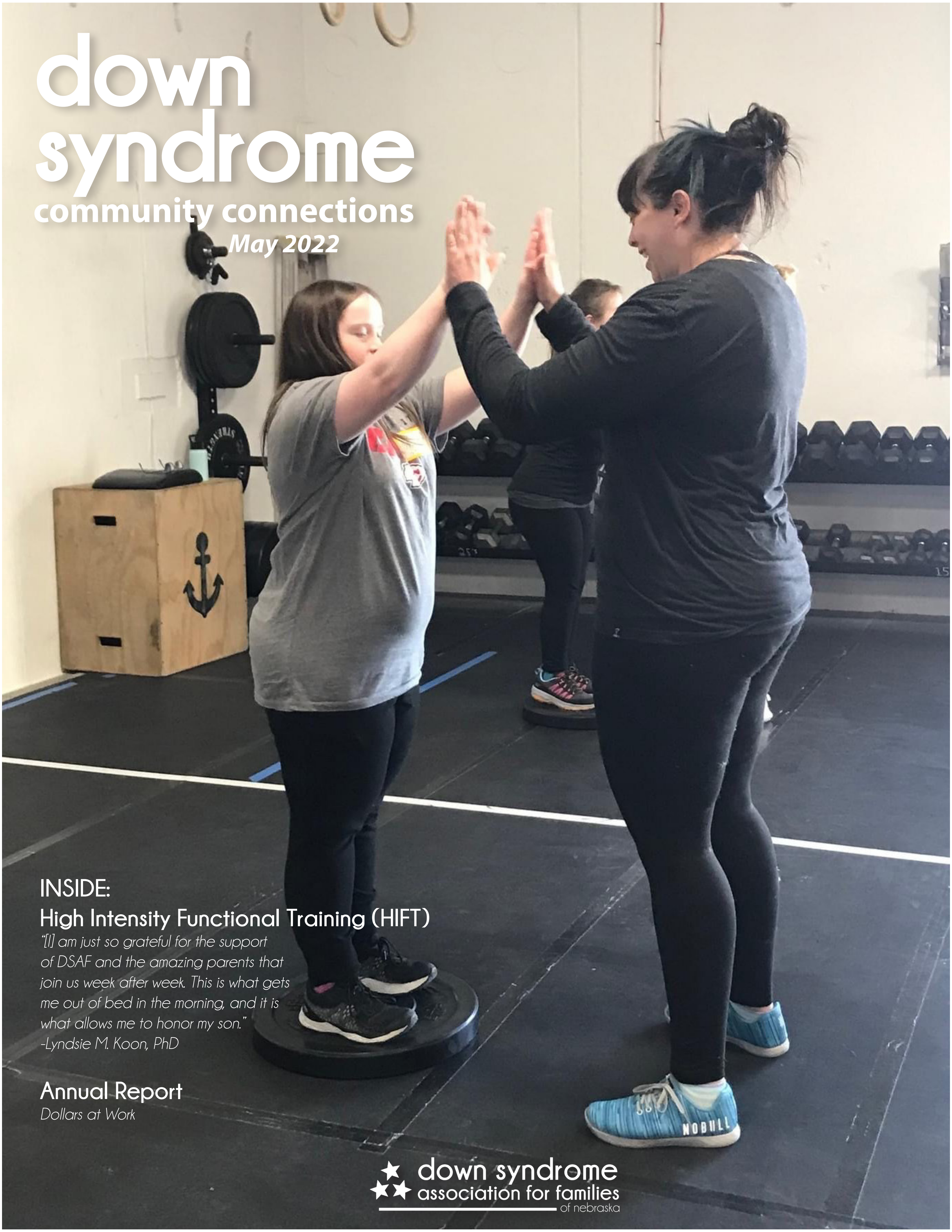
down syndrome

community connections

May 2022



INSIDE:

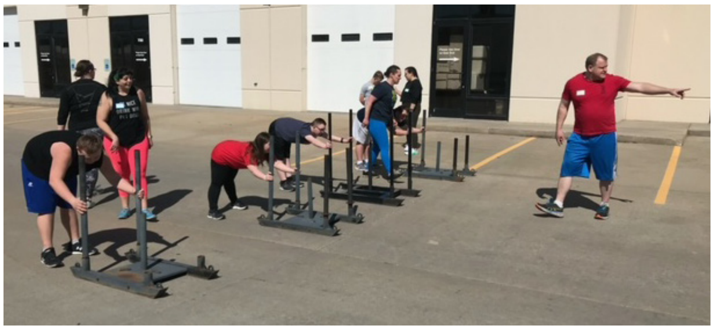
High Intensity Functional Training (HIFT)

