAMS Division of Genetics, Dr. McKelvey's goal is to better serve Arkansans by preventing cancer when possible and individualizing care for his patients based on their specific needs and unique DNA code. He currently sees patients with cancer genetics needs at the Winthrop P. Rockefeller Cancer Institute and is accepting genetics patients in the new genetics offices at Freeway Medical in Little Rock.

Dr. McKelvey has deep roots in the Arkansas medical community. He is one of six doctors from three generations of his family to practice in the state. He earned his medical degree from UAMS in 1996 and completed an internship and residency in the family medicine program in Texarkana. He has worked in the emergency rooms in DeQueen and Nashville. After two years of private practice in Mountain Home, he began a second residency in medical genetics at the University of North Carolina at Chapel Hill. Dr. McKelvey is a diplomate of the American Board of Medical Genetics and the American Board of Family Medicine—one of only 12 physicians in the nation with similar credentials.

In 2003 Dr. McKelvey returned to UAMS where he directed the Family Medicine Predoctoral program in the Department of Family and Preventive Medicine from 2003-2008. As a teacher and clinician in family

(See "McKelvey" continued on page 3)

GROUP MEETINGS

River Valley Down Syndrome Network

Meeting on 3rd Saturday of the month at McDonald's, Brooken Hill and Hwy. 71 in Ft. Smith
Contact Stephanie Young at 479-295-2795 or everybreathhasareason@centruytel.net ☼

Down Syndrome Connection of Northwest AR

Meetings 3rd Tuesday of each month at 6:30 p.m.
614 East Emma, suite M-403, Springdale
October 17—Buddy Walk at Northwest Mall.
Check www.dscnwa.org for details.
Contacts: Kim Warren at 479-443-1370 or kim@dscnwa.org or
Stacy Reed at 479-464-4272 or stacy@dscnwa.org ☼

Down Syndrome Association of NE Arkansas

Meets 3rd Tuesday of each month @ 6:30 p.m.
Calvary Pentecostal Church, 5312 Caraway Road,
Jonesboro
October 3—Buddy Walk, 11 a.m. at ASU Track Facility. For more information call 870-273-6997 or visit www.dsaofnea.org ☼

4-State Down Syndrome Society

The support group—Twin City Angels—meets every 3rd Thursday @ 6:00 p.m.
Opportunities Inc., 6101 N. Stateline, Texarkana
Contact Kristy McKean-Meeker at twincityangels@live.com ☼

“Designer Genes” in Smackover

Contact Joede Fleming at 870-866-4060 or 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 or leslielskylar@yahoo.com
www.angelsfarkansas.org ☼

We couldn't contact the group in Mountain Home—North Central Arkansas Down Syndrome Association If you know how to contact them, give us a call.

Please send information about your group to phyllis.watkins@alzark.org. We want to include contact information as well as a listing of meetings and events that each group is having. ☼

HAPPENINGS

Ribbon Cutting for the UAMS Genetics Clinic. August 4 at 4:00 p.m. was a proud moment for the Arkansas Down Syndrome Association. We were gathered in the Freeway Medical Building to watch as Lisenne Rockefeller and Dr. Kent McKelvey cut the ribbon to open the new UAMS Genetics Clinic. The idea for the clinic, which will house the Down Syndrome Clinic, began six years ago with ADSA President Suzie Hicks. The clinic is already seeing patients and will be in the new space very soon. The phone number after August 17 will be 501-526-4000. ☼

Celiac Disease Education. People who have Down syndrome are much more likely than the general population to have celiac disease. To help educate parents and providers about the risks and management of celiac, there will be a meeting on August 31 from 11:00 a.m.-12:30 p.m. at Freeway Medical Building, room 605. Bring your lunch and hear an informative presentation by Alisa Brown, RD, LD, CSO. To register call Michelle Hagood at 501-526-4020. ☼

Babies and Young Children's Brunch. On June 13 a fun group of 20 moms and children came together at the home of Dawn Adams in Little Rock. The purpose of the group is to share stories and helpful hints, as well as to offer support. For information about the next meeting call Dawn at 501-219-2148. ☼

Rivals United Football League (RUFL) is a flag football league for children with special needs. The season starts on Monday, September 14 and games will continue on Monday evenings at the Fellowship Bible Church recreational fields in Little Rock.

- 5 and 6 year olds will do drills from 5:30-6:15 p.m.
- 7-17 year olds will do drills and play a game from 6:15-7:15 p.m.

