

Mark Your Calendar

Support Meetings

Due to the Covid-19 quarantine, all FXAM meetings and events are cancelled until further notice. We will post on our FXAM Facebook page if there will be any virtual meetings/events. Stay tuned. We will gather in thanks after this has passed. Wishing you continued health!

Special Events: July 16-19, 2020

17th International
Fragile X Conference
CANCELLED
See page 7.

Fragile X Association
of Michigan

FXAM.org

Contact Information:

313-689-3340

contact@fxam.org

Three Cheers for...



James Solway & Ted Coutilish - Thumbs up for Dads supporting awareness in Ontario and Michigan! ❤️ the dueling FX DAD license plates!



Sulie Tyler - And her eXcellent chairing of the 2/29/2020 Roaring '20s Gala which raised over \$4,000!



From the President's Desk by Heather Van Dam

It's Day 500 of the quarantine and the Van Dams are white knuckling our way through it. Many of us carriers have severe, often crippling, anxiety. I for one, have never really had an issue with anxiety. The recent events have certainly changed that. For some of my friends and family, this is a time to stay home with their kids and reconnect while playing games and helping with online classes. As you know, this is not the case for most of our families. When school was first closed, I was my usual optimistic self. Everything will be fine. We'll all be fine. We can do this. We just need a plan! So I made a plan. My parents could take the kids 2-3 days a week and I would work from home the other days. EASY! My plan imploded in less than 72 hours. The first day school was closed was a Friday and Derek stayed home with Mason so I could make one last trip to the office before having to stay home for the next several days or longer. Alison was hanging out with Grandma and Grandpa for the weekend. On my way home, I called to check in and Derek said he thought he had a fever and had developed a cough. When I got home it was clear Derek was VERY sick. His fever was 103. After a call to the ER and our doctor, we were told that unless he was so sick that he could not breathe and needed to be admitted to the hospital, they would not test him for Covid-19 and directed us to go to urgent care. We loaded up Mason and proceeded to urgent care where we were greeted by a sign that read If you have a fever and cough, DO NOT ENTER! Call and wait in your vehicle. It was terrifying! After calling, I was allowed in to wash my hands, get masks for us and fill out the paperwork. After 20 minutes, they called to tell Derek his room was ready and he could come in. After about 10 minutes, Derek called to say it was Influenza A. I didn't know I could be so happy about someone having the flu! During this whole process, my anxiety was through the roof. Mason was equally concerned so he was talking NON STOP. He kept saying Is Daddy gonna be brave? Is Daddy getting a booster shot? Daddy will be back any minute. I'll wait in the truck. Is Daddy ok? Is Daddy being a good boy? It was a very stressful night for all of us and by the time we got back home it was after 10 pm. Saturday morning, I went to Kroger and bought groceries for the week and sanitizing spray. I spent the rest of Saturday cleaning my house from top to bottom. A full blown top to bottom no surface unscrubbed epic cleaning. Monday morning Mason woke up with a fever of 103 AND overnight our router and modem had both gone bad. After 4 trips to Office Max, the equipment was finally up and running again, just in time to take Mason to the pediatrician. We had to call upon our arrival and wait in the parking lot until a room was ready. Mason was uncooperative and down right impossible. Even called our wonderfully patient pediatrician a bitch. He also tested positive for Influenza A. I ended up working until 10 pm because most of the day was a complete disaster. It was one of the worst days I've had in a while. After a week, we allowed Alison to come home and she and I never did get the flu (whew!). Unlike many impacted by the pandemic, I am still working full time and my work load has increased due to the virus. While I am extremely grateful that I am able to work remotely and Derek has a flexible schedule, to say working from home with Mason is a challenge would be laughable. I have video conference calls every day. So far nothing major has happened but I'm sure its just a matter of time. As a safety net, I keep the video off if I can and mute unless I'm talking. Which is a good thing because as we know our kids can be very vocal when they want something. No need to take any unnecessary risks. Now that school is officially cancelled for the year, we will continue to white knuckle our way through the rest of the stay-at-home order knowing that we are all in this together and some days may be awful but its just a day and we can start over again tomorrow.

This time has been hard for me for many reasons. A major one is that all of my self-care, stress-reduction outlets have been vanished. I'm an extrovert. I need my people and my social time. No FXAM support group meetings, no yoga, no lunch with friends, no working at the office, no drive to and from work listening to music, no shopping, no manicures, no pedicures. NOTHING! So I want to remind all of us to try to find a new self-care routine and maybe an outlet for the stress. Taking care of ourselves is a vital part of taking care of our kids. See you soon?!

