Anne Mancini, Executive Director
Buffy Beightol, President
Sherri Harnisch, Vice President
Steve Kudlacek, Treasurer
Kalyn Kimminau, Secretary
Jen Koley, Self Advocate
Dan Kline, Fundraising
Katie Sharp, Special Events
Casie Schlueter, Parent Outreach
Nancy Meinders, Education Advocacy
Michael Chase, Legal Advisor

2013 ANNUAL REPORT
President’s Letter

I would like to start off by thanking the three board members whose terms expired in December of 2013. Katie Sharp, Dan Kline (pictured), and Steve Kudlacek put in many of hours over several years in order to grow our organization. We have Dan to thank for our first two Buddy Runs, his effort to raise money while raising Down syndrome awareness in the community of runners. Katie Sharp was responsible for getting our kids to more events celebrating the arts and sciences. She will also always be celebrated for creating the Sibling Appreciation Party.

There are not enough words to thank our amazing Buddy Walk Committee for all of their hard work this year. The culmination of their efforts, energy, perseverance, vision, and spectacular weather made for one impressive Buddy Walk that we can all be proud of as members of DSA. Our new location was refreshing and perfect for all of us to gather and celebrate our loved ones with that ‘extra-awesomeness’.

This year has been exciting with our new Executive Director, Anne Mancini broadening her scope of work, our 2 savvy interns that upped our presence in social media, joining the Chamber of Commerce, and participating in new national campaigns such as #GivingTuesday.

We, as a board, are looking ahead to 2014 and how we can improve our efforts to reach our members, provide needed information, education and events, and grow our organization into an even more formidable, ‘blue-chip’ non-profit for prospective donors. We are investing in our Board by attending conferences through NDSC and DSAIA, redefining our position descriptions to better represent the roles and responsibilities that will take us into the future. With more training and education, we can develop greater depth in our committees and bring more experience to the table. Through social media, professional networking, community outreach, and our invaluable DSA membership, we hope to keep our board diverse, objective and proactive.

—Buffy Beightol
Executive Director’s Letter

In our community, good things come in threes. I look back on 2013 and clearly see three dates that stand out as professional highlights: March 21, May 1, and October 12. On March 21 we launched our new website, on May 1 I stepped into my new role as Executive Director, and on October 12 we celebrated our Buddy Walk in glorious weather at a new location.

I get a better sense of the year when I pull out the goals I wrote and can tick off exactly what I reached, what goals I rewrote and why, and what deadlines I extended to 2014 knowing that the DSA board was due for a major turnover.

My overall goal for 2013 was to focus on the fundamentals of a strong organization.

Our first order of business, in January, was to hire the Lincoln-based company Firespring, to build and maintain our website and run our payment gateway. (In the fall we purchased the donor management platform Bloomerang, which interfaces with our website and payment gateway, allowing us to understand and communicate with our donors in sophisticated ways.)

I worked with the board to write job descriptions and recruit strong candidates for open board positions. I hired two interns to free my time for community networking. I joined a leadership circle through our Down Syndrome Affiliates in Action Trade Association and DSA joined the Greater Omaha Chamber of Commerce.

This report shares in broad strokes the successes and challenges of 2013. I am always happy to discuss in greater detail any of our programs, and invite you to contact me at anne.mancini@dsamidlands.org.

— Anne Mancini

Treasurer’s Report

Fiscally, DSA is in very good health. While our projected income fell short by $21,307, our spending was $13,691 under budget. Our 2013 net income is $29,549.

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— Steve Kudlacek
Parent outreach continues to be a successful branch of DSA’s mission, more so now that we have search-engine optimized website. In December, the mother of a baby with Down syndrome whose family was relocated to Omaha for only 3 months conducted an online search for a local organization, found DSA, checked our events calendar, and attended the Saturday mothers’ meeting.

The mothers’ meetings included six presentations on resources available to families ranging from support from parents of individuals with DS age 17+, respite care, special needs planning, reading materials, and several other community agencies. Two meetings were in support of DSA events, one in support of the Scottish Rite Walk, and 3 meetings were in celebration of motherhood, holidays, and friendship.

The mothers’ group continues to enjoy informal opportunities to support each other and explore topics of interest to them, including screenings of films exploring disabilities awareness and opportunities to create art celebrating Down syndrome.

Twenty-five families joined DSA in 2013, including eleven families of newborns with Down syndrome.

The grandparents’ group continues its bi-monthly meetings and their commitment to providing education to its members, support to their children, and the requisite spoiling to their grandchildren. Their Spring Easter Egg Hunt, Summer Picnic, Fall Hayrack Ride, Trunk-or-Treat, and December visit with Santa at the Waterloo Fire Station all provide a
measure of respite, occasions for joy, and opportunities for families to meet and bond on multi-generational levels.

