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# DOWN SYNDROME ALLIANCE OF THE MIDLANDS 2016 ANNUAL REPORT

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## STAFF

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Anne Mancini, Executive Director

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Leah Janke

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L'ara Arcishewsky

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\*Board service complete

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## LETTER FROM THE PRESIDENT

Thank you for your generous support of Down Syndrome Alliance of the Midlands this year! I appreciate you for taking the time to review our 2016 annual report. It's wonderful 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 2016 finds the organization in fantastic shape. Our financial condition remains strong and we're very pleased that situation has allowed us to continue to expand current programs and fund new ones. Among the highlights was continuing into our third year of "Down Syndrome Education Series," of which several families, educators, and medical providers keep coming back for month after month.

This past year DSA became an affiliate partner with the Learning Program™ in an effort to provide more direct educational opportunities and resources to students, parents, and teachers.

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. The highlight of this past year was playing a key role in the passage of the "Down Syndrome Diagnosis Information and Support" Act. In addition to our local outreach, DSA, once again, 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.

Thank you to everyone who attended and played a part in organizing our various events throughout the year. Our most significant event, The Buddy Walk, was once again a huge success!

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, Anne Mancini (Executive Director), Leah Janke, (Education Programs Coordinator), and L'ara Arcishewsky (Community Connections Coordinator), for all their efforts in 2016, I am looking forward to all the great things still yet to come.

Finally, and most important of all, thanks to each one of you reading this! Our organization is a 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

It has been a genuine honor and privilege to serve as President of the Board of DSA.

Kind regards,

Sherri Harnisch

# LETTER FROM THE EXECUTIVE DIRECTOR

It's always exciting to share the work we accomplish with the support we receive from our donors.

We started off with the very exciting production of two impact videos that were filmed and edited throughout January and February and debuted at our World Down Syndrome Day Party on March 21. One video poignantly welcomes new families to the DSA community while the other informs potential donors of the impact their dollars have on our service capabilities. Both videos are featured prominently on our website and have been used in medical and education outreach as well as donor cultivation.

A long-held goal was reached this year with the translation and printing of DSA's Guide for New Parents. The previous edition was printed in 2009. This book includes a great deal of updated medical information as well as culturally-appropriate information. The book was translated first by a medical translator and then by a native Spanish speaker. It was also updated with photos of our Hispanic families throughout the book as well as welcome letters from several Hispanic families. This book is already in high demand at hospitals and community agencies throughout the Omaha Metro.

In September DSA was very excited to form a three-year partnership with the Enable Savings Plan. Their support for our families and for families across the nation is key to the success of the ABLE Act. The partnership is now the most significant that the Enable Savings Plan is committed to.

In November DSA was notified that we were accepted as a non-profit partner to rent an office at the University of Nebraska Omaha's Barbara Weitz Community Engagement Center. This will enhance our networking capabilities and allow us to expand our partnerships with the several departments at the at the university.

In December we were featured in the Global Down Syndrome Foundation's *Down Syndrome World Magazine*. It was an absolute honor to be recognized for the programs and services made possible by donors like you.

Of course, none of this could be accomplished without my amazing staff and board, who have my eternal gratitude and support. Hiring Leah Janke and L'ara Arcishewsky remain the greatest accomplishments of my eight years with the organization.

Anne Mancini



## CASIE SCHLUETER, PARENT OUTREACH CHAIR, REFLECTS ON HER SIX-YEAR TENURE ON THE DSA BOARD

I had my son Vollen in April, 7 years ago. They did not have the testing they have now, so we found out after he was born that he had Down syndrome. It was a huge shock, but he was our baby and we loved him no matter what.



I knew I wanted to get involved in the Down Syndrome Alliance of the Midlands right away. My very first mom's meeting that I attended was Saturday, September 19th 2009 (Vollen was almost 5 months old). I LOVED my first meeting and hit it off so well with the moms that were there. I said in my personal blog post that, "I have a feeling we are all going to be great friends the rest of our lives and go through everything with our kids together!!! It's so nice to talk with other moms who are going through the same

things you are. We have a special bond already."

From the feelings that I had from those meetings, I knew I wanted to give that special feeling to other moms. I started out taking over leading the mom's group even before I was on the board.

On Tuesday, January 4th, 2011 (Vollen was 2 <sup>3</sup>/<sub>4</sub> years old) I became the Parent Outreach Chair on the DSA board. This December my time on the board comes to an end (for now). I will continue to be the head of the moms group and we will continue to have meetings and night outs as usual.