For all you pirates out there, remember: "The problem is not the problem, the problem is your attitude about the problem."

~ Captain Jack Sparrow

Resources and Social Stories

Social stories are a great resources to help not only explain things to our children but to also educate them. The following is a list of social stories, already made that you may use, or if you want to make your own use them as a template.

What is the Coronavirus:

<https://theadditionalneedsblogfather.files.wordpress.com/2020/03/hello-im-coronavirus.pdf>

<https://littlepuddins.ie/wp-content/uploads/2020/03/The-Corona-Virus-Free-Printable-Updated-2-The-Autism-Educator-.pdf>

Washing your hands:

<https://theadditionalneedsblogfather.files.wordpress.com/2020/03/widget-washing-your-hands.pdf>

<https://littlepuddins.ie/wp-content/uploads/2020/03/The-Corona-Virus-Free-Printable-Updated-2-The-Autism-Educator-.pdf>

Directed more at our older adult children:

https://qrcgcustomers.s3-eu-west-1.amazonaws.com/account4876975/6552153_1.pdf?0.85841887098649

In plain language, written by self advocates:

<https://selfadvocacyinfo.org/wp-content/uploads/2020/03/Plain-Language-Information-on-Coronavirus.pdf>

Why can't I go to school (in English, Spanish, Chinese, Korean and Turkish)

<https://consciousdiscipline.s3.us-west-1.amazonaws.com/Free-Resources/Printable-Posters-Tools-Activities/FREE-Printable-Why-Cant-I-Go-to-School-Social-Story.pdf>

National Fragile X Foundation (NFXF):

How to help your child cope with Covid-19 by Dr. Marcia Braden. Includes a social story template where you can insert pictures of your child and a power point presentation on ways to use a visual schedule at home. The template is in word and the power point presentation is in power point, if you have difficulty opening any of these files please connect with Sally at sallyn423@wyan.org and I can help convert them for you. Numerous other resources are listed at this website as well.

<https://fragilex.org/behavior/how-to-help-your-child-cope-with-covid-19/>

Autism Speaks: Covid-19 (Coronavirus) Information and Resources:

Numerous resources from social stories to virtual events to help individuals and families cope during this time.

<https://www.autismspeaks.org/covid-19-information-and-resources>

Just for Fun:

Looking for a fun activity while you're hunkered down at home? We've got just the thing. We created coloring pages featuring 4 brand new designs for you to color from the comfort of your couch. Post and share your finished art on Instagram @michiganawesome

<https://www.michiganawesome.com/pages/michigan-coloring-pages>

Our Families - We Are All In This Together



Keir - has learned how to prepare hot dogs (L) and in the other photo (R) Keir was participating in a virtual campfire with his summer camp, Camp Skyline. Campfires are the highlight of his week.



Maggie - doing a group Zumba class via Zoom that her Transition Program teacher set up for her whole class to do together every Wednesday at 3:00 pm. She loves it.



Austin - celebrated his 28th birthday. Mom didn't have candles for the cake, and it was probably better he didn't blow out candles on a cake. We used tealights, set up like a math problem, tens and ones.

**“When we can talk about our feelings,
they become less overwhelming,
less upsetting and less scary.”**

~ Mister Rogers

Our Families - We Are All In This Together



Langan-Coutilish Family - are taking our allowable daily walks to help pass the time during our Covid quarantine.



Langan-Coutilish Family - More than ever, Ted, Mary Beth and Andrew are exploring cemeteries! Great social distancing opportunities in pretty green spaces. Honoring relatives at various cemeteries and visiting historic Detroit ones.



Nantais Family - Social distancing changed our family dynamics. Who would have ever dreamed there would be such a thing as patio visits.



Not how we planned to spend Easter Sunday but we are so very thankful for a first floor apartment with a door wall.

“Always remember you are braver than you believe, stronger than you seem, smarter than you think and twice as beautiful as you’ve ever imagined.”
~ Dr. Seuss

Our Families - We Are All In This Together



Shea - Helping Daddy do yard work.



Evie and Henry - Enjoying a little extra home "recess" time with their new swings.



Evie - Making pancakes with Grandma.



Darienne - Painting.



Sean - Helping Daddy sort the boxes in his truck.

"When I was a boy and I would see scary things in the news, my mother would say to me, "Look for the helpers. You will always find people who are helping.""

