down syndrome

community connections

May 2020

down syndrome
association for families
of nebraska

president letter

thank you for your continued partnership!

Dear friends and allies,

Can you believe what life is like these days? Here just a couple months ago I was coordinating IEP meetings with parents and staff, planning my summer vacation, and wondering what to make for dinner. Now I'm inundated with all things COVID-19, learning to do my job as a special educator via a computer screen, and just wishing we could actually go somewhere out to eat for dinner.

The transition shock is real. It's not in your head. It can be hard on everyone from parents all the way down to the family pet – and especially difficult on our loved ones with Down syndrome. But DSAF is here for you. Whether you have a child with Down syndrome or just think people with Down syndrome are pretty awesome, the DSAF Board of Directors and Staff are working their tails off to figure out new ways to serve the needs of all Nebraskans with Down syndrome – and your support is making that possible.

It seems like a lifetime ago that DSAF had its annual strategic planning meeting. Although it was before the COVID-19 pandemic was upon us, the plan for the organization has not been altered. You may see some of the programs and services offered in a more "virtual setting," but DSAF is still standing strong. The people you love with Down syndrome are our mission and our focus and we are proud to share with you the strategic direction for 2020.

Thank you for your continued partnership! Together we can ensure these priorities come to fruition and people with Down syndrome are supported both now and when these days are all but a distant memory.

Thinking of you,

Liz Echternkamp

Liz Echternkamp
DSAF President

> "Together we can ensure these priorities come to fruition and people with Down syndrome are supported."

2020 strategic priorities

Enhance Member Communication and Engagement

Enhance Member Communication and Engagement through more structured and targeted communication campaigns on both social and traditional media platforms.

Diversify Funding and Investment Strategy

Diversify Funding and Investment Strategy through new, more broadly focused support packages available to potential donors.

Increase Programming Value

Increase Programming Value by researching potential programs around topics on health and adults with Down syndrome and formalizing volunteer engagement to aid in the coordination of programming.

Enhance Organizational Structure and Leadership

Enhance Organizational Structure and Leadership to aid in the implementation of the Step Up for Down Syndrome Walk, volunteer coordination, and involvement of a self-advocate on the DSAF Board of Directors.

member spotlight

chad bartels: independent, confident, and beautiful

by elizabeth chunn

"Insects are animals, and they won't bite if you let them be." These are the wise words of 25-year-old, Chad Bartels, as we toured Nebraska's Museum of Natural History and Mueller Planetarium in February.

Chad graduated from Lincoln Southeast in 2013 and now enjoys his independence. During free time, he likes to play "baseball, basketball, and football video games with [his] best friend Zach." When I asked who generally comes out on top during competition, he said "Zach and I both do."

In addition to video games, Chad loves "spending time with [his] one niece and four nephews." Although Zach divides his uncle responsibilities evenly among the kids, he stated his niece is his favorite because "she is so sweet." Other activities Chad enjoys include "swimming and riding [his] brother's horses" while participating in cheer with his friends Zach and Amber.

After engaging in conversation with Chad through the course of the day, one comment he made particularly resonated with me. In Chad's eyes, Down syndrome is not a barrier, for he is "independent and confident and beautiful." What a precious moment it was and how true it is.

Thank you, Chad, for your beautiful personality and keep up the confidence. It's contagious.

"Down syndrome is not a barrier."

Support from donors like you make it possible for people like Zach to participate in DSAF's Teen and Young Adult STARS program.
dsafnebraska.org/GiveToLincoln

WORLD DOWN S

Thank you for your support of the 2020 Virtual World Down Syndrome Day celebration!

Mary Widhelm Sweeney was live.
March 21 at 9:59 AM ·

Thank Down Syndrome Association for Families for the opportunity to host your #WDSD Sock Hop Dance Party!! We had SO MUCH FUN!!! Hope you all did too! #DSAFRocks

#WDSD Awareness Impact

Enable Savings Plan
March 21 at 10:00 AM ·

Happy World Down Syndrome Day! Today we honor the amazing individuals and families in the Down syndrome community.

As part of our celebration, Enable is proud to sponsor Down Syndrome Association for Families, who provide support to individuals with Down syndrome and the families, friends, educators and professionals who share in their lives.

