2012 ANNUAL REPORT

HIGHLIGHTING ACCOMPLISHMENTS
AND
RAISING THE BAR

Down Syndrome Association for Families of Nebraska (DSAF)

www.dsafnebraska.org . info@dsafnebraska.org . dsafnebraska.blogspot.com.

DSAF BOARD AND STAFF

Deb Safarik, President
Dean Fuelberth, Vice President
Kelly Ekeler, Treasurer

Lori Tackett
Ryan Bruns
Tregg Lunn
Sonya Reynolds

Angie Willey
Communications Director

Lori Prange
Program Director

Leadership Message

Reflecting on another great year at DSAF brings thoughts of the past and all the accomplishments through the years. Thankful for parents that seek better opportunity for their children and inclusion. Holding a vision of a better and brighter future for all individuals with Down syndrome.

In 2012, we continued to grow and reach out to many families thanks to our members and volunteer staff. We continued many of our successful programs and events to support our families and children of all ages. We have many individuals with Down syndrome who have grown up with us and moving into their adult lives. This is exciting to see and brings new opportunities for them and us.

New prenatal testing has made us very passionate to reach out to our medical community this past year. We want to support doctors in prenatal diagnosis and assure that all parents with a Down syndrome diagnosis are well informed about Down syndrome and the opportunities for those individuals in today's society.

Our Step UP for Down Syndrome walk was a great success in 2012 thanks to our chairs and many volunteers. Our website continues to be a great outreach to our members and state-wide audience. Our Facebook page allows for a great place for conversations, help and information.

Thank you for participating in the DSAF mission! We celebrate all that has been accomplished and the growth that continues to bring opportunity to those with Down syndrome.

DSAF Board

Thank you to our 2012 DSAF Committees Chairs:

Medical Outreach Committee - Ame Creglow
Lil' Stars Liz Echternkamp
Super Stars - Caroline Fehlhafer
Parents & Teens - Amy Svoboda
Newsletter Editor - Natasha Dobbins
Step UP Walk - Angie Willey/Tina Barrett

Working together to connect families, provide support, resources
and advocacy for individuals with Down syndrome.

Encourage Inclusion

of individuals with Down syndrome in our schools and neighborhoods. The first week of December is Inclusive Schools Week and during this week we celebrate the progress that schools have made in providing a supportive, quality education to an increasingly diverse student population. In 2012, DSAF **recognized 22 teachers and paraprofessionals** nominated by our members. DSAF sent gift cards to these educators in appreciation of their year round efforts to include children with Down syndrome in regular education classrooms.

Raising Awareness

Peer Presentations are 15 to 20 minute classroom or grade level presentations tailored around a specific student that addresses any issues related to his/her disability. Often, openly discussing Down syndrome will encourage students to understand why the child learns or behaves differently. In 2012, we offered a Train the Trainer session to show parents how to give Peer Presentations. Peer Presentation kits may be checked out by any DSAF member.

2012 DSAF Calendar: Our calendars feature pictures of our members with Down syndrome as well as many facts about Down syndrome. They were distributed throughout the community to promote education and awareness.

World Down Syndrome Day March 21 -
A Day to Celebrate! : In 2012, DSAF celebrated March 21, World Down Syndrome Day with a pizza party and Ball Night. We also celebrated with an evening at Noodles and Company benefiting DSAF.

Community

Fundraisers: In 2012, JEO Consulting group and Poker Run of Hastings selected DSAF as their local charity for their annual fundraising event. This was a wonderful opportunity to raise funds and raise awareness in these communities.

In 2012, 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 NU Athletics Department to provide a night of fun for our members. In 2012, this event was a huge success with a record number in attendance.

Promote the development of programs that enrich the lives of individuals with Down syndrome.

Lil' Stars (Birth - 5 yrs):
This group provides social events especially for our member families with children ages 0-5 and their siblings.

In 2012, events included:

- A trip to Lost in Fun
- Sessions at Kindermusik
- Play Dates at the Park

Super Stars (Kindergarten - High School):
This group provides meaningful social events for school-aged children, focusing on fostering peer relationships for the individual with Down syndrome.

In 2012, events included:

- Roca Berry Farm
- Art Dayz at the Planet
- Mobile Science Experience

Teen Stars (High School): This group provides an opportunity for teens with Down syndrome to socialize with their peers. While the teens are enjoying time with young adult mentors and their peers, the parents meet and have the opportunity to get together and share information.