~ Mister Rogers

Our Families - We Are All In This Together



Nathan - Is a YouTube Star! In this video you will see me (Nathan) make a delicious cheese pizza from scratch.

https://www.youtube.com/watch?v=LfBY_hHbxD4&feature=youtu.be&fbclid=IwAR3nKG5X86RDLw_ZvesAqQb6XqtI_CD04WX_xG3s7a4tGdmuZUGWoHvFtsIM



Michael - Practicing skills in the kitchen and enjoying a good book.

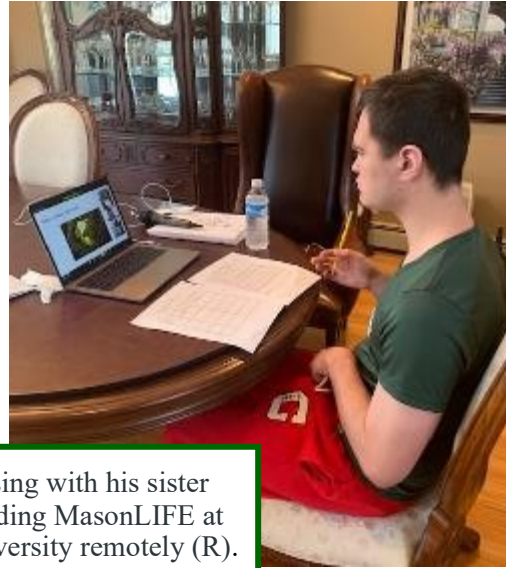
Never, Never, Never, Give Up.

~ Winston Churchill

Our Families - We Are All In This Together



Aidan - Exercising with his sister Camryn (L), attending MasonLIFE at George Mason University remotely (R).



Kevin and his lil sis Helen - Creating a little art.



Alison - Turned 19 in March! The celebration was smaller than usual.

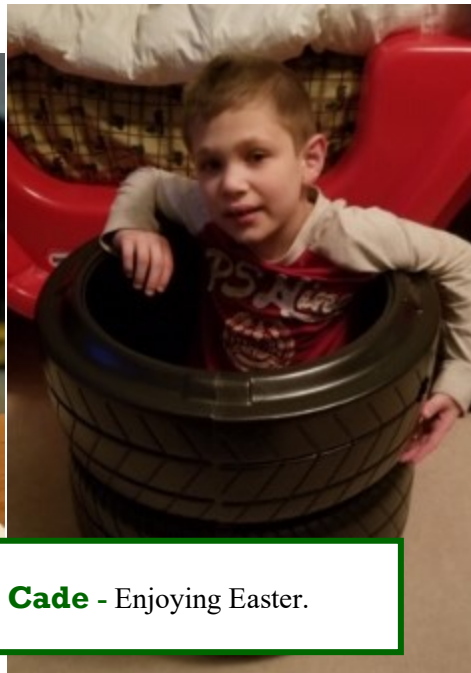
“Everyone needs a house to live in, but a supportive family is what builds a home.”

~ Anthony Liccione

Our Families - We Are All In This Together



Ayden - Week five of unplanned homeschooling. We are so thankful for the Fragile X community coming together in our new Facebook group with resources and support in this crazy time! The information shared has been extremely helpful as we navigate our new normal. See page 13 for details on the Facebook group.



Cade - Enjoying Easter.

**“It's been a long day without you, my friend,
 And I'll tell you all about it when I see you again
 We've come a long way from where we began,
 Oh I'll tell you all about it when I see you again
 When I see you again”**

~ Wiz Kahlifa

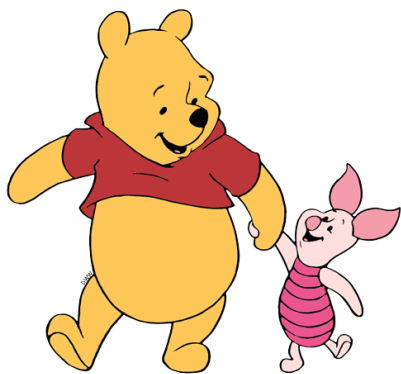
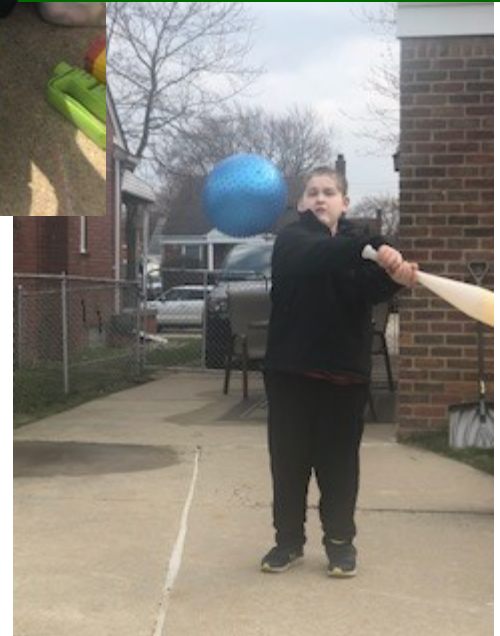
Our Families - We Are All In This Together



