Down Syndrome Alliance of the MiMidlands

Extra: Extra: 21 March

Welcome!

Arli & Kurt Boustead ~ Max Angelica & John Carrillo ~ Guillermo Anna & Tim Faulkenberry \sim Jackson Kristi & Shawn Fear \sim Elizabeth Michaela Fuquea & Jose Garcia ~ Sergio Robyn & Jason Gohr ~ Desmond Gabriela & Elmurad Hasanov \sim Arslan Veronica & Atreju Hood ~ Jaron Shereatha Green & Terry Hughes \sim Jordan Karen & Jon Jabens ~ Alexandra Leah & Luke Janke ~ Clay Lesley & Adam Leibhart ~ Tucker Teresa Alvarez & Juan Marquez \sim Sofia Angie & Luke Paladino ~ Erik Rona & Andy Pape \sim Owen Alicia & Peter Pol ~ Cooper Julie & Mark Schneider \sim Logan Sharon & Tony Schoepe ~ Kayleigh Debbie & Scott Schreiber ~ Lucas Emily & Todge Smith ~ Renee Pamela & Paul Turner ~ Cory Elizabeth Velazquez \sim Gilberto Lisa & Cameron Webb \sim Taylor Sheena Bouquet & James Young \sim Jayna Lisa & Nick Zweibel \sim Austin & Siblings

& Grandparents!

Letter from the President

Happy Spring!!

I know my family has been thrilled at the opportunity to head outside a little early this year. It's always great to visit with the neighbors that it seems like we don't see for helf the year while we hibernate inside. Of course spring is a time of renewal, but it also seems to be the time when it's most obvious to me how much my children have grown as they attempt new physical activities and practice their social skills in new ways. I encourage everyone to take advantage of opportunities that DSA provides for families to get together and socialize; both to share our experiences and to help our children improve their personal interaction skills. Our G.R.A.N.D.S. group does a great job offering family-friendly activities, and the Easter Egg Hunt in particular is a great way for kids to interact with new friends and focus on skills like sharing and problem solving!

This quarter we've been focused on parents via Parents Night Out (a rousing success!), the Medical/Technology Conference, and New Parent Orientation. During second quarter we'll be focused on planning fun activities for both parents and kids via our new Special Events Chair (see next page — Welcome, Katie!), the Down Syndrome Super Moms (DSSM) group, and the Fundraising Committee with the Buddy Run in early June.

As always, we would love to hear about what types of activities you'd like to participate in (for any and all ages)! Please hit us up on Facebook or Twitter if you're so inclined, or go "old school" via email or phone. We'd love to hear from you!

-Allison Machamer

2012

Buddy Run and Buddy Walk®

Mark your calendars for our 5K Buddy Run—June 2 and Buddy Walk—October 13.

Our first 5K is exciting in that we will draw participants from the running community. The run is a great way to celebrate Down syndrome, raise awareness and promote good health! I want to thank everyone who took the time to complete our survey. I'll address some of the feedback as we go along.

One suggestion was to go back to walking the track. While we're pretty excited about the visibility our current route affords us in terms of community awareness, we did look into the possibility of using the track as an alternate route. Unfortunately, UNO cannot make the track and field available to anyone during the summer or fall due to construction plans. We will strive to make the Pep Bowl carnival & route as fun as possible for *all* of our participants!!

New DSA Board Members

Katie Sharp, Special Events Chair



It is a privilege to introduce myself as the new Special Events Chair for the Down Syndrome Alliance of the Midlands. As someone who has benefited from this organization, in this new role I am looking forward to the opportunity to give back.

Currently, I work full-time as an Administrative Assistant at First Management, Inc. and for recreation I am a non-skating official for the local roller derby league. I have an awesome husband who cooks way better than I ever could and I have been blessed with two of the coolest kids I will ever know. My husband, Pat, keeps me sane and Billy and Danny... sorry, Daniel (they grow up too fast) keep me on my toes. Omaha has a wealth of "hidden treasures" that are just waiting to be tapped into so I'm always on the lookout for new ideas and volunteers to help those ideas come to fruition. I look forward to meeting all of you at our upcoming events.

-Katie Sharp

DID YOU KNOW? You do not have to be the parent of a child with Down syndrome to serve on the DSA board. OUR BOARD PRACTICES FULL INCLUSION! The Education Advocacy Chair is currently vacant. Email info@dsamidlands.org for more information.

Michael Chase, Legal Advisor

Michael Chase joined the Board in January as Legal Counsel. He is an attorney in the Health Care group at Baird Holm LLP and primarily represents non-profit and governmental health care organizations. Michael holds degrees from Creighton University and Saint Louis University's School of Law and School of Public Health. Before attending law school, Michael lived and worked in the Dominican Republic, serving as a volunteer coordinator for the Institute for Latin American Concern. In his free time, he enjoys trying any new restaurant in Omaha, boating on Lewis and Clark Lake in South Dakota, and adding to his art collection.





Jennifer Koley, Self-Advocate

I'm 32 years old. I work at The Ollie Webb Center as a part-time receptionist—3 years in July. I also attend Angel Works part-time. Currently I am vice-president of the Omaha chapter of the Project II self-advocacy group.

I enjoy volunteering, acting (currently part of the "It's Our School Too" production), dance lessons, bowling in a league, attending plays and movies, and karaoke. I am honored to be part of the DSA Board.

—Jenny Koley

EXTRA! EXTRA! 21

Parent Outreach

We have another New Parent Orientation coming up (March 27th 6:30-8:00 p.m.) for those of you who were unable to attend the last one or who are new to the group or area. Come on out and learn a little bit more about DSA and what all we have to provide!