DSA also provides opportunities for socializing throughout the year. Families are encouraged to get together at baseball games, bowling events, swim parties and more. We also provide an opportunity just for siblings to hang out, to let them know we appreciate all they do to help out in their families. In 2013 our Special Events Chair, Katie Sharp, sought opportunities to expose our young people to the rich Omaha Arts Scene by sending groups to *A Year with Frog and Toad* at the Rose Theater and two performances by the Omaha Symphony: *Peter and the Wolf* and *Play! A Video Game Symphony.*

Challenges faced in this area are scheduling conflicts leading to low interest, and high RSVP to low attendance at pre-paid events. These challenges are continually assessed to determine how to best serve members while remaining good stewards of DSA funds. Often tickets are traded for future events (e.g. baseball tickets for berm tickets for a future game).

For several years, based on parent surveys, DSA strived to provide more programs for teens. To meet this request, in 2013 DSA applied for and received two grants from the Meyer Foundation for Disabilities to fund two programs for teens: Ice Skating Lessons and Health and Wellness Classes. The Skating Classes, through Blade and Edge Figure Skating Club, began in June with 8 students. Skaters earned badges from the Special Olympics program. Several students continued their lessons through the year. The program was deemed a success.
The Health and Wellness program was written to offer four sessions: Nutritional Health, Physical Fitness, Social Behaviors, and Human Growth and Development (Sexual Health). The Nutritional Health Class was attended by 7 students and received 100% positive feedback. The Social Behaviors and Sexual Health classes, scheduled to be taught by Creighton professional medical students, were canceled due to low registration. The Physical Fitness Classes were re-written to provide two 1 Trainer : 3 Student Strength Training Classes instead of one large two-hour general physical fitness class. The majority of the funds granted were returned to the foundation.

In Education Advocacy, the Down Syndrome Specialist Program met in the winter, spring and fall. Presentations and materials included topics on Behavior Analysis, Proximity of Paraprofessionals in the Classroom, Neurodiversity, and iPad Apps. An effort to recruit more parents to the committee is ongoing.

In the spring DSA was one of several community organizations that supported a one-day, grant-funded seminar to train librarians in adaptive story time techniques to better serve the needs of young children with intellectual and developmental disabilities.

Our board voted to sponsor two fundraising events in 2013: the Walk-n-Roll, benefiting the Meyer Foundation for Disabilities and the WalkRite for RiteCare, a fundraiser serving children affected by speech and language disorders through the programs and services of RiteCare™ Clinics.

In our continued efforts to collaborate with other agencies and providers, DSA teamed up with D.A.D.S. Omaha, Pediatric Therapy Center, and Autism Society Nebraska to schedule an iCan Shine Bike Camp in 2014. DSA participated in the 2nd annual #GivingTuesday campaign to kick off fundraising for the camp, collecting over $1,100.
In November, Sara Weir, Vice President of NDSS, accompanied Sherri Harnisch, Anne Mancini, and several DSA parents to U.S. senator Deb Fischer’s office to discuss the ABLE Act. The ABLE Act legislation has long been championed by National Disability Institute and other disability organizations as a key to providing a pathway to a better economic future for persons with disabilities and their families.

Sherri and Anne also became NDSS DS-Ambassadors. DS-Ambassadors are volunteer advocates of all abilities committed to taking part in the democratic process and serving as liaisons between NDSS and their Congressional Delegations. The overarching goal of the DS-Ambassador program is to build long-lasting relationships with US Senators and US Representatives to continually raise awareness, educate and advocate for public policy solutions that benefit the Down syndrome community at the federal level.

DS-Ambassadors’ efforts are crucial to the success of NDSS. Each month, DS-Ambassadors are asked to work with NDSS on special assignments to advance the organization’s advocacy efforts and to share their story with important elected officials.

DSA paid the registration fee for eleven families who attended the 2013 National Down Syndrome Congress Convention in Denver, CO.

Thousands of people from across the globe attended this conference to hear the latest information from world-renowned experts. Three days of workshops covered a wide range of topics, benefitting individuals of all ages who have Down syndrome, their family members, caregivers, educators and professionals. My husband and I left the conference encourage, inspired and motivated. We were armed with an overwhelming amount of useful and productive information which we have been happy to share with anyone who asks.

People with Down syndrome are living longer, healthier, and more productive lives than ever before. Much of this is due to families and communities embracing individuals with Down syndrome, and working together to ensure individuals achieve their goals and are able to take advantage of all opportunities available to them.