Jonathan - Working on printing.



Riddick - Enjoying a nice day during quarantine.



Isabelle - Doing math work with Cheerios (math is yummy).

**“Any day spent with you
Is my favorite day.
So, today is my new favorite day.”**

~ Winnie the Pooh

Our Families - We Are All In This Together



Mike and Paul - Are growing quarantine beards..



Paul - Continues a medical study through Rush. He's become a pro at blood draws and EKGs.



“Now, Woody...he’s been my pal as long as I an remember. He’s brave, like a cowboy should be, and kind and smart. But the thing that makes Woody special is that he’ll never give up on you – ever. He’ll be there for you, no matter what.”

~ Andy, Toy Story 3

Our Families - We Are All In This Together

You are not alone

My son, Adam is 23 years old and has Fragile X Syndrome. He lives with a roommate and has staff 10 hours a day during the week and they get 12-hour coverage a day, on the weekends.

We have been struggling through all these changes. Taking away school, the bus, teachers and his daycare worksite program has been such a challenge. On top of that he can't go see his grandma on the weekends anymore because of the virus. Plus, we lost my sister's son, Ethan, to asthma or the virus we don't know for sure. He was 14 and struggled his whole life with asthma. It was right before the virus was detected in Michigan. Adam was very close with him as well.

What I'm trying to say is all our children are going through so many changes. They already have a hard time with change and add all these new changes and challenges and it just may not go well. And hasn't for us.

Adam has been calling me 20 to 30 times a day. I'm trying to be patient and answer as much as I can because I know how hard this is on him. I had him over last weekend, the one before Easter weekend and things did not go well.

We played cards and watched a movie Friday night. He called me from his room after I tucked him in and asked if I would lay with him. My heart melted and I put my arm around him and just prayed for us.

Adam has been aggressive and moody most of his life. We can manage it with meds sometimes, but the last year has been rough.

On Sunday morning, he woke up and got me up. I made him breakfast and got dressed and ready for online church. Just before church, I made lunch for Adam. Another favorite for him is food. We watched church together. After church, we went and sat in my sunroom and talked. He asked, "What's for dinner?" I told him we can have tacos, rice and beans if he wants. Out of nowhere, he starts yelling at me and then throwing his jacket at me. Just going crazy. I have a medicine I can give him when he acts like this. It's hard to give it to him when he's in a full-blown meltdown though. I was able to give him water and the pill. He threw the rest of the water from his cup into the cats' food bowl.

