



20
years strong
and **B E Y O N D**



HIGHLIGHTING ACCOMPLISHMENTS

20 Years Strong - *servicing Lincoln and the state of Nebraska* - and BEYOND!

2015 represented a landmark year for Down Syndrome Association for Families of Nebraska as we reached our 20th anniversary. We started the year with an especially festive World Down Syndrome Day celebration, due to bold new ideas by its committee chairs to revamp, refresh and grow the event.

Our search committee concluded a successful process, and on April 1st, the organization moved to hiring its first full-time Program Director—Jodi White. The board is so excited to have Jodi on-board, and helping us take the organization to new levels through programs, educational events, awareness, grants, and administration.

The board elected three new members from the community last year, adding their wealth of ideas and passion. It is truly a pleasure to work with this leadership team. The board instigated new technology to better organize our electronic file structure and collaborative abilities. We now have a Cloud-based DSAF hard-drive that is populated with files, allowing Board members, committee chairs and others to share folders within groups to allow access and updates. The structure brings greater efficiency and consistency, allowing us to maintain historical artifacts for reference as the Board and committees change over time.



Board members, DEan, Alicia, Jennifer and Chris, and Program Director, Jodi, at the 2015 Annual Holiday Brunch.

So, what is in store for DSAF as we move beyond year 20..?

Our Medical Outreach Committee and many board members collaborated with other Down syndrome organizations to help support Tom Venzor and Senator Lydia Brasch to introduce State legislation (LB891) signed into law on April 7th. (see picture, below)

The DSAF's involvement began years earlier. The DSAF sent representatives to join the Nebraska delegation in Washington D.C. three different years to speak directly with members of Congress regarding key national legislation impacting individuals with Down syndrome. The ABLE act and the Kennedy Brownback Act (the national version of LB891) resulted and were both passed into U.S. law, and have now also been addressed in Nebraska.

Please mark November 5th on your calendars for this year's exciting DSAF Educational Conference featuring national, regional, and local speakers.

This is going to be a phenomenal year, so kudos to our great volunteer leadership!

