We are excited to announce that Gregg Harper has joined the advocacy team for the National Fragile X Foundation. Many of you will know Gregg from when he served as a Member of Congress, representing Mississippi’s 3rd Congressional District. He spent 10 years raising awareness of Fragile X in Congress and supporting research funding and policies that open doors for individuals with intellectual and developmental disabilities. He is also the proud father of Livingston, his adult son who has Fragile X syndrome.

Gregg has already started advising on our 2020 advocacy priorities, and he wrote an article for us on how to effectively advocate with your members of Congress. Starting in January, he will be actively advocating with current members of Congress and their staff and will be joining all of us for NFXF Advocacy Day on February 24-25, 2020. This time he will be joining meetings from our side of the table, as a parent advocate.

Please welcome Gregg to our team and plan to join us in DC for NFXF Advocacy Day, February 24-25, 2020. In the meantime, take a moment to read his article. https://hubs.ly/H0lWcNS0
**Advocacy Day**

**Accomplishments**

Our advocacy efforts:

- Helped in securing approximately $350 million in federal funding for Fragile X research and programming.

- An annual Advocacy Day in Washington, D.C.

- A national Fragile X Public Health Program at the CDC’s National Center on Birth Defects and Developmental Disabilities.

- Fragile X research funding by the Department of Defense (DOD).

- A comprehensive National Institutes of Health (NIH) Blueprint to guide research targeting all Fragile X-associated disorders.

- The establishment of ABLE Accounts, which are tax-deferred savings accounts for adults living with disabilities, similar to 529 college savings Accounts.

*Your participation makes a difference because local voices are the most effective.*

Sign up at the website to get updates [https://fragilex.org/get-involved/advocacy/](https://fragilex.org/get-involved/advocacy/)
We are again offering ADVOCACY DAY SCHOLARSHIPS to residents of Iowa and South Dakota. An application is attached to the email.

Join our NFXF Advocacy Facebook group to be alerted of opportunities to make your voice heard.

NFXF Advocacy Day is February 24-25

We hope you can join us – all 150 or so! It is a time to connect with policy makers and other families. We have fun, we learn, and we improve lives. It is not an exaggeration to say we can’t do this without you. In the sea of voices in DC, the voices from home and from those personally impacted are the most effective. You are the ones that are heard and cause action. Your involvement will make a difference for you and for families impacted – today, tomorrow, and well into the future.

If you haven’t been before, don’t worry! We help you every step of the way when you get to DC. Once here, we gather in the same hotel and have a training from 1pm-5pm on Monday afternoon. The training covers what to do, where to go, what to say, and more. We strive to make you comfortable and at ease. We also schedule all of your meetings and coordinate with everyone else coming from your state and Congressional district. If your meeting changes, we let you know. Additionally, if you want, we have experienced advocates to mentor you and be there for all of your questions and support.

Who: Anyone who wants to advocate for Fragile X families. We always have a mix of parents, grandparents, family members, doctors, researchers, and clinicians. Siblings and self-advocates are especially encouraged to attend.

Arrive by 1 PM on Monday and leave Tuesday evening.

Where: If you are planning to come - or even thinking about coming - you can go ahead and book your room(s) at our rate of $120/night at the Crowne Plaza in Crystal City, VA. Use this link: https://bit.ly/2WRJgOv.
The hotel has a free shuttle to/from Reagan National Airport (it is just a mile or so) and the rates are available before and after the event for those who want to extend their stay.

Cost: $25 registration fee plus any travel expenses.
Where does the money go?

All of the monies raised at our fundraising events support the NFXF mission of education, advocacy, awareness and research. We have been very fortunate for the past 2 years to have successfully raised over $30,000+! Here’s where it went!

- Advocacy Day, Washington, DC—direct support and scholarships
- International NFXF Conference—direct support and scholarships
- Fragile X Research
- National Fragile X Foundation—direct support and Giving Tuesday
- Vendor participation—state-wide disability fair held annually in Des Moines, IA
- Fragile X and Autism Education Conference with Dr Marcia Braden, Ph. D, P.C. as the guest speaker.

We also budgeted for family events in 2020. We are offering twelve $1,000 scholarships to those affected by Fragile X Syndrome to attend the 17th NFXF International Conference in Orlando, Florida, July 16-19, 2020!

While the National Fragile X Foundation provides much needed support for the chapters, they do not provide direct financial support. Your donations and support for our chapter is what allows us to do these things!

If you, a family member or a friend would like to support our efforts, have them send a check made out to NFXF, Heartland Chapter to:

Nancy Carlson, 1010 NW Greenwood St, Ankeny, IA 50023

I will complete paperwork that ensures the donation is credited to Heartland Chapter.

