

# down syndrome

community connections  
*March 2021*

2020  
REMNANT





# welcome!

letter from the new board president

Dear Friends,

My name is Nikki Hobelman and I am honored to serve you as the new DSAF Board President. My daughter, Libby, was born in 2017 and made my family proud members of #TheLuckyFew.

On behalf of the entire Down syndrome community of Nebraska, THANK YOU. As we reflect on the past year in this Annual Report, we couldn't be more grateful for your support – especially during those first, dark and scary days of COVID-19.

While the pandemic is still a part of our lives, I think what has emerged from the darkness is the renewed sense of family. We aren't individuals anymore scared of what will happen. We are a family that's stronger together.

But this shouldn't come as a surprise to those of us in the Down syndrome community. It's almost exactly what happens after Diagnosis Day: The world is turned upside down for a new set of parents. Hope is gone. Life as they thought they knew it is "over." But then they slowly realize...it's not. People have their backs. Comforting gifts are given by complete strangers. Hugs, tears, laughs, and cheers are shared – virtually now these days! A new sense of hope is restored, and a new vision of the future is created.

You did exactly that for people with Down syndrome and all their families through your continued support and participation in the Down Syndrome Association for Families. YOU helped families like mine,

not to just get by in this "new normal," but to adapt and overcome and create a new way to thrive. Thanks to your partnership, the organization is growing – as evidenced by our new programming, successful fundraising, and the hiring of our first-ever Executive Director, Ms. Jamie Bertucci. In a year riddled with uncertainty and fear, we are thrilled to share with you this Annual Report illustrating the hope and opportunity YOU helped make possible for people with Down syndrome in Nebraska. We couldn't have done it without you!

Gratefully Yours,  
*Nikki Hobelman*  
Nikki Hobelman  
DSAF Board President



## meet jamie bertucci

dsaf's first executive director

Hello DSAF friends, families, and allies! My name is Jamie Bertucci and I couldn't be more excited to be the organization's first-ever Executive Director.

Moving from the south, I acclimated to my first Nebraska winter as an adult 11 years ago. I have adapted to the Good Life nicely; I know the Runza menu like the back of my hand, and I swear that Casey's breakfast pizza is the superior choice.

I welcomed my first-born son, Nicholas, 9 years ago. He is a specially-abled, chromosomally-enhanced little boy, whose birth changed the way my family would forever see the world and the people in it. Currently, I am raising three hyperactive, slightly destructive, excessively noisy, eternally busy little boys.

I am beyond excited to continue in my journey serving the Down syndrome community as the Executive Director of the Down Syndrome Association for Families of Nebraska. I have had opportunities to explore cities, schools, and other organizations in various places throughout the US, and I have always appreciated the community and support the people of Nebraska offer our loved ones with Down Syndrome. Nebraska has a strong

economic standing, one of the best in the nation, and it is the dedication and hard work of our population that keeps our state strong. During our struggle to overcome and continue living during this pandemic, most families who care for someone with Down syndrome have felt the impact of school and work closings more than the average family.

If the needs of children and adults with Down syndrome were not apparent before, they most certainly have been exposed during this pandemic. As the Executive Director of DSAF, I hope to be the bridge for families to receive the support, encouragement, and information they need. My efforts will be focused on bringing communities together to offer assistance and events that our friends, children, and loved ones with Down syndrome require.

I am excited to get to know families across the state and hear about the successes and opportunities you are experiencing now. I welcome and encourage emails to [director@dsafnebraska.org](mailto:director@dsafnebraska.org) with information about your loved one with Down syndrome!

Thank you for this opportunity! I am honored to serve you and look forward to our journey together.

## strategic priorities & progress toward goals

1

### Enhance Member Communication and Engagement

COVID-19 was an opportunity to re-envision member communication and engagement through Zoom and increased video messaging. New CRM software allowed for more tailored communication to both current and potential members and donors. And all past forms of family engagement shifted to new, successful at-home DIY projects, virtual events, and drive-thru "parties."

2

### Diversify Funding and Investment Strategy

In February of 2020 DSAF was selected to participate in Network for Good's Jumpstart Training program and fundraising coaching. This program helped increase DSAF staff capacity to nearly double grant funding and sponsorships and significantly increase individual donations, which yielded DSAF with the highest, most diversified, fundraising year thus far.

3

### Increase Programming Value

DSAF grew the monthly Education Series to include a Summer Series that benefitted ages birth-young adult and parents. Additionally, partnerships were developed with local/national groups to offer new, virtual programming like The Improvaneers improv classes for teens and young adults, baby sign language classes, and Speech, OT, and PT services.