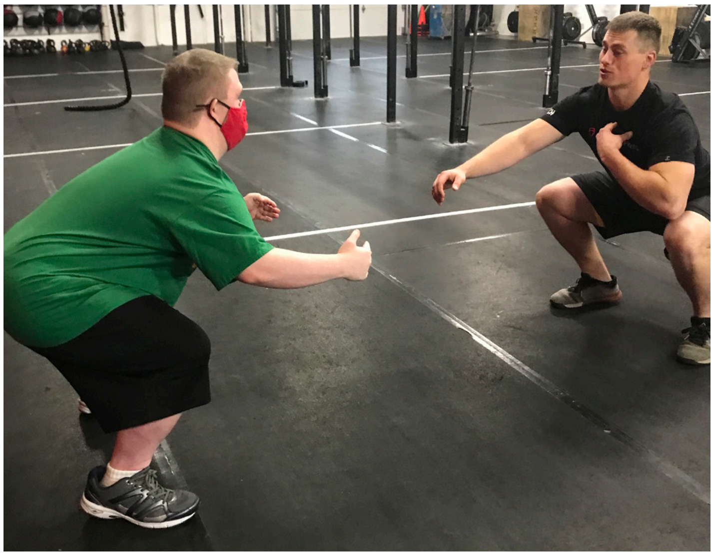
"[I] am just so grateful for the support of DSAF and the amazing parents that join us week after week. This is what gets me out of bed in the morning, and it is what allows me to honor my son."
-Lyndsie M. Koon, PhD

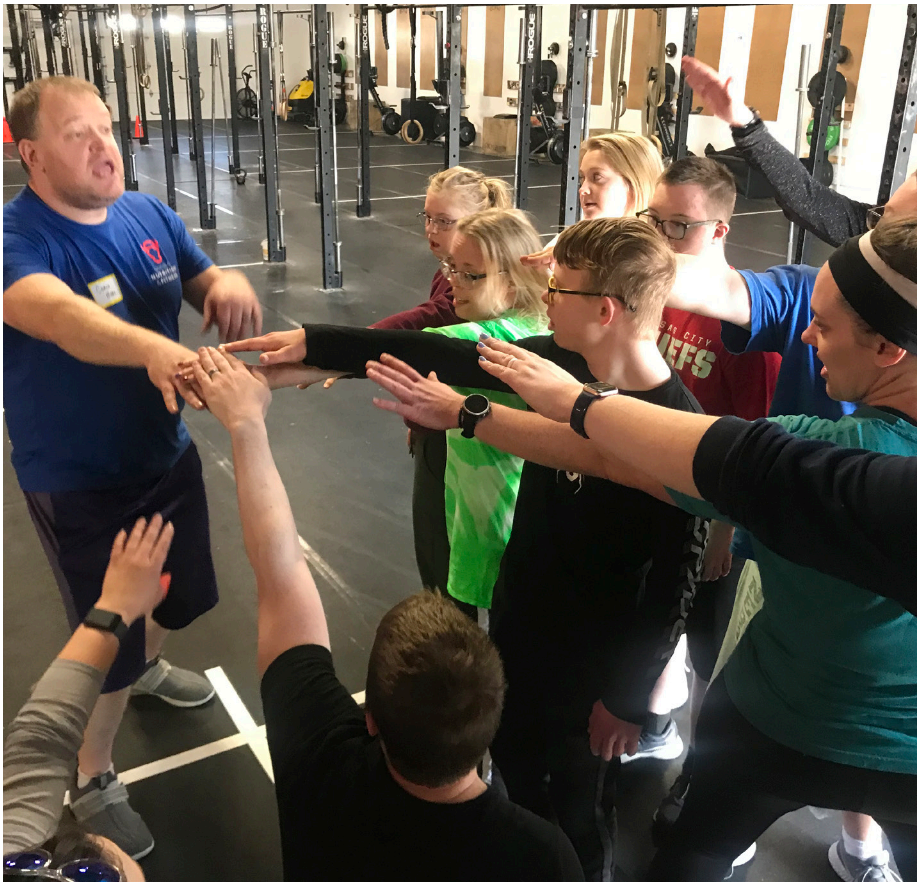
Annual Report

Dollars at Work

down syndrome
association for families
of nebraska







getting fit

members participate in HIFT training

story by lyndsie m. koon

My exercise focus is on Functional Fitness, also known as high-intensity functional training (HIFT), or more commonly known as CrossFit, defined as *"constantly varied functional movements performed at high intensity."*

The "intensity" part is self-regulated, which means that any individual, regardless of age, fitness level, gender, or impairment, can participate.

