

SPRING 2013

Extra! Extra! 21

Down Syndrome Alliance of the Midlands



We're Moving

More accurately, we are going back to a virtual office. Anne Mancini works from her home office in West Omaha. For the past two years we rented space at the PTI office at 70th and Grover, but we did not use it as an administrative office. PTI has an opportunity to move downtown to a space more suited to their needs. We are grateful for the invitation to join them in their new home but at this point it makes more sense for DSA to receive mail in Boys Town and to schedule meetings and presentations at a more central location. Our new mailing address is:

P.O. Box 269
Boys Town, NE 68010
Our phone number remains
402-991-1800

DSAMidlands.org

To celebrate World Down Syndrome Day on March 21, DSA launched a new website that features pages for new parents, existing members, education and medical outreach, community organizations, a blog, and a dynamic calendar for event information and registration. The site is equipped to accept donations through our account with Paypal. At Buddy Walk time, team pages will be built on our website instead of run through a separate fundraising platform. Stop by to browse our site! We hope you'll find it beautiful and easy to navigate.

Save the Date!

Moms' Brunch
5/4/13
Champions Run
9:00—11:00 AM
RSVP at
DSAMidlands.org

Buddy Run
6/8/13
Papillion City Park
Registrations will
be through Omaha
Running Club

Buddy Walk
10/12/13
Stinson Park
Aksarben
Village



Grants Awarded to DSA

DSA is the recipient of two grants awarded by the Meyer Foundation for Disabilities to offer programs for teens and young adults with Down syndrome and other cognitive disabilities. Dates and locations will be made available in the near future.

Ice Skating Lessons

Three sessions of ice skating lessons, each consisting of six classes, will be offered to teens and young adults with Down syndrome and other cognitive disabilities. Arrangements have been made with Roxanne Tyler, Senior Coach with the Blade & Edge Figure Skating Club of Omaha, to adapt their Learn to Skate Program to follow the Special Olympics Figure Skating Badge Program. The ratio of coaches to students is 1:4.

Our classes will accept fifteen students per six-week session. Sessions will afford each skater the opportunity to progress in the badge program. A \$15.00 registration fee will be charged per student at the beginning of each session.



Health & Wellness Class

DSA will accept ten students into our program of four two-hour classes on consecutive weekends. The topics are as follows:

- Social behavior: how to interact with peers at dances, sporting events, high school ceremonies
- Sexual health: what teens need to know before going on that first date
- Nutrition: making good choices in the cafeteria and how to pack healthy lunches and snacks
- Physical fitness: how to use a pedometer, tips for increasing activity, simple strength training, flexibility and hydration

All teens must be educated on these topics in order to make good choices for healthy minds and bodies. What is presented in the public school system may not be readily accessed by teens with intellectual disabilities. DSA will hire instructors prepared to present information in a straightforward manner geared to individuals with intellectual disabilities. We will structure the classes to include instruction time followed by role playing, hands-on practice or questions and answers. This second part of the class will indicate the success of the instruction. For the sexual health class we will split the class by gender and give the presentations separately.

Parents will be asked to pay a \$20.00 enrollment fee per student.



Letter from the President

Hello to Spring finally! So happy to see the warmer temperatures, children playing at the parks and enjoying the last two months of the school year. We had a wonderful Parent's Night Out in February at our new venue at Champions Run. We have welcomed several new families with beautiful babies and some babies that are yet to be born who are sporting the extra chromosome. At our last New Parent Orientation, we had 3 families expecting babies that had recently received a diagnosis of Down syndrome. These parents are educating and acclimating themselves to this new world of DS and I applaud them for their desire to be involved at such an early point in their journey.

