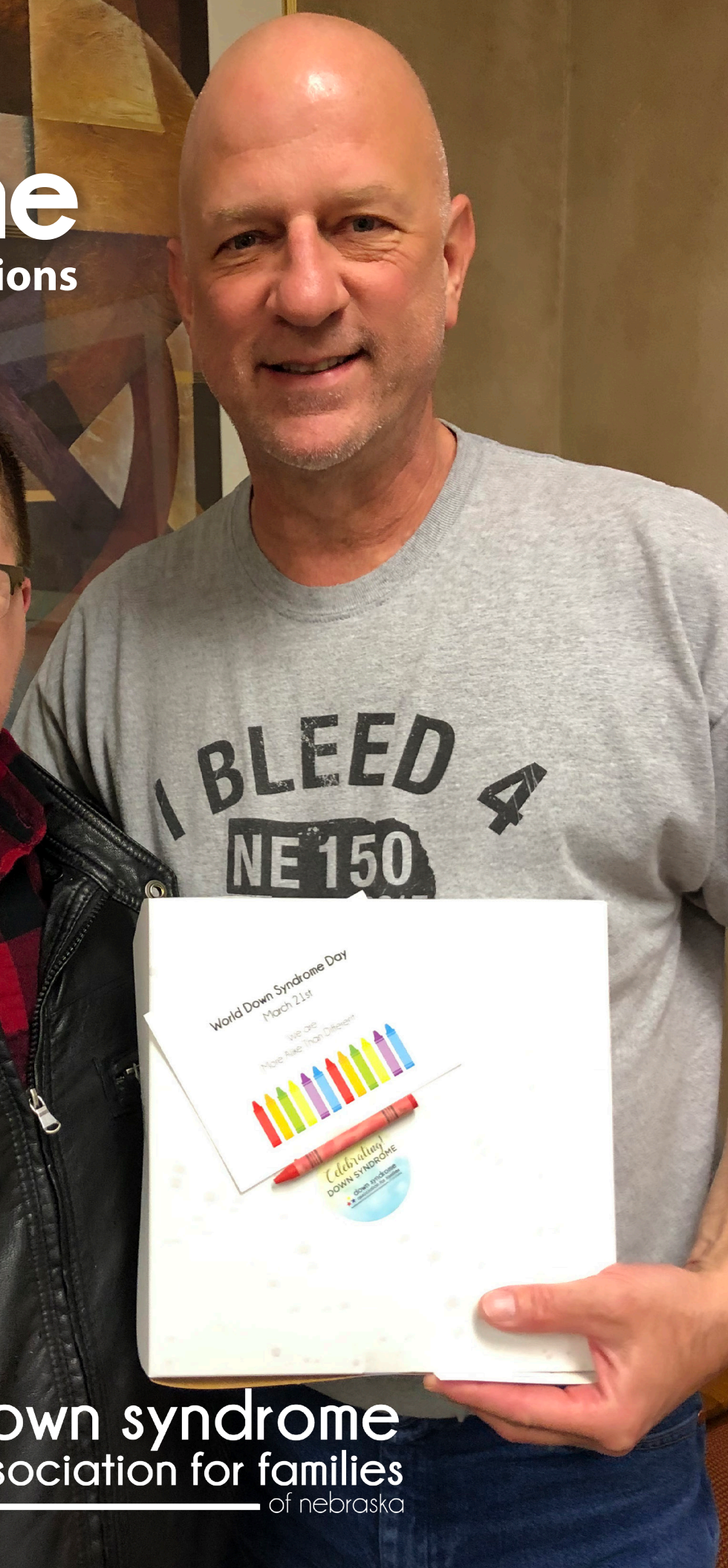


down syndrome

community connections

June 2019



down syndrome
association for families
of nebraska

president letter

board sets plans in motion

On March 23, 2019, Down Syndrome Association for Families of Nebraska Board of Directors put their heads together for their yearly strategic planning session. Thanks to valuable responses from the DSAF Member Feedback Survey, the board revised and created new strategic priorities for 2019.