—Sherri Harnisch
I got involved with DSA shortly after I received the prenatal diagnosis, at 22 weeks, that Clay would be born with Down syndrome. I was given Casie Schlueter's contact information by the geneticist we met with at the Women's Hospital. I attended a new parent orientation at the DSA office and a mom's coffee meeting within the next few months.

Before getting involved with DSA, I had so many worries. I did not know what to expect for Clay. The extra doctor visits, special education, service coordinators, etc; it all seemed so overwhelming. Going to the new parent orientation and meeting with other families was so comforting. They were understanding, encouraging, and taught me to take it one day at a time just like you would with any other child. The "5 calls to make ASAP" link on the website gave me a good place to start and made me feel like I had a head start on things. Having a support group and people who can relate to you and not judge you is so important on this crazy journey!

Clay was born on December 19th, 2011. He came into the world as such a fighter. We knew he had Down syndrome and two large holes in his heart. He had a lot of cardiology appointments those first few weeks and we were introduced to our service coordinator from our school district. We were told he would need to have heart
surgery within the next few months and we would know it was time when his breathing and eating became labored. This terrified me. Luckily, he had a cardiology appointment the day after I first noticed some labored breathing. They agreed it was time and his surgery was scheduled for a few days later. Clay was 6 weeks old. He had his surgery at Children's Hospital and proved to be a fighter once again. The surgeons were very happy with the repair they were able to do and Clay was awake and alert a few hours after surgery. He was off the ventilator by the end of the day and I was able to hold him the next day. Clay came home 7 days after his surgery, on Valentine's Day.

Clay is now 22 months old. He is smart, stubborn, and loves to snuggle. Milestone wise, Clay is doing great. He is SO close to walking and works really hard at it everyday. He is able to sign 15ish words and says about 7 words. Clay attends preschool 2 days per week at Little Leaf Learning Center and also receives private speech therapy there. He receives speech, occupational, and physical therapy at our house from our school services. His favorite things are eating, playing outside, reading books, and balls or toys with wheels. He is SUPER ticklish and gives the best hugs EVER. Clay is 100% toddler and is into everything! He knows what he wants and will let you know when he doesn't get his way.

I am so proud of Clay and all the hardships he has overcome. He is so determined and works so hard to reach his milestones. I know that his drive and determination will open endless possibilities for his future. He has taught me so much about love, acceptance, and embracing the unknown.

"Life doesn't have to be perfect to be wonderful."
My 2 1/2-year-old son, Arslan, has trisomy 21 (Down syndrome). I went for a regular check-up with my OB when I was 12 weeks pregnant and he saw an extra layer on his neck, which is a characteristic of the trisomy 21. My OB referred me to a maternal fetal medicine doctor and I had an amniocentesis when I was 14 weeks pregnant. I was driving when I got a call from the doctor's nurse confirming the diagnosis of Down syndrome. The nurse suggested to abort the baby because "he was going to suffer." I didn't like the way she delivered the news to me and I was mad to hear her horrible suggestion.

This was in 2010 when DSA was ODSPN - Omaha Down Syndrome Parents Network back in 2010. I was put in contact with Graciela Sharif from PTI who had a son with Down syndrome, she also spoke Spanish - my native language. Before I even gave birth to my son I became involved in DSA so when he was born there were families to welcome him.

DSA sponsored informative conferences like the one in 2011 with Dr. Brian Skotko; paid fees for the conference I went to in Kansas City, MO; sent birthday cards to my son every year. They also sponsor different fun activities, the most important for my family is the
annual Buddy Walk.

I would encourage other parents, families, and teachers to get involved because it is a local organization that supports individuals with Down syndrome, their families, and is a good source of information.

Arslan amazes us every day. He has reached his milestones. He receives Early Intervention which is provided through OPS - Early Development Network (EDN) - Teacher/PT/OT/Speech.

He goes to Early Head Start at Educare of Omaha with typical children in a typical room, Private OT/PT/Speech & Aquatic therapy at ProCare 3, Hippo therapy at HETRA, and speech school at Munroe Meyer Institute - Scottish RiteCare Program. We are working on his speech and, hopefully, soon the toilet training. I haven't had any major barriers or frustrations because of Down syndrome.

Arslan is the love and light of our family and we could not imagine our life without him.
Buddy Walk Top Sponsors and Teams

The Kawa Family ~ Harper Grace’s Gang
The Boustead Family ~ To the Max!
The Hayden Family ~ Bella’s Buddies
The Paladino Family ~ Erik’s Entourage
The Janke Family ~ Clay’s Crew