



since
1995



HIGHLIGHTING ACCOMPLISHMENTS

LEADERSHIP MESSAGE

8

LIL' STARS
and
SUPER STARS
events

EDUCATIONAL
CONFERENCE

90 attendees
featuring
10 speakers

1,779

registered walkers

79 teams

>\$88K raised

2

key pieces of
GOVERNMENT ACTION

200+

(record attendance)
HOLIDAY BRUNCH

43 families

DSAIA
engaging leadership
across the U.S.



Board President, **DEan Fuelberth**, shares a dance with daughter, **Elissa**, to live music at the **2016 HOLIDAY BRUNCH**.

Raising the Bar – year twenty two - 2017

All of us know that it is the seemingly small milestones that some people would take for granted are HUGE accomplishments for our kids. Please keep striving to set the bar high, obtain resources and supports, and allow for society to see how individuals with Down syndrome ARE like their peers and highly valuable, contributing members in the community.

In 2017, the DSAF continues to expand the organization's vision to allow more benefits of membership.

- The Board dedicates almost a full day each year to a Strategic Planning Retreat (after connecting at two Chair gatherings during the year to gather input from our volunteer leadership) to focus on the long term vision, what is working that needs minor adjustments, and what new initiatives could bring value to members. We arrived at several categories to contain detailed tasks:
 - Organizational Infrastructure **Objective**
 - Implement a new management tool to organize, prioritize, and monitor all DSAF yearly operational tasks
 - Communication **Objective**
 - Assess and redefine our Web and Social Media standards and needs
 - Financial Structure **Objective**
 - Quantify benefits to members
 - Expand our grants and corporate partners
 - Adolescent to Adult / Transition Services **Objective**
 - Continue partnership with other community organizations
 - Create a NEW DSAF Book Club / social program for Teens and Adults
- Expand last year's initial use of DSAF Board Minute video clips to provide another quick method for members to gain regular insight into work underway

Please utilize the DSAF resources and Step-Up to volunteer when possible to help our organization lead and provide benefits to our membership, the community of Lincoln, to Nebraska, and beyond.

DEan Fuelberth
DSAIF Board President



MEDICAL OUTREACH

Serving in dual leadership roles as members of the DSAF Board and Medical Outreach Chairperson/member, respectively, Alicia Bruning and Dr. Sonya Reynolds work to educate others regarding Down syndrome by raising the awareness of the local medical community, especially during the diagnosis of a child with Down syndrome, and provide current and accurate information to new and expectant parents.

The committee served a number of families through its **PARENTS FIRST CALL PROGRAM**. "New" parents (*those just receiving a diagnosis of Down syndrome, whether prenatal or at birth*) are paired with **FIRST CALL PARENT VOLUNTEERS** (*trained member volunteers who have a child with Down syndrome*) to provide accurate and up-to-date information, support and foster networking.

The University of Nebraska Lincoln - National Student Speech Language Hearing Association (NSSLHA) committed to focusing its group efforts toward DSAF's MEDICAL OUTREACH PROGRAM. In addition to lending invaluable hands-on help, NSSLHA's members organized fundraisers - donating proceeds to MEDICAL OUTREACH efforts. In April, NSSLHA chose Alicia to receive an **INSPIRATION AWARD** "*For providing inspiration to our students and expanding the opportunities for persons with disabilities.*" The honor is a positive affirmation of Alicia's dedication to sharing her passion as a leader and testament to the role model she is to these students and the community.



Alicia Bruning, with a congratulatory cake given to her after receiving NSSLHA's INSPIRATION AWARD.

Top left: Alicia receives her INSPIRATION AWARD.

PARENTS FIRST CALL at a glance

PLAYED KEY ROLE IN PASSING LB891

then, collaborated to provide content which Nebraska Department of Health and Human Services now offers statewide

6 FAMILIES RECEIVED GIFT BASKETS

and support from First Call Parents

3 PRESENTATIONS GIVEN

to offices/hospitals, including Medical Resident Program

33 OUTREACH VISITS representing 71+ providers

8 FAMILIES RECEIVED PRENATAL INFO PACKETS

9 NEW FAMILIES CONNECTED

*via New Parent Brunch**

**Event presenters organized by Liz Echternkamp*



NEW PARENT BRUNCH at FIRESPRING
Occupational and physical therapists, a pediatrician and a speech pathologist were on-hand to share their knowledge with new parents.



