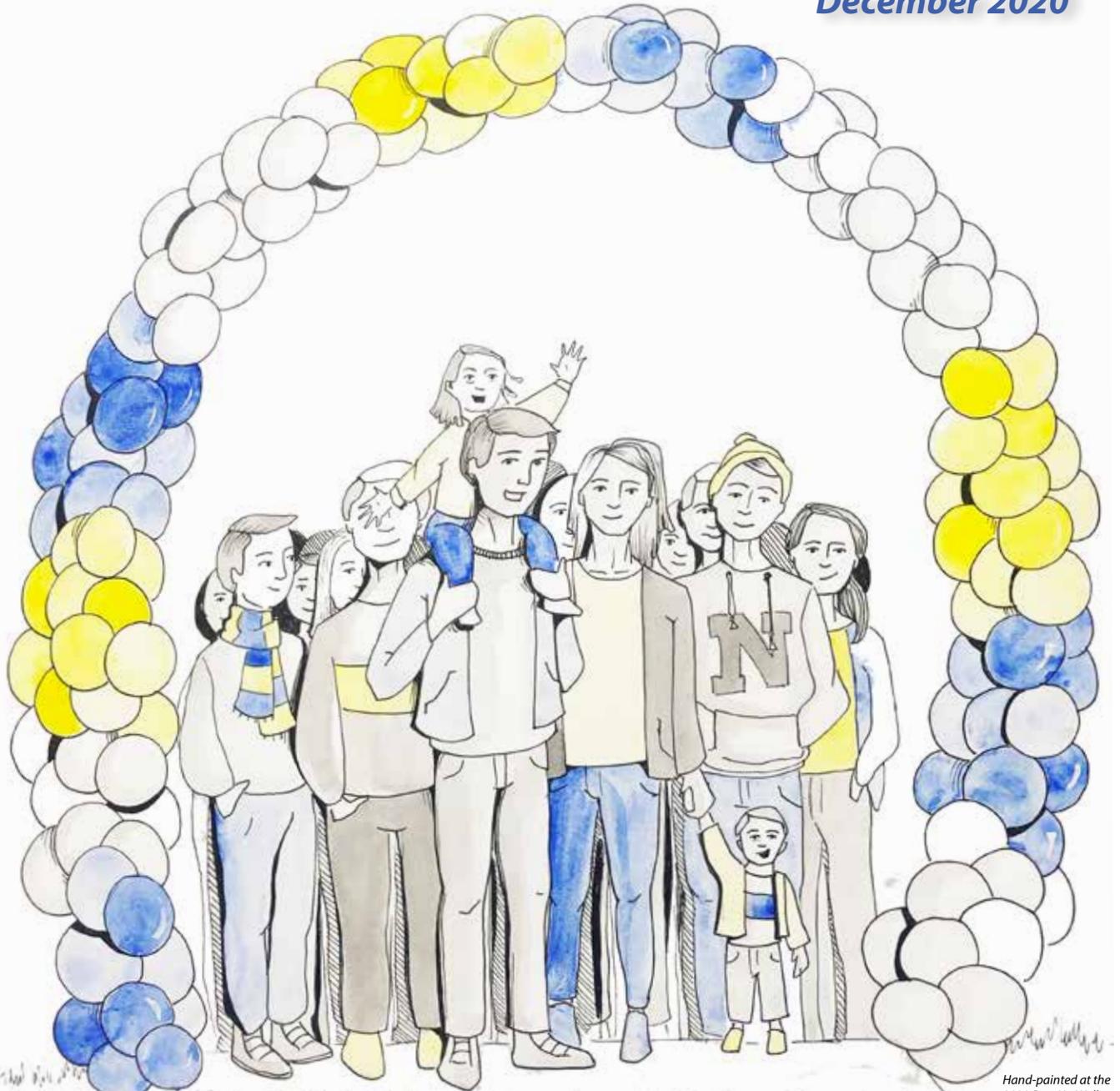


# down syndrome

community connections

December 2020



NOTHING DOWN ABOUT IT!

