

down syndrome

community connections

March 2019



down syndrome
association for families
of nebraska



“Let’s celebrate our loved ones with Down syndrome and their wonderful capabilities!”

Hello and happy (almost) World Down Syndrome Day! It is my great honor to begin a term as President of the Down Syndrome Association for Families of Nebraska (DSAF) this May. It was 13 years ago in March that I became one of “the lucky few” when my son, Ethan, was born with Down syndrome.

In the past 13 years I have chaired Little Stars, Super Stars, been a First-Call parent, volunteered for the Step Up for Down Syndrome Walk and joined the board. My career in elementary/special education has helped me with my passion for spreading awareness and improving the education and potential for our children with Down syndrome.

I knew when my son was in the NICU 13 years ago that a lot of the information that I researched and received was not the most current or up to date. The information limited what the expectations of our kids should be, and my husband and I wanted more for him.

With support from members, sponsors and donors alike, the DSAF Medical Outreach committee now

updates this information regularly so parents and medical staff always have access to the most current best practices and knowledge.

DSAF is a great resource for individuals and families to help improve the lives of people with Down syndrome and to build support and relationships throughout the community. On behalf of “the lucky few,” I want to say thank you for making this possible. I am excited where DSAF is headed.

Sincerely,

Liz Echternkamp, President Elect

P.S. Join me for World Down Syndrome Day on March 21st when we celebrate our loved ones with Down syndrome and their wonderful talents and capabilities!



you're invited
world down syndrome day
celebrate with us!

Monday, March 21 from 5:30 p.m. - 7:30 p.m.
For more information or to register visit
dsafnebraska.org/events

volunteer spotlight

sydney ferrara: teen/young adult stars leader



Hello, DSAF friends! My name is Sydney Ferrara and for a little over a year I have been the Teen/Young Adult Stars group leader.

I first volunteered with DSAF as an undergraduate in our Speech Pathology Club and have since been so inspired by my involvement that I am now working to get my Master's Degree in Speech Language Pathology.

Since beginning with the group, I have noticed some amazing transformations in the members. With every event, they seem more comfortable and confident. I love seeing this, and hope it generalizes into their daily lives.

For example, Chad Bartels is a great friend. He cares so much about the people around him. He loves telling me about his family and his friends (including

his best friend and fellow member, Zach Kriz). Chad brings joy to every environment in which he finds himself!

Another member, Hannah Hopkins, is a sweet soul. She is

“I commit to volunteer work because I love the sense of community that this organization brings.”

a beautiful girl, inside and out, who is strong and capable of so much. I look forward to getting to know her better, and seeing what her future holds. I know it's going to be great!

I commit to volunteer because I love the sense of community that DSAF offers and how they believe in interacting with the person, not their syndrome or disorder. Some of our past events have included cooking classes, art classes, and attending Lincoln Stars hockey or UNL Husker basketball games, among others. For the future, we have planned a tour of the State Capital on March 9 and a pizza party in April where we will write letters to our troops serving overseas.

I love being able to plan these age-appropriate events for the members and making new friends.

We have a blast at every event and get to know each other better each time. If you'd like to learn more or get involved, please contact me at sydneyferrara13@gmail.com.



let's get cooking!

cooking class adds spice to teen and young adult members' lives



"Eat the Rainbow" was the theme of the DSAF Teen/Young Adult Stars cooking class in November.

"Our cooking class is always a hit, but this one seemed better than ever," Teen/Young Adult Stars Leader Sydney Ferrara said. "The dietitian incorporated a rainbow theme, to try and show that eating healthy can be fun. The members were incredible at cutting peppers and fruit,

cooking rice, and, of course, eating the yummy food."

Group members cut up and skewered colorful vegetables onto chicken kabobs. While the kabobs cooked in the oven, they prepared their multi-colored fruit salads with honey-lime dressing.

"The cooking class is awesome," member Chad Bartels said. Chad has been to the last two or three

cooking classes. His parents, Stan and Jodi Bartels are charter members of DSAF and have been involved since Chad was two years old.

"Chad loves cooking class," Jodi said. "We love it. He can be with his friends and hang out."

HY-VEE CHICKEN KABOBS

Ingredients:

- 4 (12-inch long) bamboo skewers
- 1/2 lbs. Hy-Vee Cool Chicken boneless, skinless chicken breasts, cut into 1-inch cubes
- 1 medium zucchini, cut in 1-inch slices and quartered
- 1 medium red onion, cut into 1-inch pieces
- 1 large red pepper, seeded and cut into 1-inch pieces
- 1/2 c. Hy-Vee Italian dressing
- Hy-Vee salt and Hy-Vee pepper, to taste

Directions

Step 1
Grease grill grates. Prepare a charcoal or gas grill for direct grilling over medium heat.

Step 2
Grill kabobs until internal temperature of beef is 145 degrees for medium-rare, about 15 to 18 minutes. Carefully turn kabobs every 4 to 5 minutes. Let rest 3 minutes before serving.