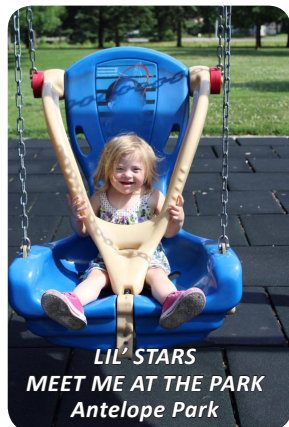
Members of UNL NSSLHA use their meeting time to assemble NEW PARENT GIFT BAGS.



UNL NSSLHA presents DSAF Program Director, Jodi White, with a donation.



UNL NSSLHA hosts a fundraiser at YORGURTINI in Lincoln. YORGURTINI gave 15% of all designated sales to DSAF.



LIL' STARS
MEET ME AT THE PARK
Antelope Park



LIL' STARS
NO-SCARE HALLOWEEN PARTY
Arbor Day Farm



LIL' STARS
PRIVATE POOL PARTY
LifeSTROKES



LIL' STARS
BACK-TO-SCHOOL PARTY
Ager Play Center



SUPER STARS
PRIVATE SWIM PARTY
LifeSTROKES



TEEN/YOUNG ADULT STARS
HEALTHY COOKING CLASS at HyVee



TEEN/YOUNG ADULT STARS
GO BOWLING



TEEN/YOUNG ADULT STARS
GO BOWLING at Parkway Lanes



SUPER STARS
AT THE MOVIES
Marcus Edgewood Theaters

LIL' STARS

Social events especially for our member families with children ages birth through 5 years and their siblings. Events included: **MEET ME AT THE PARK**, **NO-SCARE HALLOWEEN PARTY**, **PRIVATE POOL PARTY**, **BACK-TO-SCHOOL PARTY**.

CO-CHAIRS: Kathryn Brockmeier & Tracy Kadavy

SUPER STARS

Offers meaningful social events for school-aged children (kindergarten to high school), focusing on fostering peer relationships for the individual with Down syndrome.

Events included: **PAINT YOURSELF SILLY**, **AT THE MOVIES**, **PRIVATE SWIM PARTY**.

CHAIR: Liz Echternkamp

TEEN/YOUNG ADULT STARS

Provides opportunities for teens with Down syndrome to socialize with young adult mentors and their peers.

Events for the year included: **GO BOWLING**, **HEALTHY COOKING CLASS**, **SENSORY FRIENDLY VALENTINE'S DANCE** (in coordination with O.N.E. Coalition)

CHAIR: Janette Johnson (1st quarter), Caroline Fehlhafer

MOM'S NIGHT OUT

Gatherings organized to offer a casual environment for fellow parents to network and enjoy an evening out.

PARENT'S COFFEE

Opportunities offered for parents to meet and share joys, challenges and stories.



TEEN/YOUNG ADULT STARS
HEALTHY COOKING CLASS



DSAF member, Grant, enjoying **HUSKER HEROES**, by O.N.E. Coalition.



DSAF member, Ryan, receiving encouragement and direction from iCanShine staffer, Mark.



DSAF TEEN/YOUNG ADULT STARS join the fun at the **SENSORY FRIENDLY VALENTINE'S DANCE**.



COMMUNITY



Jodi White receives donation proceeds from Neat Repeatz.

In 2016, DSAF continued collaboration with other local groups to work together to bring programs to our community. We continue to be a part of **O.N.E. COALITION**, a group that represents a wide range of individuals with special needs. This alliance brought us the **SENSORY FRIENDLY TEEN VALENTINE'S DANCE** in February and **HUSKER HEROES** - where we partnered with University of Nebraska Athletics Department to provide a night of fun for our members.

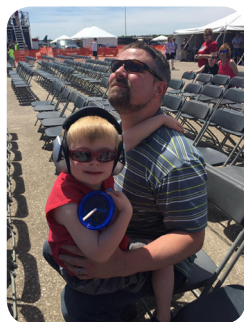
Thanks to **MADONNA REHABILITATION HOSPITAL**, **iCanBike CAMP** came to Lincoln in July. DSAF coordinated with camp organizer, Cindy Ryman Yost, to promote the opportunity to members and offered scholarships to help defray registration costs for DSAF members. 10 of the 21 participants were children with Down syndrome (*most of whom were from DSAF member families*).