OCTOBER 10, 2020

Hand-painted at the  
2020 Step Up Walk  
by Annie Timmerman

thank you!

# president letter

happy holidays

It's nearly Thanksgiving – and boy do we ever have a year to be thankful for. Yes – I did say we have a year to be THANKFUL for! I know, it's hard with all the twists and turns this year has taken us on not to look back and say, "What The---?!" But the saying is true, "Hope Floats." And with that hope always in the back of our minds – we pushed through the changes that COVID forced upon us because, like Mary Sweeney wrote in our May issue, #COVIDCan'tStopGood.

We connected with members in an entirely new way from their homes bringing them educational resources and bonding opportunities via Zoom. Medical outreach supported new families with masks on outdoors in parking lots. We pivoted in a moment's

notice and put on the first-ever Virtual World Down Syndrome Day celebration. Plan A, B, C, and D were ready and waiting for this year's Step Up for Down Syndrome Walk but yet we STILL managed to have more people registered, more awareness spread, more donations made, and the same amount of teams as last year – all during a year we were projecting a 20% decrease all across the board.

So yeah...it hasn't been a year that has always been easy. Lord knows how many tears I've cried behind closed doors! But it has been a year to be thankful for.

And it's all because of YOU. You the person with Down syndrome. You the

parent, sibling, grandparent. You the friend, the sponsor, the donor. You helped make all of this possible. And for that, we say THANK YOU. Have a happy Thanksgiving and a wonderful holiday season.

Happy Holidays,

*Liz Echternkamp*

Liz Echternkamp

P.S. Please remember DSAF as you make your year-end contributions this Giving Tuesday (December 1).

[dsafnebraska.org/donate](https://dsafnebraska.org/donate)

It's not every day you walk up to a potential sponsor to ask for their support and they agree a split second later without batting an eye. But that's exactly how the relationship started with Rock n Joe Coffee Bar when DSAF Marketing and Development Director, Mary Sweeney, approached them two years ago.

Located at 5025 Lindberg St. in Lincoln, this incredible company imbues the spirit of what a DSAF Mission Partner is all about. Not only have they donated the coffee and hot chocolate to the Step Up for Down Syndrome Walk the past two years, they have provided a beautiful space for DSAF to hold its Educational Series and Executive Team meetings and allowed the organization to display Down Syndrome Fact Posters to help spread awareness.

Most recently, though, they hosted the first ever, Round Up for Down Syndrome campaign, inviting all patrons to round their total up to the nearest dollar and donate their "spare change" to DSAF. Through their leadership, and the community's support, Rock n Joe proudly delivered a \$1,520 donation check to the Step Up for Down Syndrome Walk.

Thank you, Rock n Joe, for being an outstanding Mission Partner and supporting all our friends and loved ones with Down syndrome.



# 4 babies & 4 moms

What happens when four moms all living in or around Lincoln join #TheLuckyFew club within one year of each other – obviously, they become fast friends! Not just because they all have boys (and between the four of them their names are Jessica and Jennifer!), but because when you find out your child has Down syndrome, you begin a journey that only other moms and dads on the same journey can truly understand. It's a journey that often starts out with broken hearts and broken dreams, but it leads the traveler to encounter the beauty, the joy, and the purity of the love that is found when you are gifted with a child with Down syndrome. So what is it exactly that they love so much about their boys? Well...I'll let them tell you.

## JESSICA GUSHARD Mom of Briggs

We love how strong Briggs has been through his health journey since birth. He teaches us daily lessons and has slowed life down in the best way for our whole family. He guarantees a smile and warm heart when you are around him.

## JESSICA JOHNSON Mom of Jase

What has surprised us most is the determination he has. He wants to be just like everyone else, doing what every other toddler does. He has the strongest love I have encountered in a human being.

## JENNIFER SUEHL Mom of Patrick

My biggest (best) surprise is that Patrick has the purest love and brings everyone he meets so much joy! He has quite the personality and loves to laugh and make people laugh. I love all my blessings from God, but Patrick has been our sweetest gift yet!

