

Mark Your Calendar

Support Meetings

Due to the Covid-19 quarantine, most 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!

Fragile X Association of Michigan
FXAM.org

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 313-689-3340

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Three Cheers for...



Michael - a little pizza with your ranch?

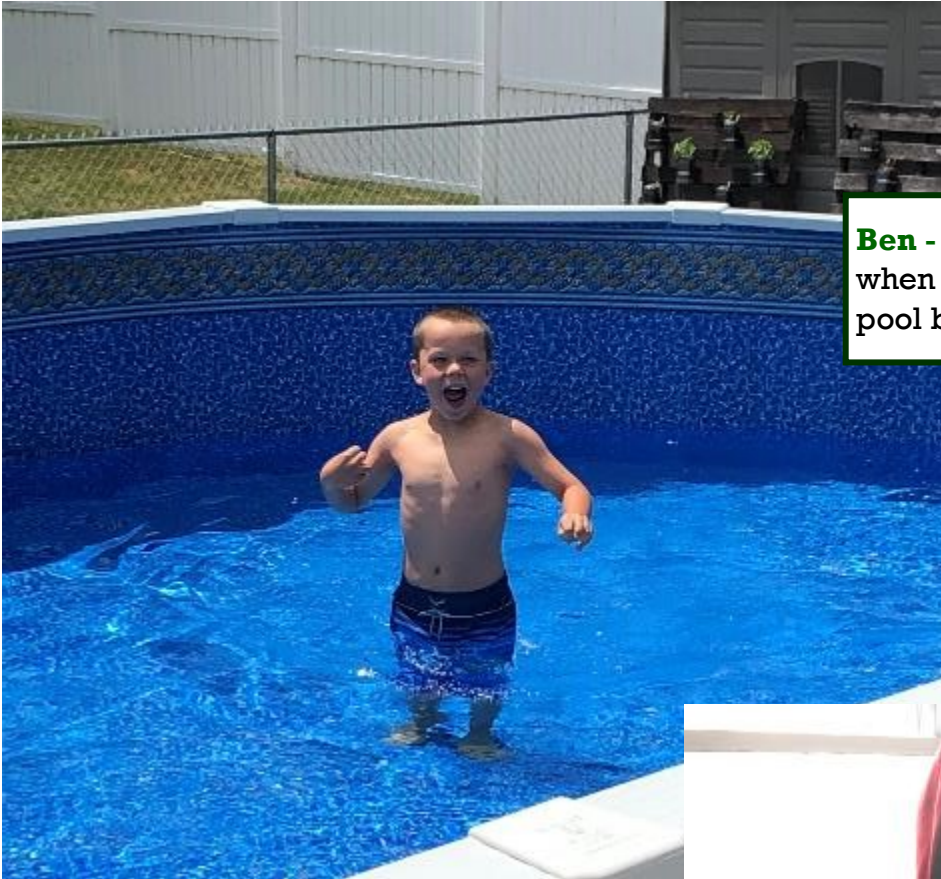


Michael - when toilet paper is no longer hard to find.

Paul - because of Covid, Paul was getting anxious that his hair wasn't "fuzzy like a peach" any more. We ordered clippers and his little sister, Katie, decided to help him out. It's been a great bonding experience each month with very mixed results.



2020

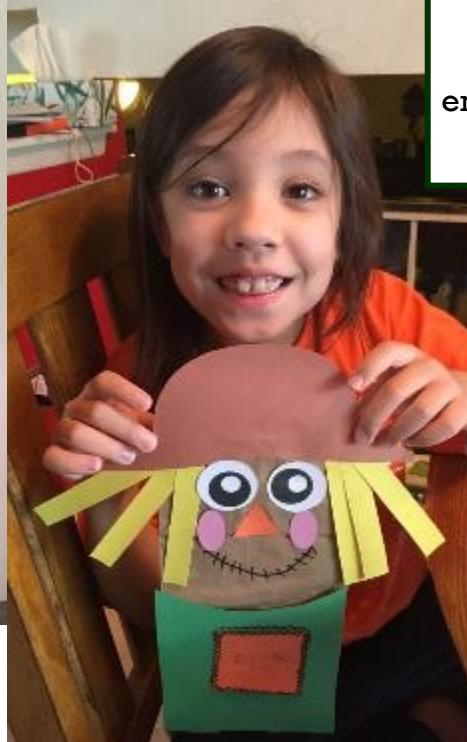


Ben - summer was great when Covid resulted in a pool being purchased.