In May, DSAF received an official invitation specific to its members with Down syndrome. Guests had an exclusive opportunity to experience the U.S. Navy Flight Demo Squadron **BLUE ANGELS** in a less crowded and more controlled environment than that of the public air show (*pictured, below*).

In September, **NEAT REPEATZ CONSIGNMENT SALES** continued its efforts of helping charities serving Lincoln families by hosting a charitable drive for DSAF. A DSAF promotional flyer was placed in each bag and **NEAT REPEATZ** matched every dollar donated.

UNION COLLEGE students have played a key volunteer role at various DSAF events throughout the year. Program Director, Jodi White, presented to more than 300 students, faculty and staff at **PROJECT IMPACT 2016** in September. Project Impact is the longest running collegiate community service day in the country and the group has dedicated countless hours of service to Lincoln and, more specifically, DSAF. Additional colleges/groups from the area to whom DSAF calls upon regularly for volunteer resources: **UNL-THETA**, **UNL-NSSLHA** and **CONCORDIA UNIVERSITY-NEBRASKA**.

DSAF offered **DHHS PRESENTS: WHAT DEVELOPMENTAL SERVICES DOES NEBRASKA OFFER FOR CHILDREN/YOUNG ADULTS?** The event was organized by Liz Echternkamp in response to member feedback and held at the **LINCOLN COMMUNITY FOUNDATION** in November. DSAF utilizes various resources and connections throughout the community, such as: **FIRESPRING**, **NONPROFIT HUB**, **CHI HEALTH-ST. ELIZABETH** and **CATALYST-UNION BANK & TRUST**.



2016 EDUCATIONAL CONFERENCE

Saturday, November 5

Country Inn & Suites Conference Center
Lincoln, Nebraska
5353 North 27th Street



HELPING CHILDREN WITH SPECIAL NEEDS



REACH THEIR FULL POTENTIAL.



The **2016 EDUCATIONAL CONFERENCE** was held in November. DSAF was one of 11 organizations across the United States to receive a **GLOBAL DOWN SYNDROME FOUNDATION EDUCATIONAL GRANT** for innovative programs impacting the lives of thousands of people with Down syndrome across the nation. The **2016 DSAF EDUCATIONAL CONFERENCE** provided accurate and up-to-date information on best practices to parents, educators, medical professionals, and direct-service professionals across the state, with a focus on education and behavior in children with Down syndrome. **GLOBAL'S EDUCATIONAL GRANT** eligibility is one of the key benefits to DSAF's GDS membership. DSAF is grateful for the opportunity to better serve its membership and greater Down syndrome community.

10 speakers offered expertise in fields such as: literacy instruction, behavior, transitioning, IEPs, recreational therapy, and alternative communication for children with Down syndrome of various ages.

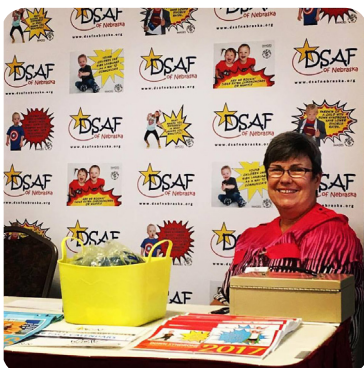
Guests had multi-track options to choose from during each of three concurrent session time blocks, for a total of 12 sessions, in addition to nationally renowned keynote opener, **DR. KATHLEEN WHITBREAD**, and conversational lunch presentation by Nebraska's own self-advocate, author and actor, **MARCUS SIKORA**, and his mother, **MARDRA SIKORA** (author, advocate and speaker).



2016 EDUCATIONAL CONFERENCE SPEAKERS

L to R: Heidi Sommer, B.A., Kathleen Whitbread, Ph.D., Denise Gehringer, Marcus Sikora, Matt McNiff, Ph.D., Mardra Sikora, Nicole Meyer, CTRS
Not pictured: Amelis Long, Carrie Kenny, M.S., CCC-SLP, Jennifer Miller, M.A.

