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2014 Annual Report



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Greetings,

Thank you for your wonderful support of Down Syndrome Alliance of the Midlands this year! I appreciate you for taking the time to review our 2014 annual report. It's an absolute honor and privilege to serve as President of DSA. It's always inspiring to reflect on the last year and recognize the impact our organization has made on the lives of individuals with Down syndrome and their families in our community.

As the report indicates, the end of fiscal year 2014 finds the organization in fantastic shape. Our financial condition remains strong and we're very pleased that situation has allowed us to continue to fund new programs for our membership. Among the highlights was launching our new "Down Syndrome Education Series," of which several families keep coming back for month after month.

We have expanded our advocacy efforts around the state as well as across the country. In keeping with our mission, we strive to connect local families with relevant and timely information – as it relates to public policy issues that effect people with disabilities, in the areas of education, research, and health care. In addition to our local outreach, DSA sent a contingent of families and self-advocates to Washington DC to share the mission of our organization and encourage support of legislative issues effecting people with Down syndrome. The Achieving a Better Life Experience (ABLE) Act was on the forefront of most discussions with lawmakers in 2014.

President's Letter (cont.)

Thank you to everyone who attended and played a part in organizing our events throughout the year. The Buddy Walk was once again a huge success! We had a great turn out for the Buddy Run, iCan Bike Camp, Annual Swim Party, family Sporting events, "Down Syndrome Super Mom's" Monthly Roundtables, Parents Night's out, Hundred Hole Hike, as well as all the successful events put on by our G.R.A.N.D.S. group (Our families have come to look forward to the Easter Egg Hunt, Picnic at the Park, Trunk or Treat, and Santa at the Fire Station).

An annual report is certainly one opportunity to reflect on past accomplishments; but we're also reminded there's much work yet to be done. DSA is a great resource for individuals and families who've already connected with us, but there are many in our community we haven't yet reached. We recognize our responsibility to engage those whose personal situations (whether it be geographic, social, cultural, or economic) make it difficult for them to participate - That's work still to be done and we look forward to making progress in these areas during the upcoming year. We welcome your help in doing so - please call us if you're able to help in any way.

Lastly, I'd be remiss if I didn't recognize the most critical contributors to our mission's success. First, thank you to a truly great Board of Directors; comprised of a diverse mix of professionals and community leaders, who contribute much time, energy, and passion. I'm especially appreciative of our excellent staff. Our Executive Director, Anne Mancini, continues to make things happen. She works so very hard, every day, to benefit the lives of individuals with Down syndrome in our community. Due to successful fundraising efforts and grant recognition, she was able to add two new staff members to her team. Leah Janke serves as Education Programs Coordinator, and L'ara Arcishewsky stepped in as Community Connections Coordinator.

Finally, and most important of all, thanks to each one of you reading this! Our organization truly is a collection of several hundred like-minded individuals. You are what makes this organization work, and makes the work we do worthwhile. Please continue to stay engaged and please continue to hold us accountable in meeting your needs.

Sincerely,

Sherri Harnisch

Executive Director's Letter

2014 was a year of incredible growth for DSA.

The biggest news by far is the addition of our Education Programs Coordinator, Leah Janke. Leah, a scientist and former educator, was hired to coordinate our newly developed speaker series. I've known Leah for many years, first as an expectant mother with a prenatal diagnosis of Down syndrome, then a mom very involved in DSA activities, and finally as a board member. When we received news of the grant to fund our new program, Leah's interest in and qualification for the job made hiring her the easiest and best decision I made in 2014.

The Down Syndrome Education Series (DSES) for Members was launched in October 2014. The program received a Global Down Syndrome Educational Grant and continues to receive funding from local philanthropists and corporations.

The series was created to hire national experts in the fields of Down syndrome education, health care, and research (who often give presentations at major 3—day Down syndrome conferences) to travel to Omaha. Our goal is to expose our families to as much education as possible without them bearing the financial and logistical burdens of traveling to conferences. All presentations are free to parents and caregivers of individuals with Down syndrome. When the topic is appropriate and the speaker is available, an afternoon session is offered to educators or health care professionals. The October – December sessions received 74—94% Excellent Overall satisfaction ratings and were attended by more than 30 parents each.

