



down
syndrome

community connections

September 2019



down syndrome
association for families
of nebraska

president letter

give to lincoln day a success!

Dear friends,

WOW...just wow! You knocked our socks off. You heard the requests for support during the Give to Lincoln Day campaign and you gave with gusto – through monetary donations as well as spreading the word!

This incredibly generous funding helps ensure a bright future for medical outreach efforts, new parent support, educational programming, and engaging socialization opportunities for parents, siblings, and individuals with Down syndrome. The DSAF Board of Directors collectively thanks you all for your support.

If you missed your opportunity to participate in Give to Lincoln Day, the Step Up for Down Syndrome Walk is right around the corner on October 5. The Walk currently accounts for over 80% of DSAF's annual budget so every Team Captain, donor, and sponsor is critical. Our son's team, Ethan's Entourage, is signed up for its 13th year! Take a look at the information on the next page and get involved today!

Best Regards,



Liz Echternkamp, DSAF Board President

\$6,845

Total Donated

1037%

Increase from 2018

60

Generous Donors

\$7,495

Total Raised

Countless

Incredibly Grateful Families

THANK YOU



step up for down syndrome walk 2019

what you need to know

What and where?

October 5, 2019
Antelope Park, near 30th and A St.
Festivities @ 8:00 a.m.
Walk @ 9:30 a.m.

What to expect?

Lots of music, free food, face painting, cheer squads, balloons, movie characters, mascots, raffle items, cool Fact Posters, and so, so many smiles.

Don'ts have a team?

YOU can create a team too! Want to walk but have no real connection to someone with Down syndrome? Recruit people to support the mission, and make an impact in the lives of people with Down syndrome and their families.

Want to skip the Lines?

Bracelets, reserved parking, and raffle tickets are being sold in advance and available for pick-up by Team Captains prior to the Walk. Skip the lines at the park and spend more time celebrating.

Want to be a sponsor?

It takes a village – and a lot of resources – to put on an event like this. You can support a worthy cause and gain great exposure by becoming a sponsor of the Walk.

important dates

August 30

Corporate sponsorships deadline

September 1

Last day to qualify for a Fact Poster (Team Captains only)

September 12

Last Day for guaranteed T-shirts

September 13

Last Day to submit STARS Bio Sheets (Team Captains only)

October 2-3

T-shirt pickup at Nebraska Farm Business, Inc.

October 3

Last day to qualify for 'Top Teams'

October 5

Step Up for Down Syndrome Walk!

Mark Your Calendars!



what's new?

Down Syndrome Support in Style:

NEW for 2019 are soft, high quality t-shirts, racerback tanks, hoodies, long-sleeved shirts, and onesies. Support your loved one or friend with Down syndrome in style. They make GREAT Christmas presents too!

There's Still Time! Visit ds-stride.org/dsafstepup to start a team, donate, learn about sponsorship, and purchase merchandise.

INTRODUCING...

DSAF

EDUCATIONAL SERIES

REVAMP

As a parent, guardian, or supporter of an individual with Down syndrome, being informed is key. It's important so you can advocate. It's important to ensure appropriate services are received. It's important for peace of mind.

With that as the guiding vision, DSAF is excited to announce a new, revamped Educational Series launching August 2019!

Utilizing the information collected from the recent member survey, DSAF members and education volunteers teamed up with Program Director, Dawna Daily, M.Ed., to come up with an entirely new educational structure for members and the general public.

Each month, a speaker in the field of Down syndrome education, health care, or research will be brought to Lincoln to present information that will positively impact the well-being

of individuals with Down syndrome.

DSAF members and their friends, family, and guests are invited to attend these free sessions, which will be held every third Tuesday night at 6:30 PM at Rock 'n' Joe Coffee Bar, unless otherwise noted on the DSAF website.

This revamped programming has been provided in part by partners like the Enable Savings Plan, PTI Nebraska, ESU #5 and generous donors and educators willing to contribute their financial resources, time, and expertise to our community.

