

SPRING 2017 APRIL / MAY / JUNE

www.dsafnebraska.org

WORLD DOWN SYNDROME DAY CELEBRATION HELD MARCH 21ST



















More than 225 guests joined the effort (and, fun) at the DSAF 2017 World Down Syndrome Day held 3-21 at the National Guard Armory—Lincoln. Union College provided nearly 40 volunteers who assisted with the novelties, played with kiddos and served free pizza. VIPs with Down syndrome (30+) were eligible for multiple door prize giveaways throughout the evening, ranging from store gift cards and fishing poles, to an all-inclusive family bowling party, and more. Guests enjoyed cookies from Eileen's Colossal Cookies, cupcakes donated by HyVee, and fresh cotton candy, while watching performances by Capital City Dance Shack. Thanks to Party Inflators (owners and DSAF members, Scott and Kelly Neal) for providing a huge obstacle course and bounce house. Balloon creations by Blinky the Clown and commemorative photos by FOTObrations FOTObooth were big hits, as well. Special thanks to DSAF members, Patrick Bruning, for facilitating our connection to the venue and to Robert Kadavy, for his unfailing assistance before, during, and after the event. Photos courtesy Ryan Widicker.

MEET MEMBERS OF THE BOARD

DEan Fuelberth has served as Board President for the past two years, filling the role of Vice President prior to that point. He has also served on various committees, including several for the Education Conference, and Publicity Chair for the Step Up Walk (where he also helps MC with Froggy98). He has represented DSAF at the DSAIA national leadership conference for many years, and participated at the Buddy Walk in Washington to meet on the Hill in DC with members of Congress to discuss current legislation impacting the Down syndrome community. DEan and his family have been active with the DSAF since moving to the city in 2001. DEan works as a Project Manager in Information Technology at the Ameritas Life Insurance Company home office. His wife, Rhonda, is a Professor of Music Education at UNL, and also founded and conducts the community i2Choir – an inclusive, inter-generational choral ensemble that partners with the UNL School of Music and the Quilt Center to provide music making opportunities for individuals of all abilities. A smaller portion of the i2Choir has sung the Star Spangled Banner at the last two Step Up Walks.

DEan's son, Hayden, is a sophomore at Lincoln Southwest HS, and is very active in band, choir, jazz show choir. completing band. and theatre, just 8 performances 'Mary Poppins'. His daughter, Elissa, is a junior at LSW and her favorite subjects have been Choir and Algebra. Elissa also happens to have Down syndrome. She has an amazing group of friends at school. Outside school she participates in Girl Scouts, Church Youth Group, DSAF events, Wonderfully Made events, four Penguin Project musicals at Lincoln Community Theatre, and sings in the i2Choir. She had some grand milestones last year, testifying before the HHS subcommittee at the State Capitol in support of the Down Syndrome Information Act, being a member of the first LSW Unified Bowling Team (the first year for these teams in Nebraska), achieving her first high school letter, and passing her written exam and obtaining her learners permit from the DMV.

OUTGOING BOARD MEMBERS

Rachel Smith joined the board in 2014 and became Vice President in 2015. She first became involved in DSAF since 2007, when her sister, Felice, was born with Down syndrome. Rachel is a doctor on staff at EyeCare Specialties of Lincoln and Beatrice, where she specializes in pediatrics and learning-related vision disorders. Rachel's term on the Board ended in March 2017. Although she has opted to step down from the Board, Rachel remains committed to contribute to the organization wherever possible within the time constraints and priorities a growing family necessitates.

Lori Prange served on the Board since 2012, serving as Board Secretary from 2012 to 2017. Lori also co-chairs the Education Conference Committee. Lori has a technology and project management background that she uses to organize DSAF programs. She the HE Implementation Manager at Nelnet Campus Commerce. Her teenage daughter Kelsi, who has Down syndrome, is involved in several school activities. Kelsi is a member of Cheer Xpress and has performed at several past Step Up Walks along with other friends from DSAF.

DSAF GOES TO THE CHILDREN'S MUSEUM, FEBRUARY 21ST

























120+ members took the opportunity to enjoy some quality family time while learning through play at DSAF's Night at the Lincoln Children's Museum—an annual member-benefit (and, favorite). The museum was closed to the public, allowing 30 children with Down syndrome with parents, siblings, and some grandparents a chance to roam the multiple levels of the facility at their own pace. More than 40 volunteers from Union College, UNL-Theta, UNL-NSSLHA, and Concordia University were on hand to lend help with the kids (giving the grown-ups a chance to chat). Guests enjoyed sandwiches and cookies catered by Goodcents. Photos courtesy Ryan Widicker.

STRATEGIC PLANNING SESSION HELD

The DSAF Board met in February for a Strategic Planning session. Randy Hawthorne, Executive Director for Nonprofit Hub, facilitated the group as they reviewed the vision plan and discussed ways to implement new ideas and programs to promote growth while maintaining high standards within the organization.