The Buddy Run is scheduled for June 8th and we've been promised spectacular weather again. If you missed it last year, please join us and bring your running partners for the 2nd Annual Buddy Run. Buddy Walk preparations are already being made and we still need volunteers to help get ready for our biggest event of the year. If you or any friends or family members are interested in helping with sponsorship phone calls, entertainment procurement, or setup/takedown please contact Anne at run@dsamidlands.org. If you own or know of businesses that may be interested in sponsoring either of our fundraisers please let Anne know. We are already sending letters out to prospective sponsors and would appreciate any new contacts.

We have several families excited about attending the National Down Syndrome Congress conference in Denver in July. Remember, DSA families may apply for conference fee reimbursements of up to \$250 annually. The application is available on our website. If you have a services coordinator, don't forget that they are a valuable resource and may know of other avenues to offset costs for educational purposes.

And finally, if you haven't checked out our all new and improved website please do so. It looks spectacular and is much easier to navigate. Thank you to Anne Mancini for all of her time and effort to make our website current, efficient and polished! Also, thank you to Sherri Harnisch for her *photographic finesse* on the website.

—Buffy Beightol

Our Condolences and Gratitude

The family of Gertrude Schroeder suggested donations to DSA in her memory. Her loved ones donated over \$3,000 to support the programs that benefit her grandson, Tommy Schroeder, and other individuals with Down syndrome. We know that there are many deserving organizations in our community and are honored to be chosen as the recipient of this memorial gift. Our best wishes for peace and comfort are with the Schroeder family.

New Board Members

Sherri Harnisch, Vice President



The former young professional in the field of Advertising and Media turned stay-at-home mom has been an active member of DSA since her second daughter was born. Sherri and her husband Joe reside in Elkhorn and have two young daughters, McKenzie and Macy.

Sherri runs a photography business and works part time at her church. She is also involved in Big Brothers Big Sisters, Kaya Children International and Special Olympics NE.

Sherri is thankful for the impact this extra chromosome has had on her and her family. She hopes that by being an active and engaged member of the board she can directly help to empower, inform and educate families, enhance communities and highlight the potential that individuals with Down syndrome possess.

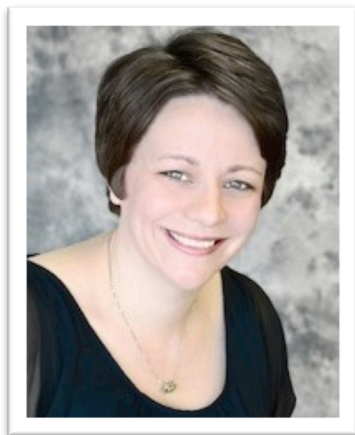
Nancy Meinders, Education Advocacy



Nancy began volunteering for DSA as a parent liaison to the South Sarpy school district through the Down Syndrome Specialist Program. In 2012 she joined the Buddy Walk Committee. This year Nancy was elected to a position that has been too-long vacant. She is committed to implementing programs and practices that benefit students with Down syndrome throughout their school years.

The mother of three boys lives with her husband Matt and their two younger sons in Springfield. Mikeal, their youngest, has Down syndrome.

Anne Rich, Medical Outreach



Anne is married to her high school sweetheart, Sean. They have four children, the youngest of whom, Eisley, has Down syndrome. "Our unexpected journey into the world of DS began 3 years ago with the birth of Eisley. It's been the ride of a lifetime and is molding me into a better wife, mother, nurse, teacher, speaker and advocate.

Anne is a registered nurse and works part time at The Nebraska Medical Center with Kidney Pancreas Transplant. She enjoys reading, blogging and spending time with family and friends.

DSA Leaders Attend National Leadership Conference

Anne Mancini, Sherri Harnisch and Nancy Meinders recently attended the Down Syndrome Affiliates in Action (DSAIA) Annual Leadership Conference in Cincinnati, Ohio. DSA was one of over 70 organizations which sent representatives to the annual event. DSAIA is a national trade association composed of 87 Down syndrome support organizations from across the country.

