2016 ANNUAL REPORT

HIGHLIGHTING ACCOMPLISHMENTS

since

1995
LEADERSHIP MESSAGE

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
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.
**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.
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.
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).
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.

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 though 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 ABLE 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-screen shot 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.
On 3-21, DSAF hosted its annual WORLD DOWN SYNDROME DAY (WDSD) 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 WDSD COMMITTEE: Liz Echternkamp (Chair), Mandy Martinez & Kathi Tiede

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.

A stop at Rousseau Elementary for Inclusive Schools Week.

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 everyday super heroes were personally delivered to schools in Lincoln and the surrounding communities.
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
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Dramco
BRONZE
NebraskaLink
Waverly United Methodist Church
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Weer Motorsports
First State Bank
Speedway Motors
A Place to Grow
POP 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

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 Echternkamp (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
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 SALTDODGS 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.
FAMILY EVENTS

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

A hayrack ride during TRIP TO THE PUMPKIN PATCH.

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.

Sharing a wagon at the ICE CREAM SOCIAL.
**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.

**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
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

BOARD OF DIRECTORS (as of December 2016)

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