Even though Member Feedback Survey showed very positive member engagement results, twice as high as other similarly-sized nonprofit organizations throughout the country, DSAF is committed to continuously improving the member experience.

We feel confident that focusing on these key priorities throughout 2019 will help to elevate the professionalism and capacity of DSAF to impact the lives of our members in Lincoln and beyond. Should you have any questions, please feel free to contact me at dean@fuelberth.com.

Thank you for your trust and confidence in DSAF and us as a collective board. We feel honored to represent you.

Sincerely,



DEan Fuelberth
DSAF Past President



Strategic Priorities and Progress Toward Goals

Diversify Funding

DSAF took a big first step in diversifying funding by hiring a fundraising consultant, Clover Frederick, and piloting a new Development Director position. That pilot position converted in 2018 to the hiring of a part-time Development Director, Mary Sweeney, with a start date of January 2019. The parameters of a fundraising committee were established along with a list of top donors to cultivate and gift procedures for the organization.

Improve Communication to Foster Member Engagement

Rebranding of the organization's logo and launch of the brand-new quarterly newsletter, Community Connections, were two of the most exciting marketing advancements in 2018. Members and friends of DSAF alike were able to clearly see the impact of their support and engagement with the organization through the compelling stories in the newsletter.

Illustrate Programming Value

The three-part, "How Your Dollars Help," video series aired throughout 2018 explaining to members the value of their membership. The Medical Outreach team updated and improved resources to ensure the most accurate and up to date information was being distributed to new parents and medical professionals.

Formalize Organizational Structure

The DSAF Board continues to formalize board processes and positions. President-Elect, Liz Echternkamp, was appointed at the end of 2018 with a transition period of January-May 2019, moving President DEan Fuelberth to the Past President position for the following year. 2018 saw the departure of our good friend, Jodi White, as Program Director. A Search Committee was established to assist with the hiring of a new part-time Program Director.

new program director

meet dawna daily, DSAF's newest staff member



“I am most excited as I join this DSAF family to see the critical daily interactions between the board, committee members, families, and community.”

This is no April Fool's Joke! DSAF is excited to announce that on April 1, 2019, Dawna Daily started with the organization as the new Program Director.

Dawna is a motivated and experienced program developer, presenter and educator with over fifteen years of experience serving in one of the best communities in the nation.

She excels at building and maintaining collaborative community relationships and bridging communities of all abilities. She has a history of executive-level decision-making, analyzing problems and finding solutions, and working within all levels of local, state, and national guidelines to deliver the best programming while maintaining policy, procedure, and documentation.

Dawna received her master's degree in Special Education from the University of Nebraska Lincoln, and she holds teaching endorsements in Work-Based Learning and Transition. She comes to DSAF with experience working within the University Centers of Excellence on Developmental Disabilities at the University of Nebraska Medical Center and previously taught resource and transition at the Elkhorn Public Schools.

“I am most excited as I join this DSAF family to see the critical daily interactions between the board, committee members, families, and community. I can't wait to be a part of helping it to grow and flourish to provide mutually beneficial opportunities throughout the organization,” Dawna said.

Dawna is the owner of Daily Yaymaker, LLC., a newly formed company, that works to bridge communities of abilities through community and travel experiences for individuals with unique and diverse needs. In her free time, Dawna enjoys spending time with her family, which includes her husband, Kevin, and their dog, Abby (a golden retriever mix), her two grown children and two beautiful grandchildren.

Please feel free to reach out to Dawna to welcome her to the organization. She can be contacted at 402-206-3092 or director@dsafnebraska.org.



WORLD

DOWN SYNDROME

DAY

HIGHLIGHTS

March 21 was World Down Syndrome Day (WDS). A day to celebrate our friends and loved ones across the globe who have Down syndrome and raise awareness about the vital role they play in society. Why March 21? Because March 21, or 3/21, represents the three copies of the 21st chromosome that all individuals with Down syndrome have.

