



down syndrome

community connections

December 2018



down syndrome
association for families
of nebraska



“You can count on us to do our part to ensure the world is changed for good for you, your children, friends, and fellow community members. Thank YOU for changing the world with us.”

In the first few minutes of finding out my brand new baby in my arms may have Down syndrome, the quote in the picture below was not the first thing that went through my mind. My husband and I were a basket-case of emotions. But little by little...with his sweet smile that lit up his entire face, the chubby hand that wrapped around my fingers, the butterball of a body I cuddled with each night...my fears simply disappeared. And what replaced it was a burning desire from deep inside me to make the world a better place for him.

The Down Syndrome Association for Families of Nebraska is doing just that. With every visit the Medical Outreach team makes to a new parent in the hospital, they spread hope. With every social event organized, parents can take a breath and realize they aren't alone. As community members come together at the Step Up for Down Syndrome Walk to show their support of children, teens, and adults with Down syndrome, they remind those individuals and their families that they are united with them each step of the way in their lives.

As an organization, we want you to know we are here for you too. We are making exciting changes to ensure a long and successful future. You'll notice our new logo which brings more attention to our mission. Updated New Parent materials are available on our website, including “A Book of

Stories,” which offers a compilation of inspiring reflections from family members and friends of children with Down syndrome. And the most recent change is the one you hold in your hands. A newly updated newsletter I'm proud to introduce you to called, *Down Syndrome Community Connections*.

Over the next year, you will notice many other exciting changes to the organization. Down Syndrome Association for Families of Nebraska is here to walk this journey with each and every one of our members. You can count on us to do our part to ensure the world is changed for good for you, your children, friends, and fellow community members. Thank YOU for changing the world with us.

Warm Holiday Wishes,

Mary Sweeney

Mary Sweeney
Board Member,
2019 Step Up for Down Syndrome Walk Chair

PS - As you consider your year-end giving, please join me in supporting the work of this organization which helps so many of us.



volunteer spotlight

step up for down syndrome walk committee co-chairs: jennifer brill & jennifer lohmeier



“Serving on the walk committee is a great way to meet new friends.”
- Jennifer Lohmeier,
Walk Committee
Co-Chair

Jen Brill and Jennifer Lohmeier wanted to make a difference in the lives of individuals with Down syndrome by joining the Step Up for Down Syndrome Walk planning committee. Jen became involved with the walk six years ago when she started as the registration chair. She served in that position for two years and then added on the co-chair role about five years ago.

“My main motivation for serving on the walk committee started with and still is my 6-year-old son Tyler, who has Down syndrome,” Jen said. “I wanted to find a way to celebrate him and to give back to the Down Syndrome Association for Families of Nebraska, which has supported us since Tyler was born.” Jennifer Lohmeier started

attending the walk meetings when she became board treasurer in 2014. She switched to a co-chair for this year’s walk as she saw that planning the event was a lot for one person.

“Before joining the board, I had attended a couple of walks as a walker. I never realized how much it took to pull off this event,” Jennifer said. “Once I started attending the meetings I couldn’t help but want to get more involved. It is very rewarding to see all of the families having such a great time on walk day.”

Jen shared that other members can get involved by reaching out and letting the co-chairs know they are interested. All tasks are important but some require less commitment than others. She has met some really

great people while working on the walk.

“Serving on the walk committee is a great way to meet new friends,” Jennifer said.

Being a part of the walk committee has been beneficial to Jen and Jennifer by knowing they are making a difference in the lives of Nebraskans with Down syndrome. DSAF is grateful for the entire planning committee sharing their time and talents to make the walks a success.

Those interested in learning more about joining the committee may email the new chair of the committee, Mary Sweeney, at sweeneymary33@gmail.com.



celebrating differences

over 1,600 participate in capital city step up for down syndrome walk



Cold weather couldn't keep over 1,600 attendees from the Down Syndrome Association for Families of Nebraska's 17th Annual Step Up for Down Syndrome Walk held on Oct. 6, 2018. Taking place at Antelope Park in Lincoln, the walk recognizes and celebrates individuals with Down syndrome as well as helps support DSAF's important programming.

Participating in the walk, 69 teams brought their friends, families and community members to celebrate, educate and raise awareness amidst a blare of cheering and music for these remarkable individuals.

Teams with names ranging from "Angel's Team" and "Rey of Sunshine" to "Grant's Gang" and "Beth's Buddies" zipped up their jackets and tied their sneakers to take on the chilly fall day.

Ricarda Castillo was able to gather 35 walkers for her team, "Carmelita's Team," which walked to celebrate her three-year-old daughter. Among the walkers was Carmelita's older sister, Elizabeth.

"I felt very happy for her because she's the only sister I have and I always wanted a sister," Elizabeth said. "My favorite part was seeing her happy."

Not only did Carmelita have the support of her family and friends, her preschool teachers were in attendance as well. Ricarda also managed to get two "virtual walkers" to participate, including a dear friend in Dallas who sent a picture wearing one of Carmelita's team shirts as she walked in a nearby park in Texas.

"I was emotional, seeing so many people and kids, and seeing so many people on our team," Ricarda said. "I was very happy that everybody that walked loves Carmelita and supports us."

Prior to the walk, participants gathered for free refreshments and entertainment provided by local organizations. While sipping hot chocolate and eating donuts, walkers were able to enjoy the Orgullo Latino Mexican Folkloric Dancers as

well as a performance by the Sunshine Cheer Team from Cheer Xpress.

"You make it possible for families to forge connections and get the support they need."

*-DEan Fuelberth,
DSAF President*

Arabelle Jackson, a member of "Team Elissa," thought the entertainment was a wonderful way to start the event.

