

# 2013 ANNUAL REPORT

## Highlighting Accomplishments



**Governor Dave Heineman signs a proclamation declaring March 21 as World Down Syndrome Day in Nebraska.**



**Capital City Step UP for Down Syndrome Walk was a tremendous success! A record 75 teams preregistered over 1600 walkers to join us to celebrate.**



**2013 Educational Conference**

# President's Message

DSAF had another great year. We are privileged to support individuals with Down syndrome and families throughout the lifespan. We want to provide resources, education, programs and assistance that help those individuals, their families and others who work with them. This is a journey that starts from the very beginning. Our "Brand New Day" notebook now is divided to address family needs whether they receive a diagnosis before or after their baby is born. We want parents to receive positive, hopeful, realistic information. To that end our Medical Outreach Committee continues to contact maternal-fetal MDs, obstetricians, other medical professionals and hospitals with the latest information. We've added a new family gift bag for babies along with our two main parenting gift books.

Our Little Stars, Super Stars and Teen/Young Adult groups reflect how our group is "growing up". Our Mom's Night Out has been a popular opportunity for mom's new and old to get together. Our committee chairs for these groups work very hard to have fun, social events for kids and families. DSAF wants to see more opportunities to collaborate with other disability groups to share resources for shared interests and to utilize limited grants out there to help the disability community as a whole. We have had information sessions for new families with a baby with Down syndrome, getting ready for kindergarten, classroom education about Down syndrome, sibling support, special needs trust and preparing for adulthood. We want to continue these and make them regular presentations.

## DSAF BOARD AND STAFF

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

Lori Tackett  
Ryan Bruns  
Tregg Lunn  
Dr. Sonya Reynolds  
Kelly Ekeler

Angie Willey  
Communications Specialist

Lori Prange  
Program Director

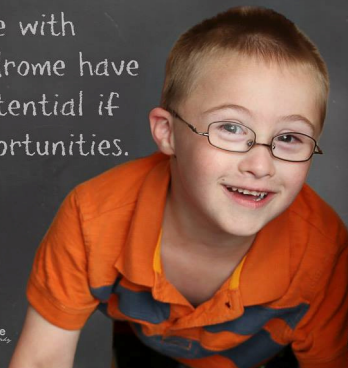
We are proud of our Step Up for Down Syndrome Walk. The walk, held the first Saturday of October, offers a chance for many people across the state to feel they are part of a majority who celebrate individuals with Down syndrome. This is a fantastic way to let the community know about Down syndrome through our Fact Posters, the STARS Tent, our information table, and their participation in our walk. This is our primary fundraiser and we are so appreciative of all who work so hard to raise funds and encourage walkers to be part of this special event.

The funds we gain allow DSAF to extend our reach to the community as well as families. Our first multi-tiered educational conference helped support families, educators and others who work with our families. We were able to have nationally recognized speakers along with local presenters. Presentations were geared to supporting individuals with Down syndrome in general, to more age level interests and concerns.

We appreciate all the work our volunteers do for the DSAF. We have more people involved in our board, the SUDS Walk Committee, our newsletter, website, and more chairs for our age level groups than ever before. We continued with a half-time program director, our only paid position. Even as we grow and can hopefully add more staff, we will be dependent on many volunteers to continue the foundation we have laid.

Of course there is more to be done. We need to support individuals with Down syndrome as they journey into the adult world. Families who live across the state need support and may have some additional concerns than those living in larger towns. We must always recognize that individuals and families have different needs and different interests at different stages. DSAF wants to be a partner at these different times so we can help strengthen individuals and families wherever they may be. We celebrate our accomplishments in 2013 and want to strengthen and support our members in the coming years.

People with  
Down syndrome have  
great potential if  
given opportunities.



# Advocacy and Awareness

## World Down Syndrome Day March 21—A Day to Celebrate!

In 2013, 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.

