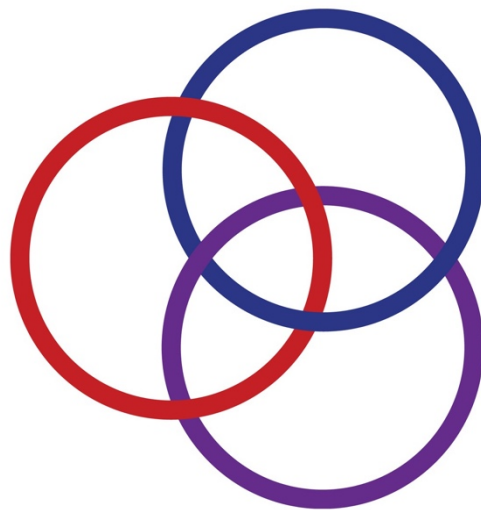


2015 Annual Report



Down Syndrome Alliance

OF THE MIDLANDS

Anne Mancini, Executive Director
Leah Janke
L'ara Arcishefsky

Board of Directors
Sherri Harnisch, President
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Letter from the Executive Director, Anne Mancini

As my seventh year with DSA draws to a close I will continue my tradition of focusing on three major accomplishments.

The best thing I did for DSA in 2015 was hire **L'ara Arcishewsky**, our Community Connections Coordinator. L'ara comes to us with a BS in Marketing from UNL and ten years experience in the field, plus the passion for serving the Down syndrome community into which her daughter was born. Hiring L'ara brought our paid staff hours up to a total of sixty.

L'ara's first order of business was to create a blog for DSA that integrates seamlessly with our website and now feeds into it. She maintains the blog and our social media platforms and database. She was also tasked with coordinating the Buddy Walk®. She recruited and managed a committee of primarily new members, researched and recommended a very successful fundraising platform, and led a collaboration with D.A.D.S. Omaha to introduce a new feature at the Walk: lunch! With L'ara's support, DSA doubled the number of paid registrants (1611 total) and raised 130% of our goal (\$147,100).

In April, after a rigorous application process, **DSA was accepted as a partner into the Heartland Genetics Services Collaborative**, whose mission is to improve and expand the capacity of state public health genomics programs and clinical genetics service programs to provide quality screening, testing, diagnostic, counseling, treatment, and management services to those who have or who are at risk for heritable disorders in a way that is culturally sensitive, collaborative, and responsive to state and regional needs. DSA's role in the collaborative is to provide training to parents of children with Down syndrome on how to create a medical home. The goal of a medical home is to provide a rationally organized health care system that ensures that patients who can benefit from specialty care gain timely access. Leah Janke and I were trained as facilitators of the program in May, one team of only two in the state (sixteen in the eight-state region). DSA was awarded a \$10,000 Global Down Syndrome Education Grant and a \$1,000 Heartland Genetics Services Grant to support the trainings. The funds allow DSA to provide \$100 childcare stipends to attendees of the two trainings we offer per year.

The 3rd major accomplishment is that **\$10,000 Global Down Syndrome Education Grant**. It is a major testament to DSA's stability, an endorsement of our programming, and an indication that we are growing in the right direction. According to Michelle Sie Whitten, CEO of the Global Down Syndrome Foundation, DSA accomplished exactly what they hope all of their grant winners will: leverage the funds from an educational grant to continue that program. Since we were able to match and exceed the original \$10,000 2014 grant within six months, we were encouraged to apply for a 2015 grant. DSA is one of only three affiliates to receive two Global Down Syndrome Foundation Education grants, and one of only two to receive the grant in consecutive years. We are also fortunate to have received the maximum funding available in both 2014 and 2015.