Another exciting new resource is our Self-Advocate Scholarship, which offers up to \$500 to a young person with Down syndrome to pursue education or an experience that will further his or her steps toward independence. Two young men applied for and were awarded funds this year. I hope many more teens and young adults will find opportunities to apply for the scholarship. Each recipient must submit a report of how the funds were used to further his or her goals. We accept reports in the form of a photo or written blog, vlog, video, or another format suggested by the applicant.

I have enjoyed this year of working and traveling with a new board, learning more about governmental advocacy (ABLE Act is the Law of the Land!), and meeting new families as darling babies are born and wonderful families move into the Omaha area.

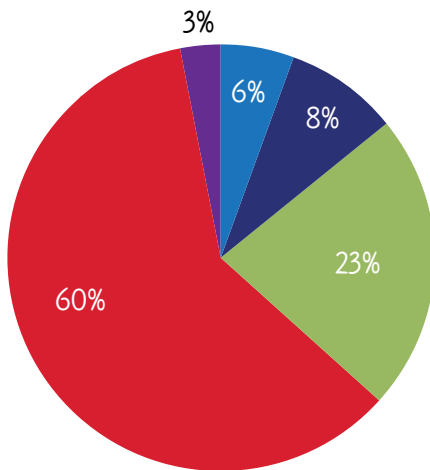
I look forward to a spectacular 2015!

Sincerely,

Anne Mancini

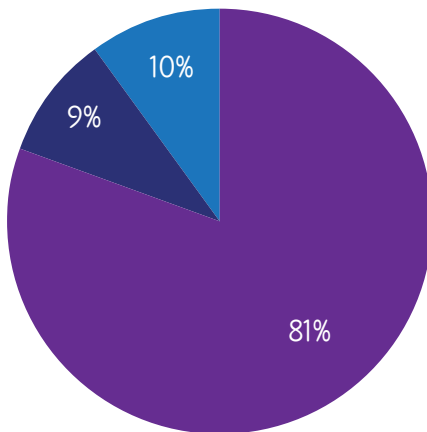
Financial Report

REVENUE \$175,501



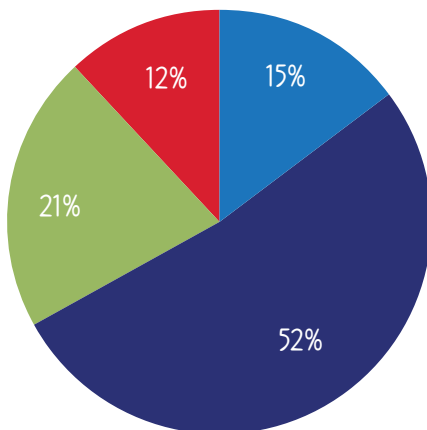
Buddy Run Contributions	\$5,140
Buddy Walk Contributions	\$105,535
General Contributions	\$39,757
Hundred Hole Hike Contributions	\$15,069
NDSC Grant	\$10,000

EXPENSES \$152,718



Fundraising Costs	\$15,159
Organization Management	\$14,387
Program Expenses	\$123,172

PROGRAM EXPENSES \$123,172



Advocacy	\$14,559
Education	\$25,862
Family Outreach and Support	\$64,382
Medical Outreach	\$18,369

Excess in Revenues over Expenses: \$22,783
Net Assets at Beginning of the Year: \$284,070
Net Assets at End of Year: \$306,853

In 2014 Medical Outreach launched its Prenatal Outreach initiative. We scheduled Lunch and Learn presentations at various OB/GYN and Maternal Fetal Medicine (MFM) offices throughout Omaha. At these lunches we provided the offices with up-to-date, accurate information about Down syndrome and how to deliver the diagnosis. The books we shared with these offices are distributed through lettercase.org. They are prepared and reviewed by experts in both the medical and Down syndrome communities. We also talked about DSA and the support and connections we are able to provide families when they join our organization. We visited 6 offices:

- Mid-City OB/GYN - 9 physicians
- Omaha OB/GYN Clarkson - 7 physicians
- Omaha OB/GYN Lakeside - 7 physicians
- Methodist Physicians Clinic - 21 physicians
- CHI Health Bergan Mercy - 1 physician
- Methodist Perinatal Center - 8 physicians

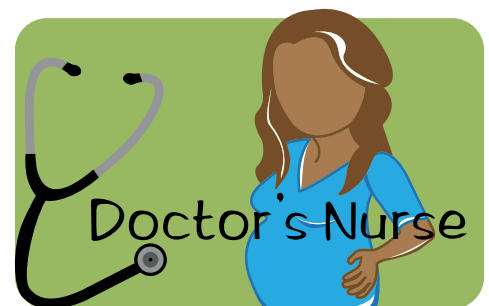
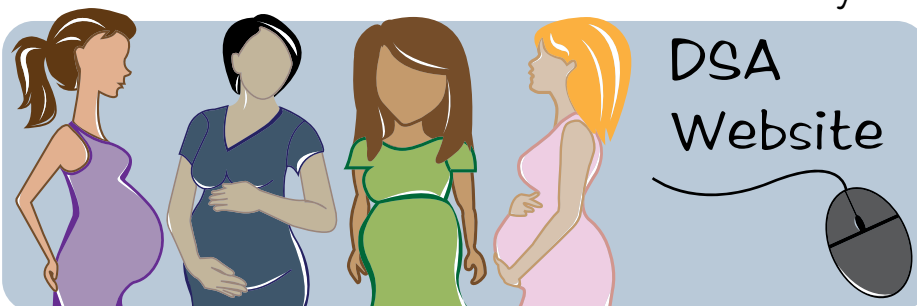
Our office visits led to more opportunities to conduct our outreach. We met with a couple of genetic counselors from UNMC that work at two MFM offices in Omaha, Methodist Perinatal Center and Olson Center for Women's Health. They deliver the results of prenatal screenings performed, work with expectant parents to provide them information concerning their diagnosis and sometimes deliver a diagnosis. In December, we presented at the Diagnostics in OB/GYN Conference at UNMC's Olson Center for Women's Health. We presented "Delivering a Diagnosis" to doctors, residents and students.

In the fall, we met with nurses from Labor and Delivery and Mother and Baby and a social worker from Methodist Women's Hospital to discuss how we can improve our outreach efforts at the local hospitals. We were asked to speak at the Mother and Baby staff meetings that will be held at the end of February. We learned from our meetings that it is also necessary to include NICUs and pediatrics into our postnatal outreach. This has since led to meetings with Methodist Women's NICU as well as presenting at the Patient Area Council (PAC) meeting. PAC is a monthly meeting attended by educators, leadership and bedside staff from UNMC, Bellevue, CHI Health Bergan Mercy, Creighton, Lakeside and Children's NICUs. Sometime in late 2015 we will be presenting at training sessions for all these NICUs excluding Methodist.

Four expectant parents contacted DSA via the website. One expectant parent was referred to DSA by a doctor's nurse.

NEW PARENT OUTREACH

Contacted DSA By:



Parent Outreach / Education Programs

We have had a lot of new members join our organization; especially several that have found out prenatally and have jumped right in even before they have had their baby! We are so excited for these parents to be getting the information and support they need and so early in their journey too. We try to make each and every person who joins DSA feel comfortable, like they are part of our family. Please give them a warm welcome if you see them out and about at our events or meetings!