DSAF held a World Down Syndrome day t-shirt contest and selected two member designs to be on our t-shirts promoting 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. We offer a

Train the Trainer session to show parents how to give Peer Presentations. Peer Presentation kits may be checked out by any DSAF member.



In 2013, 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. In 2013, this 4th annual event was a huge success with a record number in attendance.

Governor Dave Heineman signed a proclamation declaring March 21 as World Down Syndrome Day in the State of Nebraska. Individuals with Down syndrome and their families were invited to attend the signing ceremony on March 13 in the Warner Chamber at the Capitol.



## 2013 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.



# Programs

## Lil' Stars (Birth - 5 yrs.):

This group provides social events especially for our member families with children ages 0-5 and their siblings.



In 2013, events included:

- Sign Language Class
- Sessions at Kindermusik
- Ager Play Center
- Family Reading Night

## 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 2013, events included:

- Lost in Fun
- Baking Class
- Salt Dogs Baseball Game
- Movie Outings
- Paint Yourself Silly

**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
- Salt Dogs Baseball Game
- Lincoln Stars Hockey

## Networking Family Events:

- March Madness Ball Night
- Summer Picnic and Pool Party
- Roca Berry Pumpkin Patch
- 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 and share 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 (Down Syndrome Affiliates in Action) National Leadership Conference
- NDSC (National Down Syndrome Congress) Conference
- Local conferences

**Inclusion recognition program** - the first week of December is Inclusive Schools Week and during this week we recognize teachers and paraprofessionals for their work and efforts to include children with Down Syndrome in regular educational settings. In 2013, DSAF **recognized 35 teachers and paraprofessionals** nominated by our members.

## Communication and Sharing of Information

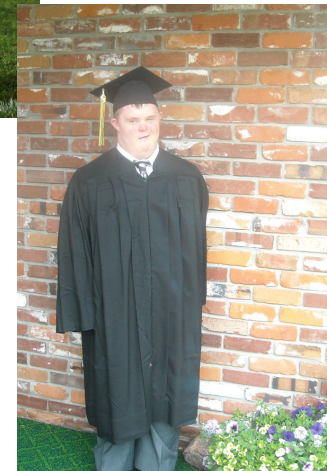
**Newsletters:** The bi-monthly DSAF Newsletter provides information on DSAF events, community events and a variety of topics that impact our families.

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](http://dsafnebraska.blogspot.com). Share stories, photos and information.

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.



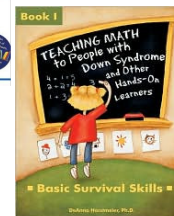
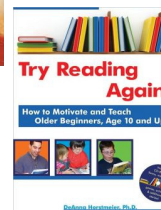
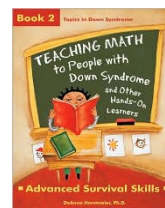
# Support and Resources

## 2013 Educational Conference

On March 2, we held a one day multi-track educational seminar for parents, college students, educators, and administrators. We covered 10 different topics, focused on multiple age brackets, 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). We had over 90 parents, educators and students in attendance. We welcomed six speakers and offered 15 sessions.

8:00 am - 8:30 am	Registration with Continental Breakfast				
8:30 am - 9:45 am	Opening Session: Inclusion				
10:00 am - 11:15 pm	Try Reading Again DeAnna Horstmeier	IEP 2.0 Dean Fuelberth and Amy Allison	Early Childhood & Elementary Managing Behavior Jean Anderson	iPad Apps for Middle School/High School Students Dixie Trevarthen	UDL 101 Bill McGrath
11:30 pm - 12:45 pm	Lunch with Self Advocate-Meredith Martin				
1:00 pm - 2:15 pm	Teaching Math DeAnna Horstmeier	Bridging the Communication Gap with Sign Language Angie Willey	Doors to Friendships Amy Allison	iPad apps for Elementary Students Dixie Trevarthen	UDL 201 Bill McGrath
2:15 pm - 2:30 pm	Afternoon Break				
2:30 pm - 3:45 pm	Try Reading Again DeAnna Horstmeier	Bridging the Communication Gap with Sign Language Angie Willey	Supporting behavior for Middle School/High School students Jean Anderson	Smart Start Kindergarten Prep Amy Allison	UDL 301 Bill McGrath

