

# Winter 2018 JANUARY / FEBRUARY / MARCH

www.dsafnebraska.org

## **HOLIDAY BRUNCH**

More than 200 members joined the fun and festivities at the annual DSAF Holiday Brunch held in early December. Several of Santa's helpers (a.k.a. volunteers from Concordia University Baseball and UNL Theta) were on hand to hang out with the kids while moms and dads took the opportunity to chat among themselves. A violinist provided festive live music as a backdrop to sitting on Santa's knee. Young and old had the chance to have a photo taken with Santa\* and VIP members received a little something extra (Target store gift cards) for being on the DSAF "nice" list. Heartfelt thanks goes to Firespring for accommodating our group and allowing us to use their outstanding facilities. \*Photos were printed and sent to those who visited Santa; please contact Jodi if you have not received yours.



















#### **REGIONAL NEWS**

Down Syndrome Association Families for (DSAF) president **D**Ean Fuelberth joined with Down Alliance Syndrome of the Midlands (DSAM) Omaha president Sherri Harnisch to represent Nebraska at the Affiliates in Action national leadership conference. groups were among the first sponsors of Global Down Syndrome Foundation's project to update the Medical Care Guidelines for Adults with Down syndrome (haven't been updated since 2000) Global's work on other critical research.



#### **MEDICAL OUTREACH**

The medical outreach committee provides information and resources to the medical community about Down syndrome and related research. Representatives also coordinate meeting with new parents when they receive a Down syndrome diagnosis for their child. If you are interested in joining the committee, please contact Holly Lohmeier at medicaloutreach@dsafnebraska.org.

In the last thirteen months, outreach representatives:

- Met with seven new parents and distributed a total of nine new parent packets.
- Created a resources booklet of many useful local and national resources. This is also posted on the website in the New Parent section.
- Updated the information that is handed to parents in place of the Brand New Day binder.
- Held a special networking opportunity for the Spanish-speaking families in our community.
- Gathered new family testimonials and pictures that we are publishing in a new booklet in the next few weeks. This will also be posted on the website in the New Parent section once it is complete.
- Hosted a informational luncheon at the Women's Health Care Center of Williamsburg where we educated medical professionals about prenatal testing accuracy and provided information for patients who may receive a diagnosis.

#### **UPCOMING EVENTS**

Lil' Stars Swim Party – February 17, 4 pm. At Lifestrokes, 1600 Normandy Ct., Lincoln.

Parents' Coffee – February 24, 9 am, Lincoln. Network with other parents. At Braeda, 4231 S. 33rd Street.

**Teen/Young Adult Stars' UNL Men's Basketball Game** – February 25, 4 pm, Pinnacle Bank Arena. Participants will meet the players after the game. Only a few tickets left, registration is required.

First Call Parent Refresher Training – March 3, Lincoln.

**World Down Syndrome Day Celebration** – March 21, 5:30 pm, National Guard Armory, 1776 N. 10th Street, Lincoln. Free and open to the public. Fresh cotton candy, inflatables by Party Inflators, balloon creations by Happy D Klown, free food.

2018 Fact Calendars are available for \$8 each. E-mail director@dsafnebraska.org to purchase yours today.

Registration is encouraged for these events. Go to http://dsafnebraska.org and scroll down to see a listing of upcoming events.

#### TEEN/YOUNG ADULT SOCIAL GROUP GOING STRONG

On November 2nd, Teen/Young Adult Stars took the opportunity to hang out and do whatever kids *do* at the mall with the help of some peer volunteers from UNL and a complimentary gift card to use however they chose. Some snacked and others showed off skills at the arcade; either way, members enjoyed hanging out with their friends and without their folks.

Twelve members took advantage of learning culinary skills a licensed dietitian from November 30th. Students received practical, hands-on instruction in meal preparation and healthy recipes, then concluded the class with a family style meal. The event received great reviews from the students and their parents and will likely be added as regular programming.

For more information, contact Sydney Ferrara or Caroline Fehlhafer. Their e-mail addresses are located in the Contacts section of this newsletter.



Pictured (L-R): Zach Kriz and volunteer Jenny Knobbe



Group and volunteers at Gateway Mall. We ate at the food court, shopped around the stores, and tried on silly clothes.



Members of the group reading the directions with the help of the dietician Kena Ludemann



Clayton Stull trying a new style at The Buckle

## **COMMITTEE CHAIRS LUNCHEON**



In appreciation of their service, DSAF leadership was invited to a luncheon, held in January at Fireworks Restaurant in Lincoln. Guests had an opportunity to network and share updates, both personal and professional. Members of the Board briefed the group regarding organizational matters and answered questions.