This World Down Syndrome Day, support DSAF by joining their virtual celebration! Share your favorite photos and videos supporting individuals with Down syndrome, and tag them with the hashtag #DSAFRocks. Can't wait to see what you come up with!

27,729: Times DSAF content was visible on Social Media

Leah Janke
March 17 at 3:49 PM ·

We got "Socked" by Down Syndrome Association for Families! This is such a cute idea and a great way to celebrate World Down Syndrome Day, while social distancing! Nice work Dawna Daily and Mary Widhelm Sweeney! 👏 ....now who should I "sock" next!? 🤔 #DSAFRocks #WDSD

7,925: Total people who saw DSAF content on Social Media

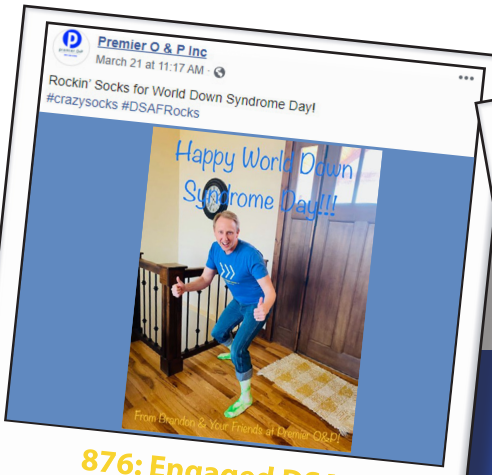
Celebrating #WDSD in a #COVID-19 World

The 2020 World Down Syndrome Day celebration (#WDSD) on March 21st was sure one to go down in the books. Due to the emergence of COVID-19 in Nebraska, the in-person event had to be re-envisioned. Thanks to some quick-thinking and teamwork on the part of DSAF Program Director, Dawna Daily, and Marketing and Development Director, Mary Sweeney, a VIRTUAL celebration took its place with wild success!

Celebrate World Down Syndrome Day with DSAF

thank you to our sponsors!

SYNDROME DAY goes virtual!


Premier O & P Inc
March 21 at 11:17 AM ·
Rockin' Socks for World Down Syndrome Day! #crazysocks #DSAFRocks

876: Engaged DSAF Facebook Followers


Down Syndrome Association for Families is at Rock 'n' Joe Coffee Bar (Lincoln, NE).
March 21 at 9:56 AM · Lincoln, NE ·
Thank you, Rock 'n' Joe Coffee Bar for the support on World Down Syndrome Day! #DSAFRocks #WDSD2020

155: Posts with #DSAFRocks


The Ruby Grace Fan Club
March 21 at 2:54 PM ·
#DSAFRocks
#WDSD2020
#worlddownsyndromeday

$3,555 Raised to Help the Ds Community in Nebraska

How we celebrated!

- Release of first-ever DSAF #WDSD Video by Digital Sky
- Lincoln Hy-Vee Coinbox Fundraiser
- Radio Interviews on Spirit 102.7 FM
- Froggy 98.1 #WDSD Ads
- Virtual Story Time
- Sock Hop at the Sweeney's Facebook Live Dance Party
- Online Silent Auction
- Jilly's Socks n' Such Fundraiser
- DSAF President's Virtual Address
- Farrell's eXtreme Bodyshaping Facebook Live Workout
- "You've Been Socked" Yard Sign Campaign
- Netflix Movie Party
- #WDSD T-shirt Fundraiser with Eclipse Inc.
- Miss Amazing, Allison Bruckner: "Don't Limit Me" Speech
- Sing-Along with Overall Buddies
- DSAF #WDSD Facebook Frame

And soooo many shoutouts and well-wishes from friends and fans all across the country!

DigitalSky

TODAY'S BEST COUNTRY FROGGY 98

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Children's
HOSPITAL & MEDICAL CENTER

down syndrome
association for families
of nebraska
dsafnebraska.org

HENRY'S hooligans

people first language

by sue rogers

What do you call a person with a disability? A person.

Many families have encountered people who use incorrect language when referring to their child or loved one with Down syndrome. Before my family had a child with special needs, we probably didn't pay much attention to the semantics. But now, it strikes us as somewhat offensive when a person says, for instance, "She doesn't look Downs," or "The girl suffers from Down syndrome," and, of course, the dreaded R-word.

