

# Down Syndrome Association for Families of Nebraska

## Summer 2018

### July / August / September

#### WORLD DOWN SYNDROME DAY

On March 21, more than 270 guests came together to celebrate World Down Syndrome Day. There were many new faces from the community as well as volunteers and old friends. Our events would not be possible, or nearly as enjoyable, without their help.

Attendees snacked on complimentary cotton candy, pizza, treats and bottled water, including gluten free and other healthy options. Blinky the Clown mesmerized onlookers with fantastic balloon creations, while a volunteer painted eager faces. For the parents, DSAF leadership offered membership meetings on each half hour throughout the evening to provide organizational information and answer questions from members. Special thanks and appreciation to those members of our community who went above and beyond for the celebration by lending a hand, sponsoring, offering goods/services free of charge, including, but not limited to:

- Happy D Klown
- Clowning Around Nebraska/Doris Lane
- Enable Savings Plan/First National Bank – *2017-18 Signature Sponsor*
- FOTObtrations FOTObooths
- Men's Wrestling team and Department of Special Education, Concordia University – Nebraska
- Party Inflators/Scott and Kelly Neal
- Premier O&P
- Spirit of '76 Armory/Patrick Bruning
- The Happy Hippy, magician/Fred Kracke
- WellnessOne Chiropractic – *2017 Signature Sponsor*
- Woods Bros. Realty/Jamie Bertucci



#WhatIBringToMyCommunity

## **DSAF REPRESENTED AT 2018 DOWN SYNDROME AFFILIATES IN ACTION LEADERSHIP CONFERENCE**

DSAF sent three leaders to the 2018 Down Syndrome Affiliates in Action (DSAIA) Leadership Conference held in Denver in late February. DSAF was represented by DEan Fuelberth, President; Torri Attebury, Board Member and Co-Chair Medical Outreach and Lil' Stars; and Jodi White, Program Director.

DSAIA partnered with Denver-based Global Down Syndrome Foundation in holding the Leadership Conference. Global hosted a pre-conference symposium of latest trends and developments in Down syndrome research and medicine at the renowned Linda Crnic Institute for Down Syndrome. While the purpose of the trip was to obtain education and up-to-date information regarding Down syndrome, networking with other affiliates from across the U.S. was also a high priority for our DSAF representatives.

Conference hosts offered several opportunities which encouraged guests to gather and exchange ideas and news. Because DSAF is a contributing member of Global, we received a special invitation to Global's Member Dinner (pictured, DEan Fuelberth, Jodi White, both of DSAF, with Ashley Sparhawk, Global, at Elway's Steakhouse).



### **THREE ACTION ITEMS FROM THE DSAIA CONFERENCE**

By Torri Attebury

Here are three ideas from DSAIA Conference that I would love DSAF to implement:

1. "Each One, Reach One" — DSAF moms distribute information about Down syndrome to local OB/GYN's and family practice physicians during their annual exams. Information passed out could include DSAF pamphlets and information about Nebraska legal requirements for giving a Down syndrome diagnosis.
2. Create a Spanish Resource page on our website that includes links for existing Spanish resources from Lettercase, and other pages. Links to the current AAP guidelines from NDSS and the Nebraska DHHS page.
3. Inform DSAF members about LuMind Research Down Syndrome.

## **MORE INFORMATION ON LUMIND RESEARCH DOWN SYNDROME**

LuMind Research Down Syndrome's (RDS) vision is a world in which people with Down syndrome are fully included in academic and social environments and where they can live independently as adults, if they so choose. LuMind is focused on developing drugs and interventions that target conditions associated with Down syndrome, such as early onset Alzheimer's. LuMind is working on developing a cognitive test for detecting early symptoms of Alzheimer's in people with varying baseline cognitive abilities. LuMind expects a drug for the treatment of Alzheimer's to be ready for a large scale clinical trial within the next two years. LuMind is building a community of people with Down syndrome who are interested in the latest medical and clinical trial information available.

