

# Arkansas Down Syndrome Association NEWSLETTER



FALL 2014

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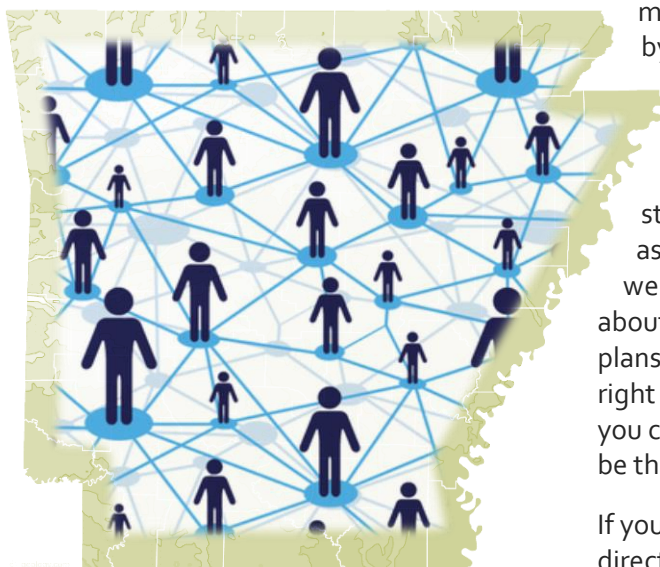
## Plans to better connect with you this New Year

**T**here is no denying it. We live in a digital age now. From blogs and text messages to e-mail and social media, it seems like the world has connected itself together in a web of cyber communication.

In some respects, the Arkansas Down Syndrome Association has decided not to jump on the bandwagon. We believe that swapping face-to-face relationships with faceless computer-to-computer exchanges is simply not worth the trade. If given the option, we would much rather see your precious smile, hear your voice, and give you a hug than to double click a few buttons on a screen and count that as our connection to our Down syndrome community. Which is why, scheduling regular events and activities for our families to get together and interact at continues to be a priority for our organization.

At the same time, we have learned that by strategically using tools like our website and Facebook page to stay in touch with you, we are able to do a much better job at bringing everyone together for our important meetups and public events.

To that end, we want to invite you to register (or update) your general contact information on our **NEW**, private online directory. It's easy! All you have to do is go to our website at [www.ardownsyndrome.org](http://www.ardownsyndrome.org) and click on the banner that says "Sign Up to Stay In Touch."



By signing up, you will enjoy the benefits that come with receiving the Arkansas Down Syndrome Association's latest news and information. You will also make it that much easier whenever you choose to apply and renew your membership with the ADSA, register for events, volunteer to serve, submit valuable feedback, and so forth.

If you are receiving this newsletter by mail, chances are you are already on our list. However, we still invite you to log on and register your information or, should you already be registered, to take a moment to update your information which gives us permission to contact you with the method of your choice, whether by e-mail, text message, postal service, etc.

The Arkansas Down Syndrome Association has big plans in store for the coming year as well as for our future years to come. As we prepare to send out more details about some of the specifics of these plans, we want to be sure we have the right contact information for you so you can stay the most informed and be the most involved.

If you have questions about this online directory, please feel free to contact us by phone at **501-223-3696**, by e-mail at [contact@ardownsyndrome.org](mailto:contact@ardownsyndrome.org), on our Facebook page at [facebook.com/130132353726328](https://www.facebook.com/130132353726328), or you can find more details online at [www.ARDownSyndrome.org](http://www.ARDownSyndrome.org).

❖ by Tim Kinnard



## "Omari"

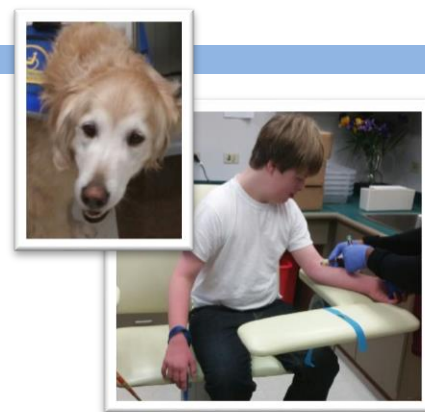
This quarter our spotlight is on Omari, a lovable and highly trained Canine Companion. Animals often serve our community members with Down syndrome and other diagnoses, as well. Most of us are familiar with service animals that aid those who may be blind or use a wheelchair, but the kind of service Omari provides is companionship and anxiety relief to those who are vulnerable in certain situations. Omari is an eight year old Golden Retriever. She works at Hippos and Fish Pediatric Therapy in North Little Rock serving her sweet friends, one of them, my son Colin.