We welcomed the following speakers to our conference: DeAnna Horstmeier, Jean Anderson, Amy Allison, Bill McGrath, Angie Willey, Dean Fuelberth and Dixie Trevarthen. We also had Meredith Martin a 25 year old self-advocate, share her story of growing up in a small community, setting goals, working with the school district to try new programs and establishing an independent living experience.



# 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 2013, we provided:

- Information for expectant or new parents
- Six welcome baskets to new parents
- Information regarding support and resources for families
- New parent meetings with Occupational Therapist, Physical Therapists, Pediatrician and Speech Pathologist present to share their knowledge, tips and resources
- 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.



# Awareness and Fundraising

## Capital City Step UP for Down Syndrome Walk

(CCSUDS): The 2013 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!



Fact Posters: DSAF Fact 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 fact posters are displayed on Facebook and get more than 2,000 shares continuing to raise awareness and educate others about Down syndrome.





# 2013 CCSUDS Committee

## Our Media Partners:



Angie Willey (Co-Chairperson/Web Coordinator)  
Natasha Dobbins (Co-Chairperson)  
Gina Dubbs (T-shirt Chairperson)  
DEan Fuelberth (Publicity Chairperson)  
Tiffany Baker, Deb Safarik (Food and Beverage Chairperson)  
Lori Kennedy (Entertainment Chairperson)  
Lori Prange (Volunteer Coordinator)

Jennifer Brill (Registration Chair)  
Dennis Kriz (Logistics Chairperson)  
Liz Echternkamp (Facts Poster Chair)  
Shawn and Brandee Talley (Prize Chairperson)  
Caroline Fehlhafer (Information Booth Chair)  
Tina Barrett (Stars Tent Chair)  
Kathryn Brockmeier (Corporate Donations Chair)



The Nebraska State Capitol building was lit up blue in honor of our Step Up for Down Syndrome Walk. It was lit in a beautiful display of blue from October 4-6, 2013.



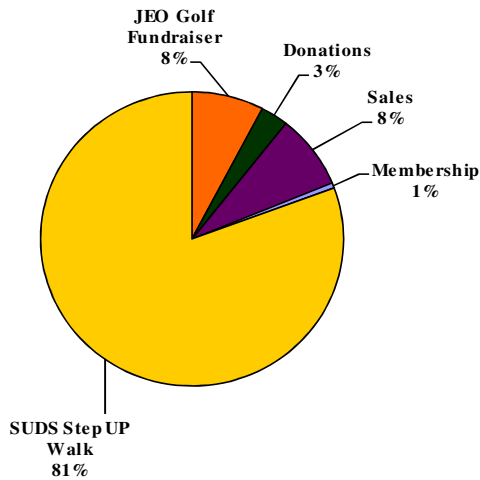
Community Fundraisers: In 2013, JEO Consulting group selected DSAF as their local charity for their annual fundraising event. This was a wonderful opportunity to raise funds and raise awareness in the communities.



# Financials

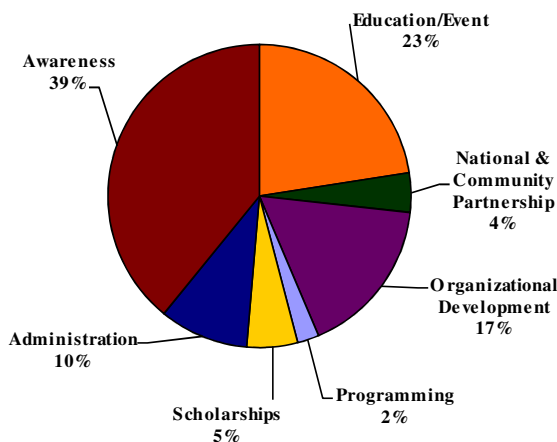
The work of DSAF would not be possible without the financial support. We greatly appreciate all those who supported our mission in 2013. Your gift makes a difference!