Self-advocate, actor and author, Marcus Sikora, signing a copy of his book, "BLACK DAY THE MONSTER ROCK BAND" for an attendee.



2016 Educational Conference Planning Committee member, **Janelle Ekeler**, helps with sales at the product table.



2016 EDUCATIONAL CONFERENCE PLANNING COMMITTEE:

Kathryn Brockmeier, Liz Echternkamp, Janelle Ekeler, Caroline Fehlhafer, Lori Prange (Chair) & Jodi White



ADVOCACY & AWARENESS



Representatives from DSAF and other leaders of the Down syndrome community in Nebraska testified on behalf of bill **LB891-DOWN SYNDROME DIAGNOSIS INFORMATION AND SUPPORT ACT**.

LB891-DOWN SYNDROME DIAGNOSIS INFORMATION AND SUPPORT ACT was introduced by Senator Lydia Brasch on January 11. DSAF Board members, its Founder and staff worked with other leaders from the Down syndrome community in Nebraska to help support the legislation (*i.e. visiting with senators, testifying at the hearing*) which became law April 7. The law helps to ensure that any family who receives a new diagnosis of Down syndrome in the state of Nebraska will be given up-to-date, accurate and non-biased information about Trisomy 21.

Additionally in 2016, Nebraska became one of the first states in the nation to offer tax-advantaged savings accounts to enable children and adults with qualifying disabilities to save and invest their money without jeopardizing benefits they may receive through public programs like SSI and Medicaid. Representatives from DSAF were part of the Nebraska delegation which traveled to Washington D.C. multiple times during the past several years to speak to members of Congress in support of the nation ABE act.

Pictured top-left, down:

DSAF President, DEan Fuelberth, Program Director, Jodi White, and Down Syndrome Alliance of the Midlands President, Sherri Harnisch (with her daughters), at the ENABLE NEBRASKA press conference held in Lincoln.

A live-screenshot of DSAF member, Elissa Fuelberth, testifying in front of Health and Human Services senate subcommittee at the Nebraska state capitol in support of LB891.

The DOWN SYNDROME DIAGNOSIS INFORMATION AND SUPPORT ACT became law in April. Governor Pete Ricketts declared March 21st WORLD DOWN SYNDROME DAY in Nebraska.

DSAF publishes a **CALENDAR** annually and distributes copies throughout the community. Calendars feature images of members with Down syndrome and include facts about Down syndrome to promote education and awareness.

CALENDARS





WORLD DOWN SYNDROME DAY CELEBRATION

3-21

On 3-21, DSAF hosted its annual **WORLD DOWN SYNDROME DAY (WSDS) CELEBRATION**. The event is open to the public and free to attend. Guests came together to raise awareness while enjoying cotton candy, balloon creations, an inflatable obstacle course, take-home snapshots, treats, door prizes and more!

Thank you, to event contributors: **RUSS'S MARKET, HY-VEE STORES, THE COOKIE COMPANY, PREMIER O&P, FOTOBRATIONS FOTOBOOTH** (featured, left), **WALMART, PARTY INFLATORS** (owners of which are DSAF members, Scott and Kelly Neal) and DSAF member, **ROBERT KADAVY**.

2016 WSDS COMMITTEE: Liz Echternkamp (Chair), Mandy Martinez & Kathi Tiede



INCLUSIVE SCHOOLS WEEK - DECEMBER 5-9

In 2016, the **INCLUSIVE SCHOOLS WEEK** theme focused on the concept of being a hero. This is particularly fitting because the definition of a hero, "a person noted for courageous acts of nobility of character," resonates with all of the students, parents, teachers, principals and community leaders who take courageous steps forward each day to promote acceptance for all.

DSAF offered its members the opportunity to nominate their heroes - teachers or staff that support inclusion in the regular education classroom. As a result, nearly 50 **CHAMPIONS OF INCLUSION** were honored by DSAF, on behalf of its members. A certificate of recognition and store gift card for these every day super heroes were personally delivered to schools in Lincoln and the surrounding communities.



A stop at Rousseau Elementary for Inclusive Schools Week.