I have been on the board and involved with DSA for a long time. I tell everyone this all the time, but my favorite thing about DSA is the mom's facebook page. The reason I love it so much is because all the moms can be involved even if they can't make it to the meetings or events. They can always get answers to questions they have that they need help on. All of our moms are so caring and helpful. They want to help out other moms who are going through the same things they once struggled with. With it being my favorite thing, it also frustrates me that there are moms out there in our area that haven't joined our group. I know they could benefit so much and find such a huge support system that they didn't even know they needed.

My other most favorite thing about DSA is our Education Series. This is the best thing in my opinion that DSA has done. The only thing better than connecting with other



moms/families in our area, is being taught by experts from around the country that specialize in Down syndrome related topics. I just don't understand why there is not standing-room-only seating when we bring these nationally known experts into our city to speak to us at NO CHARGE to the parents!!!! I have learned so much since the beginning. I just wish everyone in our area would make it a priority to get to these.

I just want to thank you all for being so wonderful and I hope that in my time as the Parent Outreach Chair that you felt welcomed with open arms and some of your fears were reduced or eliminated. I wanted nothing more than to help parents feel like they were not alone in this journey. I hope I succeeded.



## MEDICAL OUTREACH – BETH GARD

Medical Outreach in 2016 was the culmination of the work I have done over the last two years. I really started to see the impact that outreach has had over the medical community. I have continued to build relationships with medical providers from nurses, social workers to genetic counselors. By building relationships, I am contacted when new parent bags are needed at local hospitals or when a genetic counselor is in need of booklets to provide to expectant parents. I have enjoyed re-connecting with local medical providers as well as making new connections when new employees move into various positions.

At the beginning of 2016 one other member of DSA's board and I testified before the Health and Human Services Committee as proponents of LB891 – Down Syndrome Diagnosis Information and Support Act. LB891 was passed into law in April. This required that new and expectant parents receive accurate, up-to-date information at the time of diagnosis. During the summer, a Down syndrome fact sheet became available on the Department of Health and Human Services website.

Anne Mancini and I were asked to participate in a couple of educational events this year. In February, Anne and I presented at Crawford County Memorial Hospital in Denison, Iowa. We spoke about People First Language and using neutral language to the ER nursing staff. In June we participated in the "Personalized Care for Infants with Down syndrome" at Methodist Women's Hospital. This training was geared toward Labor and Delivery nurses in the Omaha metro area. We presented about DSA and People First Language. We also put together a parent panel that consisted of two parents and one grandparent to provide a perspective of experiences on behalf of the parent or extended family both pre- and post-natal.

Medical outreach continued doing Pediatric Outreach. I visited two pediatrics offices as well as a pediatrics behavioral health office

Children's Physicians – Mission Village  
(4 doctors)

Children's Physicians – Council Bluffs  
(2 doctors and 1 child psychologist)

Children's Physicians – Behavioral Health  
(25 child psychologists and mental health specialists)

As we closed out 2016, it became apparent that better Hispanic Outreach was needed. During the latter half of the year we were contacted several times from both Methodist Women's Hospital and Children's Hospital and



Medical Center about parents in the NICU who were primarily Spanish speaking. We were contacted not only to provide that initial connection, but also to get these families connected to other families in similar situations. During the summer of 2016 we had our new parent guides translated into Spanish and printed out. I delivered copies to Children's, Munroe-Meyer Institute, Bergan Mercy, and Methodist Women's Hospital. We have also recruited a new board member who is primarily Spanish speaking to help with meeting new families when requests are made.

## **EDUCATION PROGRAMS**

### **The Down Syndrome Education Series**

The Down Syndrome Education Series had its 2nd successful year in 2016! 10 presentations were held throughout the year for members of DSA and 5 presentations for educators, UNO students in the field of education, and therapists who work with children with Down syndrome. The presentations continue to be well attended by our members and receive excellent feedback.

The Down Syndrome Education Series brings well-known experts in the field of Down syndrome education, health care, research, or advocacy to Omaha so families who can't travel to annual national conventions due to the time commitment or costs, are not missing out on these great resources. The series connects our members as a monthly time to come together, learn, and ask common questions.

In late 2016, the series shifted gears a bit and brought in several local advocates. With the creation of the Enable Savings Accounts in Nebraska and big changes coming to Nebraska Medicaid in 2017, our members expressed an interest in local resources that are available to help them navigate these programs.

