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Featured photo, page left: DSAF’s NIGHT AT THE LINCOLN CHILDREN’S MUSEUM is a family affair! Zoey and her parents role play in the fire engine during the event held in February.
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13.... INSIDE BACK COVER - Picture Collage

******** BACK COVER - Board Members & Staff
Contact information for members of the Board and Staff can be found at dsafnebraska.org under “about us.”

Special thanks and recognition goes to our first SIGNATURE SPONSOR, WELLNESS ONE, for supporting individuals with Down syndrome. In addition to the sponsorship, WELLNESS ONE has committed to donate proceeds from new spinal screening visits to DSAF!

For questions regarding sponsorships or other opportunities available, contact Mary Sweeney at sweeneymary33@gmail.com.
Dear DSAF members and advocates - welcome to another exciting year!

The Board of Directors for the Down Syndrome Association for Families of Nebraska (DSAF) is an amazing team that is working for the one goal of improving lives for individuals with Down syndrome and their families. Let me share with you some information we believe will be of interest to our members.

**DSAF WALK HISTORY:** The “STEP UP FOR DOWN SYNDROME WALK,” as it is most widely known, has a long-standing tradition in Lincoln and is something our organization is very dedicated to - because it brings together people from all over the state, and is our only fundraiser. DOWN SYNDROME ASSOCIATION FOR FAMILIES OF NEBRASKA hosted its first walk in 2002 to bring about awareness and serve as the organization's annual fundraiser. Back then, it was called the “Buddy Walk” due to ties to the National Down Syndrome Society (NDSS). In 2010, DSAF joined with other Down syndrome affiliate groups across the country in re-branding the annual event to include Down syndrome in the marketing, along with creating a positive call-to-action for the entire community and state. The change also allowed DSAF to redistribute the 7% licensing fees and allocate those monies at our discretion. In addition to retaining more funds for DSAF membership, we can expend resources to support more national organizations for legislative advocacy, parent support, research and affiliate sharing (see, FINANCIALS page 12). This phenomenal walk and celebration day has grown to just under 2,000 people in 2017!

You may have heard, a new Down syndrome group in Lincoln is organizing a Buddy Walk in Lincoln. While DSAF welcomes increased awareness and further support for families, it is important to note that DSAF is not affiliated with the new group or event. We hope you will continue to support DOWN SYNDROME ASSOCIATION FOR FAMILIES OF NEBRASKA and join us at the STEP UP FOR DOWN SYNDROME WALK October 6th - it will be our 17th annual awareness walk! Funds raised from the STEP UP FOR DOWN SYNDROME WALK allow us to keep our DSAF membership dues to just $10/year. The following pages outline the many ways your family benefits from being a member.

You can be proud of the dedication and energy of our DSAF Board Members and Chairpersons. Board members meet monthly and dedicate many hours to refine the vision of our organization and outline how to achieve our goals. Volunteer leadership (better known as Chairs) work tirelessly and give of their own time to ensure our members receive the best possible support and quality of services.

We welcome you to our DSAF events, and encourage you to utilize our resources. Please update us as your information changes. Read through this report to re-acquaint yourself with DSAF opportunities. Help us support and enrich the lives of individuals with Down syndrome, their families, friends, educators, and professionals who share in their lives! THANK YOU for all your continued support.

Kind regards,

DEan Fuelberth
Down Syndrome Association for Families Board President
Holly Lohmeier accepted the role of MEDICAL OUTREACH Chairperson in 2017. Holly, Dr. Sonya Reynolds, Torri Attebury, and other members of the team strive 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. They often travel to medical offices with bags of treats and loads of information. When meeting with new parents, a bag of infant supplies, book, and pamphlets are provided.

The MEDICAL OUTREACH team worked diligently this past year to update the information which is provided to parents and also created a NEW PARENT RESOURCES booklet which lists many useful local and national resources.

The team connected with over 700 Obstetricians and Pediatricians statewide last year with a letter detailing the DOWN SYNDROME INFORMATION AND SUPPORT ACT and a fact sheet provided online by the Nebraska Department of Health and Human Services about the Act.

Answering a need to access the growing multi-cultural/lingual population of new parents, the group hosted a SPANISH OUTREACH event in 2017, held at the Cristo Rey Church in Lincoln and provided translators and information in Spanish.