Should you have ideas on future topics you'd like to see covered or sessions



you may want to support, please contact Dawna Daily at director@dsafnebraska.org.

As Nelson Mandela once said, "Education is the most powerful tool you can use to change the world."

Thank you for helping us change the world, one bright mind at a time.

"EDUCATION IS THE MOST POWERFUL TOOL YOU CAN USE TO CHANGE THE WORLD."

—NELSON MANDELA

2019 COURSE INFORMATION

AUGUST EDUCATIONAL SERIES TOPICS - AUGUST 20:

Series Kickoff: This is your opportunity to meet the Program Director and her background and let her know what your specific questions and needs are. An overview of the series and topics will also be discussed.

SEPTEMBER EDUCATIONAL SERIES TOPICS - SEPTEMBER 17:

Down syndrome 101 for parents, extended family, teachers, and advocates: Outcomes for the series include: What is Down syndrome?, Ds facts, myths & truths, 'people first' and other language guidelines, common medical issues related to Down syndrome, common educational issues: communication, strategies for success, social skills, processing time, benefits of inclusive education, and supporting friendships, and resources. This series will be presented by Dawna Daily, M.Ed., utilizing information and data from the Down Syndrome Association of Central Florida.

Tips for the IEP meeting (IEP 101): Presented by Jenn Miller from PTI Nebraska, IEPs (Individualized Education Plans) will be the focus of the series where the individuals, parents, professionals, and school come together to discuss your child's unique educational needs and create a plan to meet those needs. It is important to prepare for your IEP meeting so you can be a more knowledgeable, active participant in the decision-making process and help guide your child's educational success. Participants will walk away with information that will help both parents and students prepare for the IEP meeting and become the best advocates possible. The basic parts of the IEP will be discussed as well as some common things to look for in an IEP document.

OCTOBER EDUCATIONAL SERIES TOPICS - OCTOBER 15:

Toilet training and the Ds individual: Toilet training is a common concern for families and because of the complex nature of individuals with Ds and their development, it can become a source of worry. This training will address the common initial roadblocks, setbacks, and eventual celebration of toilet training. Presented by Matt McNiff, a behavior specialist with ESU #5, this training is for anyone wanting to gain information on how to proceed with the process of toilet training an individual with Ds.

Enable Savings Plans: Diane Stewart of First National Bank of Omaha, the Nebraska Fiscal Representative for the Nebraska Enable accounts, will review the Enable Act basics, eligibility requirements, set up and enrollment, benefits of a 529a, and the future of Enable in her presentation on life planning for individuals with Ds. Background on Enable: In December 2014, the Achieving a Better Life Experience (ABLE) Act was signed into law authorizing individuals with disabilities to open tax-exempt savings accounts to save for disability-related expenses without impacting eligibility for resource-based benefits. The Act permits individuals with disabilities to save more than a total of \$2,000 in assets (cash, savings, etc.) in their name in a qualified ABLE account.

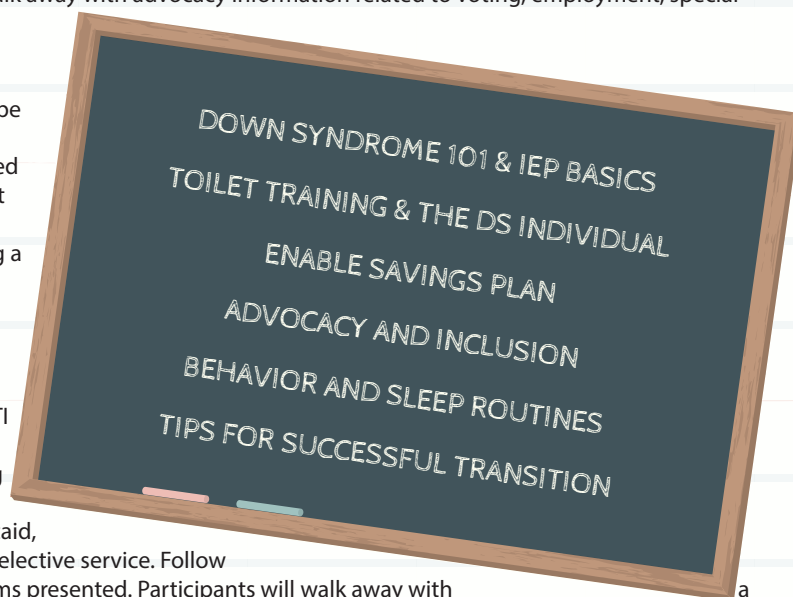
NOVEMBER EDUCATIONAL SERIES TOPICS - NOVEMBER 19:

Advocacy and Social Inclusion 101: For over 60 years The Arc of Nebraska has provided advocacy to people with intellectual and developmental disabilities and their families. This non-profit governed by a Board of Directors has over 1,500 members across the state. In this series, Edison McDonald from The Arc of Nebraska will share the wide range of programs and services offered to meet the needs of those with intellectual and developmental disabilities. Participants will walk away with advocacy information related to voting, employment, special education, Medicaid, and wait lists and will also be available to answer more specific questions as time allows.

Behavior and Sleep Routines: Sleep disturbances have proven to be a common concern for families with individuals with Ds. Behaviors associated with sleep (both positive and negative) have been studied and well documented. In this series, Matt McNiff, Behavior Specialist for ESU #5, will discuss the issues of sleep disturbances, sleep study information, and sleep behaviors and the importance of developing a sleep routine.

DECEMBER EDUCATIONAL SERIES TOPICS - DECEMBER 17:

Tips for Successful Transitions: Presented by Sandy Peterson of PTI Nebraska, the Tips for Successful Transitions session will include a brief overview of transition, Nebraska transition resources including VR and developmental disability services, career exploration and the transition plan as part of the IEP, applying for SSI and Medicaid, securing a Nebraska ID, registering to vote, and registering for the selective service. Follow up resources will also be provided at this session for each of the items presented. Participants will walk away with general understanding of what transition is, a timeline for approaching transition, and next steps and contacts for navigating the transitions to adulthood with Ds.



Childcare is not provided. Except for infants, we request that you do not bring children to the presentations.

member spotlight

sarah fuenning: from break-dancing to broadway

With a sparkle in her eye, Sarah Fuenning doesn't miss a beat in proudly sharing with me during a recent interview that she is 24 years old and dreams of one day being a "pop-star rapper."

When you talk to Sarah you can't help but feel more alive. Every ounce of her exudes a bubbly spirit that makes you want to instantly be best friends.

Sarah is one of 9 siblings and graduated in 2014 from East High School. She was quick to tell me about her three nephews, all-time favorite singer, Christian artist, Toby Mac, and her 4 cats: Bobby, Svelte, Peter, and Maggie.

When I asked her who her best friend was, she quickly looked over at her mom with a sweet smile, and said, "My mom."

And as best friends do, they took a girls-only trip a few years back to New York City for Sarah to get one step closer to her pop-star dream. Mom and daughter enjoyed Disney's The Lion King on Broadway from the second row and then the trip was topped off with hip-hop and break-dancing

classes for Sarah with the Hip Hop Consortium in Times Square. To say it was a highlight of the trip is an understatement.

Sarah enjoys DSAF's Young Adult Book Club and the monthly outings they have to MoJava coffee shop. When not singing and dancing or listening to Toby Mac's music, Sarah loves to kick-box at Phoenix Fitness and Training.

Like many individuals with Down syndrome, there is a depth and intellect that is often missed by the common passerby. As a parent of a child with Down syndrome myself, Sarah's response to my final question touched my heart and brought a joyful tear to my eye.

I asked, "What do you want people to know about Down syndrome?"

And she responded, "I am special because God loves me so, so much. I am unique and determined and compassionate."

Yes you are, my friend. Yes you are. Thank you for being you, Sarah.