Ten presentations were given for parents and five were given for educators. Speakers included four educators, two researchers, and four advocates. The presentations received an average rating of 84% Excellent Overall, with three of the presentations receiving a score of 100% Excellent Overall. Over the course of the year, the seats were filled by 418 family members and 56 students and therapists.

#### 2016 Speakers and Topics for Parents and Educators

Dennis McGuire, Ph.D., Fostering Independence

Marilyn Tolbert, M.A., Ph.D., Tips for Successful Transition

- Letters, Reading, Numbers and Math! Oh My!!

Gretchen Carroll, M.A., IEP Toolkit

- Maximizing the Learning Potential for Students with Down syndrome

Dr. Brian Belden & Dr. Cy Nadler, Ph.D., Behavior Management in All Ages

- School Behavior Management

Jawanda & Rachel Mast, NDSS Manager of Grassroots Advocacy & self advocate, Advocacy and Social Inclusion

Amy Nutter, Service District Administrator for District 1, Nebraska Department of Health and Human Services - Division of Development Disabilities  
Kendall Rider, Project SEARCH Teacher, Employment Transition Program  
James Tews, J.D., Special Needs Estate Planning  
Carmen Bachle, Communications Coordinator DHHS Medicaid & Long-Term Care, NE Medicaid  
Amelis Long, Enable Outreach Specialist First National Bank of Omaha, Enable Savings Plans

## **Care Coordination**

As a partner in the Heartland Genetics Services Collaborative, DSA provided a free Care Coordination training to 22 families in February 2016. A grant awarded by the Global Down Syndrome Foundation in 2015 covered the costs of the training and allowed families to request a \$100 stipend to cover child care during the training.

The purpose of the Care Coordination training is to provide parents with the skills, knowledge, and resources they need to coordinate care for children with genetic condition in partnership with a medical home. A medical home provides families and care givers an organized health care system that ensures that patients are receiving seamless care.

By the end of the training participants will:

- Identify the components of a Medical Home
- Define their role in coordinating care for their child
- Identify one technique they can use to build a health partnership
- Understand basic guidelines for advocacy
- Recognize effective communication skills
- Identify key members of the child's care team
- Expand concept of care coordination beyond medical
- Know how to use Coordinated Care Plan to facilitate communication between care providers
- Understand the need to plan for child's transition
- Identify two different methods of organizing information
- Identify one resource that can help them navigate insurance
- Identify one technique for dealing with denied insurance claims
- Identify three key concepts for evaluating resources

After holding two successful Care Coordination trainings with an overall excellent rating of 92%, a member survey showed little interest in holding a third training. The information and funds will now be integrated as part of our quarterly New Parent / New Member Events.



## **The Learning Program Omaha**

The Down Syndrome Alliance of the Midlands was very excited to introduce a new educational program that launched in September 2016. Omaha is now one of 19 cities with a Learning Program Partner. This partnership, founded by the Down Syndrome Foundation of Orange County, shares educational information, strategies and resources with other Down syndrome groups so they can deliver Learning Programs in their own areas.

“The Learning Program™ was created to bridge the gap between research and practice. Although researchers continue to discover more about how people with Down syndrome learn, their insight has been slow to filter to parents and teachers. The program focuses on parents as first-teachers for their children, bringing the fruits of research into practice. Knowledgeable parents can work more effectively with their children and give them a jump-start on education. The program also arms parents to serve as capable advocates for their children in the educational process. The Learning Program™ complements formal instruction in literacy and math. It also has occupational and speech therapy components. DSF has partnered with educators, researchers, therapists and administrators to develop a program that uses effective teaching strategies and customized materials to support parents, teachers and children in the educational process.” – DSFOC.org

The Learning Program Omaha is open to children ages 4-7 and their parents. The program meets one Saturday per month for 8 sessions and is limited to 12 families. This year, the cost to the family is \$200 and covers all materials for the class and home, along with the monthly sessions. Students receive 20 learning books from The Learning Program along with a number line. The program was so well received that all 12 spots filled within 24 hours of registration opening!

We also offer a parent-only option for the lecture portion of the program at a reduced cost. This is a great opportunity for parents of younger children or older children who may still need help with reading and math skills. Educators are welcome to attend any or all of the lecture portion of the program for free.

During each hour and a half session, children receive small group instruction with a focus on literacy, numeracy, fine motor skills and language development from two special educators, an occupational therapist, and a speech therapist. Simultaneously in a separate classroom, parents in the program receive instruction on a wide range of topics such as "Introduction to Literacy", "Early Number Concepts", and "Teaching about Time". Materials are distributed to allow parents to reinforce the skills learned during the session at home. Teachers and therapists affiliated with the program receive information about effective teaching strategies and cognitive, developmental and educational research. Each month we have 6-8 volunteers made up of UNO students, therapists, and family members who help the classroom run smoothly. The staff, parents, and volunteers have had nothing but good things to say about The Learning Program Omaha!