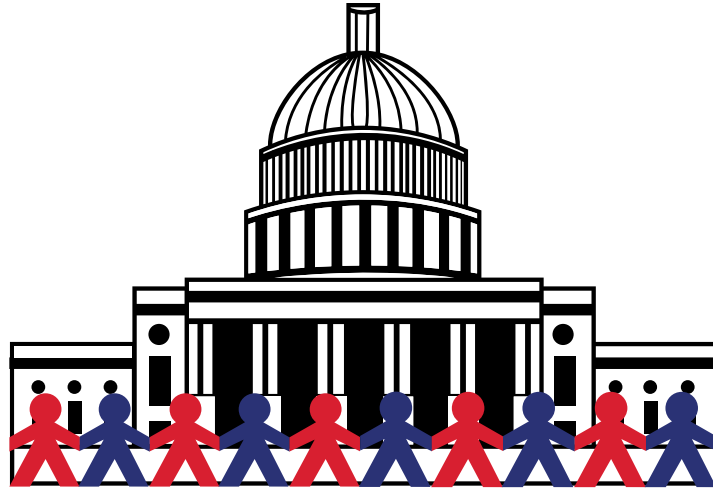


Education

In the spring DSA paid for CPR classes for interested parents and scheduled presentations by the Department of Health and Human Services and by Research Down Syndrome. DSA also scheduled a breakfast presentation for Down Syndrome Specialists (DSS) on the transition process for the general education population.

The Down Syndrome Education Series began in the fall. Each month, a speaker in the field of Down syndrome education, health care, or research is brought to Omaha to present information to DSA members that will positively impact the well-being of their children. Presentations from this series will replace the DSS breakfasts and enhance medical outreach.





DSA awarded self-advocacy scholarships to two teens to further their pursuit of independence. Jake Gehringer used his funds to take Film, Nebraska History, and Acting Classes. William Sharp used his funds toward his first week-long camp. Their reports can be found at the following links:

<https://dsamidlands.wordpress.com/2015/03/10/jacob-gehringer-thanks-dsa/>

<https://dsamidlands.wordpress.com/2015/03/23/billy-goes-to-camp/>

In February, a delegation of 3 self-advocates and 7 advocates traveled to our nation's capital to participate in the National Down Syndrome Society's Buddy Walk on Washington. Delegates met with members of Congress to encourage them to pass the ABLE Act.



Events

DSA continues to plan events that provide opportunities for bonding, respite, and just plain fun. The mothers enjoyed a Mothers' Day Brunch and two nights out. Kids were treated to a cooking class, a play at The Rose Theater, and four tumbling playdates. A pizza party was thrown just for siblings. Families enjoyed the annual summer swim party and Storm Chasers game. In March the parents were treated to a lovely dinner party, and we ended the year on a high note with a Comedy and Cocktail party at the Joslyn Castle. Rob Snow entertained 100 guests in finery and high spirits. The event was such a success we will plan a formal cocktail party next winter.



Down Syndrome Super Moms

The Moms' group continues to meet on a monthly basis. In the spring, the "coffees" were renamed Roundtables to reflect the professional tone of the meetings. Under the leadership of Casie Schlueter, the informal meetings started in 2009 grew to a regularly scheduled meeting with speakers scheduled for approximately 8 times per year.



G.R.A.N.D.S.

The grandparents' group welcomed the grandmothers and grandfathers of six kids into their fold. Not all of those kids are babies! Some of the grandparents are newly retired or for some other reason just ready to get more involved. The group continues to spoil everyone with the best parties: an Easter Egg Hunt, End-of-Summer Picnic, Trunk-or-Treat, and a Holiday Party at the Waterloo Fire Station.

D.A.D.S.

DSA and the local chapter of Dads Appreciating Down Syndrome (D.A.D.S. Omaha) collaborated with Pediatric Therapy Center, Inc. and the Autism Society to host an iCan Bike Camp. Eight children with Down syndrome were able to participate in the week-long camp.



Buddy Walk

We raised \$110,000 to support the programs and activities that benefit our community as well as national advocacy efforts! A crowd of 2,500 enjoyed a gorgeous day. The rookie team Huddy's Buddies stole the show by raising over \$6,000. For the first time we watched proudly as the flags were presented by a ROTC Color Guard that included two members with Down syndrome. And as always, the kids danced, and danced, and danced.

Buddy Walk Sponsors



Joanie and Francis Crilly Memorial