



# down syndrome

community connections

*December 2019*



down syndrome  
association for families  
of nebraska

# president letter

thank you for all of your support!

“We extend our sincerest gratitude to you for being a part of our DSAF family!”

Season's Greetings DSAF friends and supporters!

We are proud to share that, because of you, we had a record high fundraising year for the Step Up for Down Syndrome Walk with over \$100,000 raised in monetary and in-kind donations! THANK YOU for your support.

Because we take your partnership seriously in serving the individuals and families we represent, DSAF strives to continually improve itself and become a more sustainable organization. We do this by building the capacity of our employees and board members and forging new and renewed strategic partnerships. For example:

- Program Director, Dawna Daily, recently participated in a Leadership Training Seminar Series organized by the Munroe Meyer Institute and is being trained as a Master Individual Education Plan (IEP) Coach by Catherine Wichers so she can more directly assist DSAF families
- Two staff members and one board member will be attending the Annual DSAIA National Leadership Conference in February to bring back to Nebraska new ideas, advocacy efforts, and cutting-edge research findings
- New and reinvigorated relationships have been forged with DSA of the Midlands in Omaha, PTI Nebraska, Disability Rights of Nebraska, and Children's Hospital, to name a few, allowing for more resources and information to be available to members and self-advocates

Thank you for trusting us to serve your friends and loved ones with Down syndrome. As this season of thanksgiving and holiday magic is upon us, we extend our sincere gratitude to you for being a part of our DSAF family. You have made 2019 an incredible year and we are ready to ring in 2020 with enthusiasm!

Happy Holidays,



Liz Echterkamp  
DSAF Board President

P.S. As you consider your year-end giving options, please join me in supporting this organization which provides a positive vision of the future to so many of us.



**COMING SOON! INCLUSIVE SCHOOLS WEEK**

**What is it?** Inclusive Schools Weeks celebrates the progress that schools have made in providing a supportive and quality education to an increasingly diverse student population

**When is it?** December 2-6

**How to Celebrate?** Visit [inclusiveschools.org](http://inclusiveschools.org) for ideas and keep an eye out on the DSAF website and Facebook page for ways to recognize your child's favorite teachers



## i wish i would have known...

by jessica gushard



*I wish I would have known that forced smile on my face would soon be a smile I can't wipe away.*

*I wish I knew those little eyes would turn blue and stare at me to tell me it's okay.*

*I wish I knew that palmer crease on your left hand would soon grip my finger at every feeding telling me I'm needed.*

*I wish I knew all that hair would soon go in a ponytail and make your brothers laugh until they fell to the ground.*

*I wish I knew that despite all the unknowns and scares with a diagnosis, you would make us better people.*

*I wish I knew how many friends we would soon make and have by our side every step of the way.*

*I wish I knew how much life would change for the better.*

*Briggs Barrington, I'm scared for our new life, but most importantly, I'm excited and confident we are going to have a great one.*

*Diagnosis day is no joke, but day by day, it becomes a smidge easier.*

**#upsyndrome #lovemyhomie**

Your contributions make sure moms like Jessica are supported at the time of diagnosis.  
[dsafnebraska.org/donate](https://dsafnebraska.org/donate)

# 2019 Step Up Walk a Success

October 5, 2019, kicked off the 18th Annual Step Up for Down Syndrome Walk! The Walk is the culmination of months of fundraising by dedicated Team Captains and the largest awareness event for individuals with Down syndrome in this part of Nebraska. Thank you to all the sponsors, donors, volunteers, and Team Captains who made this event possible and such a huge success!

**"So much fun.  
We look forward to it every year!  
It's a time when family comes  
together!"**

**1,200**  
Walk Day  
Attendees

**60**  
teams

**2**  
Incredibly Relieved  
Co-Chairs Because  
It Didn't Rain!

**"I was overwhelmed by  
the family atmosphere  
that surrounded me."**

**\$93,105**  
Raised by Team  
Captains, Sponsors  
& Donors, &  
Matching Funds

**480**  
Cups of  
Rock n Joe's Coffee  
& Hot Chocolate Consumed

**Dahd**





"I thought the cheer squads and music along the walk were a great addition. The [Bathtub Dogs] group that sang in the Auld Pavillion was awesome. It was very nice to see things changed up this year. Keep up the good work!"



**\$8,385**  
In-Kind Donations

**96%**  
of Those Surveyed  
Feel the Walk is an  
Excellent Awareness  
Event

"Thank you for  
organizing the Walk  
each year!"