## 2013 Revenues\*



- Based on DSAF 2013 Revenues of \$105,617 and Expenses of \$90,451

## 2013 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.

## Thank you to our 2013 DSAF Committee Chairs:

**Medical Outreach** - Alicia Bruning  
**Lil' Stars** - Renae Rief/Kathryn Brockmeier  
**Super Stars** - Caroline Fehlhafer  
**Teen Group** - Janette Johnson  
**Newsletter Editor** - Natasha Dobbins

### 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.

## CONTINUING INITIATIVES

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Subgroup Networking: Lil' Stars (4 events/yr.); Super Stars (4 events/yr.); Teen Stars (monthly events)  
Mom's Night Out (bi-monthly events)  
Half-time Program Director  
S.E.A.S. Program  
Inclusive Schools Week (December - recognizing outstanding Nebraska educators)  
Book Bundles (defrayed cost current books for parents / educators) / Library Donations  
Annual Calendar  
Special Needs Trust Stipend Program (includes annual event with speaker)  
Annual Multi-Trac Educational Conference (11/15/2014)  
Medical Outreach Initiatives  
Communication - Newsletter; E-mail blasts; Website; Facebook; Chair Meetings (2x/yr.); Annual Report  
Huskers Heroes Event (community partnership with the ONE Coalition)  
Capital City Step Up for Down Syndrome Walk (Est 2002 - 360 walkers, \$20K; 2013 - 1,600 walkers; \$90K)  
4 Annual Networking Family Events: Ball Night (March - includes 3/21 World Ds Day Celebration) / Picnic & Pool Party (summer) / Roca Pumpkin Patch (October) / Christmas Brunch (December)

## 2014 VISION

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- Full time program director by June to support the needs and growth of DSAF.
- Research local college intern possibilities and how we could utilize in our future plans.
- Bike Camp - meet with Hand Prints and Foot Steps and identify a training program for internal DSAF staff allowing us to build the foundation of annual bike camps.
- Dad's Night - idea generation on how to obtain chair and define focus to allow success.
- Sibling Workshop - review partnering with ARC and grant funding possibilities.
- New Parent: First Contact Program - explore possible program structure.
- School Readiness Program - review KC program. Identify and train 1-2 DSAF members to facilitate.
- Adult / Young Adult job & life training - research AIA on available programs in existence.
- Reading Program - analysis of structure and needs to run program.
- School Advocacy - research connections in school system and design training plan.
- Grandparents outreach - ask members for E-mails to keep them informed. Invite to Picnic & Pool Party.
- Couples Retreat / Parents Night - 2014 pilot to talk with parents for structure and needs.
- Financial Planning / Guardianship - review programs and possible ARC partnership.
- DSAF Footprint - satellite group pilot; website video resource addition; grow membership reaching out to grandparents.
- Medical Outreach - grow committee with new Program Director assistance.
- Board / Leadership - growth research; annual strategic planning retreat; vision driven agendas for monthly meetings.
- Location / Staff - partnership with ARC exploration: space, certain event collaboration, grants.
- Funding - SUDS walk growth; JEO Golf event; Grants; Investments
- Membership Directory

DSAF Board of Directors spent a day in August at a strategic planning session reviewing needs and growth to meet our mission. DSAF plans to lay the foundation in 2014 for growth in several areas. We have new programs needed for members and existing programs that need to grow. Download our current 3-Year Vision Plan from our website at [dsafnebraska.org](http://dsafnebraska.org). We are excited to continue our work!



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*\*\*Photos Courtesy of John Simms and Images for a Lifetime Photography\*\**