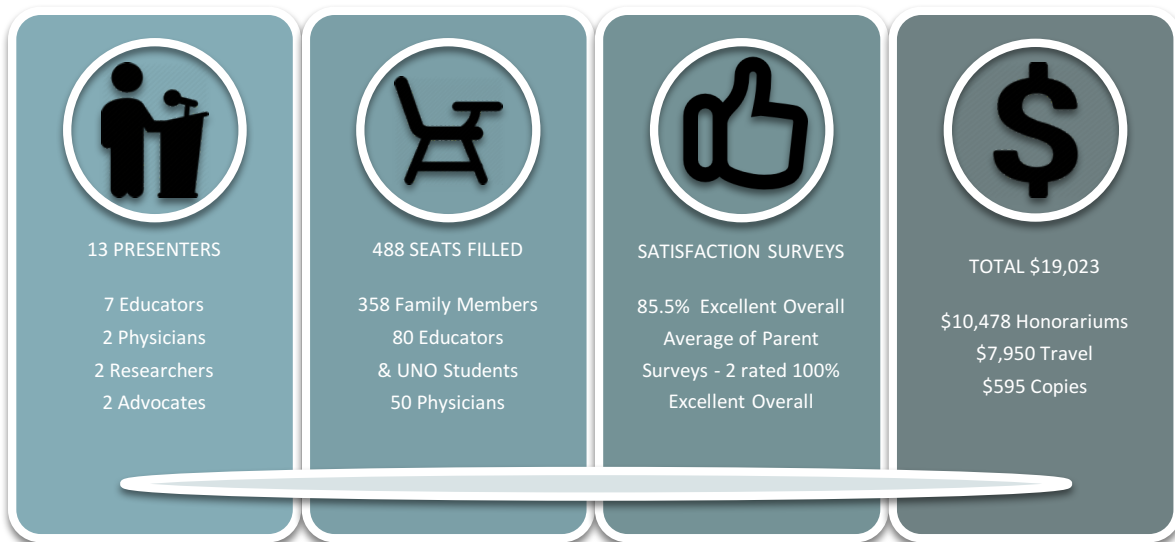
As always, I'm grateful to be included in this community and I love to hear from DSA's constituents and supporters. You all mean the world to me.

All the best,

Anne Mancini



Down Syndrome Education Series, Leah Janke



The Down Syndrome Education Series ran as a year-long program in 2015, after a great kickstart to the program in late 2014. This was also my first full year of working part time as the Education Programs Coordinator for the Down Syndrome Alliance of the Midlands. I couldn't be happier in my new role! As a former scientist turned high school teacher, I have always had a passion for both science and education. Through the Down Syndrome Education Series, I was able to bring in scientists working in Down syndrome research, doctors specializing in treating patients with Down syndrome, experts in maximizing the learning potential for students with Down syndrome, as well as presenters who work tirelessly in the field of Down syndrome advocacy. Shifting my role as an educator of "traditional students" to parents and other educators as been something I found very rewarding! I look forward to the growth of the Down Syndrome Education Series and the benefits it will bring to the members of the Down Syndrome Alliance.

Speakers and Topics for Parents

David Scott, Award-Winning Business Partner and Leader in Project SEARCH
 Sara Weir, NDSS President, ABLE Act and Grassroots Advocacy Efforts
 Stacy Taylor, M.A., B.C.B.A., Understanding and Treating Problem Behaviors
 Chris Kliever, Ph.D., Ending the Label of "Intellectual Disability"
 William Mobley, M.D., Ph.D., Down Syndrome Cognition Research
 Patti McVay M.Ed. & Laurie Pacht, Inclusive Best Practices
 Melissa Parisi, M.D., Ph.D., DS Connect™: The Down Syndrome Registry
 Brian Skotko, M.D., Keeping Children and Adolescents with Down Syndrome Healthy
 Sally Shott, M.D., Obstructive Sleep Apnea and ENT Problems
 Terri Couwenhoven, M.S., Issues and Concerns During Puberty
 Stacy Taylor, M.A., B.C.B.A., Toilet Training
 Susan Ellis, B.S., Visual Strategies and Video Modeling

Letter from the President, Sherri Harnisch

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 2015 annual report. Serving as President of DSA is an absolute honor and privilege. 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 2015 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 continuing into our second year of "Down Syndrome Education Series," attended by several families, educators, and medical providers month after month.

A new partnership with the Heartland Genetics Collaborative means DSA is able to provide additional training opportunities to our families, equipping parents with skills, knowledge, and resources they need to more efficiently coordinate care for their children.

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, D.C. to share the mission of our organization and encourage support of legislative issues affecting people with Down syndrome.

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 Annual Swim Party, family sporting events, monthly Down Syndrome Mothers Roundtables, Parents Nights out, Sibling events, playdates for the littles, as well as all the successful, and always well attended, 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 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 DSA's excellent staff. Our Executive Director, Anne Mancini, continues to make things happen. She works extremely hard, every day, to benefit the lives of individuals with Down syndrome in our community. DSA would not be who we are or where we are without her leadership. Leah Janke, who serves as Education Programs Coordinator, continues to educate



and empower our families through our DSES program, bringing world-renowned experts in a variety of fields relevant to the needs of our families to Omaha. L'ara Arcishewsky wears a lot of hats as Community Connections Coordinator. In addition to her marketing and communications related duties, she was instrumental in ensuring our 2015 Buddy Walk® was a success. Thanks again to the DSA staff for all their efforts in 2015, I am looking forward to all the great things yet to come.