4

### Enhance Organizational Structure and Leadership

The DSAF Board of Directors is thrilled to have Dexter Drbal as the first-ever self-advocate board member. The board also grew with the addition of his mentor, Kelsie Kreps. Volunteer management was improved with a short-term contracted Volunteer Coordinator. And in a year when most organizations were having to scale back, DSAF took a very well-strategized leap and hired the first-ever Executive Director, Jamie Bertucci.

# ANNUAL REPORT

## the numbers

### THE FACES OF DSAF

- 118: Self-Advocate Members
- 11: Board Members
- 3: Staff
- 45: Babies Born with Down Syndrome Each Year in Nebraska
- 1,560: Allies (All of YOU) Supporting the Down Syndrome Community

### EDUCATION, ADVOCACY, AND ENGAGEMENT

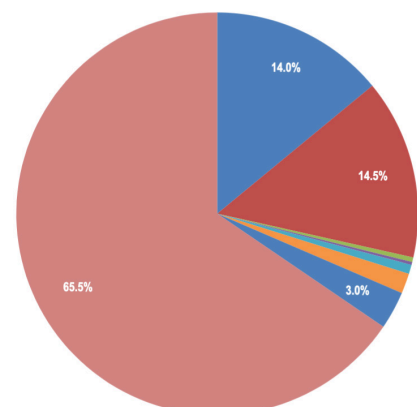
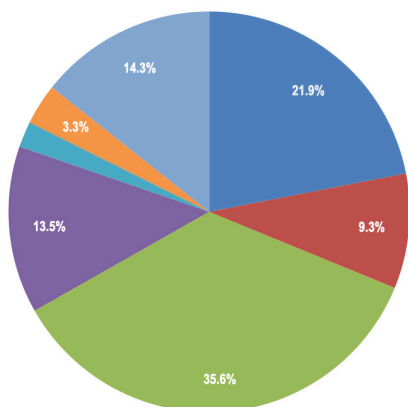
- 1,166: Registered Attendees at 55 Enrichment Events
- 59: Step Up for Down Syndrome Walk Teams
- 1,560: People Learning about Down Syndrome Through This Newsletter
- 30: Medical Professional Attendees at DSAF Medical Outreach Training (Pre-COVID)
- 26,928: # of Times DSAF's WSDS content showed up on Facebook

### DOLLARS AND CENTS

- 20%: Loss DSAF Was Told to Project Due to COVID-19
- What Actually Happened Thanks to YOUR Support!**
- \$150,207: Total Cash & In-Kind Donations Raised in 2020 (Most Ever!)
- 175%: Increase in Sponsor Support
- \$61,255: Amount of NEW Funding in 2020

### COVID CAN'T STOP GOOD

- 11: Days DSAF Staff Had to Turn WSDS 2020 Into a Virtual Event
- \$6,750: Lincoln Community Foundation Relief Grant Received to Start Virtual Summer Program
- 6: DSAF Families That Received Gifts from the New Adopt-a-Family Program
- \$1,000: COVID-19 Relief Donation Made to Support a Local DSAF Family
- 282: Donuts Distributed by Santa at the Drive-Thru Holiday Party



### 2020 EXPENSES

- \$31,016.62 Education & Events - **36%**
- \$33,767.41 Awareness - **22%**
- \$22,078.26 Programming - **14%**
- \$20,785.42 Future Growth Allocation - **13%**
- \$14,272.52 DSAF Admin - **9%**
- \$5,081.61 Organization Development - **3%**
- \$3,210.00 Partnerships - **2%**
- \$153,999.36 TOTAL EXPENSES**

### 2020 REVENUE

- \$100,856.10 SUDS Step Up Walk - **65%**
- \$22,275.00 Grants - **14%**
- \$21,610.14 Direct Public Support - **14%**
- \$4,696.64 World Down Syndrome Day - **3%**
- \$2,493.16 Sales - **2%**
- \$1,139.68 Program Income - **1%**
- \$576.64 Investments - **<1%**
- \$352.00 Membership - **<1%**
- \$153,999.36 TOTAL REVENUE**

▶▶▶▶▶ BUDGET INFORMATION ▶▶▶▶▶

# THANK YOU SPONSORS

#### PRESENTING STAR SPONSOR (\$10,000+)

Anonymous

#### SHOOTING STAR SPONSOR (\$5,000 - \$9,999)

Enable Savings Plan  
Global Down Syndrome Foundation  
Lincoln Community Foundation  
UBT

#### RISING STAR SPONSOR (\$2,500 - \$4,999)

Children's Hospital & Medical Center  
Nelnet

#### GOLD STAR SPONSOR (\$1,000 - \$2,499)

AJ  
Bryan Health  
Dental Designs  
Digital Sky  
Eclipse, Inc.  
Family Health & Wellness Center, P.C.  
Froggy 98.1  
Grandma & Grandpa Lohmeier  
HBE