Through CrossFit Lincoln and our fearless leader, Coach Mark Geist, we have been hosting monthly sessions for adolescents/young adults (13 years +) with Down syndrome since October of 2021. We have recently progressed to offering *weekly* classes at the request of the DSAF community; with the help and support of CrossFit Lincoln and all the amazing coaches and volunteers.

These athletes work hard each week, breaking stereotypes and misconceptions with their effort, growth, attitudes, and persistence.

They are mastering all sorts of functional (everyday) movements from squatting, hanging, rotating, hinging, pushing, and pulling, as well as more advanced activities such as pull-ups, burpees, deadlifts, rope climbs, overhead squats, sled pushes/pulls, wall balls, assault bikes, and so much more. The community-building aspect that is unique to CrossFit is evident from the athlete attendance and interactions with one another. The athletes are welcome to bring a "buddy" (e.g., sibling, friend) and have already built close relationships with their coaches, which has fostered a strong sense of belonging and affiliation in an environment that promotes "preventative medicine" for all.

If you are interested in HIFT or would like more information regarding classes, visit **www.dsafnebraska.org/Events** to learn more about weekly HIFT.
Classes are open to ages 13+ and all abilities. Space is limited to 15 participants.

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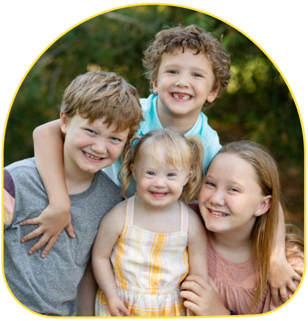

down
syndrome
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families
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WILL YOU CONSIDER PARTNERING WITH DSAF?

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member spotlight:

lyndsie koon:

dsaf member since 2021

I joined DSAF back in April of 2021, when I received a prenatal diagnosis of Trisomy 21 for my son, Henry 'Hank' Eugene Koon. After being advised to terminate by two different doctors simply because of his diagnosis, I was a pretty scared and desperate first-time mother-to-be.

I reached out to DSAF since they were in my hometown of Lincoln, and was extremely fortunate for the advice, education, resources, and support I immediately received from DSAF, particularly Jamie, Torri, and Nikki. I'm sure most mothers remember their prenatal experience – but it's such an odd and confusing place to be. On one hand, you're being told "I'm so sorry" and "You really should consider termination" by healthcare professionals – and on the other hand, you're very quickly welcomed into this club where everything is absolutely fine and wonderful, all while hesitant to join the club - but petrified at what you're being told by your doctor(s).

> "As a researcher, I firmly believe that knowledge is power, thus, with the help of DSAF, I learned everything I could: I read, I watched YouTube vidoes, I spoke to the "experts" and other families. I had a place to ask the "hard" or even uncomfortable questions, and I was connected to other mothers in the local and surrounding area."

As a researcher, I firmly believe that knowledge is power, thus, with the help of DSAF, I learned everything I could: I read, I watched YouTube vidoes, I spoke to the "experts" and other families. I had a place to ask the "hard" or even uncomfortable questions, and I was connected to other mothers in the local and surrounding area. That quest for knowledge and understanding significantly helped to reduce the perceptions of isolation, and helped me face the fear connected with my son's diagnosis. I remember Torri said to me once very gently, "You're having a baby first, so just focus on that. Down syndrome is a distant second." That gave me something to focus on, and somehow, a huge sense of relief.

Like many mothers, I doubted my ability to parent a child with Down syndrome. I even looked into the options of adoption – and remain extremely grateful for the National Down Syndrome Adoption Network (NDSAN) and all of their support and resources. I also found other maternal and fetal providers through DSAF, and switched my care from Kansas City to Dr. Kenney at Bryan East. To this day, he is the only healthcare provider who did not tell me to terminate – I saw six different maternal and fetal medicine doctors from three states, in total. Knowing what I know now, the healthcare community has a lot to learn about these pregnancies and were the primary source of stress during my pregnancy.