## JENNIFER VANCURA Mom of Camden

With a prenatal diagnosis, we had many preconceived notions about what our life may look like, and the outlook was not all positive. Wow, were we wrong! Camden continues to surprise us with his evolving, fun personality.... He is not special because of his diagnosis; he is special because he is Camden.



Pictured left to right: Jennifer Suehl and Patrick, Jessica Gushard and Briggs, Jessica Johnson and Jase, Jennifer Vancura and Camden.

"He has the strongest love I have encountered in a human being."

Whatever journey you are on in life, I think everyone can agree – especially during these trying times with COVID – that having others to walk the path with you, to cheer when you are cheering, and cry when you need to cry – those are the friends who last a lifetime. And that's what this group of moms realized early on. That's what's so great about being a part of #TheLuckyFew.



New parents or family members of someone with Down syndrome can find helpful resources at [dsafnebraska.org/newparents](https://dsafnebraska.org/newparents). Make connections to other families by requesting to join the DSAF private Facebook group at [facebook.com/groups/dsafnebraska](https://facebook.com/groups/dsafnebraska).



# NIAH'S ROAR

*interview paraphrased by mary sweeney*

Let me tell you the story about Niah Rief. The little lioness who ROARs, without uttering a sound.

Niah Sienna Rief is a 13-year-old Lincoln, Nebraska, gal who loves everything about boating – family time, riding in the boat, watching people in the water, and tubing with her brother, Cohen. She loves swinging, watermelon, listening to music and absolutely adores Christmas. Although she's a "love being NEAR the action, but not IN the action gal," she's the happiest being surrounded by family and LOVE.

Niah's journey started like many of our families do here at DSAF. A prenatal test confirmed a diagnosis of Down syndrome, which led to a doctor referring Niah's parents, Gary and Renae, to DSAF and the family then being enveloped in a community of support and education. The little lioness progressed gaining strength and words while experiencing many of the same

developmental delays consistent to Down syndrome.

Where Niah's journey takes a different turn, though, is at the age of six when she started to regress. Things that came easily before, like singing the alphabet or playing with others, were now a struggle.

Niah's mother, Renae, said, "I knew in my gut there was probably something going on. She started being very quiet and the words just went away. She would stare off in the distance...."

Through many months of appointments with a variety of specialists, it was finally confirmed that Niah Sienna Rief had a co-occurrence of Down syndrome and Autism Spectrum Disorder, or DS-ASD.

So how does this happen? According to the nonprofit, Down Syndrome-Autism Connection, "Down syndrome and

autism are both equal opportunity conditions– meaning that anyone, anywhere, regardless of race, creed or socio-economic status, can have a child with either condition. It is believed that up to 18%...of individuals with Down syndrome also have autism spectrum disorder."

Mom Renae remembers, "going to the DS Conferences after Niah had begun to regress and not feeling like we fit in... to be honest it was probably a larger blow to our system to have the added ASD diagnosis." A common sentiment among those families with a child who has DS-ASD. Renae shared that they understood what the future would look like for Niah having Down syndrome, but ASD was completely new to them. It required a great deal of planning and flexibility.