Deanna Tharpe, DSAIA Executive Director, states “it is a priority to grow the capabilities of local and regional Down syndrome organizations and create a unified effort to increase the acceptance of and opportunities for individuals with Down syndrome.” She adds that DSAIA “supports Down syndrome affiliates through a growing repository of programs and materials, regular training webinars throughout the year, and using DSAIA’s economies of scale to broker benefits for local groups.”

This was the seventh year for the conference, in which national experts and affiliate leaders shared research, successful programs and operations and development tools. More information about DSAIA can be found by visiting DSAIA.org.

Down Syndrome Specialist Program

On Friday, July 28, 2008, the first DSA Down Syndrome Specialist breakfast was held with area school district Special Education Directors and their newly-appointed Down Syndrome Specialists (DSS). It was at this first meeting that the DSS Parent Committee expressed to the school districts our desire to partner with them to assist them in obtaining the training and resources they need to teach a student with Down syndrome in their schools. The tri-annual breakfast meetings packed with information and resources have been held every year since then.

Currently, 18 school districts and educational service units in the Omaha Metro and surrounding areas are participating in the DSS program. The DSS in each district is an employee who is invested in the future of students with DS. Current specialists include teachers, speech and language pathologists, inclusion specialists and school psychologists. The DSS role is to be available for the professionals in their districts as a source for teaching students with Down syndrome. They share information and resources that have been provided for them by DSA.

Presentations are chosen based on feedback from the DSS and include Co-Teaching and Collaboration, Access to Academics for All Students, Assistive Technology, Teaching Children with DS Phonics, Paraprofessional Training, Presenting Sexuality to Students with DS, The Proximity of Paraprofessionals and the Incurred Outcome, Post-Secondary College Programs for Students with I/DD. DSA has also provided the DSS in each district with over 20 books and resource materials on topics useful to teaching a student with DS.

If a parent feels that their child’s teacher can benefit from more information on teaching a child with DS, he or she can encourage the teacher to contact the DSS in the district for support (contact information is on our website). It is our goal to support educators as they help their students with DS reach their full potential.

Welcome!



Benjamin

Kari & Mike Mansour and their son Eddie,
born 10.9.12

Jennie & Dan Dyer and their son Luke,
born 11.11.12

Amy & Josh Brown, and their son Pystol,
born 12.22.12

Lisa & Michael Pippin and their son David,
born 3.8.13

Tracy & Scott Wimmer and their
son Benjamin, born 3.15.13

Sarah & Todd Wiegman,
Expecting!

Tina & Jason Velinsky,
Expecting!



Eddie



Pystol



Luke

Happy Birthday!



January

Jarett Ayers
Teegan Becke
Ethan Bifaro
Juan Cardona
Alex Casey
Christian Cramer
Joey Drwal
Shaylie Frost
Lucas Boje
Alysa Livermore
Annabelle Livingston
Erika Lundquist
Jessica Mejia
Elizabeth Nietzel
Anna O'Connor
Jordan Oltmanns
Erik Paladino
Ranae Proskovec
Eisley Rich
Evan Rutherford
Olivia Scherr
Ian Smith
Chuck Stitt
Nicklaus Wright
John Yost

February

Addison Adams
Adan Benavente
Jordan Burtzel
Guillermo Carrillo
Amie Jo Duncan
Erick Flores
Ashlie Hite
Kelli Hudgens
Jordan Hughes
Anne Jackson
Ty Jorges
Charlotte Joseph
Harper Kawa
Jimmy Keen
Daniel Kirchner
Landon Newman
Katie Northouse
Tessa Pietro
Marshall Rabe
Richard Slagle
Gabriel Stark
Benjamin Tuccitto



March

Adam Bannister
Jenna Rothenbush
Jayna Bouquet
Jacob Kalasky
Jenessa Kimminau
Emery Rosenboom
Ellie McWilliams
Jennifer Koley
Sydney Meyer
Mikeal Meinders
Allyson O'Hara
Ben Clark
Benjamin Willey
Marissa Horstman
Alexis Jo Huls
Thomas Schroeder



David



Erik