Recently, Omari accompanied Colin to the UAMS Genetics Clinic to help him during a blood draw. Before I tell that story, let me backtrack just a bit. About three weeks before, Colin had a blood draw without Omari's help. Blood draws have always been difficult for him, but I thought now that he's older and understands more maybe he wouldn't have too much of a problem. I was wrong. At first things appeared to go well. He sat in the chair, and extended his arm for

the nurse. He allowed her to wrap the large band on the upper part of his arm and he squeezed a ball when asked. Then the needle came out. My sweet, cooperative boy turned into a crying, screaming, kicking and thrashing person that I don't see very often, if ever. Colin is over five feet tall and 140 pounds; I had bruises on my hips and arms from trying hard to help restrain him. It was awful. He cried, I cried, and the nurses were spent. We got the draw though, which was good. In fact, after the needle was inserted he was fine. It was just the anxiety of the initial stick that was so difficult for him.

The next day I got a phone call from the nurse. There was one vial of blood they didn't get! It wasn't on the orders, but the doctor wanted it. OMG! Really! No way! Ugh! I knew immediately what I needed to do. Call Colin's occupational therapist, Stacy. I wasn't going to go through that again, not without HELP. I scheduled the repeat blood draw three weeks out. In the meantime, Stacy and Omari worked with Colin to simulate the experience. They role-played the blood draw together during two separate appointments. Colin was ready.

Colin and Omari arrived to the clinic and entered the lab. There were some initial kisses, licks, and petting beforehand; Omari's



way of saying, "You can do it Colin! I'm right here." The result was nothing short of amazing. With Omari by his side, Colin didn't flinch. What took more than 30 minutes the first time took only about 2 minutes. No anxiety, no stress, no crying, screaming, kicking, or thrashing. The look on the nurse's face was priceless!

I like to think of all the people who have helped us on our journey of navigating Down syndrome and disability. I call them angels, and there are many in our lives. The medical professionals, the therapists, the parents, friends, and teachers who help us navigate our paths. However, I'm especially thankful to Omari, who may not be a person per say, but is definitely one of our angels.

❖ by Dawn Adams



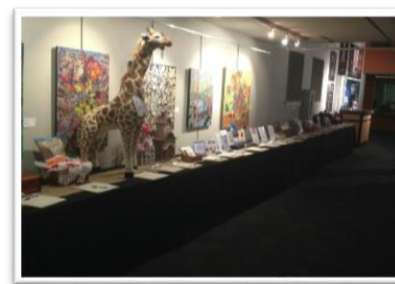
## Night At the Rep Fundraiser

The second annual "Night At The Rep" fundraiser was held October 21<sup>st</sup> at the Arkansas Repertory Theatre. The Arkansas Down Syndrome Association, the Precious Baby Outreach Ministry and SW Chance combined efforts in hosting the event that included the play "Wait Until Dark" and a silent auction. Proceeds from the night provided scholarships to families who have children with Down Syndrome. These scholarships help to pay for participation in the National Association for Child Development's (NACD) neuro-developmental program.

NACD is an organization that designs targeted individualized programs to address educational and developmental issues and needs through a model that trains parents and caregivers to provide hands-on

interventions on a daily basis. The NACD model involves quarterly assessments, program development, and ongoing communication that can all be accomplished by appointment with one of the many national chapter locations or via Skype, video and email. In addition to providing comprehensive intervention, NACD also coaches and supports families in their implementation of the NACD program. NACD believes in the unlimited potential of every child and the power of daily intervention provided by those who know the child best—the family.

Many local families currently participate in the NACD program largely due to the assistance provided by the scholarships from the Rep fundraiser. Last year four families were recipients of the scholarships and with the continued success of this event many more families will benefit. This year an honorary scholarship in the name of Arabella Mash will be awarded. Arabella earned her angel wings in early January of



this year. Her short life touched so many people and her spirit stays strong in our community.

❖ by Kerri Brunen



## ON THE CALENDAR

The ADSA is committed to remaining a healthy and active organization. Keeping an annual calendar scheduled with opportunities for you and your family to benefit from is among our cherished priorities.

