

DOWN SYNDROME

community connections

December 2024



UNWRAP

*a new year with
more adventures*

INCLUDE PROJECT

*the future of
people with Down
syndrome*

*Melissa, & Kurt Kolm with their daughter,
Hadley, joined Santa (Charles Isom with
Enable Savings Account) at the Holiday
Brunch on December 7th*



down
syndrome
association
for
families
of nebraska
dsafnebraska.org



MORE OF THE THINGS WE LOVE COMING IN 2025



Cooking Classes will be held twice a month for teens and adults starting in January. Please register in advance!



Down to Box with Farrell's is changing things up in 2025! Classes will be held on a weekly basis and fees are charged per class versus 8-week sessions.



In 2025, we will continue to serve the CrossFit for Adaptive Athletes program by supporting Lincoln Nutrition & Fitness for additional coach training, athlete fees, and the annual CrossFit competition. Classes are every Saturday.



MARK YOUR CALENDARS

BOOK CLUB



New session starts Thursday, January 9th. DSAF/UNL Young Adult Book Club is a reading group, composed of DSAF members and UNL staff & students, who read and discuss topics related to the books. This formal club meets weekly during the three sessions offered over the course of the year



Red design available in a t-shirt & hoodie style

Black WDS design available in long-sleeve & sweatshirt



design on back



FRIDAY, MARCH 21, 2025

WORLD DOWN SYNDROME DAY 2025

CELEBRATION

5:30 PM TO 8:30 PM

KARAOKE FOOD GAMES FACE PAINTING BALLOON ANIMALS

CITY IMPACT, 1035 N 33RD ST,
LINCOLN, NE 68503

A POWERFUL DAY by DEan Fuelberth



Global Down Syndrome Foundation fly-in group, consisting of 150 advocates and supporters on Capitol Hill

Elissa, Brenda Kasaty, and I had the honor of representing DSAF in Washington, D.C. We joined five others from Nebraska and individuals from 24 other states for a record-breaking fly-in organized by the Global Down Syndrome Foundation. Our mission was to advocate for the DeOndra Dixon INCLUDE Project Act, which aims to secure funding for Down syndrome research and medical care at the National Institutes of Health (NIH).

During our time on Capitol Hill, we were among 150 global self-advocates, family members, and researchers, as well as celebrities like Jamie Foxx, John C. McGinley, and Caterina Scorsone. Together, we filled the halls of Congress, meeting with Senators to urge them to co-sponsor the bill and to vote in favor. Despite being the most commonly occurring genetic condition, Down syndrome has received the least funding from the National Institutes of Health.



Nebraska delegation meeting in the Senate office building



Brenda Kasaty, DEan Fuelberth, actress and self-advocate Madison Tevlin, and Elissa Fuelberth

DeOndra Dixon INCLUDE Project Act



Elissa connecting with actress Caterina Scorsone (from Grey's Anatomy)

This congressional briefing aimed to inform Congress about the need to pass the DeOndra Dixon INCLUDE Project Act of 2024 by the end of December. This legislation would authorize the National Institutes of Health's INCLUDE Project, launched in June 2018 to address the health and quality-of-life needs of individuals with Down syndrome. Initiated by GLOBAL in 2006, advocacy for a trans-NIH funding program led to the first congressional hearing on Down syndrome, aimed at accelerating scientific discoveries.

During the briefing, the panel highlighted the importance of: (1) including people with Down syndrome in research, (2) advancing innovative science through the INCLUDE Project, and (3) ensuring successful clinical trials with thoughtful planning and support.



Jamie Foxx speaking at the historic Congressional Briefing

The INCLUDE Project supports research into therapies for Alzheimer's disease, cancer, and other significant conditions, such as autoimmune disorders and diabetes. INCLUDE also aims to increase the number of clinical trials for individuals with Down syndrome. Before this initiative, only two such trials existed; now, there are thirteen, thanks to better planning and support facilitating participant adherence.

The DeOndra Dixon INCLUDE Project Act, named in memory of GLOBAL's beloved Ambassador and Jamie Foxx's younger sister, DeOndra Dixon, will authorize Down syndrome research funding to elongate life and improve health outcomes for people with Down syndrome

For more information, please visit www.globaldownsyndrome.org/



Warmest Wishes

TO OLD FRIENDS & NEW



The annual Holiday Brunch was hosted by DSAF at Firespring on Saturday, December 7th. Members enjoyed a catered breakfast by Doorstep Diner, a visit from Santa, presented by Charles Isom with Enable Savings Plan. coffee and hot chocolate, donated by Rock'n'Joe Coffee, and support from our gracious volunteers. Thanks to Firespring, Charles Isom, and Rock'n'Joe for your generous donations to our Holiday Brunch!





Upcoming EVENTS

January

- 4: CrossFit for Adaptive Athletes
- 4: Down to Box
- 11: CrossFit for Adaptive Athletes
- 11: Down To Box
- 18: CrossFit for Adaptive Athletes
- 18: Down to Box
- 25: CrossFit for

February

- 1: CrossFit for Adaptive Athletes
- 1: Down to Box
- 7: ONE Coalition Valentine's Dance
- 8: CrossFit for Adaptive Athletes
- 8: Down To Box
- 15: CrossFit for Adaptive Athletes
- 15: Down to Box
- 22: CrossFit for Adaptive Athletes
- 22: Down to Box

March

- 1: CrossFit for Adaptive Athletes
- 1: Down to Box
- 8: CrossFit for Adaptive Athletes
- 8: Down To Box
- 15: CrossFit for Adaptive Athletes
- 15: Down to Box
- 21: World Down Syndrome Day
- 21: Lancers Hockey Night for Down Syndrome Awareness with DSAF
- 22: CrossFit for Adaptive Athletes
- 22: Down to Box
- 29: CrossFit for Adaptive Athletes
- 29: Down to Box



Information & registration details available on the DSAF website

www.dsafnebraska.org

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★ ★ ★ Families of Nebraska
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