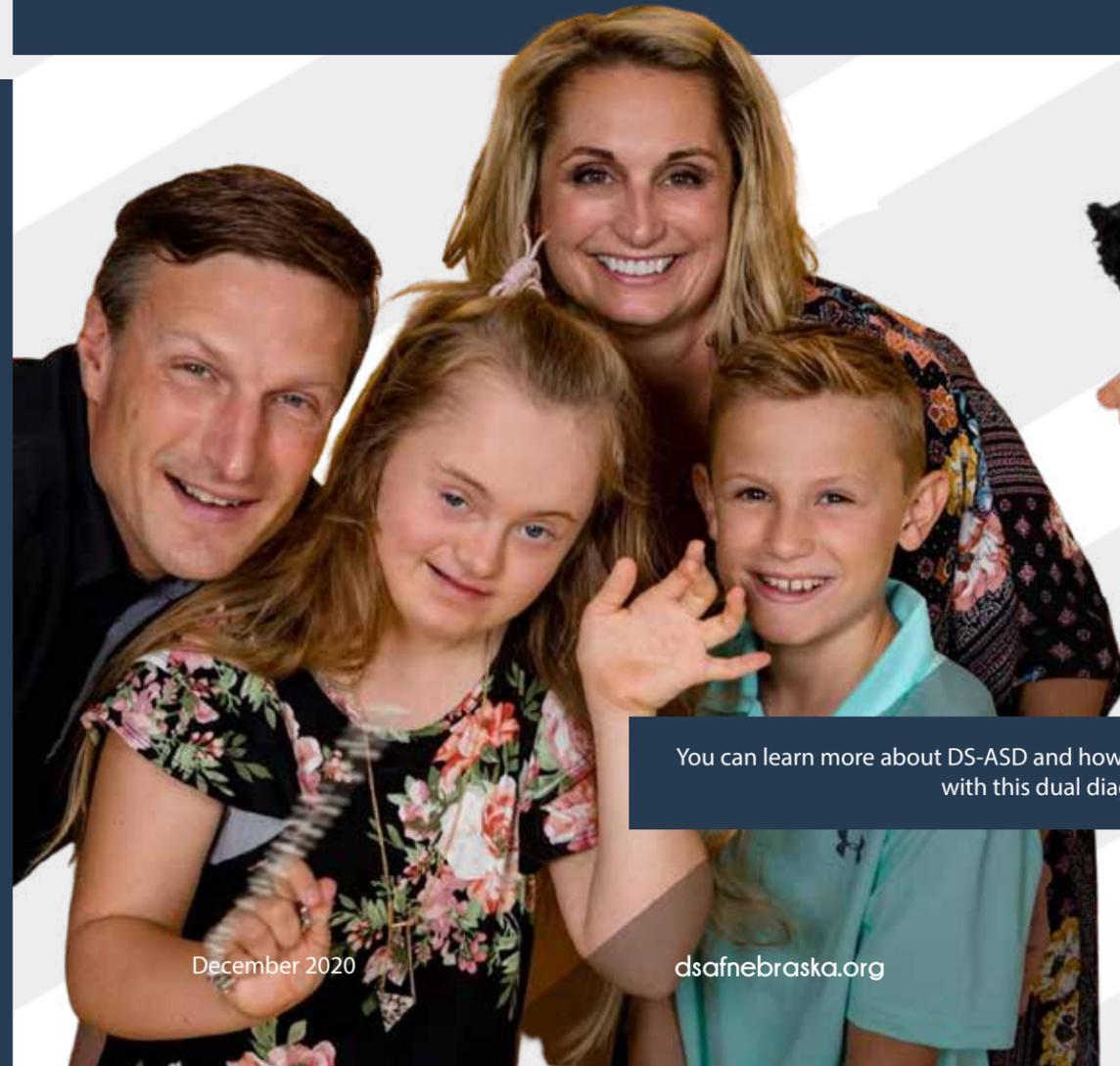
As time passed and the family learned to navigate their new normal with Niah, they wanted a Step Up for Down Syndrome Walk team name that encompassed the ever-evolving girl Niah was becoming. With the help of her friends, they nailed it with "Niah's ROAR: Reaching Out for Acceptance Rocks." Renae shared, "it was the perfect combination of Niah's love for music, a bit of irony for Niah's non-traditional communication style, and totally on target for the essence of advocacy and awareness of the DS Walk."

So, what does Niah's ROAR sound like? Well, for this little lioness who prefers to use few words, it is a resounding cry for inclusion. It is noticing Niah and asking her to join, even if she chooses not to. She remembers the connections she makes and the trust she has with each person grows. It means that some of her tendencies might not make sense (swaying, unusual sounds, using a fidget spinner). Accept it. Accept the beauty of her differences. Accept Niah Sienna.

As I write this article and Inclusive Schools Week (December 7-11) is on the horizon, I am struck by the fact that Niah's ROAR shouldn't apply to just Niah. But we should all adopt her motto and the ROAR within each of us. Because Reaching Out for Acceptance really does Rock!

