

WINTER 2015

JANUARY / FEBRUARY / MARCH

RECENT EVENTS

The tradition continues. DSAF hosted the 13th annual Capital City Step Up for Down Syndrome Walk on October 4, 2014. Thank you to all of the donors, sponsors, and fundraisers who raised more than \$87,450. 1,826 registered walkers (1,600 in attendance) joined seventy-seven teams and numerous volunteers for an exciting morning. The experience would not be possible without the hard work of volunteers and the passion of participants. Thank you and we look forward to seeing you at the 2015 Walk!

Walk photos courtesy:



On October 11, 2014, DSAF family members had a beautiful day on October 11, 2014, to visit at the Roca Berry Pumpkin Patch. More than forty-six families attended the event. It was great to see so many smiling faces!

UNIQUE ATTENTION - TOO MUCH OF A GOOD THING?

BY DEB SAFARIK, FOUNDER

One of our members recently asked me for advice on how to respond in situations where too much "positive" attention was directed towards their loved one with Down syndrome. For example, strangers have been overly touchy with their child and in one instance, someone even called loudly across a room, "Bless you for taking care of that child!"

Whew! How do you handle something like that? How do you handle any unwanted attention either positive or negative? I remember I was always bothered if people knew right away that Paul had Down syndrome when he was younger. I liked to think he was just a cute kid. The "more alike than different" mantra we celebrate every March 21 on World Down Syndrome Day mirrors my perceptions of Paul, why doesn't the world always see him as I do?

Some reactions to a baby have nothing to do with Down syndrome. Most parents have had an experience with well-intentioned strangers or even friends, who are just "all over" babies, touching their faces and asking to hold them. This kind of reaction may occur with our kids longer because they may be carried when a child without Down syndrome would be walking. In many cases, the stranger has a relative or friend with Down syndrome so they are especially drawn to your loved one. After we had Paul, if my girls saw someone older with Down syndrome we would almost "stalk" them in the store. We wanted to go up and say, "Hey, how are you. Tell me about your life." Maybe not quite that bad, but it was a strong and positive "we want to meet you" feeling.

More extreme attention, like the example of the stranger yelling across the room, is more difficult. My husband Dan always likes to use situations as learning opportunities. He would suggest a response such as, "Oh, do you know someone with Down syndrome?" or "Your sentiment may have been heartfelt but it brought a lot of unwanted attention to us."

Prepare yourself so that you are ready to respond to positive, and maybe even negative, attention. What will you say or do if someone uses the "R" word or says something really cruel like, "Why did you have that child?" Reflect on what you want for your loved one - for others to see beyond his or her differences and appreciate him or her as a human being with talents and abilities. We hope to see you at the DSAF annual World Down Syndrome Day celebration in March, where we will celebrate our differences and strive to show the world that our loved ones with Down syndrome are more alike than different.

PROGRAM DIRECTOR - OPEN POSITION

DSAF is accepting applications for a full-time program director. Job duties include assisting the DSAF Board and other volunteers to maintaining existing programs. Look for the job posting coming soon on Indeed, available online at www.indeed.com. Applications will be accepted and reviewed through February 15, 2015.

UPCOMING DSAF EVENTS

Smart Start Series - **January 10**, 8:30 to 11:00 am. **Friend Smart:** For families of children with Down syndrome ages 4 to 21 who want to encourage and support their children's friendships and active social life. Application forms available on the DSAF website. Sessions are held on UNL's East Campus. Free to DSAF members (annual membership is \$10).

Moms' Night Out - **January 16**, 6:30 pm at Las Margaritas, 2700 Jamie Ln., Lincoln, NE 68516.

Teen/Young Adult Group - **January 16**. The group is going to the Harlem Globetrotters at the Pinnacle Bank Arena. Contact Janette Johnson at janettej@windstream.net for more information and to get signed up for the monthly reminder list.

Lil' Stars (ages 0-5) - **January 21**, Theatre Event at the Lied Center, Lincoln. Jim Henson's Dinosaur Train Live! This is a Lied "Fam Fest" event so come early for free food and games, show starts at 7 pm. Limited number of tickets (including proximity near stage seating) on sale for \$5 each. Contact Tracy Kadavy at drkadavy@yahoo.com to order your tickets.

2nd Annual Trip to the Lincoln Children's Museum - **February 7**, 5:30—7:30 pm. More details to follow on the Events page of the DSAF website.

Smart Start Series - **February 28**, 8:30 to 11:00 am. **IEP Smart:** For families of children with Down syndrome ages 3 to 12 who want to understand the assessment requirements for eligibility and school performance in special education and inclusive programs and how to contribute to development of meaningful Individualized Education Plans (IEPs). Sessions are held on UNL's East Campus. Free to DSAF members (annual membership is \$10).