The committee continues to serve families via the PARENTS FIRST CALL PROGRAM. “New” parents (with prenatal or at-birth diagnoses for their children) are paired with FIRST CALL PARENT VOLUNTEERS to provide accurate and up-to-date information, support and foster networking. These trained DSADF members act as FIRST CALL PARENTS, because they have a child of their own with Down syndrome and want to assure that parents new to the diagnosis have someone to call if they have questions.

The UNIVERSITY OF NEBRASKA LINCOLN - NATIONAL STUDENT SPEECH LANGUAGE HEARING ASSOCIATION (NSSLHA) began partnering with DSADF in 2016. It continued its commitment last year by focusing its efforts to support the DSADF MEDICAL OUTREACH PROGRAM. The group collated and assembled packets which are given to new parents. In addition, NSSLHA members have answered many calls to action as volunteer assistant at many of our events throughout the year.

MEDICAL OUTREACH AT A GLANCE

SENT up-to-date & accurate information to 700+ OB/GYNS in Nebraska
PRESENTED to 4 OB/GYNs regarding prenatal testing and diagnosis
VISITED 15 doctor/medical offices and 2 hospitals quarterly
CREATED New Parent Resources booklet
UPDATED new parent packets of information
PROVIDED a new parent packet & gift basket to 9 families in 2017
FIRST CALL PARENTS met with 7 families in 2017
HOSTED networking event for Spanish-speaking families
**NEWSLETTER**

**CO-CHAIRS: Kelly Ekeler & Kathryn Brockmeier**

A news source printed and sent to members quarterly offering a calendar of upcoming events, informative stories, and photos from events.

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**PARENT'S COFFEE**

Opportunities were offered for parents to meet for a couple of hours at Braeda in Lincoln to share joys, challenges and stories.

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**PARENT BOOK STUDY** *(new)*

This pop-up offering in 2017 was organized by Liz Echternkamp. Participants gathered weekly over the course of two months to discuss the book, *Supporting Positive Behavior in Children and Teens with Down Syndrome – The Respond but Don’t React Method*. DSAF offered the book for purchase at a discounted rate to members and volunteers were provided for those who needed childcare.

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**SOCIAL BOOK CLUB** *(new)*

Thanks to DSAF Board member, Dr. Chris Marvin, DSAF partnered with UNIVERSITY OF NEBRASKA-LINCOLN SPEECH-HEARING CLINIC to bring members ages 18-35 this semi-structured social opportunity. The club met weekly at the UNL Barkley Center and a local coffee shop for approximately 12 weeks during the Fall semester. UNL graduate students drove the gatherings, complete with syllabus of topics and plans for each session based on the book selection. Student clinicians were supervised by nationally-certified Speech-Language Pathologist Alicia Davis. All reading levels were welcome. Six participants paid $5/session, with balance of costs being unwritten by DSAF.

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**LIL’ STARS** *ages birth through 5 years*

**CO-CHAIRS: Tracy Kadavy & Torri Attebury**

This group organizes social events, especially for our member families with very young children and their siblings.

Events in 2017 included: PRIVATE SWIM/PIZZA PARTIES, LIL’ STARS GO TO MY GYM, PLAY DATE IN THE PARK, GO WIGGLING AND GIGGLING TO KINDERMUSIK

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**SUPER STARS** *kindergarten - high school*

**CHAIR: Liz Echternkamp**

Meaningful social events for school-aged children in 2017 focused on fostering peer relationships for the individual with Down syndrome.

Events included: PRIVATE SWIM PARTY, SUPER STARS GO TO CHAMPIONS FUN CENTER, GO TO THE MOVIES

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**TEEN/YOUNG ADULT STARS**

**CHAIR: Caroline Fehlhafer**

**GROUP LEADER: Sydney Ferrara**

Provided opportunities for older teens and young adults with Down syndrome to socialize with young adult mentors and peers in 2017. The addition of another leader enabled this group to grow and members benefited from the extra assistance and energy.