Today we probably look astonished that people can be so ignorant. But they're not ignorant. They don't mean to be offensive, in most cases. They just don't know. The best thing we can do is educate them. Even if that means giving examples of correct language over and over…and over again.

Person First Language emphasizes the person, instead of the disability. By identifying the person first, the disability is no longer the first focus of a person, but one of many aspects of the whole person.

People with Down syndrome are – first and foremost – people. It's that simple.

They are people who have individual abilities, interests, emotions and needs. Every individual, regardless of ability, deserves to be treated with dignity and respect. As part of the effort to end discrimination, it's important to eliminate prejudicial language.

People First Language refers to the individual first and the diagnosis second. In practice, it's saying, "a child with Down syndrome" instead of "the downs girl."

It's important a person does not repeat negative terms that stereotype, devalue or discriminate. Instead, if you encounter this, give the speaker the benefit of the doubt that being offensive wasn't their intention. Then, repeat what was said in Person First Language so you can begin to educate them.

Avoiding negative words that imply tragedy is also important. Our children are not afflicted with, suffering from, or victims of Down syndrome. It is not unfortunate that they are "living with this condition." Recognize that Down syndrome is not a challenge to be overcome.

When talking about someone with a disability, focus on the person, not the disability. Put "People First."

Let's work together to gently and positively educate the community, the media, our friends, family, coworkers – even strangers – about Person First Language. Help them to see that the children, young men and women, and adults with Down syndrome living in our communities deserve to be recognized for the incredible people they are – with likes, dislikes, achievements, and dreams – and not just by their diagnosis.

On behalf of all parents of a child with Down syndrome, thank you for your partnership in making the world a better place for our children!

Adopted from the Texas Council for Developmental Disabilities

Your contributions for this Give to Lincoln Day will help DSAF continue to do good all throughout Nebraska. Please spread the word and be generous on May 28, 2020! **dsafnebraska.org/GiveToLincoln**

#COVID CANT STOP GOOD

COVID can't stop good

by mary sweeney

It's nearly 5pm when I should be wrapping up my usual day's work, but I can't because I'm sitting here still trying to think of what to write to DSAF friends and allies to lighten your load. Everything is so different these days now that COVID-19 is part of our lives. I'm now not only a mom, wife, and marketer/fundraiser – I'm also a teacher, special educator, psychologist, referee, sidewalk chalk artist, nurse, and SO much more.

I share this not to have you feel sorry for me – but rather to let you know that I'm right there with you. DSAF is right there with you. When you wonder how on earth you will be able to handle it all, DSAF is thinking about you. As you are reading this know that YOU are in our minds. YOU and your loved one with Down syndrome are our beacon. YOU give us purpose. YOU make us search out new ways to connect virtually so we can share smiles, be inspired, cheer each other on, and provide (virtual) shoulders to cry on.

There is good in the world. And YOU are that Good. COVID may have altered what our reality looks like right now, but **COVID Can't Stop Good**.

Together we will get through this. Together we will continue to support all people with Down syndrome in Nebraska. Thank you for carrying the torch and walking this journey with us. We are here for you!

Down Syndrome Association for Families of Nebraska
P.O. Box 57362
Lincoln, NE 68505

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Check out the 2019 Annual Report to see what all YOU helped make possible!
dsafnebraska.org/AnnualReports

upcoming events

be on the lookout for future member opportunities

may

27: Teen/YA Stars Virtual Movie Night

june

16: DSAF Ed Series: Speech Disorders and Children with Down Syndrome

july

18: DSAF Virtual SWIM (Sprinkler) Party
21: DSAF Ed Series: Emergency Preparedness
25: ONE Coalition Swim Night (Tentative)

october save the date!

10: **Step Up for Down Syndrome Walk**

Please Note: All DSAF-hosted events have been shifted to virtual events through the month of July. The future of in-person events will be assessed by the DSAF Board following the guidelines of state health officials to determine when it is safe for our members to resume these activities. Stay tuned for updates at

dsafnebraska.org/events

Every donation, large or small, makes a bigger impact.
Help spread the word!

dsafnebraska.org/GiveToLincoln

thank you sponsors!

Please consider supporting the companies working with DSAF to provide a positive vision of the future for all people with Down syndrome in Nebraska.

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