Step 3
Grill kabobs until internal temperature of chicken is 165 degrees, about 18 to 20 minutes. Carefully turn kabobs every 4 to 5 minutes.

more info can be found at: hyvee.com/recipes



Jennie Dunavan, dietitian at the Hy-Vee where the class took place, has experience conducting cooking classes with individuals with special needs. She likes to keep the class simple and hands-on.

"I like that this group is so social," Jennie said.

During food preparation and while eating the meal, there was a lot of chatter and laughter happening. While the kabobs went in the oven, participants and volunteers gathered for group hugs.

Hannah Hopkins, a DSAF member and student at Norris High School also attended the event.

"I like cooking with other people," Hopkins said. "People who have special needs like me are nice to me."

Hannah had so much fun, she hopes to get involved in a culinary class soon. "I want to take the cooking class next semester at my school."

To finish off the meal, the group had some brownies that had a mystery vegetable ingredient.

"We ate brownies made with black beans," Ferrara said. "Even I had to be convinced to try them."



a series of FORTUNATE events

teen/young adult book club one of countless member opportunities

Thanks to a partnership with the University of Nebraska Lincoln's Barkley Speech-Language and Hearing Clinic, DSAF teens and young adults with Down syndrome are enjoying a book club like no other.

These young adults get to leave their parents at the door and dive into real conversations with trained SLP graduate and undergraduate students about the book they are reading, their thoughts on the subject, and life in general. Interactions like this allow participants to practice appropriate behavior and communication in a controlled environment, like the Barkley Center at UNL, while also meeting about once a month at MoJava Coffeehouse where they get to be in the "real world" and put what they are learning into practice.

Now in its third season, the book club has read the books, *Wonder* and *Marley and Me*. This spring semester, they will be diving into Lemony Snicket's, *A Series of Unfortunate Events*.

"Thank you to all DSAF supporters who have given the gift of reading to make this series of fortunate events possible."

"I love to sing, and I love to read. This [book club meeting] was the best day ever," said young adult participant, Sarah Fuenning.

Madison, a graduate clinician with the Barkley Center couldn't agree more.

"One of my favorite parts of the book club is how wonderful all the participants are and how much joy they bring to life. I would like to continue a book club like this in my own professional career after I graduate."

Each Book Club session is just \$60 for DSAF members with Down syndrome and includes 12 meetings. DSAF offsets the remaining costs associated with running the book club.

Thank you to all DSAF supporters who have given the gift of reading to make this series of *fortunate* events possible. If you are interested in joining or learning more, please contact DEan Fuelberth at dean@fuelberth.com.

welcome, all the fish in the sea

wish fish theatre provides opportunities for all



The Down Syndrome Association for Families of Nebraska is proud to announce its partnership with Theatre Arts For Kids (TAFK) with the Wish Fish program.

Wish Fish's goal is to encourage children with Down syndrome to experience the benefits of theatre despite any challenge.

The TAFK's Kiwanis Builders Club has raised funds to offer scholarships to DSAF children ages 3-12 and toilet trained to participate in the summer programming. Wish Fish will pair a veteran TAFK student/ Builder's Club member

with a child from DSAF. TAFK's spring show, *The Little Mermaid Jr.*, launches the Wish Fish program.

Members ages 3-12 and their families are invited to attend one of the dress rehearsal performance free of charge, to be held on March 23.

Theatre Arts For Kids believes that theatre is for "all the fish in the sea." To learn more about the upcoming performance and summer programs offered, visit TAFK.org or contact Kathryn Brockmeier at kathryn.brockmeier@gmail.com.

Theatre Arts for Kids
dress rehearsal performance of
The Little Mermaid, Jr.
Saturday, March 23
11:00 a.m.
at Christ Lutheran Church
4325 Sumner Street
Lincoln, NE



upcoming events

be on the lookout for future member opportunities

march

- 9: Teen/Young Adult Stars Tour of the Nebraska State Capital
- 21: Medical Outreach Training for Doctors & Nurses at Bryan Health @ 11:00 a.m. - 1:00 p.m.
Continuing education credits available
- 21: **2019 World Down Syndrome Day Celebration at The Armory @ 5:30 p.m. - 7:30 p.m.**
- 23: Lil' Stars and Super Stars partner event with Theatre Arts For Kids Spring production of *The Little Mermaid* @ 2:00 p.m. and 4:00 p.m.
- 28: Step Up for Down Syndrome Walk Volunteer Kick-off Meeting

april

- 13: Lil' Stars Event at Swimtastic Swim School @ 2:00 p.m. - 4:00 p.m.
- TBD: Pizza Party
Writing Letter to Troops Overseas

may

- 31: NEW Step Up for Down Syndrome Website Launches
- TBD: Teen/Young Adult Stars Painting Class at Painting with a Twist



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