Renae shared that "in a moment of weakness some time ago I thought out loud that I just wanted [Niah] to blend in. Cohen was quick to note, 'Niah was born to stand out.' He is right, she was. Hopefully Niah inspires others to change how they think about DS-ASD and show kindness towards those who are different."

To read the full interview, visit [dsafnebraska.org/blog](https://dsafnebraska.org/blog).



You can learn more about DS-ASD and how to support families raising a child with this dual diagnosis at [ds-asd-connection.org](https://ds-asd-connection.org).

# 2020 – A Walk to Remember

families & friends walk to spread love and awareness despite pandemic  
*story by mckenna deriese & milana doné*

2020 has been a year of change. Things that were once taken for granted are now no longer, or have significantly changed. So that's why on the morning of Saturday, October 10, it felt a bit like being reconnected with an old friend when over 800 masked attendees came to Lancaster Event Center to enjoy the 19th annual Step Up for Down Syndrome Walk. Although it looked a little different (what with a new venue, new time, and pretty much new everything!), nearly 60 teams participated, both in-person and virtually, to show their support, spread awareness, and help raise funds for DSAF, an organization that assists people with Down syndrome all throughout Nebraska.

As this article is being written, \$98,225 in monetary donations has been raised (the most ever in DSAF-history) and more keeps trickling in. Combine that with the value of in-kind donations from donors and sponsors like you, and you have a total well over \$100,000 raised to support all our friends and loved ones with Down syndrome.

So why so much support in a year where nonprofits were told to expect a 20% loss all across the board? Well, for those who are not as familiar with the Walk, each team is made up of family and friends supporting an individual with Down syndrome. Teams spread awareness by telling the story of their child or loved one with Down syndrome and help raise money for DSAF prior to the walk. Wendy Leach worked to raise money in support of her daughter's team, Zoey's Party. "The money that we raise supports the activities our children and other individuals with Down Syndrome get to do," Leach said. "People with Down syndrome are a person first. They're so much more alike to everyone else than they are different."

Tyler Borcyk and his family walked to reconnect with the DSAF community, raise awareness, and support his son, Joseph. "[Joseph] can do what everyone else can do; it just takes a little bit longer. We love that DSAF has resources to help network and to connect with services we can use," Borcyk said. "Lately, it's been more difficult to do events with the group, so it's great to be reminded today that there's so many other people out there that are in the same walk of life."



Tyler Borcyk and son, Joseph, walk for Jammin' with Joseph at the 2020 Step Up for Down Syndrome Walk at the Lancaster County Event Center. Over \$100,000 was raised to support friends and loved ones with Down syndrome.

Kris Turner attended the Step Up Walk to support his young daughter, Phoebe, and her team. "In 2016, we hosted [Phoebe] over the holidays. Then we decided to adopt her, and she fit really well," Turner said. "It means a lot to still be able to represent and contribute to causes like this, especially during this more isolated time."

DSAF didn't experience a loss because love and community prevailed. Whether it's at the time of diagnosis or when our world is turned upside down, you show up. THANK YOU!

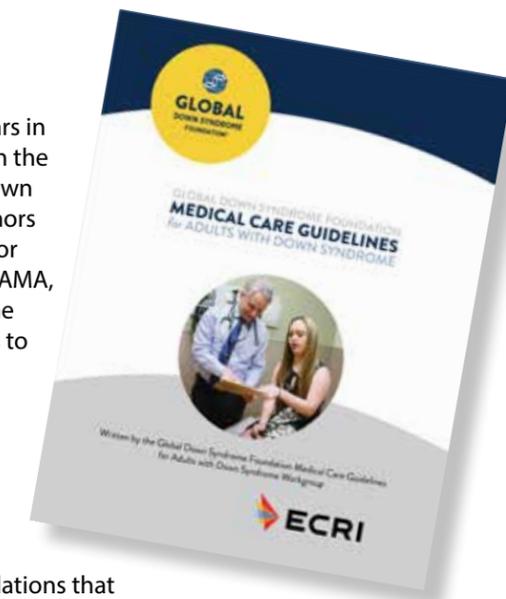
So although the Coronavirus may have prevented some events from happening these last several months, this walk has proved what everyone already knew: this community is strong enough to get through anything, even a global pandemic. Because, remember? #COVIDCan'tStopGood.