So much more than an extra chromosome.



# WALK TALK

By Jennifer Brill and Jennifer Lohmeier

Each year the walk takes place rain or shine in October at **Antelope Park in Lincoln, NE**. It is a morning filled with fun, friendship and smiles. Funds raised for the walk provide support and information for members and the community. This year's walk will take place on **Saturday, October 6th**. Be sure to watch your email and Facebook for updates and posts. Visit <http://dsaf.ezeventsolutions.com/StepUp> for more information.

## Dates to remember:

- **Sunday, September 2** — Deadline for donations to qualify for the Early Bird Fact Posters
- **Thursday, September 13** — Deadline to register to get a free t-shirt
- **Thursday, September 13** — Deadline to turn in Stars Bio sheets
- **Wednesday & Thursday, October 3 and 4** — T-shirt pick up (teams can also drop off donations at this time)
- **Thursday, October 4** — Deadline for donations/walkers to qualify for "top teams"
- **Saturday, October 6** — The Capital City Step Up for Down Syndrome Walk!

Note: To be eligible for team prizes, donations and/or registrations need to be received prior to 11:59 p.m. on October 4, 2018. Feeling overwhelmed? No worries! Our co-chairs are here to help you set up your online walk team page and get started! To get the ball rolling, just email them at [stepupwalk@dsafnebraska.org](mailto:stepupwalk@dsafnebraska.org).

## 7 easy ways to raise \$500 in a week

- |   |       |
|---|-------|
| 1. Sponsor yourself for \$25...                           | \$25  |
| 2. Ask three family members for \$25...                   | \$75  |
| 3. Ask five friends to donate \$15...                     | \$75  |
| 4. Ask five co-workers to sponsor you for \$10...         | \$50  |
| 5. E-mail fifteen contacts and ask for a \$10 donation... | \$150 |
| 6. Ask your company for a \$75 contribution...            | \$75  |
| 7. Ask two businesses you frequent for \$25...            | \$50  |

**Total: \$500**

YOUR  
CO-CHARS



Jennifer Brill will once again be co-chairing the walk. She brings great experience as she has co-chaired the last three walks and been a part of the walk committee for five years.



This year, Jennifer Lohmeier joins Jennifer Brill in co-chairing the CCSUDS walk. She recently served as the DSAF Treasurer and has been a part of the walk committee for the past three years.



## SUMMERTIME SOCIAL & SWIM PARTY

On July 27th, a great crowd gathered at University Place Park and Aquatic Center, despite the clouds and cool weather. There were many familiar faces, along with several new. Thanks to Culver's for supplying the frozen custard—the sundaes were a big hit!





## RECENT EVENTS



Lil' Stars (pictured top left) had a great time at My Gym Children's Fitness Center, on May 6th. This group organizes social events, especially for our member families with young and very young children and their siblings. Take Me Out to the Ballgame with DSAF (pictured top center and right) featured the Chicago Dogs versus the Lincoln Saltdogs. DSAF members and their families were eligible for free tickets. DSAF members and their immediate family (pictured left) received free admission to the Henry Doorly Zoo and Aquarium through a special arrangement with the zoo, the Special 1 Pass.

## CONTACTS

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

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**Down Syndrome Association  
for Families (DSAF)**

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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](http://www.dsafnebraska.org)

Telephone: 402-421-1338

**NON-PROFIT  
US POSTAGE  
PAID  
PERMIT 1024  
LINCOLN, NE**



**Der Viener Schlinger**  
**Healing Hearts**  
**Therapy Dogs**  
**Mascots** Face painting  
**Hair painting** **Music**  
**Cheer Xpress**  
**Sunshine Cheer Team**  
**Food** Balloon artist  
**Emergency vehicles**

**SATURDAY** Festivities start at 8 AM  
Walk begins at 9:30 AM  
**OCTOBER 6**

<http://dsaf.ezeventsolutions.com/StepUp>

**FEATURING** Orgullo Latino Mexican Folkloric Dance

