



**down
syndrome**
community connections
March 2020

★ down syndrome
★★ association for families
of nebraska

president letter

thank you for all of your support!

Happy (almost) World Down Syndrome Day!

It seems like just yesterday it was 2019 and now we are well into a new year – and an entirely new decade! Ten years ago, I remember trying to maneuver this world of Down syndrome that was still relatively new to our family. Now our son, Ethan, has attended his first school dance and is showing us just how independent he can be.

DSAF was there to walk with us along the journey then and continues to do so for our family and so many others. I am proud to share with you some highlights of the past year and how much of an impact DSAF has had on families just like mine all throughout the state. (More to come in the official Annual Report distributed at World Down Syndrome Day!)

You will continue to see this impact and the offerings of DSAF grow year after year. Program Director, Dawna Daily, has an exciting lineup of educational and social programming for 2020 and beyond, which you'll see highlighted in this newsletter. Marketing and Development Director, Mary Sweeney, continues to tell our story throughout the state to shine a light on Down syndrome and foster new support and partnerships for the organization. And volunteers keep signing up to help with events, act as peer mentors, update databases, take pictures, visit new parents, and the list goes on and on.

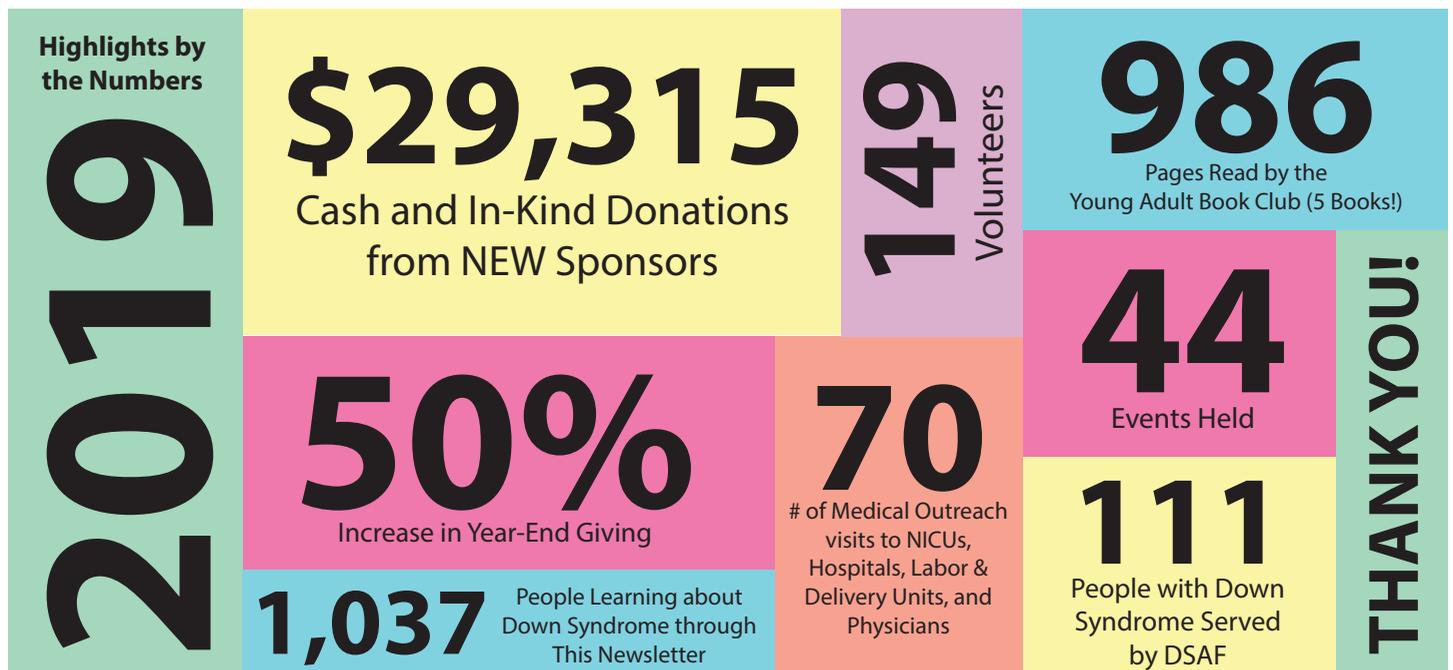
Thank you for making 2019 such a great year. Whether you enjoyed a DSAF event, gave monetarily, helped spread the word, offered support to a family or person with Down syndrome – YOU are what makes this organization great. I can't wait to see what the next decade brings!