DSAF couldn't pass up the opportunity to join with members in celebrating and educating the community at large about the VIPs they have living right in their own backyard. Special visits were made by our Medical Outreach team and self-advocates to deliver cookies to DSAF partners and supporters. Crazy socks were worn. Even a conference was hosted for medical staff and social workers. And LOTS of celebrating was to be had at the massive World Down Syndrome Day celebration at the National Guard Armory. Thanks to our generous sponsors and donors, all event festivities remained free and open to the public.

It's not always an easy journey, but together, little by little, we walk the road to a bright and beautiful future for all. And boy does it look promising. Cheers to all the achievements, little or big, that you celebrate in the lives of your loved ones with Down Syndrome.



40
NURSES & SOCIAL
WORKERS ATTENDED
"DOWN SYNDROME:
DIAGNOSIS,
TREATMENT,
& SUPPORT IN
2019," A MEDICAL
CONFERENCE HOSTED
BY DSAF'S MEDICAL
OUTREACH TEAM

20
WDS VISITS
TO DSAF
PARTNERS

504
SLICES OF PIZZA
EATEN




360
COOKIES

DISTRIBUTED
TO DOCTOR'S
OFFICES, NICU'S,
LABOR & DELIVERY
DEPARTMENTS,
SPONSORS
& DONORS

275
REGISTERED
ATTENDEES
AT WDS
CELEBRATION

\$2,600
RAISED IN
SPONSORSHIP &
IN-KIND DONATIONS



13,387
PEOPLE
REACHED ON
FACEBOOK
THROUGH
WDS POSTS





THANK YOU!

KELSIE PRANGE, TREVOR HOWE,
AND HENRY SWEENEY FOR VOLUNTEERING
TO DELIVER COOKIES TO OUR
WONDERFUL
SPONSORS

dental Blending
Science,
Technology
& Art
designs

ENable™
SAVINGS PLAN

Oceans
DENTAL

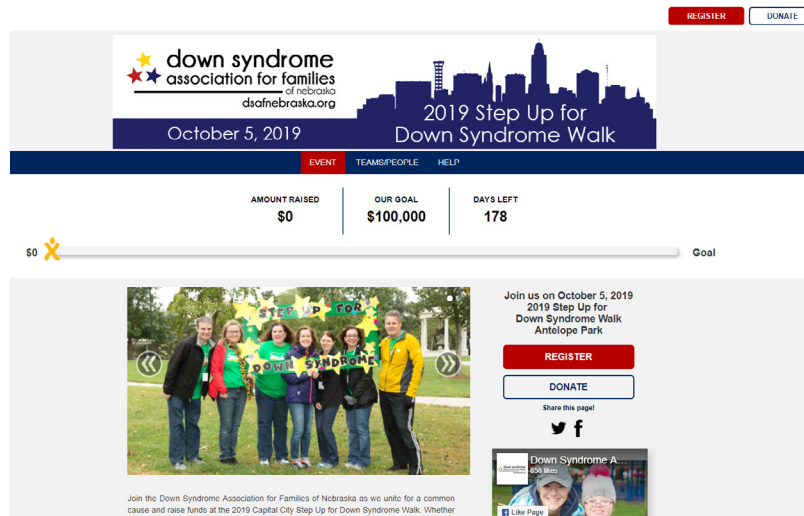
P premier o&p
orthotics and prosthetics

Happy D Klown LLC Services
The Cookie Company
La Paloma
HyVee
Party Inflators
Runza

Star Digital Print
Super Saver
TerraSumoto
Theatre Arts for Kids
Valentino's

have you heard?

step up for down syndrome walk is getting a face lift



Hold on to your pants Step Up for Down Syndrome Walk attendees and Team Captains. The Walk website is getting a facelift!

As of June 2019, registration will open on a new website hosted through DS-Connex's Stride Solution. This platform is designed specifically for Down syndrome walks to encourage participation, raise more funds, and engage the community in a day of celebration.