I appreciate DSAF's connection to the healthcare community, and the education material and approaches they continue to share with them. Using DSAF and NDSAN material, I have since gone back to my providers here in Kansas to offer additional resources for the next mother who comes through their doors with a prenatal diagnosis. If I can help just one mother who was as scared, alone, and confused as I was – then I've done my job.

Like many T21 pregnancies, Hank's health issues began at 14 weeks and only progressed. At 16 weeks, I was told my son wouldn't likely make it but another couple of days, and to call when I was going into labor so they could help me deliver a stillbirth. I left that appointment absolutely shattered, and after about 24 hours of shock (denial, anger, etc.), I reached back out to DSAF, and before I knew it, I was connected with local, and not-so-local, Down syndrome communities (Lincoln, Omaha, Kansas City, Denver, you name it) where I was further connected with other mothers who specifically had been given similar diagnosis of impending death to their baby. One after another, they all took the time to share their "miracle stories", showing pictures of their now healthy babies, children, teens, and young adults - providing medical advice, words of encouragement, and passed on the true grit only a mother fighting for their child can understand. Because of them, I went into the biggest fight of my life. I was told time and time again he had a 1 in 100 chance of making it – and each time I left the appointments desperately convinced that my son would be that 1/100 miracle. I prayed, I meditated, I went to acupuncturists, a Chinese Herbal Medicine doctor, functional medicine doctors, a Shaman, and even moon-bathed, hoping the moon would pull the fluid that had accumulated in his little body like it does the tide. After every doctor appointment I shared the information with the other mother's, who would consistently refute their claims, and tell me not to give up – which helped me to persevere and not give up on my son as I was advised time and time again to do. If nothing else, he deserved every last ounce of fight I had in me.

I lived out my son's entire life in my mind's eye as his heart continued to beat and body continued to grow in my belly: holding him during his first round of trick-or-treating (dressed as a scarecrow from the Wizard of Oz – no idea why, but that is what I saw); standing in line for kindergarten with an oversized backpack engulfing his body; petting the barn kittens at the local stable where we participated in equine therapy, and yes, even doing CrossFit with me with his styrofoam barbell and kettlebell I was so eager to get for him.

Thanks to these mothers and DSAF, I learned about the unconditional love Hank would show the world. I very easily connected with his soul – he would come and hold my hand during acupuncture sessions, or sit next to me on the mountains I would visit during my meditations where I would scream out my pain and desperation. I loved to dance with him in my belly to the most ridiculous songs (e.g., Pennies from Heaven, Run-Around Sue), and loved to feel him flip and turn and kick during my many work meetings, sitting there with a ridiculous grin on my face not hardly paying attention.


Lyndsie Koon works as an assistant research professor at Univ of Kansas in the Research and Training Center on Independent Living (RTC/IL) in the Life Span institute. Her PhD focus was Social Psychology of Sport and Physical Activity from the University of Northern Colorado. Lyndie holds a CrossFit Level 1 and Adaptive and Inclusive Training Certification (through the Adaptive Training Academy; ata.fit)

In the end, the doctor's all got to put a feather in their cap, and I lost my son. We were just shy of 24 weeks when I learned Hank no longer had a heartbeat. He survived almost 7 weeks longer than any doctor thought he would. I came back to Lincoln and was fortunate enough to have the help and support of Nikki, and the care of Dr. Kenney. After three days of trying to induce me with no luck, they took him with a c-section. I held my dead son for 3 days in that hospital, and now live in the eternal hell that is losing a child.

From there, I was quickly handed my hat and coat by many of the other Down syndrome community's that had welcomed me in. I admit it was an incredibly difficult and lonely place to be, ushered into such a beautiful club that you're not even sure you want to be a part of, and then just as quickly shown the door once you no longer hold the magic key. Except DSAF… fresh out of the hospital, Jamie met with me personally, and she reassured me I could still be involved with DSAF and serve the community as much, or as little, as I wanted. Nikki continued to check in with me, and quite frankly I was never once handed my hat.

