



# NATIONAL FRAGILE X FOUNDATION HEARTLAND CHAPTER

## IOWA • SOUTH DAKOTA

[www.heartlandfragilexalliance.org](http://www.heartlandfragilexalliance.org); [heartland@fragilex.org](mailto:heartland@fragilex.org)

Find us on Facebook

National Fragile X Foundation, Heartland Chapter—Iowa and South Dakota

### **MAY 2019 NEWSLETTER**

**Print this flier to bring with you.**

**Send to your friends in the  
Boone/Ogden/Ames, Iowa area!**

**Group Name:**

NFXF, Heartland Chapter—Iowa and South Dakota

**Date:**

Monday, May 20

**Pizza Ranch Location:**

1703 South Story St, Boone, IA



5PM to 9PM

**Turn this slip in and the group  
will receive \$2.00 per adult buffet  
purchased from Pizza Ranch.**

**Thanks to Angie Bacon and her friends and family  
for hosting this event!**

<https://www.facebook.com/events/334949043828205/>

**SHARE ON YOUR SOCIAL MEDIA!!**



## **SAVE THE DATE!** **FRAGILE X AND AUTISM** **EDUCATIONAL CONFERENCE**

**Saturday, August 17**  
**DMACC Campus in West Des Moines, IA**

*featured speaker:*

**Dr Marcia Braden, Ph.D., P.C.**

Dr Braden is a licensed psychologist with a clinical practice specializing in children and adolescents. She has written and published numerous articles related to education and behavior management strategies, techniques, and interventions.

**<https://www.facebook.com/events/345310699671515/>**

I've been busy gathering email addresses for various agencies, medical professionals and educational professional in Nebraska, Iowa and South Dakota. I am also contacting many autism groups within those states. I'm working on getting CEUs for Social Work and Behavioral Science. As soon as that is pinned down, I'll be sending a 'save the date' message to all, hopefully next week.

**If there is anyone you want me to include, please respond with their email, phone number, town, name and name of the organization.** I'm creating a master list for future conferences.

As of this writing, we'll start at 8:30am and end at 4pm.

**DRURY**  
**HOTELS.**

**We have rooms reserved at**  
**Drury Inn & Suites West Des Moines**  
**5505 Mills Civic Parkway, West Des Moines, IA 50266**

Rooms with king beds are \$140 per night. Rooms with double queen beds are \$150 per night; up to 4 guests per room.

**Group room rates include the following for overnight guests:**

**Free Hot Breakfast** - Start every day with make-your-own Belgian waffles, scrambled eggs, sausage, fresh fruit, oatmeal, biscuits and gravy, KELSO+BROS® coffee and more. Free hot breakfast is served daily from 6–9:30 a.m. on weekdays and 7–10 a.m. on weekends.

**Free Evening Drinks and Snacks\*** - Join us from 5:30–7 p.m. every evening to enjoy free hot food and cold beverages at our 5:30 Kickback®. We feature a rotating menu of hot food, beer, wine, mixed drinks and soft drinks.

**Free Wi-Fi Throughout the Hotel** - Get the score, check your social networks or email family members from anywhere in the hotel – for free!

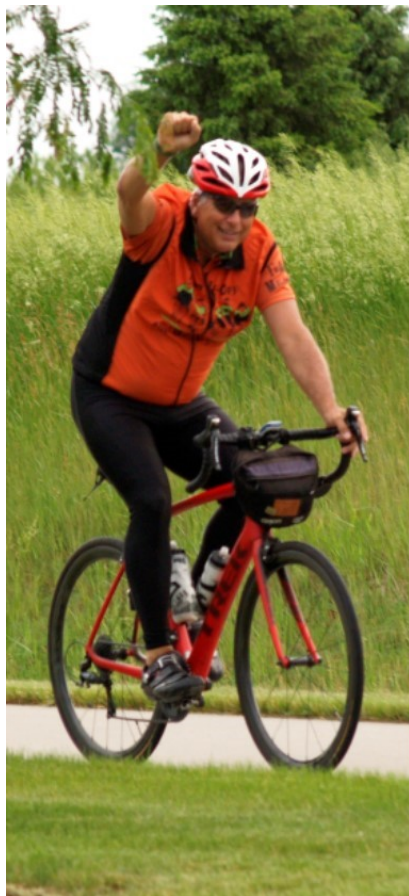
**Free Soft Drinks and Popcorn** - Complimentary freshly-popped popcorn and a refreshing beverage are available each evening for a great nighttime snack!

**On-Site Facilities** - Take advantage of the business center, fitness center or pool while you're away from home. Print your boarding pass, finish a presentation or check e-mail in our business centers.

**RESERVATIONS** [www.druryhotels.com](http://www.druryhotels.com) OR 1-800-325-0720

**Refer to group number 2371195.**

Individual reservations must be cancelled prior to 12:00 p.m. on the confirmed date of arrival in order to avoid a non-refundable fee equal to one night's room rate plus tax. Reservations by attendees must be received on or before **Monday, July 15, 2019**



**Join the fun on  
June 1st**

**YOU COULD WIN!**

**Top individual fundraiser**

wins \$100 Gift Card to  
Mistress Brewing Co in Ankeny  
and a \$50 Gift Card to  
Northern Lights Pizza Co!

**Register Today!**



**Start your own fundraiser!**

**You could win and have a party with friends in Ankeny, Iowa!**

Here's the link to the registration page.

**<https://give.fragilex.org/event/bike-to-x-out-fragile-x-2019/e219880>**

Donations are welcome. Tell your family and friends!