FACT POSTERS Over 90 **FACT POSTERS** were displayed along the one mile CCSUDS WALK route and featured pictures of our loved ones with and important facts about Down syndrome to raise awareness. These images are used throughout the year for further promotion of Down syndrome awareness.

CALENDAR and FACT POSTER photography credit:



FACT POSTERS



STEP UP FOR DOWN SYNDROME WALK 2016

The 15th Annual Capital City Step Up for Down Syndrome Walk (CCSUDS) took place on October 1st. The CCSUDS committee, headed by co-chairs Jennifer Brill and Jamie Bertucci, coordinated our largest awareness event to date! A new t-shirt design commemorated the noteworthy anniversary and guests enjoyed performances by i2Choir and Cheer Xpress (with many DSAF members represented in both groups), live music by The String Beans, a LPD motorcycle and a LFD firetruck up-close, photos with Princess Elsa and more. Festivities were emceed by media partner FROGGY 98.

Whether in-person or in their hearts, teams (ranged in size from a few walkers to 140) walked to celebrate their loved ones with Down syndrome.

Silent auction items included a hand-sewn quilt made from past CCSUDS t-shirts, original artwork, HUSKER game tickets, and many other items.

Over 100 students from surrounding colleges were on-hand before sun-up to volunteer their time, energy and goodwill.

2016 SPONSORS

Froggy 98
Images for a Lifetime

PLATINUM

In Memory of Don Lovegrove
Boyd's Electric

GOLD

Dental Designs
Allo

SILVER

T.O. Haas
Schneider Electric
Women's Clinic of Lincoln, PC
Wellness One
Complete Children's Health
Dramco

BRONZE

NebraskaLink
Waverly United Methodist Church
Lincoln Surgical Hospital
Ehlers Animal Care
Chick-fil-A
Dr. Mota
Weer Motorsports
First State Bank
Speedway Motors
A Place to Grow
FOP Lodge 32
Hannappel Inc.
Solid Orange Architecture
HomeServices of Nebraska
Debra Placek MD
Channel Seed
Edward Jones
Premier O & P
Lincoln Pediatric Dentistry





2016 CCSUDS

at a glance

79 TEAMS

1,779 REGISTERED WALKERS

RECORD 1,650 DAY-OF PARTICIPANTS

OVER \$88,000 RAISED



STARS POSTERS



2016 WALK COMMITTEE partial group

2016 CAPITAL CITY STEP UP FOR DOWN SYNDROME WALK COMMITTEE MEMBERS

Jamie Bertucci (Co-Chairperson), **Jennifer Brill** (Co-Chairperson), **Dean Fuelberth** (Publicity), **Holly Lohmeier** (T-Shirt), **Kathryn Brockmeier** and **Liz Echterkamp** (Entertainment), **Dennis Kriz** (Logistics), **Mandy Martinez** (Food and Beverage), **Tina Barrett** (Stars Display), **Brandee Talley** (Fact Poster), **Courtney Downs** (Registration), **Tracy Kadavy** (Volunteer), **Jamie Bertucci** and **Amie Lovegrove** (Corporate Sponsorship), **Mary Sweeney** (Prize), **Jennifer Lohmeier** (Finance) & **Jodi White**



Our volunteers are
VERY good sports.



A rising star takes the stage
during NIGHT AT THE LINCOLN
CHILDREN'S MUSEUM.



NIGHT AT THE LINCOLN CHILDREN'S MUSEUM

DSAF offered several opportunities throughout the year, appropriate for the entire family. Annual events such as, **WORLD DOWN SYNDROME DAY CELEBRATION**, **NIGHT AT THE LINCOLN CHILDREN'S MUSEUM** and **HOLIDAY BRUNCH** are free to attend and members are encouraged to bring extended family and friends. Most events in 2016 had record participation.

In 2016, DSAF was granted a **SPECIAL ONE PASS** to **OMAHA'S HENRY DOORLY ZOO & AQUARIUM**. The pass allows DSAF members (*as a group*) to visit the zoo at no cost for admission. Trips were organized in June and July. The pass was renewed for 2017 and plans are underway for the next outing.

TAKE ME OUT TO THE BALLGAME gave members the chance to catch a game in the name of dads, when DSAF offered free tickets to the **LINCOLN SALTDogs** at **HAYMARKET PARK** on Father's Day.