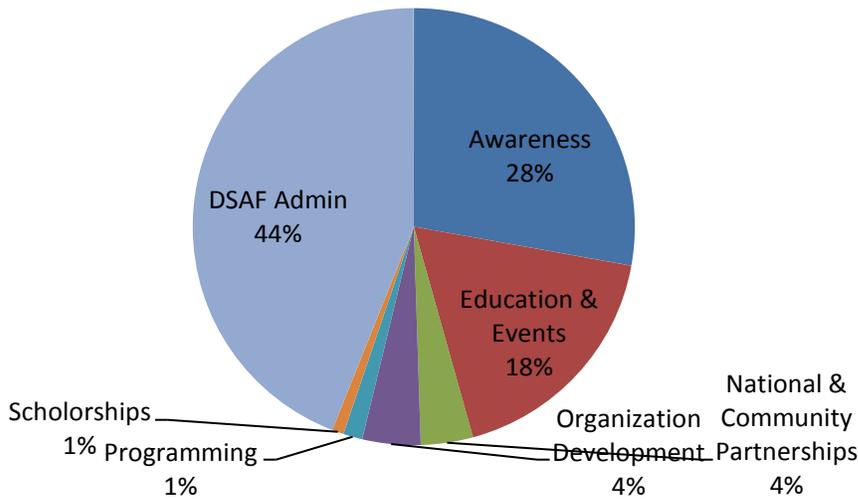
DEan Fuelberth,
DSAF Board President



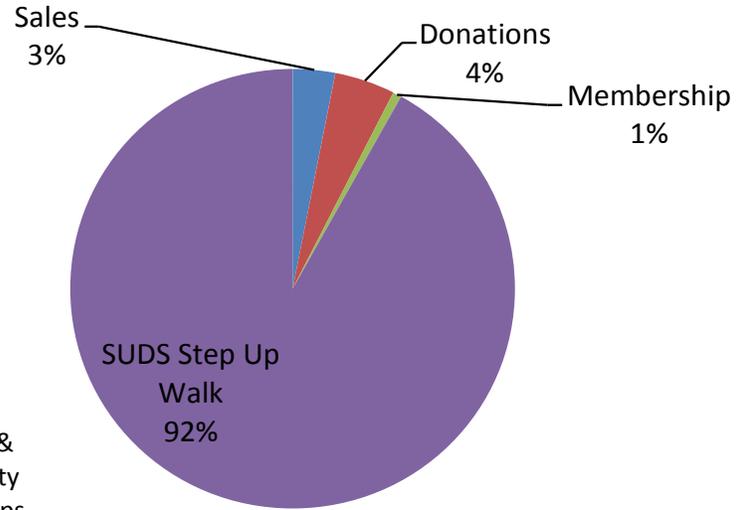
Representatives from DSAF of Nebraska and DSA Midlands with Gov. Ricketts as LB891 - Down Syndrome Diagnosis Information & Support Act - was signed into Law on April 7, 2016

FINANCIALS

2015 EXPENSES



2015 REVENUE



**Based on 2015 Expenses of \$103,149 and Revenues of \$93,458*

90% of SUDS WALK funds raised remain in the Lincoln area to benefit local DSAF membership

10% of SUDS 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

ADMINISTRATION – cost to run the organization that cannot be allocated elsewhere.

AWARENESS – cost of providing information about Down syndrome and DSAF, i.e. Step Up Walk and World Down Syndrome Day.

EDUCATION/EVENTS – cost of providing specific information about Down syndrome to parents, medical professionals, teachers and others and the all group events.

** \$2,000 funds Medical Outreach, including hospital packets and new parent baskets*

** <\$6,500 funded Sibling Workshop*

NATIONAL/COMMUNITY PARTNERSHIPS – cost of organizational memberships and donations to national and community organizations of mutual benefit.

ORGANIZATIONAL DEVELOPMENT – cost of training and developing DSAF staff and volunteers.

PROGRAMMING – cost of DSAF programs for specific populations, such as Stars and Parent group events.

** \$3,700 to group networking events*

** \$2,500 to Lil' Stars, Super Stars, and Teen/Young Adult Stars events*

SCHOLARSHIPS – cost for members to attend local conferences and national conventions about topics relating to Down syndrome.

member BENEFITS

AWARENESS

- Calendars
- Website and Social Media
- Step Up Walk

EDUCATION & EVENTS

- Quarterly Newsletter
- World Down Syndrome Day Celebration
- Sibling Workshop
- Member Picnic & Swim Party
- Trip to the Pumpkin Patch
- Lincoln Children's Museum
- Holiday Brunch

PROGRAMMING

- Mom's Night Out
- Parents First Contact Program
- SMART Start
- Lil' Stars Events
- Super Stars Events
- Teen Stars Events

ORGANIZATIONAL DEVELOPMENT

- Board Strategic Planning
- DSAIA Leadership Conference

WORLD DOWN SYNDROME DAY CELEBRATION

In 2015, DSAF reinvented its **WORLD DOWN SYNDROME DAY CELEBRATION** event (3/21 representing the 3 copies of the 21st chromosome), thanks to a dedicated committee led by DSAF members, Liz Echternkamp and Caroline Fehlhafer.

The event took place in a brand new venue, with many fun activities for kids, including an inflatable obstacle course, and a unique photo booth which provided cool picture strip momentos to all participants.

The event is free to attend and is open to members, their family and the general public.

Governor, Dave Heineman, signed a proclamation declaring March 21st as World Down Syndrome Day in the State of Nebraska.

EDUCATION & AWARENESS

SIBLING WORKSHOP In July, DSAF was extremely excited to host national speakers and authors Dr. Brian Skotko and his colleague, Sue Levine, to lead a **BROTHERS-AND-SISTERS WORKSHOP**.