With appreciation,



Liz Echternkamp
DSAF President

“Thank you for making 2019 such a great year. YOU are what makes this organization great.”





LB994: libby's law down syndrome advocacy in action

Despite federal protection, people with disabilities still do not receive equal consideration for organ transplants.

the back story

You might remember seeing the "Parent Perspective" article in the June 2019 Down Syndrome Community Connections newsletter about the Hobelman family and their daughter, Libby. Libby experienced several life-threatening conditions upon her birth but is now thriving and just turned three. Unfortunately, though, one of Libby's conditions may require her to have a heart transplant someday. Libby's mom, Nikki, a DSAF Board Member and Medical Outreach representative, knew that although current federal laws are in place making it illegal to discriminate during the organ transplant process, they do not have any penalties associated with them. "If someone knows that something is wrong but also knows that nothing will happen if they do it, they will be more likely to do it. We need to have state-level legislation that has penalties for those that do discriminate and gives clear directions as to what those that have been discriminated against may do," said Hobelman.

advocacy in action

With the partnership of DSAF and the National Down Syndrome Society (NDSS), Nikki began approaching state senators asking for support of a bill that would protect people with disabilities in need of an organ transplant, just like her daughter may need one day. Because of Nikki's determination, Nebraska State Senator, Dave Murman, introduced a bill, LB 994 – Libby's Law, that will prevent discrimination against people with Down syndrome and other disabilities from getting these life-saving procedures. The bill went to the Judiciary Committee on January 30 where Nikki and others from the Down syndrome community testified in support of the bill. Unfortunately, the bill has been met with opposition due to it being 'prescriptive legislation.' "In other words, it tells the people in charge of making the transplant decisions what to do, and they don't like that," said Hobelman.

what can YOU do?

"You can help by reaching out to your representative!" urged Hobelman. The bill will now be reviewed by committee. They may vote to send the bill to general file with or without proposed amendments for legislature debate and/or vote, indefinitely postpone (kill) the bill, or take no action on it. Every person's story shared will help to bring light to the importance of Libby's Law.

Visit dsafnebraska.org/LibbysLaw to learn more about the bill, see which states have already passed similar legislation, and find a link where you can send an email directly to your state senator.



Educational Series 2020

An Ed Series Takeaway: the IEP Process

The DSAF Educational Series kicked off in August of 2019 and has been empowering parents and families to support and advocate for their loved ones in positive and meaningful ways.

One example is a presentation covered by Jenn Miller of PTI of Nebraska which focused on some important acronyms you may hear people talk about in relation to their child's education – IEP and IFSP. Perhaps you are wondering – what the heck is that? Here is an Ed Series Takeaway* so now YOU are in the know as well!

What Is an IEP?

An IEP (Individual Educational Plan) is a map that lays out the program of special education instruction, supports, and services kids need to make progress and succeed in school. It is covered by special education law, or the Individuals with Disabilities Education Act (IDEA).

Who Is Placed on an IEP?

IEPs are a part of public education. They're given to eligible kids who attend public schools, charter schools, and students in private schools. Even before they attend school, babies and toddlers can get services through early intervention and may receive home or other services through an IFSP (Individual Family Service Plan). There are no IEPs in college, but eligible students often can still get accommodations through college disability services.

What are the Benefits of an IEP?