"I am special because God loves me so, so much. I am unique and determined and compassionate."

ENable[®]

SAVINGS PLAN

PROUD
SIGNATURE
SPONSOR!

Since the creation of the Enable Savings Plan three years ago—one of the first ABLÉ plans in the country—it has been our mission to advocate for equality and empower individuals with disabilities to be the hero of their own financial independence journey.

The Enable Savings Plan provides individuals with disabilities the opportunity to save for their future by creating a financial reserve to pay for long-term and everyday disability-related expenses, without impacting eligibility for resource-based programs like SSI, SNAP and Medicaid. The plan offers a variety of investment options, as well as features like Automatic Investment Plans, Gifting Options and Systemic Withdrawals to help Account Owners streamline their savings strategy and boost the wellbeing of their account as seamlessly as possible. In addition, Enable offers resources including a blog and seasonal newsletters to help further support and educate Account Owners on their financial journey.

DSAF Marketing and Development Director, Mary Sweeney, shared her reasons for starting an Enable Savings Plan for their 5-year-old son, Henry. "It was important for us as parents to know that as we are nurturing him now toward success and security in life, we can also set him up for financial success and security in the future. We loved the investment ability, the checking account option with a debit card, tax break, and all the ways the account could be used."

We have seen firsthand the success of our Account Owners and are continuously inspired by them, as well as by DSAF and the disability community as a whole. We are proud to have partnered with DSAF over the past three years by participating in the Step Up for Down Syndrome Walk and sharing their mission in posts on our blog at enablesavings.com.

Are you interested in being the hero of your financial journey? There are no superhero capes needed to begin—to learn more about the Enable Savings Plan, visit our website enablesavings.com, contact us at **1-844-ENABLE4** or send us an email at clientservices@enablesavings.com.

treasurer update

please welcome tami urwin



It's with bittersweet emotions that we bid farewell to DSAF Treasurer, Stephanie Longwell, as she takes on the new role of motherhood and cuddling up with her twin babies. We thank her for her two years of service to the organization!

Beginning in July, Tami Urwin, Accounting Operations Specialist with FACTS, accepted the position as the new DSAF Treasurer. She is excited to get involved in the mission and can be reached at tami.urwin@gmail.com.

upcoming events

be on the lookout for future member opportunities

august

- 20: Ed. Series: Kickoff and Introduction
- 24: New Parent's Brunch, 10-11:30 a.m.
@ City Impact

september

- 5: Fall Young Adult Book Club Begins,
6:30-7:30 p.m. @ UNL Barkley Center
- 15: O.N.E. Coalition Husker Heroes
- 17: Ed. Series: Down Syndrome 101
for Educators & IEP Basics
- TBD: Teen/YA Stars Go Bowling

october

- 2/3: Step Up Walk Team Captain T-shirt Pick-up
@ Nebraska Farm Business, Inc.
- 5: Step Up for Down Syndrome Walk,
8:00 a.m. @ Antelope Park
- 15: Ed. Series: Toilet Training and
the Ds Individual & Enable Savings Plan
- 19: DSAF Takes Over the Pumpkin Patch, Roca
Berry Farm - **all ages and families invited!**

november

- 19: Ed. Series: Advocacy and Inclusion and
Sleep Routines and Behavior
- TBD: Teen/YA Cooking Class @ Hy-Vee

december

- 5: Fall Young Adult Book Club Ends,
6:30-7:30 p.m. @ UNL Barkley Center
- 7: Holiday Brunch, Firespring -
all ages and families invited!
- 17: Ed. Series: Tips For a Successful Transition
- TBD: Teen/YA Meet Me at the Mall!
(Help with holiday gift shopping)

Learn more and register for any of these events at
dsafnebraska.org/events



REMEMBER...THE DSAF SUPER PASS TO THE LINCOLN CHILDREN'S MUSEUM IS ALWAYS AVAILABLE FOR FREE ENTRANCE FOR MEMBER FAMILIES!