Dr. Brian Skotko talks with older siblings at the Brothers-and-Sisters Workshop

This was an amazing opportunity for children who have brothers and sisters with Down syndrome to come together to discuss their common hopes, concerns, and questions.

Eight siblings attended the breakout session for children under 10 years of age, while 13 older siblings attended a concurrent group. Many parents joined the speakers for an end-of-day session geared specifically to them. Several of the 15 volunteers on hand to help throughout the day received training to become instructors for future DSAF sibling workshops.

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



SMART START SERIES

SMART START: For families of children with Down Syndrome ages 4, 5 & 6 years who are anticipating transition to Kindergarten

SCHOOL SMART: For families of children with Down Syndrome ages 4 to 12 years who want to build healthy relationships with school professionals

FRIEND SMART: For families of children with Down Syndrome ages 4 to 21 who want to encourage and support their children’s friendships and active social life

IEP SMART: For families of children with Down Syndrome ages 4 to 12 years of age who want to understand the assessment requirements for eligibility and school performance in special education and inclusive programs and how to contribute to development of meaningful Individualized Education Plans (IEP).

CAPITAL CITY STEP UP FOR DOWN SYNDROME WALK

The 14th Annual walk took place on October 3rd, 2015. The CCSUDS committee, headed by co-chairs Jennifer Brill and Jamie Bertucci, coordinated our largest awareness event yet! This amazing celebration event is our primary funding source for our annual budget. Our walk has tripled in size over the past 14 years, and continues to fulfill its promise of bringing smiles to everyone’s faces that morning!



2015 CCSUDS AT A GLANCE
77 TEAMS
1,700+ PRE-REGISTRATIONS
RECORD 1,620 DAY-OF PARTICIPANTS
OVER \$81,000 RAISED



FACT POSTERS

Over 100 **FACT POSTERS** were displayed along the one mile **CCSUDS** route and featured pictures of our loved ones with Down syndrome and important facts about Down syndrome to raise awareness. These same images are used throughout the year for further promotion of Down syndrome awareness.

CALENDAR and FACT POSTER photography credit:





Alicia and Sonya, preparing goodies for medical office visits.



Examples of gift baskets

MEDICAL OUTREACH

In 2015, the **MEDICAL OUTREACH** Committee worked tirelessly to accomplish a huge number of milestones. Alicia Bruning, chair, and Dr. Sonya Reynolds attended the national Affiliates in Action leadership conference at the beginning of the year, bringing back a wealth of ideas. This committee educates others regarding Down syndrome by raising the awareness of the local medical community, especially during the diagnosis of a new child with Down syndrome and providing current and accurate information to new and expectant parents.

The committee served a record number of families in the **PARENTS FIRST CALL PROGRAM** (below). “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.

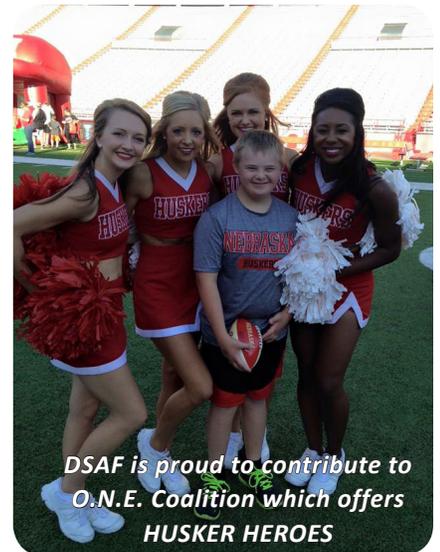
The committee also worked with Tom Venzor, former staff member of Senator Lydia Brasch, to support the authoring of the Down Syndrome Diagnosis Information and Support Act in Nebraska. They met with other Senators prior to the start of the year when the bill was introduced (see pg. 2).