With an IEP, a child gets individualized instruction that focuses on improving specific skills. Kids might get accommodations, like extended time on tests, or related services, like speech-language therapy. Having an IEP gives parents and their child certain legal protections, too. It also allows them to be involved in decisions that impact their child's education and learning goals.

All these factors can help a child build skills, improve self-esteem, and find success at school.

DSAF is proud of and thankful for its continued partnership with PTI of Nebraska, Enable Savings Plan, ESU #5, Rock n Joe's Coffee Bar, and all the organizations that have helped thus far to make this educational experience a success. Visit dsafnebraska.org/ed-series to view past and future courses and related resources, sign up to attend for free, and (new for 2020!) watch digital recordings of future meetings – especially nice if you don't live in Lincoln!

The remaining 2020 courses are listed to the right and just awaiting your learning pleasure. Mark your calendars to attend!



Education Series

2020

Course Information

Parents, friends, family, educators, and other support providers are welcome. All sessions will be held on the 3rd Tuesday of the month at Rock n Joe's Coffee Bar at 5025 Lindberg Street. Register at dsafnebraska.org/events.

March 17: IEP Workshop - A Review of your IEP Components: Did you know our Program Director, Dawna Daily, holds a master's degree in Special Education? Join us as she presents information on the required components of the Individualized Education Plan (IEP) and how they apply to developing a comprehensive plan for your child's education.

April 21: Special Olympics Offerings to Individuals with Ds - The mission of Special Olympics is to provide year-round sports training and athletic competition in a variety of Olympic-type sports for children and adults with intellectual disabilities, giving them continuing opportunities to develop physical fitness, demonstrate courage, experience joy, and participate in a sharing of gifts, skills, and friendship with their families, other Special Olympics athletes, and the community. Alicia Hoffman will present the offerings of Special Olympics Nebraska and how to get involved in the many events they host.

May 19: Self-Advocacy - What is it and How do I become one? Presented by self-advocate, Dillon Denton, self-advocacy and self-determination are important as an individual ages and becomes more independent. This session will focus on what self-advocacy is and why it is an important skill for an individual with Ds to develop as they age. Most appropriate for High School and above.

June 16: Speech Disorders and Children with Down Syndrome - UNL professor, Beth Dinneen, will present on common speech disorders among those with Ds and types of speech therapy designed to assist in the development of communication skills.

July 21: Emergency Preparedness (How to Prepare Your Child) - This session will focus on how to prepare your individual with Ds to interact with first responders in the case of emergency. Participants will walk out with an identification card to share with their families in the event of an emergency. Presented by Dawna Daily as part of an available larger BE SAFE national curriculum.

August 18: Down Syndrome 101 for Educators - Master IEP Coach and Program Director, Dawna Daily, will offer teachers and families the opportunity to listen to information about Down syndrome as it relates to education. Topics will focus on communication and developing an inclusive environment for the individuals in their classrooms.

September 15: Intimacy and Relationships (Utilizing the Circles Curriculum) - Utilizing the Circles curriculum, individuals and families are invited to explore the differences between an acquaintance and close family and what boundaries should be set for each.

October 20: A Roadmap to Independent Living - In this educational series PTI Nebraska's Nina Baker will present tips on how to set your middle school-young adult on a road to independence. Included in the presentation is information about education, employment and independent living.

November 17: Social Opportunities in the Community - Set up as informational speed round-table discussions, area community agencies will present on their offerings from preschool through adult living.

December 15: Enable Savings Plan - Why and How to Set It Up: Diane Stewart from First National Bank will present information on the Enable Savings Plan offered by First National Bank of Omaha, including how to set up a plan, common and uncommon uses of Enable, and some the main rules and regulations that guide the plan in Nebraska.

CELEBRATING WORLD DOWN SYNDROME DAY

3.21

THE LUCKY FEW

★ down syndrome
★★ association for families
of nebraska
dsafnebraska.org

YOU'RE INVITED!