UNIVERSITY PLACE PARK was the perfect backdrop for an **ICE CREAM SOCIAL & SUNSET SWIM PARTY** (*frozen custard, compliments of CULVER'S*) held in August. **UNIVERSITY PLACE AQUATIC CENTER** is a tried-and-true favorite of members, complete with water slides, sand and zero entry.

DSAF leadership arranged for college-age volunteers from the community (e.g. **UNION COLLEGE**, **UNL-NSSLHA**, **UNL-THETA** and **CONCORDIA UNIVERSITY NEBRASKA**) to join the fun at several events - lending assistance to parents by playing with the kids. Other volunteers attended as adult mentors, simply hanging out and making friends with their peers. With the help of the volunteers, parents found it easier to network with each other.



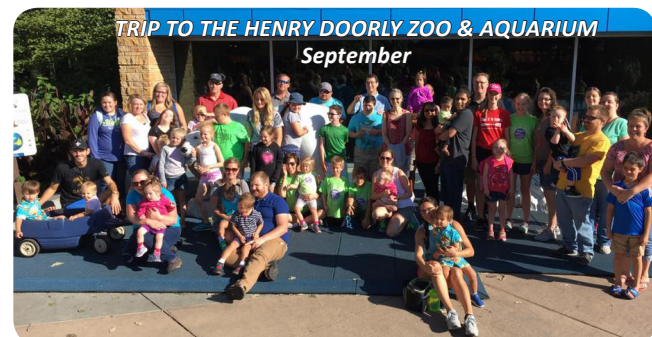
some of the 38 families at
TRIP TO THE PUMPKIN PATCH
Roca Berry Farms



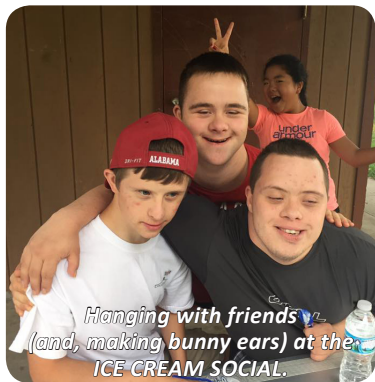
TAKE ME OUT TO THE BALLGAME
Haymarket Park



23 families enjoyed
TRIP TO THE HENRY DOORLY ZOO & AQUARIUM
in June



TRIP TO THE HENRY DOORLY ZOO & AQUARIUM
September



*Hanging with friends
(and, making bunny ears) at the
ICE CREAM SOCIAL.*



*Sharing a wagon at the
ICE CREAM SOCIAL*



*A hayrack ride during
TRIP TO THE PUMPKIN PATCH.*

FAMILY EVENTS



*Hank enjoyed the live music by
E-Z-B TRIO
at the HOLIDAY BRUNCH.*



*The older members enjoyed getting to know the
volunteers at the HOLIDAY BRUNCH.*



A pretty picker at the HOLIDAY BRUNCH.