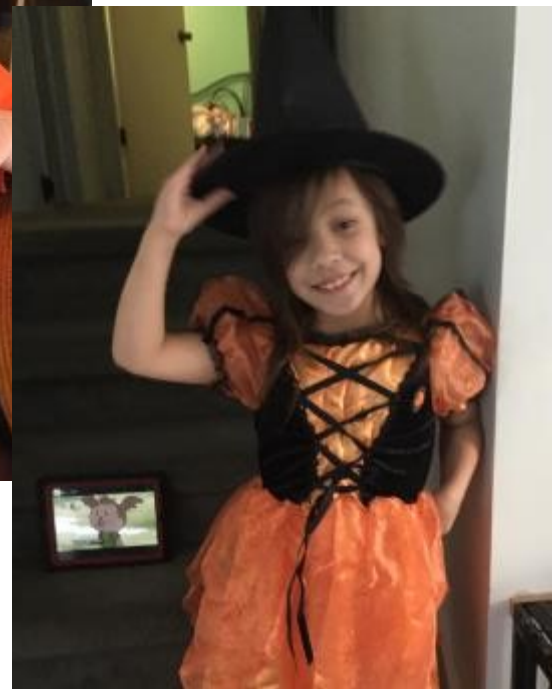
Ben - 4th grader who loves his new job on safety patrol.



2020



Evie is having fun at home with her Pirate Witch Princess costume. And enjoying a school-at-home craft project.



Henry is enjoying socially distanced snack time with his squirrel friend.

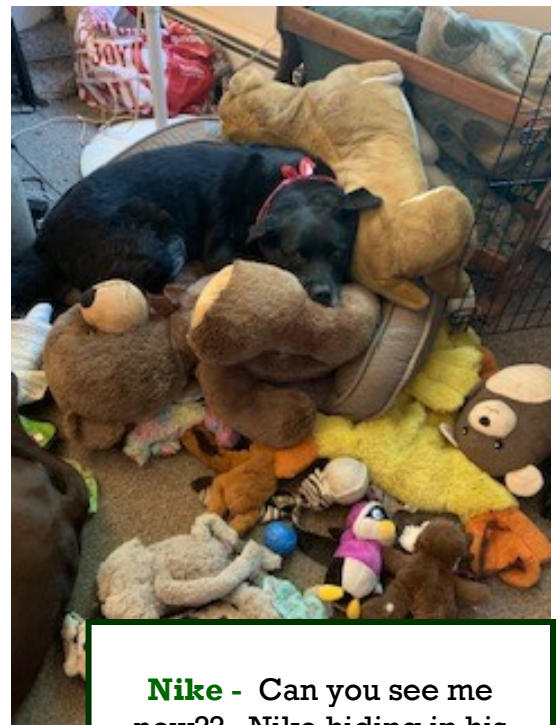
2020



Nicholas is virtual schooling with puppy assistance. Here we see (L to R) Nicholas, Max and Nike.



Nicholas - Covid home haircut. Nicholas getting a trim from sister Meghan.



Nike - Can you see me now?? Nike hiding in his woobie pile-total chaos. LOL!

2020



Austin using messenger with filters to visit with his sisters Natalie & Genevieve.



Austin - Wyandotte's Farmers market had some very special guests.



Haircuts - do we see a pattern here? Austin's sister Natalie giving him his first Covid haircut and beard trim.



Austin & Gramps - out for a trip to the apple orchard.

2020



Andrew -
Knows how to
travel!



Visiting Dr. Berry-Kravis in Chicago - Andrew was NOT happy when we cancelled our June EBK visit due to Covid. He let us know in many ways. Here we are at our October 29 appointment in Chicago, (L to R) Liz, Andrew, Ted and Mary Beth.