**1,078**  
Raffle  
Tickets Sold

*thank you!*

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**STEP  
UP** DOWN  
for SYNDROME  
WALK

SIGNATURE SPONSORS

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**ENable**  
SAVINGS PLAN

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Our interest is you Member FDIC

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Theatre Arts for Kids  
Morrow Poppe Watermeier  
& Lonowski, P.C.  
Neogen Corporation  
Pine Ridge Dental  
Schoettger Orthodontics

# member spotlight

elissa fuelberth: reaching for the stars

Your support helps Elissa and others like her feel empowered.  
[dsafnebraska.org/donate](https://dsafnebraska.org/donate)



Hi! My name is Elissa.

I just finished a year-long internship at the Embassy Suites for Project Search. This fall, I started my first job at an elementary school about 1/2 mile from my house where I am a teacher's assistant. I walk to and from work every day. I am also taking a college class this year at Southeast Community College called Intro to Early Childhood Education.

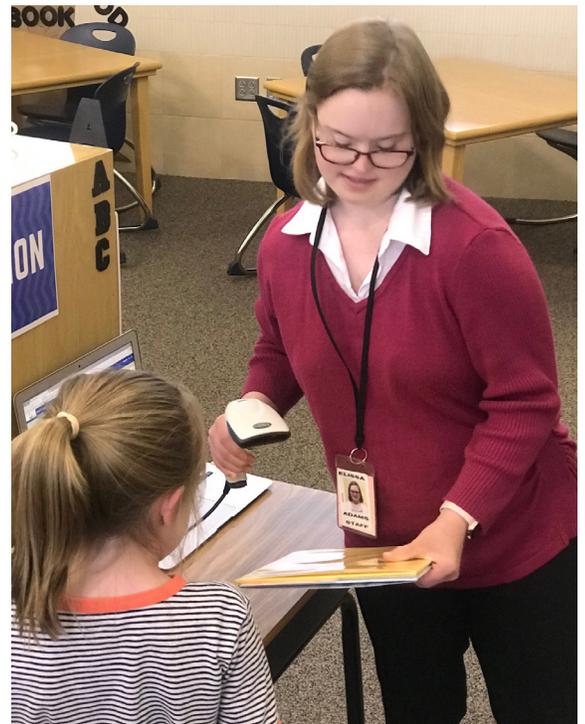
In early October, I had the opportunity to sing the Star-Spangled Banner with recording artist and friend, McKenzie JaLynn, at the Step Up for Down Syndrome Walk. It was very exciting, but I was still shaking a bit onstage.

Last year, I auditioned and was chosen as one of three speakers at my high school graduation. I was a bit nervous about speaking in Bob Devaney Auditorium in front of thousands of people and my class of 450 students. We were able to practice the week before in an empty auditorium, though, so that I could feel more confident.

My speech was titled, "Add to the World - We Can Make A Difference." I spoke about one of the five powerful life lessons that my softball coach taught me years ago - How Can I Help You. I spoke about how during school, we receive a lot of help from others. Once we graduate, it becomes our turn to go into the world and help others.

"I am not sure that it will always be easy, but I will keep trying to make a difference with a smile on my face."

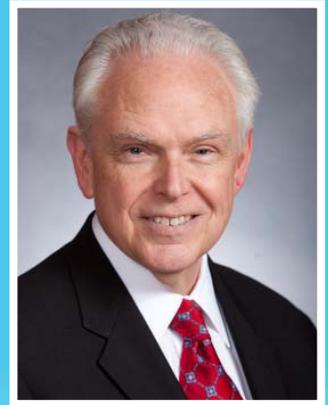
I love math. Algebra was one of my favorite classes. When you think of the plus sign in the future, maybe it can help you remember this main idea: Make a difference in the world by adding to it with all that you have learned from others. Add to the world. Be positive. Create the plus one.



in case you missed it...

# Dr. William Mobley

## virtual q&a



Dr. William “Bill” Mobley, considered one of the most prominent academic neurologists in the United States, was recently invited to Lincoln as a part of DSAF’s Educational Series to give a joint presentation with DSAF’s Medical Outreach team to the Lincoln Family Medicine Residency Program. During his visit, he also met with DSAF member families and held a Facebook Live Virtual Q&A for any members or supporters outside of the Lincoln area. Here’s a summary\* of what you may have missed from the Q&A!