The group also needs volunteers to help coach and be “buddies” to some of the children. Information and applications are available at www.communityconnectionsar.org. To secure a playing spot, applications are due by August 21. ☼

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 BRIEFS

NATIONAL DOWN SYNDROME STUDY RESEARCH ANNOUNCEMENT

The National Institute of Health has funded a study to identify genetic and environmental factors that increase the chance of congenital heart defects. The purpose of the study is to determine why some children with Down syndrome (DS) have heart defects while others do not.

The collaborative effort between multiple sites, including Kennedy Krieger Institute and Johns Hopkins University, both in Baltimore, will enroll 1200

CAUSE OF DOWN SYNDROME AND OTHER GENETIC DISORDERS INVESTIGATED

Scientists have a better understanding of what causes an abnormal number of chromosomes in offspring, a condition called aneuploidy that encompasses the most common genetic disorders in humans, such as Down syndrome, and is a leading cause of pregnancy loss.

To pinpoint what goes awry in these cases, researchers at the U.S. Department of Energy's Lawrence Berkeley National Laboratory and the University of Tennessee, Knoxville studied mice. They found that if a mother's egg cell has a mutation in just one copy of a gene, called *Bub1*, then she is more likely to have fewer offspring that survive to birth.

Usually, both copies of a gene in a chromosome must carry the same mutation in order for an organism to be adversely effected.

"But we found that a mutation in a single copy of the *Bub1* gene can have an impact — and this is not the case with most genes. With *Bub1*, if you have one bad gene and one healthy gene, there's a problem," says Francesco Marchetti of Berkeley Lab's Life Sciences Division. He worked with Sundaresan Venkatachalam of the University of Tennessee and other scientists on the research. Their findings appear in the online early edition of the Proceedings of the National Academy of Sciences the week of July 13.

More of this article can be found at http://www.eurekalert.org/pub_releases/2009-07/uota-nrf072109.php

McKELVEY (Continued from page 1)

medicine he was the highest rated preceptor by the junior medical students and was voted by peers as one of the best family doctors in Arkansas. Dr. McKelvey has been director of the medical genetics course in the College of Medicine since 2006. ☼

children born with DS. Half of them will have atrioventricular septal defect (AVSD) and half of them will have no heart defect. Children must be under age 18.

Parents will be asked to complete a telephone survey and to donate a saliva sample for DNA analysis. Blood samples will be collected from the children either at one of the study sites or by arrangement with the primary care physician.

There are no direct medical benefits or significant risks for participating in the study.

For information about the study contact: Charnan Koller at Kennedy Krieger Institute, 800-873-3377 ext. 9131 or koller@kennedykrieger.org. ☼

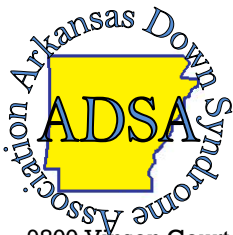
THYROID (Continued from page 1)

If blood tests show an elevated TSH with a normal or low T4 level, then this person would be considered "hypothyroid". In some infants and young children with Down syndrome, the hypothyroidism may go away with time, but it is difficult to predict when and in which individuals.

Another common cause of hypothyroidism is due to an autoimmune process, where the body makes antibodies directed against the thyroid. Thyroid antibodies can be measured by a blood test. The incidence of thyroid antibodies increase with age, and antibodies are not commonly detected before the age of 6-8 years in children with Down syndrome. Autoimmune hypothyroidism affects between 15-20% of adults with Down syndrome. It is important to note that only about half of all children and adults with Down Syndrome who develop thyroid antibodies actually become hypothyroid at some point in their life.

The American Academy of Pediatrics has published guidelines for the health supervision of children with Down syndrome. It is recommended that thyroid screening tests be performed after birth, at 6 months of life, at 12 months of life, and then every 12 months thereafter. If a child or adult is found to be hypothyroid, treatment involves taking a small tablet of thyroid hormone that can be crushed, chewed, or swallowed every day. After thyroid hormone replacement is started, blood tests are periodically done to assure that the dose of medicine is correct. ☼

(By Todd D. Nebesio, M.D., Indiana University School of Medicine, Riley Hospital for Children
Reprinted from Indiana Down Syndrome Foundation)



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*"Gettin' Down For
Down Syndrome"*

**5th Annual Dance at the
Little Rock Zoo
September 26, 2009**

Thank You!!

*Newsletter printing compliments of
Horton Brothers Printing*

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-DOWN (3696).

Summer/09