#### RED STAR SPONSOR (\$500 - \$999)

Anonymous  
Boys Town National Research Hospital  
Eagle Nursery LLC  
ENT Specialists PC  
In Honor of Don Lovegrove  
Indigo Bridge Books and Cafe

#### BLUE STAR SPONSOR (\$250 - \$499)

Anonymous  
Amie Lovegrove  
Anne Klimke  
Caroline Hug  
Chick-fil-A SouthPointe Pavilions  
Coldwell Banker NHS Real Estate  
Daniel Ginting  
Dave's Heating & Air  
DC's Waterhole  
Delores Bundy  
Eunice Mahloch  
EyeCare Specialties



Henry's Hooligans  
Hy-Vee, Inc.  
Images for a Lifetime  
Morningstar Counseling  
Nana and Kay-Kay  
Party Inflators  
Pediatrics PC  
Pinnacle Bank  
Premier O & P Inc.

Rock n Joe Coffee Bar  
Runza  
Ryan & Kim Abell  
Sid Dillon of Lincoln  
The Printer  
Tina Kearney  
Warrior Family  
West Gate Bank

Liberty First Credit Union  
Lovegrove Homes  
Lovegrove Racing  
Q2  
Realty Works  
Russells

Schneider Electric  
Seward Jr. Jays Baseball Team 2008  
Thomas M Fritsch, DDS  
Weers Motorsports

Gentle Family Dentistry PC  
Gina V Physical Therapy  
Jack Sugrue  
Jara Speech Language & Literacy Clinic  
Jared Nielsen - Realtor RE/MAX Concepts  
Jennifer Hegemann  
Jody and Tim Sweeney  
Mark and Stacy Rolland  
Megan Chinander  
Melissa & Brian Payne  
Nebraska Animal Medical & Emergency Center  
Oceans Dental, PC  
Pepsi-Cola of Lincoln

Pine Ridge Dental  
RE/MAX CONCEPTS  
Renea & Anne  
Rick Meyer  
Ron & Pat King  
Ruby's Magnets  
Schoettger Orthodontics  
Sutton Dermatology + Aesthetics  
Tenneco Automotive  
TerraSumoto  
The Waffleman  
Theatre Arts For Kids  
William Swain

### LIST OF BOARD MEMBERS

- Nikki Hobelman, President, RN, Bryan Health
- Liz Echterkamp, Past-President, Hamlow Elementary
- Tami Urwin, Treasurer, FACTS
- Dexter Drbal, Self-Advocate, Sonic
- Kelsie Kreps, Self-Advocate Mentor, Student
- Beth Dinneen, M.S., CCC-SLP, University of Nebraska-Lincoln
- Brandi Benson, Lincoln Public Schools
- DEan Fuelberth, Ameritas
- Rick Bohaty, CHI Health St. Elizabeth's
- Rick Meyer, Pinnacle Wealth Management
- Scott Neal, Bryan Health

### LIST OF STAFF

- Jamie Bertucci, Executive Director
- Mary Sweeney, Marketing Director
- Dawna Daily, Education Specialist



# member spotlight

sam schreiner

People with Down syndrome are great. So great that we want you to get to know them. Check out our newest spotlight on Sam Schreiner. Sam answered the interview questions all by himself – all we did was compile it into a story. Pretty great if you ask me.

## Who I Am

My name is Samuel Allen Schreiner and I am twelve years old. I'm in the 6th grade and I have two older brothers – Noah who is 19 and Aaron who is 16.

## Likes and Dislikes

I like basketball, golf, baseball or working out with my mom. When I want to be alone, I like to play cars or have a picnic in my room. I do not like going to bed, getting my insulin pump changed, or running through the sprinklers.

## Talents and Proudest Abilities

I am fast and good at making baskets with my basketball! I am also proud of how active I am and that I can help make my breakfast each morning.

## Favorite Memory

My favorite vacation was going to Estes Park because we got to climb on rocks around a waterfall, play musical instruments along the river walk, and eat ice cream every day.

## Dreams for the Future

I want to work at Hy-Vee like my brothers and drive a car like them. I want to be independent and do things for myself.

