

# down syndrome

community connections  
December 2022

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daughter, Bo, in Bulgaria, and  
bring her home to Lincoln.

*Bringing Home Bo*



# step up walk a success!

a message from the executive director

Friends of the Down syndrome Community,

The 21st annual Step Up for Down Syndrome Walk at Antelope Park was a success, thanks to every participant, volunteer, team, & family that made the event an unforgettable experience! This is DSAF's biggest celebration & fundraiser & we are so grateful to have a community of partners to help us to continue to serve people with Down syndrome in Lincoln & across the state of Nebraska.

Our Step Up Walk sponsors & donors fund the majority of DSAF events for the year & we intend to show those businesses love year-round! In addition to the sponsors who provide the funds to continue our work, the

following businesses contributed to the Step Up Walk with their presence & participation. We would like to recognize these & extend our gratitude for their help on Walk Day!

With love & gratitude,

*Jamie Barrier*

Jamie Barrier  
Executive Director

## thank you sponsors ★

Fleet Feet  
Genesis Health Club  
Lincoln Saltdogs  
Runza  
Pepsi Cola of Lincoln  
Hy-Vee  
Nothing Bundt Cakes

Jilly's Socks 'n Such  
Freddy's  
Maize Popcorn  
Lazlo's Brewery & Grill  
Fireworks Restaurant  
Waverly Nail & Spa  
Paint Yourself Silly

Russ's  
Eileen's Cookies  
Costco  
Target  
Healing Heart Dogs

# opportunities for young adults

## join best buddies!

Best Buddies is a vibrant international organization dedicated to the mission of inclusion of individuals with intellectual and developmental disabilities (IDD). Best buddies is devoted to creating one-on-one friendship matches to cultivate an inclusive, fun environment for all! At the University of Nebraska - Lincoln, our chapter provides opportunities for UNL students to expand themselves and build inclusive and lasting friendships with individuals with IDD in the Lincoln Community!

We would like to invite the young adult members (ages 19-40) of DSAF with an IDD to join Best Buddies! We typically meet on the 2nd Thursday of the month and do an additional activity later in the month (All specific dates posted on our online platform BB360 at [bestbuddies.force.com](http://bestbuddies.force.com)). We also match our members in friendship pairs (optional) to give members specific opportunities to build friendships outside of our designated meeting times.

To get involved, visit [www.bestbuddies.org/join](http://www.bestbuddies.org/join) to register your child and gain access to BB360!

### BEST BUDDIES®



*For more information, check out our Instagram @bestbuddies\_unl or reach out to us via email [huskerbestbuddies@gmail.com](mailto:huskerbestbuddies@gmail.com)*

## research participant opportunity



Researchers at The University of Nebraska-Lincoln and The University of Alabama are collaborating on a study to examine

### READING SKILLS IN INDIVIDUALS WITH DOWN SYNDROME

We are looking for children and adolescents, 9-16 years, with Down syndrome to complete language and reading tasks. Participation will take about 4 hours but can be broken up across different days.

**Families will receive a \$40 gift card for participation.**

For questions or to sign-up, contact:

Susan Loveall  
402-472-3243

[sloveall-hague2@unl.edu](mailto:sloveall-hague2@unl.edu)

-Or-

Frances Conners  
205-348-5083

[fconners@ua.edu](mailto:fconners@ua.edu)



## Exciting News!

The RiteCare Clinic in Lincoln/MMI is hosting Total Communication Kids Club groups this Winter! This pediatric program is for children ages 3-5 years in groups of 2-4, which provides speech-language services with a focus on: communication and social language development within a schedule similar to preschool. These weekly 50-minute sessions are no cost to families and are run by a RiteCare Speech-Language Pathologist and two UNL speech-language pathology graduate students.

If you are interested, please contact Holly Schlautman at 402-472-0642 or [holly.schlautman@unmc.edu](mailto:holly.schlautman@unmc.edu).

## in honor of dr. sherrill echternkamp

Dr. Sherrill Eldren Echternkamp, 79, of Lincoln, Nebraska, passed away peacefully on August 11, 2022. Sherrill was born in Columbus, IL, to Eldren and Eleanor Echternkamp. He graduated from Southern Illinois University, Ohio State University and Cornell University. He was a physiologist for the USDA for 40 years. He and his wife Lynn raised their children Renee and Eldren in Clay Center, Nebraska, and volunteered in the community. He enjoyed restoring antique and vintage Fords. Sherrill is survived by his wife, Lynn; his son, Eldren and his wife, Elizabeth and their children, Kennedy, Ethan, and Keagan; and his daughter, Renee and her husband, Ty and their children, Lake and Kylan.