Finally, and most important of all, thanks to each one of you reading this! Our organization truly is made up of several hundred like-minded individuals who have a collective desire to improve the lives of people with Down syndrome. You are what makes this organization work, and makes the work we do worthwhile. Please continue to stay engaged and hold us accountable in meeting your needs.

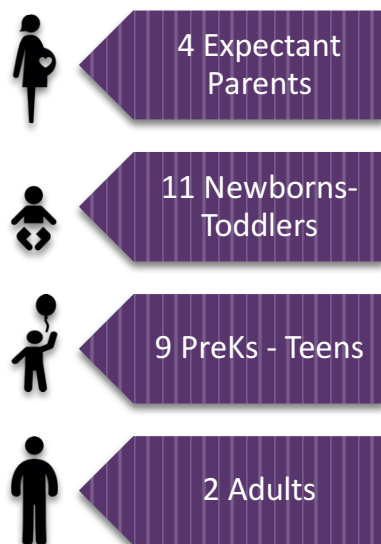
Kind regards,

Sherri Harnisch

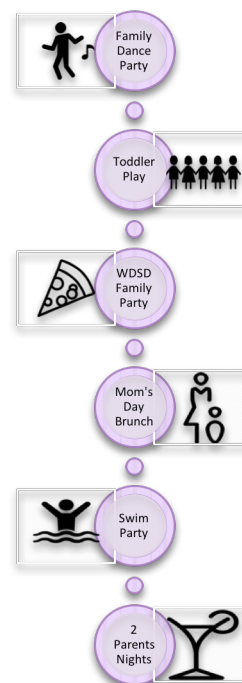
Parent Outreach

We have a community of nearly 440 households, representing the immediate and extended families of just over 400 individuals with Down syndrome.

New Members



Special Events



Mothers Connected by Down Syndrome

Over the last six years, Parent Outreach Chair Casie Schlueter elevated the group from its very beginnings as a few brave moms meeting each other for the first time over coffee to a well-organized network of hundreds of women. She created welcoming physical and online spaces. She scheduled a standing monthly meeting and then she started bringing in community speakers. In 2014 we changed "moms' coffees" to "mothers' roundtables" to reflect the forward movement.

This year I considered the powerful advocates the mothers are all helping each other become. I decided the sweet "Super Moms" did not accurately reflect their bond and their actions. I saw Mothers Connected by Down Syndrome. (Since that is a little long, we use DSA Moms for their Facebook group and other places we want a shorter version.)

Bonus - and this was done intentionally: The Diagnosis comes after the Person(s) and the name uses the key word from DSA's mission statement, which is to connect those touched by Down syndrome through education, advocacy and support.

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

We are so fortunate in that we have a very active group of grandparents dedicated supporting the families (read: spoiling the children). The social opportunities they organize are extraordinarily popular and give families a chance to unwind, let the kids run, and have a bit of respite from day-to-day activities. That is their gift to us. My gift to them this year was a redesigned logo that incorporates the DSA colors, the "three" motif, and their sense of fun. The logo gets dressed up for their holiday events.

—Anne Mancini



Medical Outreach, Beth Gard

Medical Outreach launched its Pediatric Outreach Initiative in December 2015. Our first office was Children's Physicians – Spring Valley, where we put together a Lunch and Learn for three pediatricians, nurses, a social worker and other staff. This office has a high amount of Spanish speaking families so this was a terrific start for Pediatric Outreach as well continuing to expand our Hispanic Outreach efforts.

We continued our Prenatal Outreach by conducting Lunch and Learns at local OB/GYN offices. This year we visited four offices and had lunch with a genetic counselor from UNMC who works with the perinatology office at Methodist Women's Hospital. We visited:

Metro OB/GYN (Omaha) – 4 doctors

Metro OB/GYN (Council Bluffs) – 4 doctors

Kruszka, OB/GYN, PC – 1 doctor

Kirsch Medical/Aesthetic Associates – 1 doctor and 1 midwife

While Dr. Brian Skotko was here July as part of DSA's DSES series we were able to have him included in the OB/GYN Grand Rounds schedule at UNMC. He spoke to a group of 50 doctors and residents about how to deliver a Down syndrome diagnosis.