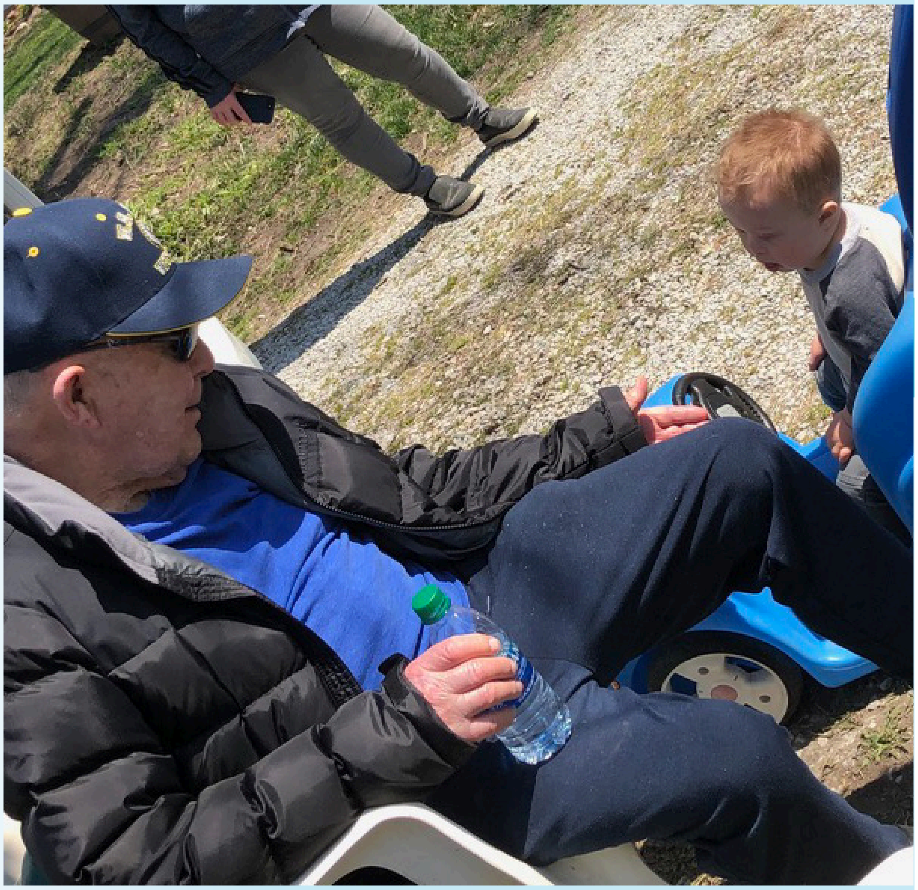
I've since learned there are many "still" mothers like myself, confused as to what their place is with the community after their loss. While there aren't solid statistics on the viability of T21 pregnancies, it is estimated that roughly 50% do not make it. I would have given anything to have given my son a shot at life – extra chromosome and all. The gratitude that I have for DSAF and those that allowed me to stay involved is overwhelming, and something I can never fully repay. I remember volunteering in October 2021 for the Ds walk, and absolutely swallowing the lump in my throat through my cheers for these amazing kids, young adults, and families as they proudly walked by with their signs and banners. When Nikki and Libby walked by, I waved and cheered loudly for Libby. Her little heart must have known how much mine was breaking, and she wiggled out of her Mother's arms and ran over to give me a hug. I had never met Libby before that day, but she unknowingly gave me a piece of my heart back with that hug.

in loving memory of

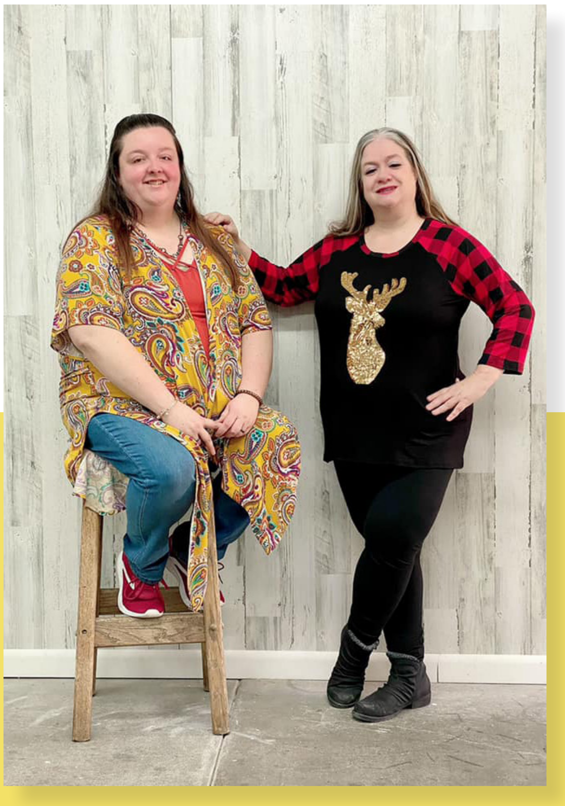
louis michael barry

September 14, 1937 - March 20, 2022

Louis Barry requested that memorial gifts be sent to the Down Syndrome Association for Families in his honor. Louis was committed to making a difference in the lives of people with Down syndrome, especially for his great grandson, Briggs Gushard. Our hearts go out to the family and friends of Louis Barry. May we always honor his memory in the work we do for those with Down syndrome.