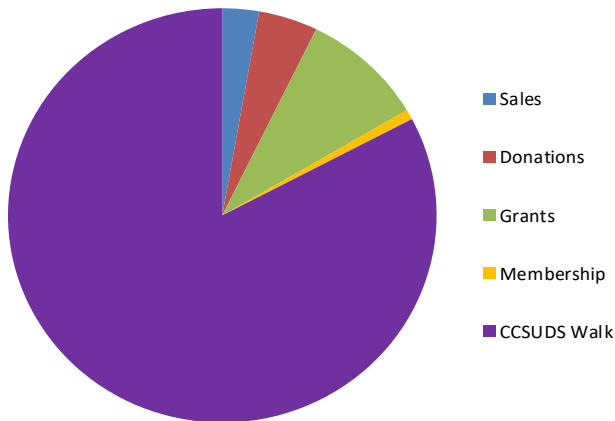


*The HOLIDAY BRUNCH gave Marley and
Sophia a chance to chat.*

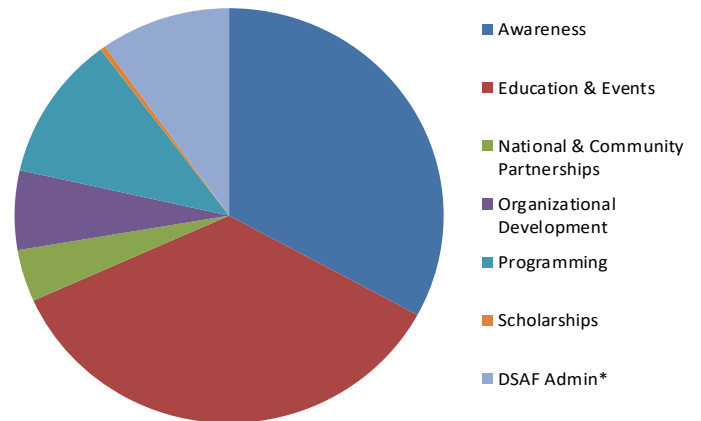


FINANCIALS

2016 REVENUE



2016 EXPENSES



Based on 2016 Revenues of \$107,558.82 and 2016 Expenses of \$120,786.42

| | |
|-------------|-----|
| Sales | 3% |
| Donations | 4% |
| Grants | 9% |
| Membership | 1% |
| CCSUDS Walk | 83% |

| | |
|-------------------------------------|-----|
| Awareness | 33% |
| Education & Events | 35% |
| National & Community Partnerships** | 4% |
| Organizational Development | 6% |
| Programming | 11% |
| Scholarships | <1% |
| DSAF Admin* | 10% |

A portion of **CAPITAL CITY STEP UP FOR DOWN SYNDROME WALK funds are distributed to multiple national organizations who provide benefits to the larger Down syndrome community (*reviewed annually*), currently: **NATIONAL DOWN SYNDROME SOCIETY (NDSS)** - legislation, **NATIONAL DOWN SYNDROME CONGRESS (NDSC)** - parent resources and annual convention, **DOWN SYNDROME AFFILIATES IN ACTION (DSAIA)** - resource sharing and annual convention, **GLOBAL DOWN SYNDROME FOUNDATION** - research.

EXAMPLES OF EXPENDITURES

EDUCATION & EVENTS

Such as:

Educational Conference
Holiday Brunch
Ice Cream Social & Swim Party
Night at the Museum
Trip to the Pumpkin Patch
WDSO Celebration

ORGANIZATIONAL DEVELOPMENT

PROGRAMMING

For example:

Lil' Stars
Parents First Call
Super Stars
Teen/Young Adult Stars

AWARENESS

Including, but not limited to:

CCSUDS Walk
FACT calendars
Inclusive Teacher Recognition
Newsletter*
Social Media
Website

SCHOLARSHIPS

NATIONAL & COMMUNITY PARTNERSHIPS

As listed, above**

DSAF ADMIN

*cost to run the organization that cannot be allocated elsewhere

*2016 NEWSLETTER COMMITTEE:
Kelly Ekeler & Kathryn Brockmeier



WE HOPE YOU'LL JOIN US
OCTOBER 7TH
FOR THE
2017 CAPITAL CITY
STEP UP FOR DOWN SYNDROME
WALK



www.dsafnebraska.org

MISSION

The Down Syndrome Association for Families (DSAF) is a Lincoln 501 (c)(3) 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.

PROGRAM DIRECTOR

Jodi White

FOUNDER

Deb Safarik



@dsafnebraska.org



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PO Box 57362
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NON-PROFIT
US POSTAGE
PAID
PERMIT 1024
LINCOLN, NE

BOARD OF DIRECTORS *(as of December 2016)*

DEan Fuelberth, President

Project Manager, Ameritas

Rachel Smith, Vice President

Doctor of Optometry, Eye Care Specialists

Lori Prange, Secretary

IT Manager/Higher Ed Implementation, Nelnet Business Solutions

Jennifer Lohmeier, Treasurer

Accounting Specialist, Lincoln Surgical Hospital

Rick Bohaty

Director of IT, CHI Health St. Elizabeth's

Alicia Bruning

Financial Systems Analyst, Lincoln Surgical Hospital

Christine Marvin

Professor Special Education & Communication Disorders, University of Nebraska

Sonya Reynolds

Pediatrician, Complete Children's Health

Jen Brill

Business Analyst, Allstate