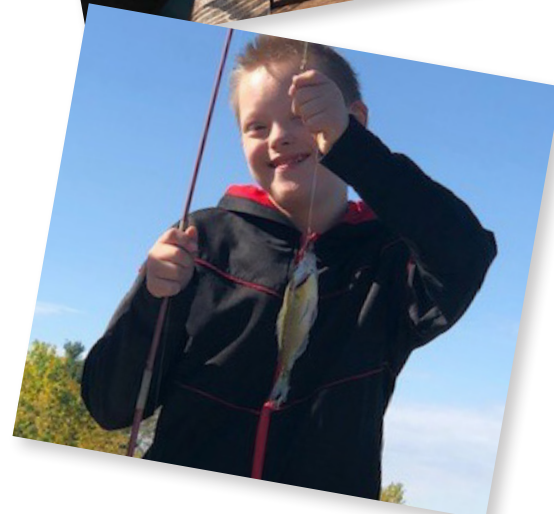
## Role Models

I look up to all the Ninja Warriors, my dad, and my brothers.

## What my parents want you to know about Down syndrome

A diagnosis of Down syndrome can be scary. You don't know what the future will look like. We have learned that every day brings a new surprise filled with growth, strength, and reaching milestones you thought may not be possible in the beginning. Down syndrome is a gift. An individual with Down syndrome teaches us patience, understanding, acceptance, and that anything is possible.

*Thanks, Sam, for letting us get to know you. We wish you many fun vacations, an endless supply of basketballs, and can't wait to see you working at Hy-Vee someday.*



# New Nebraska License Plates Spreading Down Syndrome Awareness

While 2020 went down in history as a frustrating year for most, the D.A.D.S (Dads Appreciating Down Syndrome) of Omaha marked 2020 as the year they finally received victory in their fight to make Down syndrome awareness a priority in Nebraska by creating a Down Syndrome Awareness license plate available to all Nebraskans!

The battle began back in the summer of 2018. After following the necessary steps to create a license plate and having gone through the state's approval process for about a year, the D.A.D.S were unable to get their Down Syndrome Awareness license plate. That's when they enlisted the help of State Senator Rick Kolowski, who agreed to sponsor a Bill in the 2020 session.

"I was proud to sponsor a bill for the Omaha Chapter of Dads Appreciating Down Syndrome. These fathers have banded together to support each other, their families and their children - and to raise awareness of Down syndrome. I applaud them in their mission and am happy the license plate bill passed to allow them to further that mission," said Senator Rick Kolowski.

On January 9, 2020, Senator Kolowski introduced the Bill, which was co-sponsored by Senator Lou Ann Linehan. Several representatives from Down syndrome groups throughout the state, including DSAF's DEan Fuelberth and his daughter, Elyssa, who has Down syndrome, testified in support of the Bill. The Bill was then amended into LB 944 and was signed into law on August 6, 2020 by Governor Ricketts.

"We are ecstatic to finally have the plates approved and be available as of January 2021," said Mark Kuecker, Omaha President of D.A.D.S, and father of 16-year-old daughter, Ellie, who has Down syndrome. "It's not just a win for Omaha D.A.D.S, it's a win for all of the Down syndrome advocate groups of Nebraska."

Visit [dmv.nebraska.gov](http://dmv.nebraska.gov) to order your Down Syndrome Awareness specialty plate today!

*Thanks, D.A.D.S. of Omaha for your hard work! DSAF couldn't be prouder to have helped support this important endeavor and the dads who worked tirelessly to get the plates approved.*



*Dean and Elyssa Fuelberth prepare to testify at in support of LB 944.*

When you support DSAF, you help people with Down syndrome just like Sam. Visit [dsafnebraska.org](http://dsafnebraska.org) to make your donation in honor of World Down Syndrome Day.

If you are a father of a child with Down syndrome and would like to get involved in or support a Dad's group here in Lincoln, or be connected to D.A.D.S of Omaha, contact Luke Sweeney at [luke@dentaldesignsinc.com](mailto:luke@dentaldesignsinc.com).

★ ★ **Down Syndrome Association for Families of Nebraska**  
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 Lincoln, NE 68505

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## upcoming events

### march

16: DSAF Ed Series – Developing Reading and Literacy Skills with the Down Syndrome Population

17: Young Adult Stars St. Patrick's Day Virtual Movie Night

**21: World Down Syndrome Day!**

### april

3: Super Stars – DIY Easter Bunny Race Car Crafts

13: Young Adult Stars Virtual Game Night

20: DSAF Ed Series - Individual Education Plans in the Public Schools, An Overview

### may

18: DSAF Ed Series - Levels of Academic Achievement and Functional Performance - How They Are Included in the IEP

TBD: Young Adult Stars Outdoor Park BBQ



**Please Note:** As COVID-19 makes each day a little uncertain, be sure to visit [dsafnebraska.org/events](https://dsafnebraska.org/events) or the **DSAF Facebook Page** for the latest event information.

**thank you mission partners!** Please consider supporting the companies working with DSAF to provide a positive vision of the future for all people with Down syndrome in Nebraska.