- Bowling
- Star Red Army Dance and Choral Ensemble
- Harlem Globetrotters

Networking Family Events:

- March Madness Ball Night
- Ice Cream Social
- Summer Picnic and Pool Party
- Christmas Brunch

SEAS (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.

Book Bundles: DSAF offers books in our Book Bundles at a highly discounted price. Book Bundles are a great way to gain more information about Down syndrome.

DSAF provided books to local libraries and schools on a variety of topics relating to Down syndrome. Resources relating to Down syndrome are available locally for check-out by parents and schools from the DSAF lending library.

Scholarships: DSAF provided scholarships for DSAF members to attend local and national conferences that focus on issues pertinent to individuals with Down Syndrome.

- DSAIA
- NDSC (National Down Syndrome Congress) Conference
- Local conferences

COMMUNICATION

Newsletters: The bi-monthly DSAF Newsletter provides information on DSAF events, community events and a variety of topics that impact our families.

Our website is updated regularly to keep members and the general public informed about current activities and important Down syndrome related information.

DSAF's facebook presence provides a virtual meeting place to chat and post comments staying in touch with others. A forum for the exchange of experiences and ideas.

DSAF of Nebraska BLOG is up and running at dsafnebraska.blogspot.com. Share stories, photos and information.

E-mail Blasts: E-mail blasts are sent out on a regular basis to keep members informed about upcoming DSAF events and events in the community that may be of interest to our members.

Outreach

Medical Outreach:

This committee educates others regarding Down syndrome by raising the awareness of the local medical community, particularly during the diagnosis of a new child with Down syndrome and providing current and accurate information to new and expecting parents.

In 2012, we:

- Provided information for expectant or new parents
- Welcome baskets for new parents
- Provided information regarding support and resources for families
- New parent meetings with Occupational Therapist, Physical Therapist, Pediatrician and Speech Pathologist there to share their knowledge, tips and resources.
- Presented up-to-date information about Down syndrome and recommendations on giving pre-natal/post-natal diagnosis to OB/Gyn physicians and hospitals

Parent Outreach:

Provide education, resources and support to parents and educators who will prepare individuals with Down syndrome for further education, employment and independent living.

Moms' Night Out—Dads' Night Out:

A time in a casual environment to talk with other moms and dads of children with Down syndrome. Meet others that share your joys and challenges; share stories, advice or just enjoy a night out.

Fundraisers

Capital City Step UP for Down Syndrome Walk (CCSUDS): The 2012 Annual walk was a tremendous success! A record 75 teams preregistered over 1600 walkers to join us and celebrate individuals with Down syndrome and promote awareness, inclusion and acceptance within the community of Lincoln. Over **$90,000** was raised to support individuals with Down syndrome.

Stars Tent and Shooting Stars BLOG: The Stars Tent highlights the accomplishments of our children by displaying Bios within the tent. As an extension of our Stars Bios, which sit static on the walls of the tent, we created the "Shooting Stars" concept to allow a group of volunteer college students to follow the DSAF Stars outside the tent and into their lives during the morning of the walk. Through text, quotes, and pictures, we hope that this blog captured the heart-warming magic that is the Step Up Walk!

Facts Posters: DSAF Facts Posters, an incentive for early fundraising, were displayed along the route of the walk and featured pictures of our loved ones with Down syndrome and important facts about Down syndrome in an effort to continue to raise awareness. Many images of our facts posters are displayed on Facebook and get more than 2,000 shares continuing to raise awareness and educate others about Down syndrome.

2012 CCSUDS Committee

Our Media Partners:

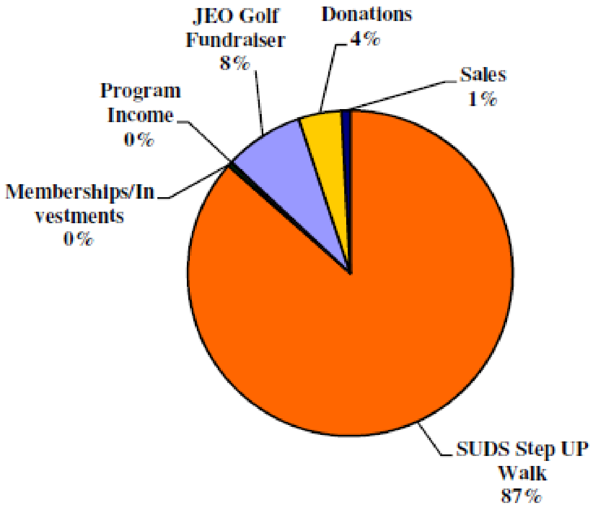
Lincoln Journal Star
journalstar.com
Connect.
TODAY'S BEST COUNTRY FROGGY 98