WHEN: March 21 from 5-7pm

WHERE: National Guard Armory, 1776 N 10 St.

WHO: Open to the public!

COST: FREE

Celebrate your
friends & family
with Down
syndrome!

BOUNCE HOUSES • PHOTO BOOTH • OVERALL BUDDIES ENTERTAINMENT
DJ • DOOR PRIZES • FACE PAINTING • TONS OF FOOD • AND SO MUCH MORE!

Please RSVP at dsafnebraska.org/events

THANK YOU IN ADVANCE TO ALL OUR INCREDIBLE SPONSORS AND DONORS WHO MAKE IT
POSSIBLE TO KEEP THIS EVENT FREE AND OPEN TO THE PUBLIC YEAR AFTER YEAR!

Thank you, Jack Rolland, and all our AMAZING volunteers for the hours you donate to benefit DSAF families.



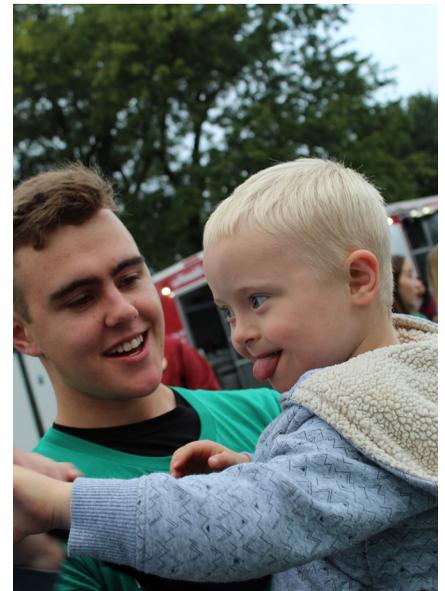
volunteer perspective

jack rolland

My experience with Down Syndrome Association for Families started back in February 2019 at the Night at the Children's Museum event. I volunteered at this event because of a good friend of mine, Henry Sweeney, who was going to be there. I was simply overwhelmed by the family atmosphere that I was surrounded by as a volunteer. I remember thinking, this group truly cares about these kids and wants to celebrate their differences together.

Fast forward a month, I heard about the opportunity to join the 2019 Step Up to Down Syndrome Walk Planning Committee. For the next 7 months I enjoyed coming to meetings and working to improve the Walk wherever I could. I also applied this committee experience to my senior action project in high school. I couldn't think of a more appropriate organization to work with and volunteer for than DSAF!

Last year's Walk was my first, but I knew it wouldn't be my last. I got to help with recording Facebook live videos throughout the morning and walk with this incredible group to show my support! I left that morning with a smile on my face and a desire to continue to volunteer with DSAF – which I still do now as a Freshman at Concordia University!



“I was simply overwhelmed by the family atmosphere that I was surrounded by as a volunteer.”

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

march

- 7: Lil' Stars Get Musical
- 11: Dad's Night Out - Bowling
- 17: DSAF Teen/Young Adult Stars Goes to the Movie "Onward!"
- 17: DSAF Ed Series #8: IEP Workshop A Review of Your IEP Components
- 21: **World Down Syndrome Day Celebration! - all ages and families invited!**

april

- 21: DSAF Ed Series #9: Special Olympics Offerings to Individuals with Ds
- 23: Mom's Night Out
- 30: Final Young Adult Book Club Session of Spring Semester
- TBD: Young Adult Group Cheers on Husker Baseball

may

- 19: DSAF Ed Series #10: Self-Advocacy: What is it and how do I become one? **Recommended for self-advocates high school age and older**

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

DON'T FORGET TO ORDER YOUR WORLD DOWN SYNDROME DAY GEAR!

Place your order online at <https://stores.inksoft.com/dsaffon>

Must be ordered by Sunday, March 1st!

SCAN ME

thank you sponsors!

Companies large and small are working with us to provide a positive vision of the future for all people with Down syndrome in Nebraska and their families.

