

down syndrome

community connections

May/June 2021

Celebrating Older American Month

Did you know that May is #OlderAmericansMonth?! It's a wonderful time to recognize the contributions that older adults across the country make each and every day. Meet Amy Walla, featured on page 4, a 51-year-old Fremont resident, who just happens to also have Down syndrome!



thank you, donors!

letter from the executive director

Dear Friends and Member Families,

Happy belated Mother's Day to all the beautiful mamas out there. As we approach Give to Lincoln Day on May 25, I wanted to extend my gratitude on behalf of the DSAF board and all member families who benefit from the organization.

Thanks to donor support like yours over this past year, the Down Syndrome Association for Families of Nebraska has helped members survive this pandemic with scholarships and gifts. The Medical Outreach team has modified their methods to continue to reach every family that has a new diagnosis of Down syndrome. And community members have donated and offered time and resources to help keep children and adults with Down syndrome engaged.

DSAF is as strong as the businesses, families and individuals that support it, and we are so very grateful to be centered in the city of Lincoln, serving all of Nebraska.

As the organization continues to grow, supporters like you will allow DSAF to begin to offer more through partnerships and increase our reach through building relationships, until we have effectively reached every family that needs support and assistance.

This Give to Lincoln, consider continuing your generosity by making a contribution, large or small, to Down Syndrome Association for Families of Nebraska. Every dollar raised will allow DSAF to continue to position ourselves

as leaders in the community; advocating for the rights of individuals with unique capabilities, expanding career options and solutions for adults with Down syndrome to live out their dreams, and working with the legislature to continue to expand opportunities for families and caregivers to have access to medical care from birth through adulthood for their loved ones.

Thank you again!

With gratitude,

Jamie Bertucci

Jamie Bertucci
Executive Director

Encourage health and wellness this year with your Give to Lincoln donation! Every dollar donated will be matched by DSAF members in the form of 1-minute of exercise the week leading up to Give to Lincoln Day.

LET ME SEE YOU MOVE!

Not only will your donation help DSAF advance its mission, but you will also be fostering a healthy lifestyle in the lives of people with Down syndrome!

Help spread the word!

Visit GiveToLincoln.com/nonprofits/DSAF to make your online donation today.



Education Series

2021

helping families one educational session at a time:

new 2021 ed series to focus on individual education plans (IEP)

What's better than getting a chance to sit down at a table and talk to your child's school team about his or her future Individual Educational Plan (IEP)? It's feeling equipped and prepared with all the tools and training you need to feel successful at that meeting!

And that is exactly what this year's DSAF Educational Series will focus on – preparing parents and guardians to be active, positive, and effective participants in their child's IEP meetings.

The free series, originally launched in August 2019, has been widely successful and informative, providing monthly training and education for parents of children, teens, and adults with Down syndrome. The IEP series sessions began in April and will continue through December on the third Tuesday of the month via Zoom, from 6:30 to 8:30 p.m. Friends, families, educators, and other providers are also welcome.

In addition to the new IEP topics for 2021, all courses are recorded, and handouts and other resources are made available online so families in all parts of the state can benefit from the incredible speakers and topics covered. Upcoming session topics are as follows:

- **May** - Summary of Present Levels of Academic Achievement and Functional Performances in IEP
- **June** - Annual Goals, Progress, and Levels of Achievement in the IEP Document
- **July** - Special Education Services, Related Services, Aids, Modification, and Accommodations in IEP
- **August** - Annual IEP Reviews and Prior Written Notices and Re-Evaluation
- **September** - Re-Evaluation and Due Process
- **October** - Behavior Intervention Plans—What About Restraint and Seclusion?
- **November** - Transportation within IEP
- **December** - Transition and the IEP

To learn more or sign up for the series, visit dsafnebraska.org/edseries.

Thanks to generous donors like YOU supporting the DSAF Ed Series, hundreds of people across the state have found the valuable resources and confidence they need to support their friend or loved one with Down syndrome.

amy walla: an #olderamericanmonth spotlight

Amy is the beloved younger sister of Mike Walla of Arizona and Mary Beth Rice of Lincoln and the devoted daughter of Carolyn and the late Bill Walla.