RISE N SHINE
BOUTIQUE



Natasha Dobbins, owner of Rise N Shine Boutique, located at 2719 N 48th street in Lincoln, has been a member of DSAF for over a decade. She & her husband, James, are the proud parents of two children, Asher, 19, & Jim, 12. Natasha opened her boutique in October of 2020, and has been living out her dream and passion as a local business owner. Rise N Shine Boutique carries clothing and accessories in sizes from small to 3XL, in addition to an assortment of other goods. Whether you're shopping for yourself or checking off items for special events for friends and family, Rise N Shine has you covered! From poured wax melts & candles to self defense items, you can shop in person or online at www.risenshineboutique.com.

ANNUAL REPORT

the many faces of DSAF

- 170 Individuals with Down syndrome served
- 9 Board Members, 2 Mentors
- 1 Executive Director, 1 Marketing Communications Specialist
- Approximately 37 babies were born with DS in Nebraska
- 1800+ Community Allies receive communication from DSAF

education, advocacy, & engagement

- 577 Registrants & Attendees benefited from 44 Member Events
- Step Up Walk: 55 teams, 867 Participants, & raised $70,000+
- Over 2000 Followers & Supporters
- Introduced new Health & Wellness Program, called HIFT, for Members

Sponsors

TODAY'S BEST COUNTRY FROGGY 98
LINCOLN COMMUNITY FOUNDATION
IMAGES FOR A LIFETIME
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COMPLETE CHILDREN'S HEALTH
Morningstar Counseling
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List of Board Members

- Nikki Hobelman, President, *RN, Bryan Health*
- Liz Echternkamp, Past President, *Hamlow Elementary School*
- DEan Fuelberth, Project Manager, *Ameritas*
- Tami Urwin, Treasurer, *FACTS*
- Brandi Benson, *Lincoln Southwest High School*
- Rick Bohaty, *CHI Health St. Elizabeth's*
- Rick Meyer, *Pinnacle Wealth Management*
- Susan Loveall, *University of Nebraska-Lincoln*
- Dexter Drbal, Self-Advocate, *Sonic*
- Jarrod Rosbert, Self-Advocate Mentor
- Bailey Snow, Self-Advocate Mentor

List of Staff Members

- Jamie Rejda, *Executive Director*
- Shauna Contouis, *Marketing Communications Specialist*

2021 MEDICAL OUTREACH STATISTICS

OFFICE VISITS
(3 VISITS EACH)

56
PHYSICIANS
(18 OFFICES)

2
2 NICUS
(NURSES, SOCIAL WORKERS)

2
2 LABOR & DELIVERY
&
1 BIRTH PLACE

NEW DIAGNOSES

10
7 PRENATAL
&
3 BIRTH

3
SPANISH
SPEAKING

REFERRAL RESOURCES

3
BYRAN
MFM

3
SOCIAL
WORKERS

4
DIRECT CONCACT
(EMAIL, PHONE, FACEBOOK)

Down Syndrome Association for Families of Nebraska
P.O. Box 57362
Lincoln, NE 68505

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Educational Series are offered the third Tuesday of each month. HIFT are scheduled every Saturday of each month and are limited to the first 15 registrants. Visit* ***www.dsafnebraska.org/Events* *for additional information.*

upcoming events

may

21: **DSAF goes to the Children's Museum!**
26: **GIVE TO LINCOLN DAY**

june

5: **"Let's Explore" @ My Gym**
18: **ONE Coalition Swim Night**

july

23: **"Lucky Strokes" Golf Tournament**
30: **Family Picnic/Swim Event**

october

1: **Step Up for Down Syndrome Walk**
8: **Market to Market Relay Race**
15: **Pumpkin Patch**
30: **Trunk or Treat**

thank you mission partners!

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LINCOLN COMMUNITY FOUNDATION
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Pediatrics, P.C. Infancy through Adolescence
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