## PARENT OUTREACH

DSA's membership increased by 29 in 2016. Thirteen of those families welcomed their infants this year. Two families moved to the area.

In the 2016 Strategic Planning session, the board wrote a goal to increase event reach and participation. The Year 1 step was to find a baseline (metrics) to determine event participation.

Event	Date	Attendance
Bowling Party	February 5	62
World Down Syndrome Day Party	March 21	95
Murder Mystery Parents Night Out	April 30	78
Mothers' Day Brunch	May 7	50
Berry Pickin' Picnic	June 11	101
Storm Chasers Game	July 16	79
Swimming Party	July 24	234
Moms' Craft Night	Sept 16	25

Attendance at G.R.A.N.D.S. events has proved impossible to count as they are generally held outdoors or in venues that can be approached from all sides, and children refuse to hold still to be counted when there is candy involved.

## BUDDY WALK® – THE EVENT



The 15<sup>th</sup> Annual Omaha Buddy Walk was a great success. Over 1,700 walkers registered to attend to support 90 teams. It's amazing to watch these numbers grow year after year. The Buddy Walk® Committee was made up of 8 enthusiastic volunteers who worked tirelessly to give our community an amazing event:

Christine Tran, Sam Kruse, Nikki Wulff, Tiffany Norton, Angie Paladino, Amanda Holliday, Rachel Herrman, and Jeanna Pine.



One of the favorite additions to the walk this year was the Advocacy Tent. Under the tent were games and crafts to promote education and advocacy. The biggest hit was the pumpkin decorating station. Walkers were given a pumpkin and a variety of blue and yellow craft supplies. They then were able to take their creations home and display them proudly on their front porches.

The Storm Troopers were very popular!

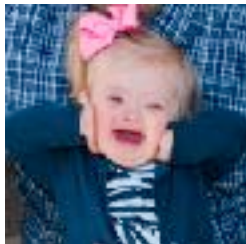
We also enjoyed our second year of collaborating with Dads Appreciating Down Syndrome (D.A.D.S.) Omaha for a fantastic grilled lunch!



## BUDDY WALK® – THE PRIZEWINNERS



Property of Joseph raised a whopping \$10,876, the most funds raised in one year by a team in the history of the Omaha Buddy Walk®! The Tran Family is headed to the National Down Syndrome Congress Conference in California next summer!



Ally's Army raised \$4,267 and also won the Spirit Award for most team members. The Walker Family chose the Henry Doorly Zoo Membership as their prize.



Landon's Luau raised \$4,234, a mere \$33 behind Ally's Army. The Ely Family took home the Creighton Men's and Women's Basketball Season Tickets.

## BUDDY WALK® – THE SPONSORS

Enable Savings Plan

Ralston Open Golf Tournament

Kutak Rock

Dads Appreciating Down Syndrome

Rotella's Italian Bakery    Caretech, Inc.    Complete Nutrition

Seim Johnson    US Bank    Kubler Financial Inc.    Dino's Storage    Hy-Vee

UNO Student Council for Exceptional Children

Advanced Family Eye Care    Baird Holm    Pediatric Therapy Center

Lindsay Corporation    Nebraska Medicine    Sebastian J. Troia, M.D.