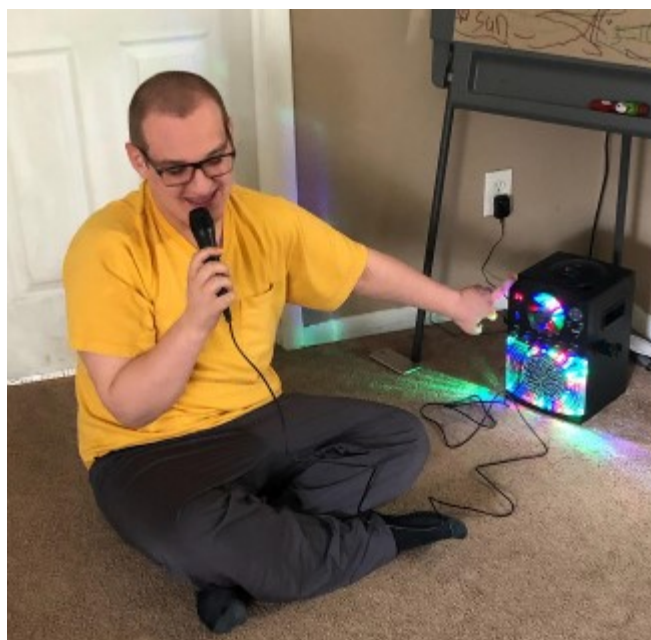
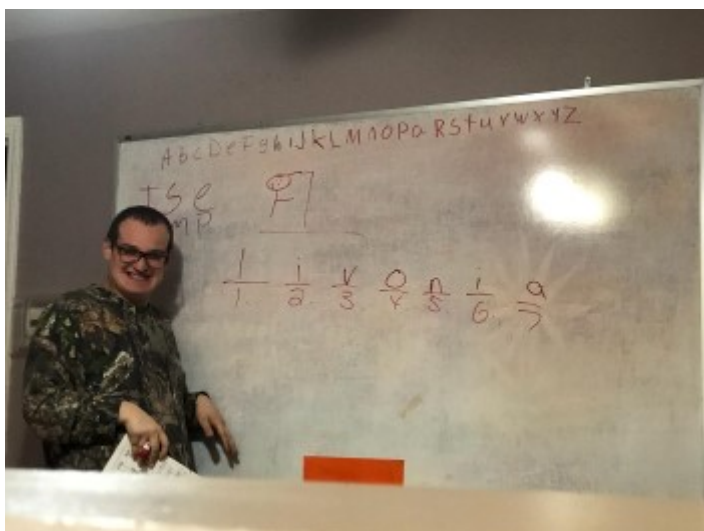
I took him to his home and now I am using boundaries with him. Limiting the calls I pick up and only going to his house to see him. He tried to get me to bring him to my house for Easter weekend, but I couldn't after that last incident.

The mental drainage after this type of meltdown takes me a few days to recuperate. I feel like I'm the whack a mole and every time I get my head out of the darkness it gets hit again.

I know it can be hard for all of us at this time. We all have different circumstances and I am blessed to have Adam living outside my home. But please know, you are not alone and there are others struggling too. Life is so challenging and then add all this and all the changes life has thrown at us right now. I try to imagine Adam and his mind, what he is going through. I think that is what helps me forgive him.

I am praying for all of us as we go through this uncharted time in our lives.

Sincerely, Malinda.



What's going on ...

The Unplanned FX Homeschoolers

On March 13, a new Facebook group was created by Fragile X Moms Melissa, Holly, Cortney (from Michigan!) and Kristie. Look for "The Unplanned FX Homeschoolers" in Facebook.

"In light of the many school closures, this group has been created as a place for families affected by fragile X to share resources, advice and tips regarding educating their children and fighting boredom in the coming weeks."

At this writing, there are 241 members in the group. If you need some help with keeping your child engaged, happy, busy and yourself sane, you may want to join in the fun!

Aimee Jo (from Michigan!) recently shared an interesting post about making a Covid-19 Time Capsule.



17th International Fragile X Conference

**The conference which was scheduled to be held July 16-19, 2020
at Renaissance Orlando at SeaWorld has been canceled**

From Linda Sorensen, NFXF Executive Director:

As much as I hoped it would not come to this, I'm very sad to let you know that we have made the decision to cancel the 17th NFXF International Fragile X Conference in Orlando, Florida. The entire team debated the pros and cons of this decision and came to the conclusion that given the circumstances, the most prudent thing to do is to keep everyone's health our first and foremost priority this year. We also understand that even if it were to become safe to gather 800+ people in Orlando, that the financial realities of the crisis may significantly impact many attendees' ability to attend.

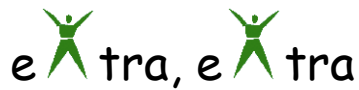
The good news is that we have received tons of incredibly interesting and valuable presentation proposals from prospective conference speakers. And we are actively engaged in determining how we can make these educational available to everyone in the weeks and months to come. Stay tuned for more details shortly.

In the meantime, we are committed to delivering timely and helpful support to families as we adapt to our new normal.

If you have already registered, please request a refund by emailing Jen Barber at jen@fragilex.org. If you booked your hotel, please contact Renaissance Orlando at SeaWorld directly to cancel your reservation.

As always, please let me know your questions and comments.

Virtual hugs, Linda



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**Three Cheers for our FXAM families
who attended Advocacy Day
in February!**

In Memory of Jean Laske



The FXAM family was sad to hear of the death of Jean Laske on March 14 following a long journey with FXTAS. She and Roger were/are the best kind of grandparents to Kyle Laske (son of Michelle and Ken), who is affected by Fragile X. We've known the Laske Family for many years as they have been active in our group. Although they had to have a private funeral due to Covid-19, the Laskes remain in our thoughts and prayers.