Pictured: (Front row, L-R) Jodi White, Jennifer Lohmeier, Mary Sweeney, Kelly Ekeler, DEan Fuelberth. (Back row, L-R) Rick Bohaty, Stephanie Longwell, Sydney Ferrara, Liz Echternkamp, Jennifer Brill, Torri Attebury, Holly Lohmeier, Kathryn Brockmeier

#### **CCSUDS WALK TALK**

The "Step Up Walk," as it is most widely known, has a long-standing tradition in Lincoln. Down Syndrome Association for Families of Nebraska (DSAF) hosted its first "Buddy Walk" in 2002 to bring about awareness and serve as the organization's one annual fundraiser. In 2010, DSAF joined with other Down syndrome affiliate groups across the country in re-branding the annual event in an effort to include Down syndrome in the marketing, along with creating a positive call-to-action for the entire community and state. The Capital City Step Up for Down Syndrome Walk has since grown to 78 teams and more than 1,700 participants. Thanks to the walk, DSAF has expanded what it can provide to Lincoln and beyond. The 2017 Annual Report, expected to hit mailboxes in March, will outline the details.

Don't forget to mark your calendars and make plans to join us at the 2018 Capital City Step Up for Down Syndrome Walk on Saturday, October 6, at Antelope Park.

It won't be long before we kick off the 2018 planning season for the walk. Want to join our planning party? You may choose to sit on a sub-committee, but you are also welcome to provide your input on the general committee. Contact Jennifer Brill and Jennifer Lohmeier at stepupwalk@dsafnebraska.org for more information.













Photos courtesy John Simms

# 2017 Statistics

1,712 registered walkers • 25 corporate sponsors \$82,281 raised • 78 teams • 81 fact posters

### **INCLUSIVE SCHOOLS WEEK, DECEMBER 4 - 8**



Inclusive Schools Week celebrates the progress that schools have made in providing a supportive and quality education to an increasingly diverse student population. The Week also provides an important opportunity for educators, students and parents to discuss what else needs to be done in order to ensure that their schools continue to improve their ability to successfully educate all children.

This year, the Inclusive Schools Week theme focused on standing up for inclusion. This is particularly fitting because in our world today, we are embracing changes necessary to protect the practices in education and society essential to making a positive difference for all. In schools where inclusive education flourishes, there is an inspirational, more positive culture.

To help celebrate, DSAF gave its members the chance to nominate a teacher who stands up and sits tall for inclusion. Submissions were reviewed and selected awardees received a special Certificate of Acknowledgement and a gift card. In addition, all nominees (and respective principals) received a letter of acknowledgement and a copy of the nomination narrative. Thank you to everyone who submitted nominations and especially to those who stand up and sit tall for inclusion!

#### **CONTACTS**

DEan Fuelberth, Board President Chris Marvin, Board Secretary Stephanie Longwell, Board Treasurer Rick Bohaty, Board Member Jennifer Brill, Board Member/Step Up Walk Co-Chair Julie Huls, Board Member Mary Sweeney, Board Member Holly Lohmeier, Medical Outreach Chair Torri Attebury, Lil' Stars Co-Chair Tracy Kadavy, Lil' Stars Co-Chair Liz Echternkamp, Super Stars Chair Caroline Fehlhafer, Teen/Young Adult Stars Chair Sydney Ferrara, Teen/Young Adult Stars Leader Jennifer Lohmeier, Step Up Walk Co-Chair Kelly Ekeler, Newsletter Editor Kathryn Brockmeier, Newsletter Editor Jodi White, Program Director

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Other DSAF e-mails: info@dsafnebraska.org finance@dsafnebraska.org stepupwalk@dsafnebraska.org

# Down Syndrome Association for Families (DSAF)

P.O. Box 57362 Lincoln, NE 68505

Return Service Requested

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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# LIL' STARS WIGGLE AND GIGGLE TO KINDERMUSIK











# Celebration

March 21, 5:30 pm National Guard Armory 1776 N. 10th Street Lincoln

In an effort to accommodate a greater audience, DSAF leadership will offer abbreviated multiple annual membership meetings intermittently throughout the evening to offer information organizational (e.g. financials, updates, etc.) in lieu of the meeting formally held prior to the main event. Please communicate questions, areas of focus, or concern to dean@fuelberth.com.