Events in 2017 included: GO TO THE MOVIES, GO BOWLING, MEET ME AT THE MALL, HEALTHY COOKING CLASS, SOCIAL BOOK CLUB, SENSORY FRIENDLY VALENTINE’S DANCE (in coordination with O.N.E. COALITION)

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**MOM’S NIGHT OUT**

Gatherings are organized to offer a casual environment for fellow parents to network and enjoy an evening out. In 2017 moms met in Lincoln for dinner at Lazlo’s and la Paz.
DSAF continued to collaborate with other local groups to work together to bring programs to our community in 2017. We support O.N.E. COALITION, a group which represents individuals with a wide range of special needs. This alliance brought us the SENSORY FRIENDLY TEEN VALENTINE’S DANCE in February and HUSKER HEROES in September. With partners from University of Nebraska Athletics Department, a night of fun was provided for our members at Memorial Stadium.

In 2017, LINCOLN CHILDREN’S ZOO granted our request to obtain 75 admission tickets through the CHILDREN AT THE ZOO (CATZ) program, whose goal is to ensure that no child or family with limited income is without access to the learning and play opportunities available at the Zoo. CATZ tickets were then distributed for individual DSAF member use.

CONCORDIA UNIVERSITY (CUNE), UNION COLLEGE, UNIVERSITY OF NEBRASKA-LINCOLN (UNL), along with CUNE-BASEBALL, CUNE-WRESTLING, CUNE-SPECIAL EDUCATION, UNL-THETA, UNL-NSSLHA organizations continue to provide us with college students who play a key volunteer role at DSAF events throughout the year.

DSAF utilizes various resources and connections throughout the community, for example: FIRESPRING (Holiday Brunch), CHI HEALTH-ST. ELIZABETH (monthly board meetings and workshops), NONPROFIT HUB (facilitator), CATALYST-UNION BANK & TRUST (Walk and strategic planning meetings), LINCOLN COMMUNITY FOUNDATION, and EVENTLINK. Partnerships such as these help to keep operational costs low.
The 2017 **EDUCATIONAL CONFERENCE** was titled **INCLUSION IN 3D**. The one-day conference was held in late October at Country Inn and Suites Conference Center in Lincoln. **INCLUSION IN 3D** addressed a critical need for educators and parents to look differently at their collaborations toward successful school experiences for students with Down syndrome.

Attendees enjoyed the “All Paula All Morning” agenda by nationally renowned inclusion expert, Dr. Paula Kluth, and received a copy of her book, *Don’t We Already Do Inclusion?*. The afternoon line up offered multi-track options to choose from during each of two concurrent session time blocks. A conversational lunch included a presentation by self-advocate, restaurant manager and college graduate, Jack Murphy, and his mother, Bridget Murphy who offered two sessions of the renowned **“MURPHY METHOD”** of toilet training your child with Down syndrome later in the day.

A panel of local leaders highlighted success stories of inclusive experiences. Panelists discussed how to direct individual efforts to establish similar school experiences. Attendees also learned about apps and tools for students to facilitate inclusion. In total, seven presenters contributed to the day.
SPECIAL THANKS TO OUR 2017 SPONSORS

SIGNATURE SPONSORS $5000 - up
- DSAF of Nebraska
- WellnessOne Chiropractic

SUDS PARTNERS $500 - $999
- Ameritas
- Bryan Physician Network
- dental designs
- Froggy 98
- IMAGES FOR A LIFETIME
- In Memory of Don Lovegrove
- nelnet

SUDS PARTNERS $250 - $299
- First United Methodist Church, Waverly
- Handprints & Footsteps
- Hannapel Inc.
- Lincoln Pediatric Dentistry
- Mario Mota, MD, P.C.
- Raising Cane’s
- Solid Orange Architecture
- Thomas M Fritsch, DDS, P.C.
- Weers Motorsports

$500 - $999, cont’d
- ENable SAVINGS PLAN
- Family Health & Wellness Center, P.C.
- Lovegrove Homes
- Pinnacle Bank
- Schneider Electric
- Union Bank & Trust

2017 CAPITAL CITY STEP UP FOR DOWN SYNDROME WALK COMMITTEE CHAIRPERSONS
- Jennifer Brill (Walk), Dean Fuelberth (Publicity), Kathryn Brockmeier and Tracy Kadavy (Entertainment), Holly Lohmeier (T-Shirt), Dennis Kriz (Logistics), Julie Huls (Food and Beverage), Tina Barrett (STARS Display), Liz Echternkamp (FACT Poster), Mary Sweeney (Prize and Sponsorship), Jennifer Lohmeier (DSAF Treasurer) & Jodi White (DSAF Program Director)

Photography credit:
- Day-of WALK-HANNAH VERENE PHOTOGRAPHY & JOHN SIMMS, FACT POSTERS-IMAGES FOR A LIFETIME
The CAPITAL CITY STEP UP FOR DOWN SYNDROME WALK has a longstanding tradition in Nebraska. The DSAF hosted its first walk in 2002 to bring about awareness and serve as the organization’s primary fundraiser. It has grown from 360 walkers in 2002 to 78 teams and more than 1700 walkers in 2017! Thanks to this success, the “STEP UP WALK” annually provides DSAF with funds which then provide its members and the community with needed supports and information.