Our Postnatal Outreach continued to expand beyond hospital visits to drop off new parent bags. In February, we were invited to speak at Mother and Baby staff meetings for nurses at Methodist Women's Hospital. There were two meetings held which included over 20 nurses at each meeting. In April we presented at the Genetics Case Conference at Munroe-Meyer Institute. We presented to nine genetic counselors and five geneticists. This group primarily sees newborns and infants at 6 months old or older who have already been diagnosed.

DSA's growing connections to the medical community continue to open more doors and to broaden our outreach and raise awareness in the Omaha metro area. Connections through social workers and nurses have enabled us to meet with new parents upon their requests while their child is in the NICU. Also as a result of these connections we have been invited to speak at educational events on Down syndrome. We are currently preparing to present to ER nurses at Crawford County Memorial Hospital in Denison, IA about people first language and how to better communicate with parents of children with Down syndrome. In June we will be participating in a Down syndrome educational event for nurses at Methodist Women's Hospital.

Scholarships and Stipends

\$500 Self-Advocate stipend awarded to Daniel Holm to travel to NYC. Daniel submitted a blog post with photos for DSA's Down Right Perfect Blog (<https://dsamidlands.wordpress.com>).

Out-of-State conference stipends were awarded to families attending the National Down Syndrome Congress Conference in Phoenix, the NDSS Buddy Walk on Washington, and a regional Down syndrome conference in Kansas City. Two staff members and two board members attended the Down Syndrome Affiliates in Action Conference.



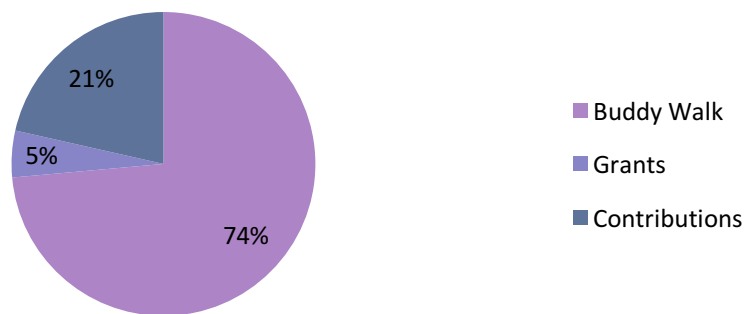
Treasurer's Report, Justin Hope

In 2015, DSA was the recipient of several grants and contributions allowing the creation, continuation, or expansion of several of our programs. Care coordination training, Down Syndrome Education Series (DSES) and translation of the new parent guide into Spanish were all possible as a result of these funds.

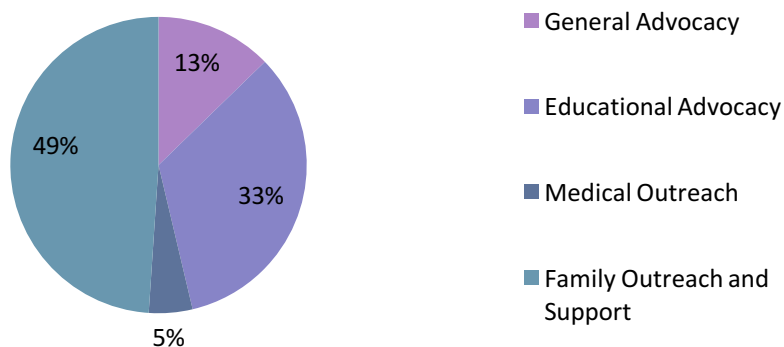
Nearly 80 cents of every dollar raised by DSA goes back into supporting and furthering our mission of connecting those touched by Down syndrome through education, advocacy and support. Funds provided by Buddy Walk and other contributions support such great programs and activities as DSES, new parent guides, a self advocate scholarship program, outreach to medical providers and social events where individuals with Down syndrome and their families are able to interact and connect. Your continuing support is critical to DSA's ability to continue to provide and facilitate these opportunities for our members.

Our total revenue for the year was \$201,557 and total expenses were \$200,412.

Revenue Breakdown



Program Expense Breakdown



Omaha Buddy Walk® Teams and Corporate Sponsors raised a record \$147,100



Huddy's Buddies
Veteran Spirit Award



Erik's Entourage
Veteran Fundraising Award



Camden's Crusaders
Rookie Spirit Award



Sophie's Superheros
Rookie Fundraising Award

Presenting Sponsor – KETV

Diamond Sponsor – Ralston Open Golf Tournament

Gold Sponsors

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Midwest Neurosurgery & Spine Specialists	US Bank	Kubler Financial
Rotella's Italian Bakery	Dino's Storage	Union Pacific
		UNO

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