"They were a great way to kick off the walk because they really got the energy going," Jackson said. "I also loved hearing the cheerleaders cheer on the walkers as they came by. It made the walk even more special to have people cheering

you on and being positive."

Participants were also able to purchase raffle tickets for various items including holiday gift baskets, sport event tickets and dinner and hotel stays within the area. Along with smaller item raffles, DSAF also offered a grand prize drawing. Tickets were \$20 each with lucky DSAF member, Sophia Nelson, winning an iPad.

While the main purpose of the walk was to generate conversation and raise awareness within the community, the secondary purpose of the walk was to provide funding for the DSAF organization. All of the funds donated help to ensure that this organization can continue to support, educate and provide opportunities and community events to aid members and beyond.



reaching for the stars

member spotlight: zach kris

Zach is a busy, energetic 23-year-old with Down syndrome, with a fun personality and a quick wit about him. A Southeast High School graduate of 2003, and more alike than different from people his age, he enjoys working, volunteering, spending time with his family and friends, dating, and playing sports.

"I like to be grown up and to learn to take care of myself," Zach said.

While he was enrolled in school, Zach's mother, Paula, worked with his teachers to get him involved in his classroom as much as he could and to be included.

Learning independence has been vital through Zach's involvement in the community. He has worked for two years as a sacker at HyVee.

"I love it because I get to see all the customers and all of the little kids," he said.

He has been a volunteer for several years at CHI Health St. Elizabeth hospital, escorting patients to their locations after registration. Zach and his girlfriend, Amanda, are constantly talking about the future, with the dream of getting married and living on their own. Each day, Zach strives to learn boundaries with others, make good decisions and think things through, use his cell phone responsibly, and address safety issues.

"I would love to keep him with me forever, but I don't think that would be the best for Zach.

He needs to learn to get by without me always being there to do things for him," Paula said. From the day he was born, she has worked towards trying to make his life as normal as possible and to get him involved in everything he can.



"He wants so much to be able to do all the things that a person without Down syndrome can do," she said.

The Down Syndrome Association for Families has played a key role in Zach's and his parents' lives. He attends all the DSAF events that he can. He says he loves it when the Young Adult Stars get together.

"We always do fun things and I get to hang out with friends and my parents are not there," Zach said.

His parents have taken advantage of every resource that has been available to them. DSAF provided them with a group of parents that were in the same life situation.

"This group is a lifesaver to any new parent and to all of us older parents, as a resource and an advocate group to work for inclusion for all of our kids," Paula said.

All of this has helped Zach grow into an active, social, and fun adult with friends everywhere he goes. She says, "Each day is a new experience and some days we never know what is next with Zach!"

You help make sure Zach & others like him gain independence.

the life of a welcome basket

medical outreach offers support

Having a baby should be one of the happiest days in a parent's life. But for parents of a baby that has been diagnosed with Down syndrome, the early days after birth may be beset with worry and concern for the future of their child.

Holly Lohmeier, chair of the Medical Outreach committee, says the Down Syndrome Association for Families of Nebraska gives gift baskets as a way to welcome new babies into the world. It's a positive gesture when parents may be going through several emotions. Fourteen baskets were delivered to new parents in 2017 and 2018. The goal is to help parents celebrate their new baby and to let parents know that DSAF is here to

listen, provide support, and help them connect to other parents who are going through a similar journey.

Desiree Cries For Ribs and her husband Antonio Diaz welcomed Laken into the world on Dec. 13, 2017. Kathryn Brockmeier, a First Call Parent through the Medical Outreach committee, visited them and their three other children at the hospital a couple of days later. She brought along a basket.

"The visit was not awkward like I initially thought it would be. It was nice to have someone answer questions that we had. This also helped us feel connected when we went to our first DSAF event," Desiree said.

To them, the basket felt like a warm welcome to the organization.

Desiree appreciated meeting Kathryn. She says, "The visit provided reassurance that we weren't alone, that we can do this and we had a network for support. I knew that we would need help along the way and this was a needed introduction to the group."

If you are interested in becoming involved in the life of a welcome basket, please contact Torri Attebury at medicaloutreach@dsafnebraska.org.



what's in a basket?

- Baby receiving blanket
- Newborn outfits
- Lovey blanket
- Children's book
- Infant toiletries
- Small toy
- Diaper caddy
- Babies with Down Syndrome: A New Parents Guidebook
- Down syndrome themed decorated onesies

**Each basket delivered has a retail value of \$120.
We are looking for donations to help reduce costs.
The committee is also currently seeking
volunteers that can sew or crochet for a project for NICU babies.**

upcoming events

be on the lookout for future member opportunities

december

- 3-7: Inclusive Schools Week
- 8: Annual Holiday Brunch*
Firespring, Lincoln.
- 15: Lil' Stars Sing & Play
Kindermusik of Lincoln @ 11:30 a.m. - 1:30 p.m.
Age information can be found on DSAF website

january

- 25: Mom's Night Out
La Paz Restaurant @ 6:30 p.m.

february

- 2: Night at the Lincoln
Children's Museum
5:30-7:30 p.m.
- 23: Parent's Coffee
Braeda @ 9:00-10:30 a.m.

- TBD: Lil' Stars Annual Swim Party

march

- 21: World Down Syndrome Day
Annual Celebration*
The Armory @ 5:30-7:30p.m.
- TBD: "The Little Mermaid"
**Lil' Stars & Super Stars partner
w/Theatre Arts for Kids**
- TBD: Medical Outreach Training for
Doctors & Nurses @ Bryan Health

**This event is free and membership is not required to attend*



save the date!

October 5, 2019

18th Annual Capital City
Step Up for Down Syndrome Walk

have questions or want to get involved?

402.421.1338 or info@dsafnebraska.org