PARENTS FIRST CALL AT A GLANCE

- **13 FAMILIES RECEIVED GIFT BASKETS AND HAD A FIRST CALL PARENT VISIT**
- **4 PRESENTATIONS GIVEN AT OFFICES/HOSPITALS**
- **71 DELIVERIES TO OFFICES/HOSPITALS** THROUGH QUARTERLY MEDICAL OUTREACH VISITS, PLUS ADDITIONAL VISITS AS NEEDED
- **3 FAMILIES RECEIVED PRENATAL INFO PACKETS** UPON RECEIVING THEIR DIAGNOSIS ALTHOUGH THEY NEVER CONTACTED DSAF TO PARTNER WITH A FIRST CALL PARENT

COMMUNICATION & BENEFITS

- **BOOK BUNDLES:** print resources at highly discounted prices
- **SPECIAL NEEDS TRUST / GUARDIANSHIP STIPEND:** Life planning for people with disabilities can be very complex. A Special Needs Trust is a legal document to address many of the common planning issues. The DSAF provides a limited number of stipends to families toward the legal cost to create or review a special needs trust or guardianship.
- **COMMUNITY CONNECTIONS:** In 2015, 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 Husker Heroes where we partnered with the Nebraska University Athletics Department to provide a night of fun for our members. This 6th annual event was a huge success with a record number in attendance.
- **SCHOLARSHIPS:** DSAF provided scholarships for its members to attend local and national conferences that focused on issues pertinent to individuals with Down Syndrome.
- **S.E.A.S. (Summer Enrichment Activities Support):** This program helps parents provide paraprofessional support during summer programs. This allows a child with Down syndrome to participate fully and meaningfully in community summer programs open to all children, encouraging an inclusive environment.



DSAF is proud to contribute to O.N.E. Coalition which offers HUSKER HEROES

FAMILY EVENTS

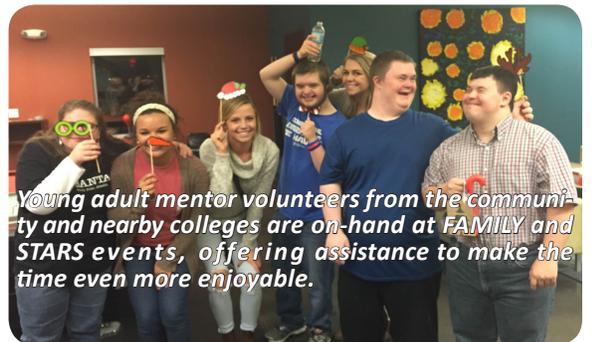


WORLD DOWN SYNDROME DAY CELEBRATION - TAKE ME OUT TO THE BALLGAME AT HAYMARKET PARK - NIGHT AT THE LINCOLN CHILDREN'S MUSEUM - ANNUAL MEMBER PICNIC & SWIM PARTY - TRIP TO THE ROCA BERRY PUMPKIN PATCH - ANNUAL HOLIDAY BRUNCH



STARS

DSAF STARS are age specific groups which provide meaningful opportunities for children with Down Syndrome to socialize with their peers. **LIL' STARS** events are especially geared toward families with children ages birth - 5 years. Events include: swim parties at LifeStrokes, Kindermusik, Meet Me At the Park, Back-to-School Party, Signing Class, and various play center play dates. **SUPER STARS** (K- grade 8) provide social activities for school-aged children, focusing on fostering inclusive peer relationships for the individual with Down syndrome. Events include: new release movies at Marcus Theatres, bowling, and Art Planet. **TEEN/YOUNG ADULT STARS** have the opportunity to make new friends and increase self-confidence in a safe and supportive environment, focusing on social and life skills with the help of peer mentors. Events include: bowling, Harlem Globetrotters at Pinnacle Bank Arena, and a Holiday Party.



Young adult mentor volunteers from the community and nearby colleges are on-hand at FAMILY and STARS events, offering assistance to make the time even more enjoyable.



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.

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