Pictured: L to R, Jodi White (Program Director), Jen Brill, Julie Huls (new to the Board), DEan Fuelberth (President), Mary Sweeney (new to the Board), Rachel Smith (Vice President), Jennifer Lohmeier (Treasurer), Rick Bohaty and Chris Marvin.

MEMBERS OF NSSLHA VOLUNTEER

UNL National Student Speech Language Hearing Association (NSSLHA) continues its support of DSAF: Seen here, members of NSSLHA use meeting time to assist in collating new parent packets with Medical Outreach Chairman, Holly Lohmeier (and, Dottie). The group also helped to prepare a mailing being sent to medical providers statewide containing information regarding the Down Syndrome Diagnosis Information and Support Act.



UPCOMING EVENTS

DSAF Goes to the Henry Doorly Zoo & Aquarium, Omaha – June 9. Free admission to DSAF members with Down syndrome and their immediate family.

Lil' Stars go to My Gym, Lincoln - June 24, 4 - 6 pm. Most of the equipment is geared for kids ages 0 to 6. Kids go barefoot and adults have to wear socks. Each Lil' Star is free and accompanying children pay \$10 each.

National Down Syndrome Congress Convention, Sacramento, CA - July 20 - 23. Contact DSAF if you would like more information. Scholarships may be available.

Be watching on the DSAF website and Facebook for future summer photo session opportunities for our loved ones with Down syndrome. Erica from Images for a Lifetime will attend some of our Little Stars, Super Stars and other group events. These photos may be used for future publications and fact posters that teams can earn for the Step Up Walk.

2017 CAPITAL CITY STEP UP FOR DOWN SYNDROME NOTABLE DATES



- Corporate Sponsors forms due 8/30
- Early Bird fact posters donations due 9/2
- Stars Bios due 9/16
- T-shirts donations due 9/14
- T-shirt pick up 10/4 and 10/5
- Donation deadline to qualify for top teams due 10/5
- Walk 10/7, Antelope Park, A St. & Normal Blvd.
- Coming soon...the registration website

MEET ONE OF OUR NEWEST BOARD MEMBERS

Mary Sweeney joined the board in January of 2017 but has been involved with DSAF since 2014 when her first-born son, Henry, was diagnosed with Down syndrome. She is the Donations and Sponsorship Committee Chair for the Step Up for Down Syndrome Walk and coordinates the raffle.

Mary received a Bachelor's degree in Communication and Spanish from Nebraska Wesleyan University in 2004 and is a Certified Arborist by the International Society of Arboriculture. Currently, she is a Program Manager at the



Arbor Day Foundation and brings to the board 13 years of experience in the development of strategic partnerships, marketing, event planning, and project management. Mary loves to spend time with her husband and two sons, Henry (3 years old, who has Down syndrome) and Jack (1 year old). When not chasing them around, Mary enjoys running, cooking, traveling, and brushing up on her Spanish.

GIVE TO LINCOLN DAY IS THURSDAY, MAY 18

For 24 hours, every donation given to local nonprofits is made bigger by matching funds. Gifts given on May 18th make a bigger impact because nonprofits also get a proportional share of a \$350,000 challenge match fund provided by Lincoln Community Foundation and sponsors. Go to GivetoLincoln.com, and please consider giving to DSAF of Nebraska on May 18th.

CONTACTS

DEan Fuelberth, Board President Jennifer Lohmeier, Treasurer Chris Marvin, Board Member Rick Bohaty, Board Member Jennifer Brill, Board Member/Step Up Walk Chair Julie Huls, Board Member Mary Sweeney, Board Member Brandi Benson, Board Member Holly Lohmeier, Medical Outreach Chair Torri Attebury, Lil' Stars Co-Chair Tracy Kadavy, Lil' Stars Co-Chair Liz Echternkamp, Super Stars Chair Caroline Fehlhafer, Teen/Young Adult Stars Chair Kelly Ekeler, Newsletter Editor Kathryn Brockmeier, Newsletter Editor Jodi White, Program Director

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Other DSAF e-mails: info@dsafnebraska.org finance@dsafnebraska.org stepupwalk@dsafnebraska.org

Down Syndrome Association for Families (DSAF)

P.O. Box 57362 Lincoln, NE 68505

Return Service Requested

Mission Statement: The Down Syndrome Association for Families is a Lincoln based non-profit organization that provides support for individuals with Down syndrome, their families, friends, educators and professionals who share in their lives.

Every person with Down syndrome is an individual who has a unique purpose and abilities. DSAF provides networking and a positive vision for the future.

Website: www.dsafnebraska.org Telephone: 402-421-1338 NON-PROFIT US POSTAGE PAID LINCOLN, NE PERMIT 1024

LIL' STARS AND SUPER STARS GO SWIMMING



















On March 19th the Super Stars met at the YMCA for some swimming fun. More than 20 family members attended the event.

No foolin', seven Lil' Stars and their families attended the swim and pizza party at LifeSTROKES on April 1st.

Everyone had a great time! Thank you to DSAF for supporting these events! Be watching the website (click the EVENTS tab) for more opportunities to become involved in DSAF activities.