Dr. Sherrill Echternkamp requested memorial gifts go to the Down Syndrome Association for Families in his honor. Dr. Sherrill was committed to making a difference in the lives of people with Down syndrome, especially for his grandson, Ethan Echternkamp. Our hearts go out to the family and friends of Sherrill Echternkamp. May we always honor his memory in the work we do for those with Down syndrome.



# market to market

## dsaf's lucky few running crew



Runners (Left to Right): Hillary Swain, Allison Luth, Nikki Hobelman, Samantha Kenning, Jessica Gushard, Jessica Johnson, Desiree Cries for Ribs, Matt Hague, (not pictured) Driver Elizabeth Echterkamp

On October 8th, 2022, 8 runners assembled at 3:30 am to journey to the start line for a race beginning in Omaha, Nebraska, and ending in the Haymarket in Lincoln, NE. Dubbed the "Lucky Few Running Crew," these runners spent months training for this 75+ mile relay race and fundraising for DSAF.

This is DSAF's first year participating in the Market to Market race and we are grateful to each of these dedicated and hard-working runners, who took time from their busy lives to devote themselves to the training and completing the race successfully! Each runner was assigned legs of the race and those miles were completed on gravel backroads, trails, streets and sidewalks between Omaha and Lincoln. The support that these runners showed each other and the Down syndrome community is unparalleled. They crossed the finish line over an hour earlier than anticipated, with a finishing time of 13 hours and 47 minutes. (Play with pictures in the text and build a story-telling page of race day. Van trip, running pics, ending with the team pic at the bottom of the page).

As part of our Health & Wellness programming, DSAF will continue to create opportunities for members & supporters to represent individuals with Down syndrome in our community and promote fitness and healthy lifestyles. We are excited to announce our participation in the 2023 Market to Market relay race! We are looking for run-loving, committed runners, who will be able to raise funds with the Lucky Few Running Crew of 2023. 8 runners will be selected based on pace (10min/mile minimum) and interest in meeting an individual fundraising goal.

Please email [Director@dsafnebraska.org](mailto:Director@dsafnebraska.org) for details.



**8** RUNNERS  
**75+** MILES  
TOTAL TIME OF  
**13:47**



## member spotlight:

### bringing home bo:

*hague family welcomes new family member*

Our featured family, Susan & Matt Hague, share their experience in adopting Bo, a baby with Down syndrome, from Bulgaria. Bo came home to Lincoln, Nebraska, with Susan & Matt in August 2022. We are honored & excited to share their beautiful journey with this community!

Susan & Matt are from the Wichita, Kansas area. They went to college in Kansas & started dating after graduation. Susan went to graduate school at the University of Alabama, & Matt started working as a nurse in Kansas. After finishing her PhD in development & cognitive psychology, with a focus on learning development in individuals with intellectual & developmental disabilities, Susan moved back to Kansas to do a postdoctoral fellowship at the LifeSpan Institute at the University of Kansas. They married in 2015 & moved to Oxford, Mississippi, where Susan took a faculty position at the University of Mississippi. Matt completed his master's degree & moved into health care administration. When a position opened at the University of Nebraska – Lincoln, they made their move back to the Midwest. Susan is now an assistant professor in the Department of Special Education & Communication Disorders. Her research focuses on learning, language, & literacy in individuals with intellectual & developmental disabilities across the lifespan, with a particular focus on individuals with Down syndrome. Matt works at the VA as a mental health nurse case manager.

#### **Can you share the parts of your journey that led you both to adoption?**

SUSAN: As a college student, I worked at a summer camp in New York that served children from a variety of backgrounds, including children in foster care, children with intellectual & developmental



disabilities, & children with emotional & behavioral difficulties. This is where I became interested in adoption & fell in love with working with children with intellectual & developmental disabilities. As a graduate student, I was lucky enough to work as a research assistant on one of my advisor's (Dr. Frances Conners) NIH-funded grants that was examining learning & language development in children with Down syndrome. This was where I fell in love not only with working with kids with Down syndrome specifically, but also working with their families. If you are reading this, then you know what a wonderful & supportive community the Down syndrome community is – there is not much else like it out there.

However, adoption was a long journey for us. We had countless conversations about it & tried to get pregnant for a couple of years before moving forward with adoption. Once we decided on adoption, we spent a lot of time researching options. We settled on international adoption because we knew that there were children in orphanages who needed a family, & we had a lot of love to share. When we expressed interest in adopting a child with Down syndrome, they encouraged us to consider Bulgaria, which is where our daughter Bo is from.

#### **What piece of advice would you offer to someone who shares in your vision to adopt?**

SUSAN: Start reaching out to others to make connections & learn about their experiences. Adoption is beautiful, but you want to make sure it is the right fit for your family. Adoption is a lot of paperwork, so be prepared for that too.

MATT: Be persistent.

### **Tell us about Bo & the process of bringing her home.**

Bo's given name is Bozhidara (pronounced Bo-zha-dara). It means "divine gift." We thought it was a beautiful name & decided to keep it. We call her "Bo" for short.