Amy enjoys music, dessert, a good kolache, and watching her favorite show, Little House on the Prairie, on her new iPad. And like any woman, she loves to have her nails done and a good lipstick in her pocket.

While she may not have a lot to say, she knows exactly how to stand her ground and get her point across when someone is rushing her – definitely an item on her list of “dislikes.” And she can charm her way into getting her favorite thing on the planet – a CL&S (a Cup, Lid, and Straw), which is the largest cup possible from Super C, filled with her favorite soda, topped with a lid and straw for her drinking pleasure.

After Amy’s father passed away in 1992, the family came together and made the decision to work with Nebraska’s ENCORE program, now called DUET, which provides day support centers, residential support, employment opportunities, continuing education, and many other services. Although a difficult decision for any family to make, the siblings and their mother loved the opportunity it provided for Amy to gain more independence and allowed them to move away from the “caregiver role” and focus more on celebrating and being a family. More recently after Amy’s mother was diagnosed with Parkinson’s and her health has been deteriorating, the family feels validated that this was the right

decision to have made because Amy is so well cared for and has routine, which is important for her to thrive.

They all still get together for holidays, birthdays, and other special occasions, but Amy is quite busy with her own life activities too. As a young adult she was an active participant in bowling, special Olympics, and swimming, and now lives in a duplex in Fremont with her two roommates and a 24/7 staff member. While COVID did shut down services for a time and opportunities for Amy to be out in the community were discontinued, they are slowly resuming. She goes everyday with her roommate to their DUET activities where they do crafts, participate in fun and educational activities, and learn new skills, like making homemade ice cream.

Mary Beth shared that she’s most proud seeing how loving and nurturing Amy is to their mom as they both age. “She is so protective and caring.” Rice admits that a sense of humor is definitely required at times when interacting with Amy, but the benefits and love far outweigh the costs.

For typically developing people, 51 might seem a far cry from an “older American.” But individuals with Down syndrome, until as recently as 1983, were only projected to live until about 25. Thanks to improvements in medicine, early intervention and health screenings, and most importantly the ending of the inhumane practice of institutionalizing people with Down syndrome, the average lifespan of someone

with Down syndrome is approximately 60 years!

And with that longer lifespan, Amy, like so many people with Down syndrome, continues to touch lives – and has been since she has been a child.

Dr. Laura Nielson, lead pediatrician for Children’s Hospital and Medical Center’s Down Syndrome Clinic in Omaha, and a doctor who many DSAF member-families have seen, was a childhood friend of the Walla family and grew up around Mary Beth and Amy. Recently when talking with Mary Beth, Dr. Nielson shared with her that it was because of her interactions with Amy growing up that she developed such an affection for individuals with Down syndrome.

It’s conversations like that which have led Mary Beth to realize that families that have a child with Down syndrome are making an impact in the lives of others, even if they don’t know it. “How we love each other in our families can have a ripple effect in other families. A ripple effect in how we love and how we fold in these special people. [Individuals with Down syndrome] can teach us way more than we can teach them.”

So, while we can all agree that the squishy-cheeked little ones with Down syndrome are so darn precious, let’s not forget the impact and contributions that older adults with Down syndrome, like Amy, have made and are still making today to help pave the way for a brighter tomorrow for all.



When you support DSAF this Give to Lincoln Day, you help DSAF expand programming to engage individuals with Down syndrome from birth all throughout life – just like Amy. Make your contribution at givetolincoln.com/nonprofits/DSAF.

“How we love each other in our families can have a ripple effect in other families.”



**CALLING
ALL SELF-
ADVOCATES
!!!**

YOU KNOW WHO YOU ARE!

Your skills, your story, your passion, your energy is needed on DSAF committees, for visits with partner companies, in TikTok or YouTube videos, and so much more.