**DSAF is a proud supporter of the 1st Evidence-based GLOBAL Medical Care Guidelines for Adults with Down Syndrome®.**

The lifespan of people with Down syndrome has increased from an average of 28 years in the 1980s to 60 years today. However, research and medical care has not kept up with the large number of people with Down syndrome who are living well into adulthood. Down Syndrome Association for Families of Nebraska is proud to share that, because of donors like you, we are addressing this by supporting the GLOBAL Medical Care Guidelines for Adults with Down syndrome® that were published in the October 20, 2020 Issue of JAMA, the Journal of the American Medical Association. Publication in JAMA underscores the quality of the Global Guideline and ensures that clinicians across the U.S. have access to this important resource.

The Global Guideline is for clinicians and addresses nine medical areas: Behavioral Health, Dementia, Diabetes, Cardiovascular Disease, Obesity, Atlantoaxial Instability, Osteoporosis, Thyroid, and Celiac Disease. It is made up of 14 recommendations and 4 statements of good practice. Some of the recommendations align with existing guidelines in individuals without Down syndrome, and two are markedly different. There were several questions associated with the recommendations that had no published research evidence, and therefore were answered based on the clinical expertise of the authors.

DSAF is grateful to GLOBAL for leading this difficult and important initiative and we encourage our families and supporters to use the Global Guideline in ensuring better health outcomes for our adults with Down syndrome. Learn more at [globaldownsyndrome.org/global-adult-guidelines](http://globaldownsyndrome.org/global-adult-guidelines).



Contributions from donors like you make it possible for DSAF to support national medical efforts like the Global Guidelines. To make your year-end contribution, visit [dsafnebraska.org/donate](http://dsafnebraska.org/donate).

## Coming Soon! Inclusive Schools Week

### What is it?

Inclusive Schools Weeks celebrates the progress that schools have made in providing a supportive and quality education to an increasingly diverse student population

### When is it?

December 7-11, 2020

### How to Celebrate?

Nominate an "Inclusivity Hero" in your life for them to receive special recognition and gift card to Rock n Joe's (up to 2 per family).

[dsafnebraska.org/events](http://dsafnebraska.org/events)



**Please Note:** As COVID-19 makes each day a little uncertain, be sure to visit the DSAF Facebook page for the latest event information or check online at [dsafnebraska.org/events](https://dsafnebraska.org/events).

## upcoming events

### december

- 1: Giving Tuesday!
- 2: Young Adult Stars Virtual "Chopped" Cooking Competition
- 7-11: Inclusive Schools Week
- 11: Super Stars Gingerbread House Decorating Challenge
- 12: Drive-Thru Holiday Party with Santa
- 15: Lil' Stars Story and Craft Night  
Enable Savings Plan- Why and How to Set It Up

### january

- 14: Mom's Night Out: Meal Prep at Hy-Vee
- 19: Young Adult Stars Virtual Yoga

### february

- 15: DSAF Ed Series: Dental Care for the Down Syndrome Family
- TBD: Young Adult Stars Drive-Thru Valentine's Event

### march

- 15: DSAF Ed Series: Developing Reading and Literacy Skills with the Down Syndrome Population
- 21: World Down Syndrome Day



# DRIVE-THRU HOLIDAY PARTY WITH SANTA

**WHAT:** Meet Santa from the safety of your car! His sleigh will be packed with donuts, coffee, hot chocolate, holiday cookie decorating kits, and gift bags for each child!

**WHEN:** Saturday, December 12 - 10:00am-11:30am

**WHERE:** Dental Designs - 3580 Union Dr. (Next to Region V-Behind Williamsburg Hy-Vee)

**RESERVE YOUR SPOT:** [dsafnebraska.org/events](https://dsafnebraska.org/events)


  
 down syndrome association for families of nebraska  
 dsafnebraska.org

## 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.