Step Up Walk co-chair, Maggie Stuckey, couldn't be more excited about the change.

"We feel the new website will make it easier for new and return Team Captains to encourage more walkers and sponsors to join their team. The site is clean, easy to navigate, and looks professional," Stuckey said.

"The new website will make it easier for new and return Team Captains to encourage more walkers and sponsors to join their team."

In addition to the change to the website, veteran Team Captains, Walkers, and Donors will notice other exciting changes as well, like a reduced registration rate, easy-to-find Team Captain resources, brand new t-shirt design, and expanded high quality apparel options for purchase. These include adorable onesies and toddler t-shirts, soft racerback tanks for women, soft short-sleeved and long-sleeved t-shirts, and hooded sweatshirts to keep you warm while walking.

Registration and fundraising begin June 1 so start spreading the word. Any Team Captain that signs up and has at least \$50 raised by the Swim Party in July will receive a special DSAF beach ball!

For questions, contact Walk Co-Chair, Mary Sweeney at mary@dsafnebraska.org.

what you should know...

Registration opens
June 1st

Remember to save the Date!
**Step up for
Down Syndrome
Walk
October 5, 2019**

Any team captain that signs up by the swim party in July will receive a
special DSAF beach ball!



**Check out
the NEW logo!**

parent perspective

nikki hobelman



“Your support ensures Libby and others like her have the confidence and respect to advocate for themselves.”

On February 15, 2017, sweet Libby Louise Hobelman was born into a whirlwind of a new life with each initial moment being touch and go. Diagnosed with Down syndrome and an extremely rare heart condition, this little fighter has endured countless surgeries and will likely have to endure several more. Despite all the odds stacked against her, though, Libby is thriving! We sat down with her mom, Nikki, to get her perspective on life as a parent of this inspiring sweet baby girl.

What would you like people to know about Libby?

Even though Libby has limited speech (for right now), she has so much understanding. She is one of the brightest little girls I know, and she is amazing at problem solving!

What are some of Libby’s best qualities?

Libby is the strongest, most determined girl I know. Her doctors and therapists are always so shocked when they see how much progress she makes from one visit to the next.

What are your hopes and dreams for your child?

My hopes and dreams for Libby are the same as they are for my other kids. I expect her to do her best through high school and graduate. I would like her to go to college. I hope she dates, but never has a broken heart. I would also like her to live independently in a nice apartment. I hope that she finds a career that she likes to go to every day. And one day, I hope she finds the love of her life, gets married, and lives happily ever after. First and foremost, though, throughout her entire life, I expect her to have the confidence to respect and advocate for herself.

upcoming events

be on the lookout for future member opportunities

may

30: Give to Lincoln Day

june

1: Step Up for Down Syndrome Walk
NEW Website Launches - Fundraising Begins

13: Young Adult Social Book Club
Summer Session Begins
@ Barkley Center, 6:30 p.m.-7:30 p.m.

29: Teen/Young Adult Group Tours
Memorial Stadium, 11:00 a.m. -12:30 p.m.

july

12: Lil' Stars Story and Craft Time
@ Indigo Bridge Books, 6:30 p.m.

TBD: DSAF Swim Party

TBD: Teen/Young Adult Group Goes Baking
@ Cookie Company

august

1: Young Adult Social Book Club, Last Summer
Session Meeting, 6:30 p.m.-7:30 p.m.

4: Teen/Young Adult Group Cheers on
Lincoln Salt Dogs, 5:05 p.m.

september

TBD: Teen/Young Adult Group Goes Bowling

october

5: Step Up for Down Syndrome Walk

TBD: Teen/Young Adult Group @ Roca Berry Farm

Support a VIP with
Down syndrome this

give
To Lincoln Day

Go to:

GiveToLincoln.com/nonprofits/DSAF

to make your online donation by

May 30th!

have questions or want to get involved?

402.421.1338 or info@dsafnebraska.org