The 16th Annual CAPITAL CITY STEP UP FOR DOWN SYNDROME WALK took place on October 7th despite the chilly temperatures and rain. The Walk committee, headed by Jennifer Brill, coordinated another memorable awareness event! Hot cocoa warmed tummies and hands and healthier snack options were added to the usual free fare. The crowd was especially fond of the many dogs provided by HEALING HEART THERAPY DOGS, INC. of Crete. The CHEER XPRESS: SUNSHINE TEAM performed, escorted the Top Team to the balloon arch start, and got each new walker fired-up with chants of encouragement. THE STRING BEANS musical group shifted their highly energized live concert into the Auld Pavilion where the crowd danced along to the tunes with RUNZA REX. Lincoln’s finest graciously allowed photo ops from atop a Lincoln Police Department motorcycle and a Lincoln Fire Department firetruck and PRINCESS ELSA was met with bright-eyes and hugs. Students from JOSEPH’S COLLEGE OF BEAUTY painted hair and faces, while those waiting in line watched balloon art being created. Family member, Abby Nelson, graced the official opening of the Walk by singing the NATIONAL ANTHEM. Festivities were emceed by media partner FROGGY 98.

Whether in-person or in their hearts, teams walked to celebrate their loved ones with Down syndrome. The weather didn’t deter anyone from visiting the wall of STARS BIOS. Raffle items included a children’s vintage-style pedal car, hand-crocheted blue and yellow “You Are My Sunshine” afghan, a child-size outdoor patio set, 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. Each Walk team was paired with a volunteer who proudly carried the team sign along the route. Others directed traffic, set up Top Team Tents, or helped at one of the various stations.

The 2018 CAPITAL CITY STEP UP FOR DOWN SYNDROME WALK on OCTOBER 6 will be our 17th awareness walk and fundraiser. We sincerely hope to see you there!
On 3-21 in 2017, DSAF hosted its annual WORLD DOWN SYNDROME DAY CELEBRATION. The date MARCH 21, or “3-21,” was chosen to signify the uniqueness of the triplication of the 21st chromosome, which results in Down syndrome. The event is open to the public and free to attend. More than 250 guests came together to raise awareness while enjoying cotton candy, balloon creations, a bounce house, an inflatable obstacle course, take-home snapshots, treats, many door prizes and more! New for 2017, dancers from the CAPITAL CITY DANCE SHACK performed several routines while the crowd gathered ‘round and grooved along.

The NATIONAL GUARD ARMORY provided a great, safe space where the kids could run while still under their parents’ watchful eyes. More than 30 UNION COLLEGE students were on-hand to assist.

Thank you, to event contributors: PARTY INFLATORS, PREMIER O&P, FOTOBRATIONS FOTOBOOTH, RUSS’S MARKET, HY-VEE STORES, THE COOKIE COMPANY, WALMART, and DSAF members, PAT BRUNING for his part in securing the venue and ROBERT KADAVY for his extensive assistance at the event.

The DOWN SYNDROME DIAGNOSIS INFORMATION AND SUPPORT ACT became a law in April of 2016. This 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.

In follow up, DSAF’S MEDICAL OUTREACH team worked diligently in 2017 to connect with medical offices statewide by sending a letter detailing the new law along with a fact sheet from NEBRASKA DEPARTMENT OF HEALTH AND HUMAN SERVICES.

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. In June 2017, DSAF coordinated with an ENABLE Outreach Specialist at FIRST NATIONAL BANK to offer members the opportunity to meet personally with specialists to ask questions and register for an account.

