



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 Executive Director





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.

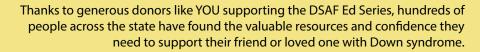
The free series, originally launched in August 2019, has been widely successful and informative, providing monthly training and education for parents of children, teens, and adults with Down syndrome. The IEP series sessions began in April and will continue through December on the third Tuesday of the 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 Series, 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.





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 squishycheeked 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.









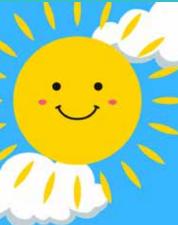


YOU KNOW WHO YOU ARE!

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!

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.



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!



f 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.



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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 Give to Lincoln Day!

28: Lil' Stars Family Movie Trivia Night

Final Day to Submit Testimonials for Medical

Outreach Book of Stories

TBD: Young Adult Stars Outdoor Park BBQ

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25.

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

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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.



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.













Family Health & Wellness Center

