World Down Syndrome Day Celebration - **March 21**. DSAF hosts a spectacular "Ball Night" every year for you and your family in celebration of this day. Join us for pizza. Watch the DSAF website for more details on location and date.

Registration is recommended for most of these events and is made available on the DSAF website, www.dsafnebraska.org (click on the Events tab).

HO HO HO!

DSAF hosted a Merry Christmas Holiday Party on December 6, 2014. Every individual with Down syndrome and their families are invited to this annual event. A delicious hot brunch was followed up with a visit by St. Nick. Parents and families mingled while the kids jingled in the playroom and shared their wish lists with Santa.



DSAF LIL' STARS TO HOST FAMILY THEATRE EVENT

Sponsored by Harding & Shultz, PC, LLO

Jim Henson's Dinosaur Train Live! Buddy's Big Adventure (based on hit PBS series)

When: January 21, 2015 at 7pm.

This is a FamFest event! Come early for free food and fun activities for the kids.

Where: Lied Center, Lincoln

Cost: \$5 per ticket, all ages

A limited number of orchestra row seating is available, order your tickets today!

Contact Tracy Kadavy at drkadavy@yahoo.com to order your tickets.

CAROLINE'S CORNER

TIPS & QUIPS FOR YOUR EVERYDAY LIFE

Over the past few years, I spent a lot of money on apps I thought would be great but ended up not meeting my expectations. Now, instead of spending my time and money trying to make the "wrong" apps work, I go to this website before I buy an app: Apps for Children with Special Needs, available online at <http://a4cwsn.com>. This website allows you to watch videos where each app is tested. You can see how each app works and the website also provides recommendations on which apps work best.

Another great resource for guidance in purchasing the right app is the public school system. Each educational service unit has a technology person who can help you set up an app and even let you try some of the more expensive apps before you buy them.

DID YOU KNOW? DSAF HAS BOOK BUNDLES

DSAF has book bundles available for sale for \$25. If you are interested in purchasing a book, please e-mail info@dsafnebraska or call 402-421-1338. Titles include: Down Syndrome Parenting 101, Fasten Your Seatbelt, The Boys' Guide to Growing Up, The Girls' Guide to Growing Up, Stars of Success: Understanding How Children with Down Syndrome Learn, ABC Building Blocks for Growing Up with Down Syndrome - by Nebraska self-advocate Meredith Martin, The Power to Spring Up, Early Communication Skills, Fine Motor Skills, Body Talk, Try Reading Again, Classroom Language Skills, The Down Syndrome Transition Handbook, The Down Syndrome Nutrition Handbook, Teaching Reading/Literacy Skills Development, WrightsLaw Book Bundle (Special Education Law, From Emotions to Advocacy, All About IEPs)

2014 EDUCATION CONFERENCE

DSAF hit the mark with its annual Education Conference. The 2014 Education Conference was held in November. A multi-track program featuring national experts fueled a strong attendance by Nebraskans near and far. Look for more great programming at the 2015 Education Conference, you will not want to miss this unique opportunity.



CONTACTS

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Return Service Requested
**Down Syndrome Association
for Families**

Mission Statement: **The Down
Syndrome Association for Families** is a
Lincoln based non-profit organization
that provides support for individuals with
Down syndrome, their families, friends,
educators and professionals who share
in their lives.

Every person with Down syndrome is an
individual who has a unique purpose and
abilities. DSAF provides networking and
a positive vision for the future.

Website: www.dsafnebraska.org
Telephone: 402-421-1338

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ABLE ACT PASSES WITH FLYING COLORS

Eight years ago, a group of parents developed a common-sense solution to an injustice affecting individuals born with disabilities. Give individuals with disabilities similar financial opportunities as children without disabilities. Fill the gap in the tax code so individuals with disabilities from low and average income households are not forced into poverty, but instead can experience the advantages of a third-party special needs trust, a privilege usually reserved for the wealthy. Eight years ago, the Achieving a Better Life Experience (ABLE) Act was born.

In December 2014, the ABLE Act (H.R. 647/S. 313) passed the U.S. Congress with flying colors (404-17 vote in the House, 76-16 vote in Senate) and was signed by President Obama. This landmark Act may soon impact the life of your loved one with Down syndrome. Thanks to the Act, your loved one will be able to save and personally own up to \$100,000.00 without being disqualified from receiving government benefits (previously, individuals who owned more than \$2,000 risked losing government benefits). Local banks may be able to assist you with opening an ABLE account as early as 2015, depending on final regulations. The ABLE Act may not be a perfect remedy, but it nudges open the door to a life of independence for individuals with Down syndrome.