DSAF publishes a CALENDAR annually and distributes copies throughout the community. Calendars feature images of DSAF members with Down syndrome and include facts about Down syndrome to promote education and awareness. Images used for the calendars are some of the same as those seen in the over 80 FACT POSTERS displayed along the one mile STEP UP
WALK route. These featured pictures of our loved ones are accompanied by important facts about Down syndrome to raise awareness. The images are used throughout the year for further promotion of Down syndrome awareness. CALENDAR and FACT POSTER photography credit goes to IMAGES FOR A LIFETIME.

In November, members and others were invited to visit CHARMING CHARLIE store for a special event to benefit DSAF. Leadership greeted shoppers with a sweet treat and information about our organization.

The 2017 INCLUSIVE SCHOOLS WEEK (December 4-8) 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.

DSAF wanted to help recognize those teachers who stand up and sit tall for inclusion. DSAF members had the opportunity to tell us in 100 words or less why their nominee is exemplary in providing an inclusive educational environment. Awardees received a copy of the book, Don’t We Already Do Inclusion?, by Dr. Paula Kluth, a special Certificate of Acknowledgment and gift card. Additionally, all nominees and their respective principals, received a letter of acknowledgment and a copy of the nomination narrative.

Your DSAF membership is important - to DSAF leadership, you, your child and the community. It allows us to offer the education opportunities, medical outreach, and support that benefit your family. Providing updated, accurate information with your membership registration form helps us to tailor these events and empowers us with critical demographics needed as we seek grant funding for the organization.

DSAF held a membership drive in December of 2017 encouraging everyone to update existing information, renew otherwise “lapsed” membership, or become a new member. We received wonderful response! Please take a moment to check your information to ensure you stay abreast of everything DSAF has to offer. Please note membership policy change: Annual membership renewal will take place in January of each year.
FAMILY EVENTS

DSAF offered several social opportunities for members throughout the year that were 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 2017 had record participation.

OMAHA’S HENRY DOORLY ZOO & AQUARIUM renewed our SPECIAL ONE PASS in 2017. The pass allows DSAF members to visit the zoo at no cost for admission. Trips were organized in June and September. The pass was renewed for 2018 and plans are underway for the next outing.

University Place Park in Lincoln was the perfect backdrop for an ICE CREAM SOCIAL & SWIM PARTY in August 2017. UNIVERSITY PLACE AQUATIC CENTER is a tried-and-true favorite for this private party, complete with water slides, sand and convenient zero entry. Special thanks to CULVER’S of Lincoln for supplying plenty of frozen yogurt for everyone!

DSAF leadership arranged for college-age volunteers from UNION COLLEGE, UNIVERSITY OF NEBRASKA-LINCOLN, and CONCORDIA UNIVERSITY 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 Down syndrome. With the help of the volunteers, family members found it easier to network with each other.
ADVOCACY & AWARENESS: Step Up for Down Syndrome Walk, FACT Posters & Calendars, Website, Inclusive Teacher Recognition, Newsletter

EDUCATION & EVENTS: Night at Lincoln Children’s Museum, WDSD Celebration, Goes to Omaha’s Henry Doorly Zoo, Ice Cream Social & Swim Party, Educational Conference, Trip to the Pumpkin Patch, Holiday Brunch

NATIONAL & COMMUNITY PARTNERSHIPS (reviewed annually): **National Down Syndrome Society (NDSS) for legislative advocacy, National Down Syndrome Congress (NDSC) for parent support and national parent convention, Down Syndrome Affiliates in Action (DSAIA) for affiliate resource sharing and leadership conference, Global Down Syndrome Foundation for research

ORGANIZATIONAL DEVELOPMENT: Strategic Planning, Grant Writing Seminar, Leadership Conference

PROGRAMMING: Parents First Call, Lil’ Stars, Super Stars, Teen Stars, Social Book Club, Parent Book Study

DSAF ADMINISTRATIVE: Cost to run the organization
Volunteers anxiously awaiting the arrival of the Teams.

Kelsi poses with her FACT poster and a volunteer from CUNE.

A few members of Grant's Gang, aka his sister and besties.

The rain was no match for Chad.

Zach, sharing a hug and smiles.

This family didn't let the dreary weather dampen their spirit!

Lily was partial to this pup from Healing Heart Therapy Dogs, Inc.

Benjamin enjoyed a lift from dad.

We hope to see you October 6th at the 2018 STEP UP FOR DOWN SYNDROME WALK!

This shoulder is definitely Elly’s happy place.
MISSION
The Down Syndrome Association for Families of Nebraska (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.