Moms, remember to jump on that DSSM Facebook page to get helpful advice on anything that you are dealing with and to see what is going on with the group. There has been a lot of discussion about what people are planning for World Down Syndrome Day (March 21st). You can get some great ideas on there from our clever moms! We had a fun night out at Brix at the end of February. We would love to do more of these night out gatherings at the wine or tea places or even a restaurant (let me know if you want to set one up, basically just pick a date and time you can go and then we will post it and that's pretty much it). It's just a comfortable, fun, relaxing time to sit and chat with other moms. We will resume the Saturday Moms' Coffee on April 14th. Hope to see a big turnout so we can talk about the conference and what everyone learned!

The G.R.A.N.D.S. group is getting really excited for their first annual EASTER EGG Hunt (Saturday, March 31st 11:00-11:30 a.m.). They are filling TONS eggs at their next meeting (March 19th 6-8 p.m.) with all sorts of fun little prizes, tattoos, stickers and of course CANDY! Any grandparents who haven't attended yet can sure come any time! Get your parents to join. They only meet every other month and always have a fun time.

DSA members showed a tremendous outpouring of love and support for the Bunt family with the loss of their baby girl Sophie. The moms who attended the memorial service and all the moms who signed up to make meals for the family just warmed my heart. I know that is what each and every one of us would have wanted, to see that we are not alone. We are all together through thick and thin.

-Casie Schlueter

Medical Outreach

The Advocacy in the Midlands conference was great! Many of you might wonder what it takes to plan this kind of event. Number one is a Budget! Thanks to all the community donations and Buddy Walk money raised we were able to offer this conference two years in a row. The budget is for the speakers' fees, location, and interpreters, to name the bigger break down of the cost. We were fortunate to be able to bring Dr. Brian Skotko back as the keynote speaker for the conference and for presentations at Children's Hospital and Bergen Mercy Hospital. The audience at those lectures is physicians, medical residents and registered nurses in the Labor and Delivery field. Last year at the end of the conference we had attendees fill out an evaluation and asked for

suggestions, which we took into consideration when planning this year's event.

We printed a new edition of the Guide for New Parents. Those are the guides left at the hospitals along with a gift for the new baby. I will also be putting a packet together to send out to over 400 Obstetrical and Pediatric offices, local hospital with Labor and Delivery units, Children's Hospital and other clinics that would utilize our information with their services. Included in the packets are our publications on prenatal diagnosis for physicians and parents (English and Spanish) and a nurse's guide for caring for a family delivering a baby with Down syndrome. I will be in contact with all the social workers in the hospitals to build a relationship with



Ryan & Mason Wessendorf use the iPad won in the conference drawing.

them so they feel comfortable with the information we provide for talking to the new parents of a child with the diagnosis of Down syndrome.

—Roberta Tonjes

Dur Condolences

It is with great sadness that we share the news of the loss of two children in the DSA family. Dakota Karns, 14, son of Chris & Jeanie, believed everyone was his friend, and it may have been true. Dakota passed away on Wednesday, January 11, 2012. Sophie Analie Bunt, born March 7, 2011, adored daughter of Christopher and Stephanie Bunt and sister of Brayden, passed away on Tuesday, Feb 21, 2012.



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DOWN SYNDROME Alliance

Enhancing the lives of individuals and families touched by Down syndrome

Baby Blanket Project

Terry Schulte, former co-chair of G.R.A.N.D.S., recently took up the knitting needles. When her grandson Jaxson was born in Colorado, the family was given a homemade blanket from a Down syndrome support group. The blanket, lovingly made by another parent or grandparent of a child with Down syndrome, provided a measure of comfort for Jaxson (because it was soft & cuddly!) and for his parents, because they knew they were not alone.

Teri has been searching out patterns that incorporate "3" and "21" in a subtle yet meaningful design. Her first blanket will be finished soon and she will give it to DSA to include in one of the gift and information bags we leave for parents of newborns in the Omaha Metro hospitals. We'll start with the NICU at Children's Hospital.

If you like to knit or crochet we invite you to make a blanket, too! Email Teri at teri0314@msn.com

Happy Birthday!

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Jarett Ayers **Teegan Becke** Ethan Bifaro Juan Cardona Alex Casey Christian Cramer Joey Drwal Shaylie Frost Lucas Heller Annabelle Livingston Erika Lundquist Jessica Mejia Elizabeth Nietzel Anna O'Connor Jordan Oltmanns Erika Paladino Abby Plato

Ben Plato Ranae Proskovec **Eisley Rich** Evan Rutherford Olivia Scherr Ian Smith Chuck Stitt Henry Wood Nicklaus Wright John Yost Dylan Zephier February Addison Adams Adan Benavente Jordan Burtzel Guillermo Carrillo Amie lo Duncan Ashlie Hite

Kelli Hudgens Jordon Hughes Anna Jackson Ty Jorges Charlotte Joseph Harper Kawa Jimmy Keen Daniel Kirchner Landon Newman Katie Northouse Tessa Pietro Marshal Rabe Gabriel Stark Benjamin Tuccitto March **Benjamin Willey** Kinley Goshorn Marissa Horstman

Ellie McWilliams Alyse Archer Cody Gelvin Chloe Seim Jenna Rothenbush Alexis Jo Huls Jennifer Koley Jacob Kalasky Marissa Thompson Jenessa Kimminau Sydney Meyer Emery Rosenboom Mikeal Meinders Adam Bannister Ben Clark **Thomas Schroder** Kaleb Gass Trenton Smaus