We completed the adoption application before learning of Bo. That means, we completed all the paperwork & got through the entire approval process without a specific child in mind. About three months later, we got a phone call that there was a "sweet baby girl" that the government of Bulgaria had matched with us. That was in February of 2022. Over the next months, we received her file & met her via Zoom. We finally got to bring her home August 31, 2022.

Bo was born with a congenital heart defect & spent the first year & a half of her life in & out of the hospital & an orphanage. She lived into a wonderful foster home. She had open heart surgery before she turned one. She is our little zipper club hero.

The positives far outweigh the challenges. We are impressed by Bo's resiliency. However, our challenges include the language barrier (Bo does not know English, & we butcher any Bulgarian we try to speak), figuring out Bo's diet & nutrition, & bonding (letting her know that we are safe & dependable). The jet lag was brutal coming back from picking her up in Bulgaria too!

### **What was your first thought when meeting & holding Bo that first time?**

SUSAN: There really are not words. It was such a surreal & overwhelming moment. The "pick up" went quickly, with a lot of information thrown out in both English & Bulgarian, so it was hard to process everything fully. We also had to remind ourselves that while we had been dreaming of getting her for months, Bo did not know us. So, we tried not to add to her stress in that moment.

MATT: I realized this was one of the biggest changes of my life & that I was ecstatic. I knew that what we, as a couple, could offer would not be perfect, but that we could have a positive impact on Bo's life & that she was going to positively impact us too. I knew that having Bo would change us, change who we are.

### **What are your hopes for Bo & her future?**

SUSAN: I imagine what every parent wants – for my child to be happy & healthy, surrounded by people who love her, for her to find what she loves to do & to use her unique talents & gifts to make the world a little bit better & nicer of a place.

MATT: I hope Bo grows up feeling loved and that opportunities to achieve her goals and dreams are readily available.

### **How has this experience changed you?**

Having a child changes your priorities. It is not that other things matter less now, but that our child rises above all other priorities.

MATT: Going through the experience has reinforced that Susan & I are on a team & need to have each other's backs & support each other.

SUSAN: I do not know that it has "changed" Matt but becoming a father has really highlighted so many of his good qualities: patience, humor, & how deeply he cares for others. This experience has also connected us to other people in unexpected ways. Those experienced in adoption have reached out, those who have someone they love who has Down syndrome, and others, who just want to know how they can support us. It reminds me that everyone has a story & that people are good. It also really touched my heart to see how much our loved ones immediately loved Bo. It was like the love we share with our friends & family instantly grew to encompass her.

### **What is the biggest challenge you are facing?**

MATT: The language barrier is one of our biggest challenges. If she seems off on any given day, we cannot ask her how she is feeling or what is wrong. It is not insurmountable, but it is a challenge.

SUSAN: Yes, that & naptime!

### **What do you want other people to know about Bo & you, her family?**

SUSAN: My whole life my mom has been my hero, & she still is, but Bo is now also my hero. She has been through so much in her short life, & I am just in awe of how she is still so curious, fun, & loving towards others. I hope other people take the time to get to know her & see how great she is. We often get compliments on how amazing it is that we adopted & how lucky Bo is, but I want people to know how lucky we are to have gotten her. She is the most amazing part of our story.

### **What does the future look like for Bo & others with Down syndrome?**

The future is bright! With modern medical advancements, individuals with Down syndrome are living longer & healthier lives than ever before. With improved education, individuals with Down syndrome are showing how much they can learn & achieve, & thanks to self-advocates & their families & friends, there is greater visibility & understanding of Down syndrome in society. As a community, we still have a long way to go, but it is clear, individuals with Down syndrome make our world a better place.



★ ★ **Down Syndrome Association for Families of Nebraska**  
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 Lincoln, NE 68505

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**cfaa**  
 (crossfit for adaptive athletes)



DSAF teens & young adults have been hitting the gym every Saturday for CrossFit classes at Lincoln Nutrition & Fitness. Thanks to a grant provided by GLOBAL Down Syndrome Foundation, up to 10 participants can enjoy free personalized coaching, use of the facility & equipment each week through mid-2023. In August, CFAA had their first CrossFit competition. DSAF athletes were paired with coaches, and they competed alongside their CrossFit peers. Participants were challenged with various exercises throughout the day. This was a truly inclusive experience for all the CrossFit athletes and a wonderful example of how successful athletic events can be when we include people with varying abilities!

Donations & sponsorships are needed to continue this program to the end of 2023. Please contact Jamie at [Director@dsafnebraska.org](mailto:Director@dsafnebraska.org) for ways to help us meet the needs of this growing community or designate your donation here:



**Gi♥ing Tuesday**



Join the global generosity movement and celebrate all acts of giving.

#givingtuesday #unselfie

**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.