Angie Willey (Co-Chairperson)
Tina Barrett (Co-Chairperson)
Gina Dubbs (T-shirt Chairperson)
Dean Fuelberth (Publicity Chairperson)
Ame Creglow (Food and Beverage Chairperson)
Lori Kennedy (Entertainment Chairperson)
Lori Tackett (Volunteer Chairperson)
Dennis Kriz (Logistics Chairperson)
Liz Echternkamp (Facts Poster Chair)
Angie Willey (Web Content Chairperson)
Natasha Dobbins (Prize Chairperson)
Caroline Fehlhafer (Information Booth)
Deb Safarik (Committee Member)
Renae Rief (Stars Tent)

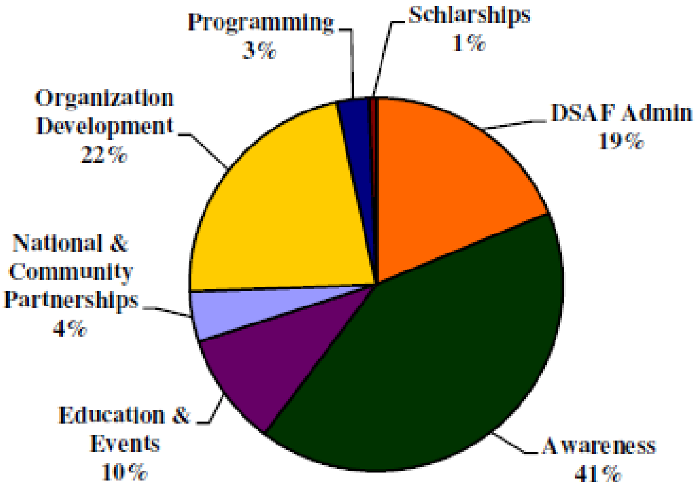
Financials

The work of DSAF would not be possible without the financial support. We greatly appreciate all those who supported our mission in 2012. Your gift makes a difference!

2012 Revenues*



2012 Expenses*



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

Awareness – cost of providing information about Down syndrome and DSAF, such as the 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.

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 Lil' Stars, Super Stars, and Parent and Teens group events.

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

*** Based on DSAF 2012 Revenues of $108,791 and Expenses of $53,026**

Looking Forward

DSAF looks forward to how we can continue to meet our mission. We will continue our current **programs.**

Along with the programs we provided in 2012 we will:

- Continue our Kindergarten roundup program to assist parents with questions and concerns that come with starting school.
- Bike camp has been a very successful event in the past and we are looking at how we will continue that event. Teaching children to ride a bicycle independently without training wheels increases their balance control, self-confidence and self esteem.
- Sibling workshops and outings to provide an opportunity to meet other brothers and sisters as well as an environment for siblings to feel comfortable to ask questions and learn from each other.
- Special Needs Trust Stipends, in past years we have provided stipends to families towards the legal cost to have special needs trust created or reviewed.

Help our members stay **educated** by:

- Attending national conferences to continue our learning and knowledge.
- Provide scholarship programs for our members to attend conferences.
- We plan to bring resources and educational seminars to Nebraska. In March 2013, we held a one day multi-track educational seminar. We covered 10 different topics, brought in top speakers and authors as well as a new set of principles for curriculum development that give all individuals opportunities to learn, Universal Design for Learning (UDL).

Continued **outreach**:

- Reach out to school administrators and teachers in collaboration on continuing to build knowledge to best help those with Down syndrome reach their full potential.
- Connect with medical providers to deliver up-to-date information on Down syndrome. We feel very passionate to make sure that new parents with a Down syndrome diagnosis are well educated and provided with resources. We will continue to provide books and resources to new parents and gift baskets welcoming their new baby.
- Grow our parent outreach with more events and couple outings, allowing parents to connect and share face to face.
- Continue to look at ways to grow within the state. Grow the board with LPS contacts and an advocate.

We are excited to continue our work for all individuals with Down syndrome.

DSAF Board

Mission:
The Down Syndrome Association for Families (DSAF) is a Lincoln 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.

People with Down syndrome attend school, work, participate in decisions that affect them, & **contribute** to society in many **wonderful** ways.

DSAF
of Nebraska

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Helping individuals with Down syndrome reach their full potential!

Photos Courtesy of John Simms and Images for a Lifetime Photography