We hope you take note of our list of scheduled events and consider participating in as many as may interest you:



### Estate Planning & Special Needs Trust Talk

On Tuesday, February 17, 2015 from 6pm to 8pm, Collier Moore with the Moore Reed & Young Law Firm will be speaking about estate planning and special needs trust for those who have children or loved ones with special needs. For more information, visit [www.dscnwa.com](http://www.dscnwa.com)




### Valentine's Dance

Come enjoy fun, food, and music with your Buddy Talk Family on Saturday February 14<sup>th</sup> from 6pm to 8pm at the Jacksonville Community Center. Dress however you wish—casual, dressy or even in your Elsa dress! There will be a play area for the little ones who are not quite ready to get their groove on. Organizers are asking for any volunteers who want to help with set-up and prep. And last but not least, please bring a side dish, chips, drinks, or dessert!




### "Gettin' Down" Dance Pictures and T-Shirts

Whether you were able to attend our 10<sup>th</sup> annual *Gettin' Down for Down Syndrome* Dance or not, you can still share in some of the great memories!

Portraits and casual shots are available online for you to view, share, like, and comment on. Just visit our website at [www.ARDownSyndrome.org](http://www.ARDownSyndrome.org).



You can also still order an event t-shirt for \$10, but supplies are limited. Call 501-223-3696.




### Presentations by Amy Allison

Amy Allison, Executive Director of the Down Syndrome Guild of Greater Kansas City will be coming to North West Arkansas in April. Parents, special educators, and school counselors are invited to attend one or both of the presentations she will be giving while there. The presentations, "Opening the Door to Friendship Through Education and Peer Presentations" and "Down Syndrome 101 for Educators" are provided at no cost! Specifics about each class are provided at [www.dscnwa.com](http://www.dscnwa.com).





### Spring Health Conference

Save the date for Friday, May 29, 2015 for our Spring Health Conference. In partnership with UAMS, the ADSA is proud to present the topic "Puberty Issues and Sexuality in Adolescence" with a special session focused on dating and adults.

Attendees will hear from returning speaker, Terri Couwenhoven, M.S.. Terri is a well known sex educator and author, specializing in the design and implementation of sexuality programs and resources for people with cognitive disabilities, their parents, and the professionals who support them. Her gentle, matter-of-fact approach combined with extensive knowledge and experience make her a popular speaker with self-advocates, parents and professionals around the country.



Stay tuned on our website and Facebook page for more details.



### A Big "Thank You" to All Who Attended Our Holiday Party

We want to thank all who attended our 6th annual *Holiday Party*. A special thanks to ThatChurch! for allowing us to be their guests. Thanks to our volunteers, and to the Anthony School for their wonderful performance. Thanks to Black Dog Photography, and last but not least.... Santa! We truly enjoyed the chance to catch up with our Down syndrome families, and to celebrate the Christmas season together.



### Amazon Smile Fundraiser

If you shop much on Amazon.com, you can start supporting the ADSA with your purchases. All you have to do is use the link [smile.amazon.com](http://smile.amazon.com) when you log on and select our organization. Every dollar makes a difference!



### Kroger Card Fundraiser

Simply register your Kroger Plus Card online at [krogercommunityrewards.com](http://krogercommunityrewards.com) using the # 80386, and ADSA will receive \$5 for every \$100 that you spend for groceries and gas. Thank you to everyone who participates!




### Monthly Webinar Series

Each month, the NDSS provides a free educational web-based seminar, or webinar, to anyone who is interested in learning more about Down syndrome and related topics, such as health, education, research and family life.



Visit [www.ndss.org](http://www.ndss.org) to learn more.



### A Call for Volunteers

The ADSA wants to hear from you if you are interested to volunteer in some capacity to help us continue to make a strong impact in Arkansas. Whether that's fundraising, event planning, or public awareness, e-mail us at [volunteers@ardownsyndrome.org](mailto:volunteers@ardownsyndrome.org) and tell us about your interests and availability.





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## Want to receive a free copy of our newsletter?

Register on our private, online directory of Arkansas Down syndrome individuals, families, friends, and centers. Help us stay in touch with you and keep our Down syndrome community connected.

Visit us online at [www.ARDownSyndrome.org](http://www.ARDownSyndrome.org) to sign up today.



## Want to become a member of the Arkansas Down Syndrome Association?

By becoming a member of the Arkansas Down Syndrome Association you take the rewarding step of partnering with us in our mission. Members of the ADSA are not spectators, nor are they merely supporters, of our organization. To be a member of the ADSA is to be a true contributor and champion for Down syndrome interests in Arkansas.

Visit us online to learn more.



## Want to find a list of other Down syndrome groups, sponsoring businesses, or Down syndrome family businesses in Arkansas?

We think it's important to foster a spirit of appreciation and mutual support within our Down syndrome community. To that end, we point you to a listing of those groups and businesses in Arkansas that we want to acknowledge, and which we think you might enjoy acknowledging too.

Visit us online to begin your search.



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