All donations are 100% tax deductible.
The Heartland Chapter receives grant from The Valero Texas Open and Benefit for Children

For four years employees at Valero Renewable Fuels in Albert City, Iowa have been providing sweet treats for those participating in the Golf To X Out Fragile X event held late July in Pocahontas, Iowa. This year, two of the employees, Kelly Davey and Travis DeLance decided to take that support a step further by nominating the Heartland Chapter for a grant that would benefit children in the Albert City area.

Brenda Slama, co-leader, put thought to the challenge, after all the Heartland Chapter supports families, not just children. What could be done for children in the area? Something that could benefit even those without Fragile X Syndrome. She was instrumental in advocating for a sensory room in the elementary school in Pocahontas to support her son, Gus and other special needs children in the school district. Why not submit the idea of supplying additional buildings and schools in the area with the same?

Valero thought it was a great program and has awarded the Heartland Chapter $6,200 to do just that! Brenda will be contacting schools in the area and providing a wish list of items for a sensory room. The Heartland Chapter will then purchase the items they choose, up to $1,000 per school.

Valero Renewable Fuels

In the community, Valero is proud of its legacy of support and positive outreach through an international network of Volunteer Councils. Valero Volunteers proudly dedicate more than 153,000 volunteer hours to community outreach annually. Special missions on behalf of the United Way, the National Multiple Sclerosis Society, Wounded Warriors and countless children’s charities are a source of pride and motivation for every Valero employee. Valero, its employees and its philanthropic organization – the Valero Energy Foundation – annually generate more than $54 million to support worthy charities or causes, through direct donations or fundraising, to improve the lives of those living in communities near Valero operations. Overall in 2018, Valero, its employees and charitable organizations generated more than $55 million for worthy charities or causes, through direct donations or fundraising.

Always a leading supporter of the United Way as a two-time national Spirit of America Award winner, employee pledges and projected company matches topped $14.6 million in 2018, for donations in 2019.

The Valero Texas Open and Benefit for Children, operating within the Valero Energy Foundation, generated $15 million in net proceeds for charities across the United States in 2019. The contribution is among the largest charity gifts on the PGA Tour. The tourney was just the second PGA Tour event to surpass $100 million raised in its lifetime, totaling $153 million through 2019.
FAMILY BOWLING FUN!

TIGER BOWL
205 Annex Rd, Madrid, IA
SUNDAY, JANUARY 12 • 1:00 PM

Bring your family to Madrid to enjoy an afternoon of bowling with other FX families!

Heartland Chapter will pay for two games of bowling, shoe rental and pizza for each participant.

RSVP NOT NECESSARY, BUT APPRECIATED!

An email will be sent if the weather causes cancellation.

17th NFXF INTERNATIONAL CONFERENCE

Save The Date
July 16-19, 2020 | Orlando, Florida
Marriott Renaissance at Sea World

12 scholarships $1,000 each

are available for FXS residents in Iowa and South Dakota or those who have a loved one affected by FXS. Request an application at heartland@fragilex.org.

Next Conference Call: MONDAY, January 13 @ 8PM
1-605-313-5111 access code is 489682#
To Paul Mulhausen for his work on the Heartland Chapter board for the past three years.

To Angie Bacon, Meagan Sundine and Jackie and Dan Bruck for hosting the first ever Pizza Ranch fundraiser in Boone, IA.

To Ryan Trilk for hosting the first ever Pizza Ranch fundraiser in Dubuque, IA.

To Joel and Kristen Lundstrom, Kay Gradoville and the Carroll crew for hosting their 2nd Pizza Ranch fundraiser in Carroll, IA.

To Susan Brown, Mary Cross, Ken Carlson, Paul Mulhausen and Joel Lundstrom for their work on the Fragile X and Autism Educational Conference.

To Jeff and Kristi Sexton for hosting the 2nd annual X-Strides in Ankeny, IA.

To Brenda and Brian Slama for hosting the 4th annual Golf To X Out Fragile X event in Pocahontas, IA.

To Nancy and Ken Carlson for hosting the 4th annual Bike To X Out Fragile X ride in Ankeny, IA.

To Brenda Slama for securing the Valero grant to benefit the area’s special needs classrooms.

To all who attended, supported, donated and promoted our events.

To all of you who live with Fragile X everyday and still persevere.

**OUR MISSION & VISION**

Our mission is to provide unwavering support for every family affected by Fragile X, while relentlessly pursuing a cure.

**AWARENESS**—to increase public and professional awareness of Fragile X to influence public policy, support legislative advocacy, and increase funding for research.

**RESEARCH**—to fund and facilitate research that drives scientific and medical advances toward effective treatments and a cure.

**COMMUNITY**—to assist and educate individuals and families living with Fragile X in all stages of life, through outreach and personal support.

**Make 2020 the year you get involved!**

We are looking for board members! Please contact Nancy and Brenda at heartland@fragilex.org if you’d like to know more!