If you or someone you know with Down syndrome is interested in getting involved, please contact Jamie Bertucci at

**director@
dsafnebraska.org**



**Save the
Date!**

**NEBRASKA'S STEP UP FOR
DOWN SYNDROME WALK IS TURNING 20!**

 **down syndrome
association for families
of nebraska**

You are cordially invited to the 20th anniversary Step Up for Down Syndrome Walk on October 2, 2021

NEW LOCATION - We are returning to Antelope Park!

Please spread the word and get ready to join in the fun at DSAF's largest awareness and fundraising campaign of the year!
The Step Up Walk website will open for team creation in June.

**STEP
UP**  **DOWN
for SYNDROME
WALK**

October 2, 2021

Questions? Contact Amie Lovegrove at amie.lovegrove@outlook.com.

covid-19

vaccine advocacy update

In February, individuals with Down syndrome and their caregivers were just days away from their spot in line to receive the COVID-19 vaccine when out of nowhere, state officials removed them from published Phase 1B vaccine prioritization category. Since then, DSAF staff, board of directors, and partners throughout the state and beyond have come together to advocate for individuals with Down syndrome to get their spot back in line.

DSAF is proud to share that thanks to everyone's hard work, people with Down syndrome, and all individuals with intellectual disabilities AND their caregivers were provided with early opportunities beginning in April to access vaccine clinics in Omaha, Lincoln, Grand Island, and Norfolk.

A special THANK YOU goes out to all the people who helped contact the media, signed letters of support, shared the story in the news, got petitions signed, acted as collaborators, and ultimately, those who set up the vaccine clinics for individuals with intellectual and developmental disabilities (IDD):

- ARC of Nebraska
- Disability Rights Nebraska
- Down Syndrome Alliance of the Midlands
- Down Syndrome Association for Families of Nebraska
- Felicia Quintana-Zinn, Deputy Director of Public Health
- Global Down Syndrome Foundation
- Mayor Leirion Gaylor Baird, Mayor of Lincoln
- Munroe Meyer Institute
- National Down Syndrome Congress
- Nebraska Consortium for Citizens with Disabilities
- Nebraska Department of Health and Human Services
- Volunteers, friends, and community advocates – like YOU!



DSMIG-USA
Down Syndrome Medical Interest Group-USA

GLOBAL
DOWN SYNDROME FOUNDATION

LuMind
IDSC
DOWN SYNDROME FOUNDATION

NATIONAL
DOWN SYNDROME
CONGRESS

national down syndrome society
ndss

ntg
National Task Group
on Intellectual Disabilities
and Domestic Practices

If you are a Nebraska resident who hasn't been vaccinated yet and would like to register for the COVID-19 vaccine, visit Vaccinate.NE.gov. Or learn more at dsafnebraska.org/covid.

upcoming events

may

- 17: Registration is open for Summer Enrichment Boxes
- 18: DSAF Ed Series – Levels of Academic Achievement and Functional Performance - How They are Included in the IEP
- 19-25: "Let Me See You Move" Give to Lincoln Day Exercise Campaign
- 25: Give to Lincoln Day!
- 28: Lil' Stars Family Movie Trivia Night
- 31: Final Day to Submit Testimonials for Medical Outreach Book of Stories
- TBD: Young Adult Stars Outdoor Park BBQ

june

- 5: Homer's Heroes Begins
- 10: DSAF Young Adult Book Club Summer Session begins
- 15: DSAF Ed Series – Annual Goals, Progress, and Level of Achievement in the IEP Document

july

- 4: Super Stars Assemble 4th of July Craft Kits
- 20: DSAF Ed Series – Special Education Services, Related Services, Aids, Modifications, and Accommodations in the IEP Document

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

GET READY FOR SOME FUN (AND A LITTLE LEARNING TOO)

DSAF SUMMER ENRICHMENT BOXES!



Thanks to a generous donation from the Lincoln Community Foundation, DSAF is offering summer enrichment boxes for infants/toddlers, school-aged children, and young adults/adults with Down syndrome! 15 boxes are available on a first come, first served basis for each age group while supplies last. New boxes will be available for pick up monthly at a location to be determined in Lincoln.

Visit dsafnebraska.org/summer to reserve your box today!

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.