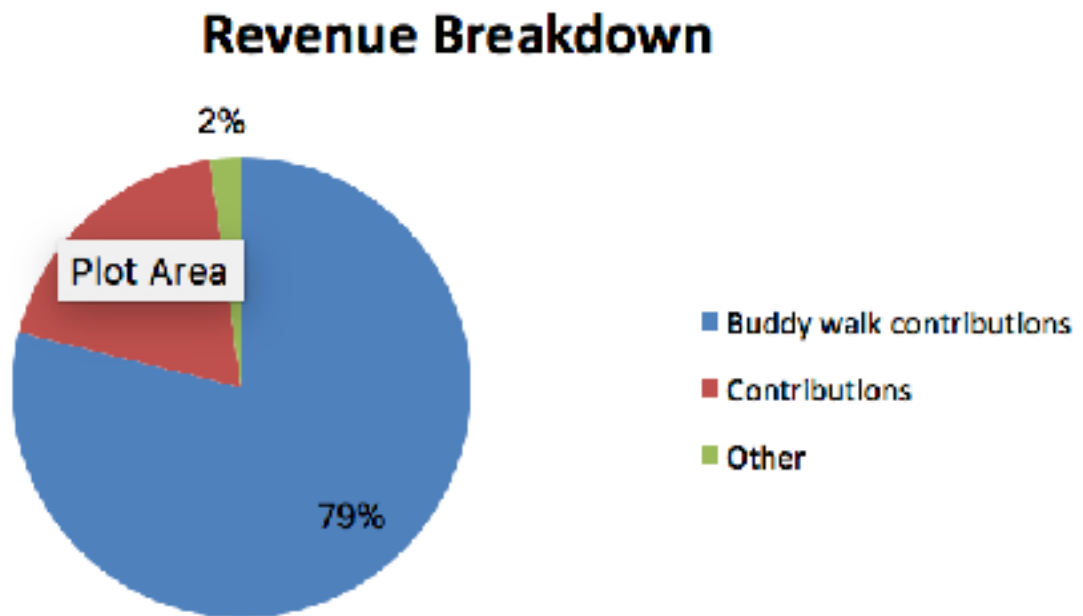
Children's Hospital & Medical Center    J.P. Cooke Company    Hawks Foundation

Creighton University    Northern Natural Gas    Stones Worth Stepping

Adult Pediatric Urology & Urogynecology PC    J.F. O'Neill Packing Co.

## TREASURER'S REPORT – Justin Hope, CPA

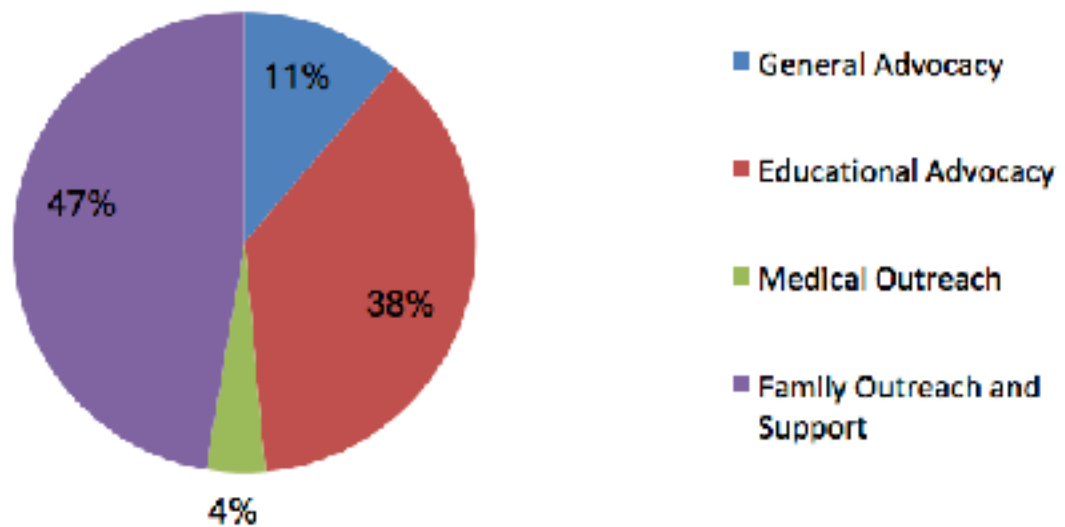
Down Syndrome Alliance of the Midland's ability to fulfill its mission is directly linked to the support received through the year from donors. The graph below illustrates the sources of support for 2016. As you can see, Buddy Walk provides the great majority of the funds used to provide the various programs and events that DSA hosts during a given year. We are especially grateful for and appreciative of all those who contribute and participate in our annual Buddy Walk.



So, just where do those funds that get raised through Buddy Walk and from grants and other contributions go? The graph below shows a breakdown of DSA's program expenses, or those that are directly linked to fulfilling our mission "The Down Syndrome Alliance of the Midlands is committed to connecting those touched by Down Syndrome through education, advocacy and support". General advocacy includes things such as travel and registrations for DSAIA and NDSC events. Educational advocacy represents DSES, The Learning Program and Care Coordination activities. Medical outreach involves meeting with and sharing

information with various physician groups and offices throughout Omaha. Family outreach and support includes the various outings and events through the year, such as the swimming party and berry pickin' picnic, and the party at Buddy Walk.

## Program Expense Breakdown



The Down Syndrome Alliance of the Midlands is committed to connecting those touched by Down syndrome through education, advocacy and support.