### **What drew you to focus research on Alzheimer’s disease and Down syndrome?**

*I grew up in Lincoln, Nebraska, and graduated from Pius X High School. Then went off to college and did a PhD focusing on a protein that was thought to keep neurons alive that were dying because of Alzheimer’s disease (AD). What led me to focus on AD and Down syndrome (Ds) was because, at the time, the only model of AD available for study was a model of Ds found in a mouse that had some of the same genes and extra copy as Ds. As a doctor, you want to make a difference. I thought, maybe I can make a difference in these people’s lives [with Ds] who are more affected by this disease.*

### **Why is it so critical that doctors and nurses be properly trained on the correct way to give a Down syndrome diagnosis in a positive way?**

*I’ve heard so many stories from new moms and dads who received their diagnosis in such terrible ways, and I feel for them. Often times, the doctors walk into the room as if it is a funeral, tell the parents they are sorry that the baby has Down syndrome, and provide information to the parent to suggest this is not a human being. They share exceedingly low expectations for the child and it’s devastating. Especially because it isn’t correct!*

*What we want is for doctors and nurses to say, ‘Congratulations! Your baby has Down syndrome. Here are the great things you can expect your child to do.’ That’s how a diagnosis should be given.*

### **What are some current clinical trials taking place and how can we connect families to them?**

*There are a number of clinical trials. The risk of Alzheimer’s in people with Down syndrome is quite high after the age of 45, so we are focused on preventing Alzheimer’s in Down syndrome. A current trial I am leading is focused on a vaccine against a peptide*

*called, ‘Abeta.’ The goal is to remove the peptide from the brain so it can’t do damage to the brain. If you are interested in learning more about clinical trials, contact DSAF and they can connect you to me or another trial nearby.*

### **What advice do you have for parents who are just finding out their child has Down syndrome?**

*Make sure you know the facts. Understand from groups like DSAF what’s really going on here. What are the challenges that may face your child? What are the joys? What are the medical issues you need to keep an eye out for as a child, teen, and adult? And stay informed about research out there because it is making such a difference.*

*I have this dream. The dream is 20 years from now and a man and a woman have just been given a diagnosis of Down syndrome. The doctor walks in and says, ‘I have terrific news for you. Your baby has Down syndrome and there are all kinds of interesting things that are going to happen in his life. You may have heard things about Down syndrome that are not so positive, but research in the last 20 years has completely changed things. Here’s what I want you to know. Your baby is going to go home with you. He’s going to thrive. If he has heart disease, we are going to fix that. He’s going to go to a ‘regular’ school, with ‘regular’ kids. He’s going to go to high school and college, drive a car, and fall in love. And guess what...he’s never going to get Alzheimer’s disease.’ I want parents to know that THAT’s the future for their child.*

### **Any last parting inspirational words/comments to share with our members?**

*Life is good. Life is better with somebody with Down syndrome in it.*

*\*Interview responses have been paraphrased. To listen to the complete 15-minute interview, with more in-depth medical-related questions, visit [dsafnebraska.org/EdSeries](https://dsafnebraska.org/EdSeries).*

Remember...the DSAF Super Pass to the Lincoln Children's Museum is always available for **FREE** entrance for member families!

## upcoming events

be on the lookout for future member opportunities

### december

- 2-6: Inclusive Schools Week
- 3: **Giving Tuesday**
- 5: Fall Young Book Club Ends, 6:30 - 7:30 pm  
@ UNL Barkley Center
- 7: Holiday Brunch - **all ages and families invited!**  
@ Firespring
- 17: Ed Series: Tips for a Successful Transition
- 31: Super Stars NYE Party, 5:00-7:30 pm
- TBD: Teen/YA Meet Me @ the Mall!  
(Help with Holiday Gift Shopping)

### january

- 21: Ed Series: Developmental Disability (DD) Qualification w/Ds & Nebraska Medicaid-When & How to Apply

### february

- 1: Night @ the Children's Museum
- 18: Ed Series: Improving Fine Motor Skills

### march

- 17: Ed Series: IEP Goal Writing & Advocacy
- 21: World Down Syndrome Day Celebration

## #GivingTuesday

Dec. 3, 2019



Check out the DSAF Holiday Wish List for ideas of how you can support people with Down syndrome this #GivingTuesday.

[dsafnebraska.org/donate](https://dsafnebraska.org/donate)

Learn more and register for any of these events at [dsafnebraska.org/events](https://dsafnebraska.org/events)

**YOU'RE INVITED!**

**DSAF HOLIDAY BRUNCH**

**December 7, 2019**  
**9:30 a.m. - 11:30 a.m.**  
**Firespring**  
**1201 Infinity Ct., Lincoln, NE 68512**