



NATIONAL FRAGILE X FOUNDATION HEARTLAND CHAPTER

IOWA • SOUTH DAKOTA

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

MARCH 2019 NEWSLETTER



THE CAPITOL

If you were wondering what it's all about, here's a breakdown.

Nancy Carlson, Ankeny, Susan Brown, Waukee and Paul Mulhausen, Swisher, all from Iowa, traveled to Washington, DC on February 25 to give voice to those affected by Fragile X Syndrome.

The trip started with a 4 hour delay from Des Moines, but it all worked to good. Paul was seated on the flight across the aisle from newly elected Representative Cindy Axne. As our meeting was scheduled with her staff the next day, he grabbed the opportunity to education her about FXS and the issues.



We made it to the hotel a little after 2 and were able to participate in 1/2 of the training. For those that have

never attended, the National Fragile X Foundation is good at providing handouts on the issues or bills, so the training is really about telling your family's story. We then attended a reception with Dr Berry-Kravis speaking about the latest FX research.

The next morning it was off to the hill for a group photo and a full day of meetings. We were able to meet with staff in Senators Grassley and Ernst and Representatives Axne and Loeb's offices.



Unfortunately the weather was not so kind to those planning on attending from South Dakota, Michele & Jordan Burgers, so we dropped off information at their three congressional offices.

It was a whirlwind two days, but definitely worth the time.

We all would encourage you to consider attending in 2020.

YOUR VOICE DOES MATTER.

You can also take some time in the summer to meet with your representatives or their staff when they are in the state.

HELP PUT A FACE ON FRAGILE X.

If this is something you are interested in, please let us know so you can be contacted about summer appointments.

You can make a difference in DC and at home!



Ryan and Paul

experts on how to most effectively share our message – and we were effective! We met with friends and fellow families affected by FX, sharing stories of challenge and joy.

Our team met with our entire congressional delegation and educated each and every one of them about Fragile X Syndrome, its impact on the lives of our loved ones, and its impact on us! And, they listened to our stories. They learned about Fragile X. They learned about the people we love. They listened to the requests we had for research funding and legislation to make life better for people affected by Fragile X. And we had fun: sights to see, things to learn, messages to share, people to meet, and new food to explore.

A trip to NFXF's Advocacy Day is worth your while!

I encourage all of our families to work out an opportunity to participate in future NFXF Advocacy Days. The Heartland Chapter– Iowa and South Dakota can help you do it! Get connected, find the time, get involved, have an impact!

Paul Mulhausen, Swisher, IA

I've learned in church and in work events and in life – there's power in stories. Stories connect the “head” – the fact sheets, the statistics, the funding requests, the legislation – to the “heart” and leave a lasting impression. Sharing my story in a positive yet realistic manner, has been the best way I've found to advocate for my kids, myself, my family and all those affected by Fragile X. I wondered when I first attended Advocacy Day if the few minutes spent in each office made a difference – then was so pleased when Joni Ernst, Iowa Senator, already knew about Fragile X from previous Advocacy Day visitors. I never meet people that already know about Fragile X! I plan to continue attending this event, including my daughter as a self-advocate, which I think will be even more impactful.

I plan to continue attending this event, including my daughter as a self-advocate.

The advocacy experience is very cool – but honestly my favorite part is spending time with other families, comparing notes, getting new ideas, and coming together for a common purpose. Looking forward to future years and meeting new families!

Susan Brown, Waukee, IA

FRAGILE X NEWSLETTER
Up-to date information about events, advocacy and more

If you are not receiving emails from the National Fragile X Foundation, take a moment a sign-up at <https://fragilex.org/sign-up-newsletter/>

LEADERSHIP SUMMIT

Ever other year the National Fragile X Foundation hosts a summit for Chapter leaders. As a Chapter, one of our leaders is required to attend. Nancy Carlson will be attending the summit that is being held on April 4 & 5 in Orlando, FL. The Renaissance Marriott at Sea World is the location of the 2020 International Fragile X Conference and the summit!



Nancy Carlson, Jen Barber, Central CA and Missy Zolecki, NFXF Directory of Community Engagement in DC

Each summit is different, the Bike To X Out Fragile X ride came directly out of the first leadership summit that Nancy attended. The second summit resulted in the Heartland Fragile X Alliance becoming an official Chapter of the National Fragile X Foundation, hence the name change to Heartland Chapter—Iowa and South Dakota. We'll be discussing what she learns at the 2019 summit as part of the April conference call.

**Next Conference Call: MONDAY, April 15 @ 8PM
1-855-424-6066 access code is 88498**

COMMUNITY IMPACT EVENTS

What is Fragile X? I've never heard of Fragile X? He/she doesn't look disabled.

**If you are tired of these questions and comments,
here are 3 ways you can take action!**



HOST A FUNDRAISER. Not only can you raise funds to help the Chapter advocate and educate. You are raising the awareness level of Fragile X in your community. Get creative. Email us for ideas.



BE A PARTICIPANT AT A DISABILITY FAIR. The Chapter has set aside funds for you to have a table with information at a disability fair, conference or seminar. We have banners, brochures and business cards.



BECOME A PUBLIC SPEAKER. Speak up! Offer to speak in your children's classroom, not just the classroom your FMFX child is in. Contact your local service groups, like the Rotary and offer to speak at a meeting. We would be happy to help you with your presentation.

See the fact sheets attached to the email. Please feel free to use them at events and with your legislators.



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.



RESEARCH OPPORTUNITY

Why do some individuals with Fragile X syndrome have seizures and others don't? Researchers at Emory University are trying to answer this question, and you might be able to help. Researchers are looking for participants who have Fragile X

syndrome and have had at least one seizure OR adult males with Fragile X syndrome who have never had a seizure. Participation can take place through the mail and includes a DNA sample (saliva or blood) and parent-completed questionnaires.

Visit our website for more details and to contact the study coordinator.

<https://fragilex.org/opportunities-for-families/why-do-some-people-have-seizures-and-others-do-not/>

[utm_campaign=Research&utm_content=86477539&utm_medium=social&utm_source=facebook&hss_channel=fbp-126571939696](https://fragilex.org/opportunities-for-families/why-do-some-people-have-seizures-and-others-do-not/?utm_campaign=Research&utm_content=86477539&utm_medium=social&utm_source=facebook&hss_channel=fbp-126571939696)

from a recent facebook post

FAMILY DAYS IN IOWA AND SOUTH DAKOTA

Contact Nancy, heartland@fragilex.org if you are willing to be a host and help plan an event in your area.

**The ONLY bike ride in the USA
that raises funds to support Fragile X!**

education • advocacy • research



SATURDAY, JUNE 1

56 miles

Ankeny to Waukee

(and back)

It's all happening in Iowa

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/>

Also, 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!



Golf to X Out
Fragile X
Last Saturday in
July
Pocahontas,
Iowa



We have multiple
people across
Iowa and South
Dakota planning
restaurant
fundraisers.

Watch for details!



XStrides
September/
October
Ankeny, Iowa

We'd still like one
in South Dakota!

FYI Birthday fundraisers on social media are an easy way to raise funds for the National Fragile X Foundation. None of the funds directly support the Heartland Chapter-Iowa and South Dakota.

The funds that we raise support the National Fragile X Foundation, provide Advocacy Day Scholarships to those in Iowa and South Dakota, provide scholarships to the International Fragile X Conference and enable us to keep our educational conferences affordable.

**We encourage you to support NFXF and
the Heartland Chapter if you can!**