Even if you don't ride, please share our event on social media...you never know who'll see it! **<https://www.facebook.com/events/292061658335279/>**

**56 miles, Ankeny to Waukee** (and back)

It's all happening in Iowa



**Pizza Ranch Fundraiser  
Monday, May 20 • Boone, IA**

**RESTAURANT FUNDRAISERS IN THE WORKS**  
Dubuque, Waukee, Carroll, IA & Sioux Falls, SD



**Golf to X Out Fragile X  
Saturday, July 27 • Pocahontas, IA**



**XStrides • Ankeny, IA  
Saturday, September 28**  
We'd still like one in South Dakota!



# COMMUNITY IMPACT EVENTS

## Carroll Summer Fun Camp

An education-based summer day camp for elementary school children, with spaces reserved for children with autism-spectrum disorders in Carroll, IA.

This camp is a fun, safe, and structured 1/2 day summer program for your child that reinforces academics while encouraging character building, leadership skills, and physical activity. This education-based, fun summer day camp was designed by local parents for children **currently in preschool through sixth grade**.

The camp, led by experienced teachers, is designed to integrate children with an autism-spectrum diagnosis (ASD) into a population of typical peers (our goal is a ratio of one typical peers for every child with an ASD). The typical peers learn patience, compassion, and leadership, while the children with an ASD learn from daily social interactions with children their own age. All children participate daily in age-appropriate academic activities that prevent them from losing skills over the summer — and hopefully help them get ahead for the upcoming school year!

In addition to academics, all campers participate in arts activities (music, drama and visual arts) and engage in a fun physical activity that gets their bodies moving —gymnastics, outdoor games, dance, drama, sports, and more! Students will participate in field trips around the community as well.

***Kristen Lundstrom, parent of two FX boys, created this program when she and her husband, Joel relocated from the Kansas City area. If you'd like to look into starting something similar in your community, contact Kristen at [lundstrom.kristen@gmail.com](mailto:lundstrom.kristen@gmail.com). Check out their FB page: Carroll Summer Fun Camp.***



# RARE ACROSS AMERICA

EVERY VOICE, IN EVERY DISTRICT, MATTERS

## You can make a difference at home!

Take some time in the summer to meet with your representatives or their staff when they are in the state.

Under the Rare Across America program, RDLA staff organizes meetings for rare disease advocates with their Members of Congress and/or the Member's staff. The meetings take place in the Member's district office during the month of August, while Congress is in recess from July 29th to September 8th, 2019. The RDLA team also helps to prepare advocates for their meetings, providing legislative resource materials and Hosting pre-meeting training webinars. No prior advocacy experience is necessary.

**Advocates interested in participating should register between May 8th and July 3rd at [www.RareAcrossAmerica.org](http://www.RareAcrossAmerica.org).**

The first training webinar for registered advocates, entitled "What to Expect at Your Meetings," will be hosted on July 25th.

*This is the same organization that makes the appointments for NFXF for the national advocacy day. Last year, I had two in person meetings with another Rare Disease gentleman and one phone-in meeting. It didn't take much time! I'd encourage you to register and they will try to make an appointment with the congressperson when they are in your area.*

## HELP PUT A FACE ON FRAGILE X.

### FAMILY DAYS IN IOWA AND SOUTH DAKOTA

Contact Nancy, [heartland@fragilex.org](mailto:heartland@fragilex.org) if you are willing to help.

## FORWARD Registry & Database

Beginning in 2008 and continuing to the present, the U.S. Centers for Disease Control and Prevention has supported the Fragile X Clinical & Research Consortium (FXCRC) through grants designed to increase our understanding of Fragile X syndrome.

Studies of co-occurring conditions have typically focused on each condition alone by using cross-sectional data, without examining the associations with other features of FXS or without taking a systems approach. In order to conduct well-designed clinical trials that capture the entire spectrum of the disorder, the natural history of those with FXS needs to be determined. This is particularly true for adults with FXS, about whom almost nothing is known regarding life trajectory and medical complications.

**FORWARD—Fragile X Online Registry With Accessible Research Database**—was implemented in 2012 to fill the recognized gap in knowledge. FORWARD Registry & Database consists of a patient and family registry plus a longitudinal database populated by clinician- and parent-reported data from individuals living with FXS.

One of the best ways for families to help advance our understanding and to improve treatment is to become part of the FORWARD Registry & Database.

### FIND OUT MORE AT:

<https://fragilex.org/our-research/nfxf/forward-registry-database/>

## Need a FRAGILE X t-shirt?



Brenda Slama is taking orders until July 1 for this cool design.

**\$15** S, M, L, XL

**\$17** XXL, XXXL

Shipping is an additional \$5 for the first shirt, \$2 for each shirt after that.

Contact Brenda at  
**heartlandfxgolf@gmail**  
if you'd like one!

Nancy Carlson and Nicole Stribe spreading FX awareness at the Ask Resource 'Together We Can' conference in Des Moines.



We were able to sign up 26 people that wanted more information about our Fragile X and Autism Educational Conference with Dr Marcia Braden! Plus we visited the other vendors for information for our families. I was able to attend a session about MCOs and federal law. Anyone in Iowa knows it's been a struggle under the new managed care system!

**Do you have a disability or Autism fair that you'd like to have Fragile X represented at?**  
**LET US KNOW! WE CAN HELP!**

*(I will be showing the slide presentation at the conference.)*

**Next Conference Call: MONDAY, June 17 @ 8PM**  
**1-855-424-6066 access code is 88498**