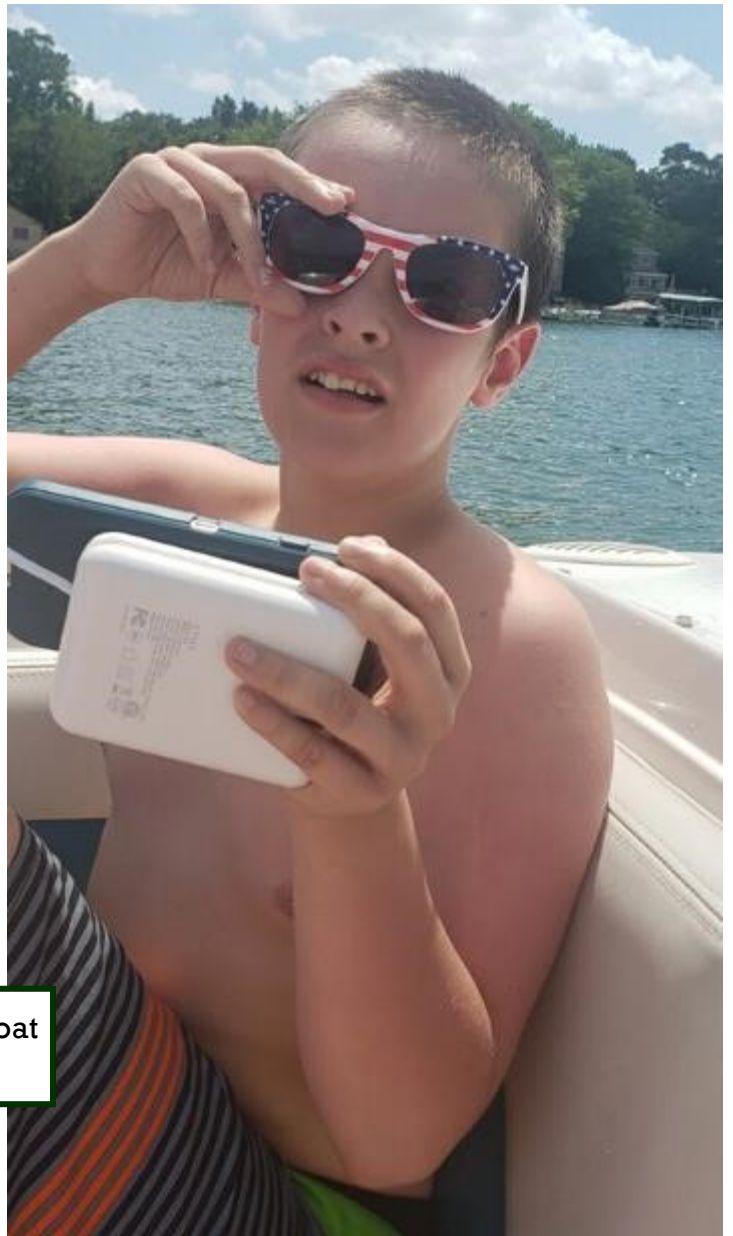


Andrew - As for haircuts, Andrew's hair has been cut at home for many years. Since Covid began, MB's clientele has expanded to include Ted and her BIL/ neighbor Bruce. Ironic how haircuts are another commonality in our homes!

2020



Mason and his monster mask - both scary & adorable.



Mason - looking like a star on the boat in the odd summer of 2020.

From the President's Desk *by Heather Van Dam*

As we enter the last two months of the year, I find myself in a constant rush to get it over with while also trying to make the best of what's left. I am determined to not let Covid ruin the holidays. We only see our small circle of family that we know are being diligent about wearing a mask and staying away from large gatherings or other activities that may put them at risk. For the first time in years, we cancelled our Halloween party which bummed me out so much, but I just wasn't willing to risk it. For families like ours, this has probably been the hardest year ever. We rely on the odd Covid routine of school, work and social activities to allow us time to breathe and reset.

Mason had been home from school since the lockdown began in March. Like many other families, we had to pivot and develop a new plan to manage Mason's new routine or complete lack of! Summer was a bumpy ride. I am very fortunate to be able to work from home so I could be home with Mason. Unfortunately, that meant I was only home in the physical sense. I was still working upwards of 50-60 hours of work per week and Mason has no

interest in sitting at the computer talking to his class. His teacher and entire team really worked hard to keep the kids engaged in any way possible. We had daily calls for an hour with his class. They sent video and activity links, but Mason wanted nothing to do with it and after working all day, we didn't have the energy to fight him. So he basically lost six months of school. We are very fortunate that our school district made the decision to start face-to-face CI classes 4 days per week on September 14. Mason was absolutely thrilled to get on the bus and go to school and I may have cried tears of JOY! We have been able to go back to a new slightly modified routine. For those of you that have not gone back to in-person learning, I am thinking of you and sending hugs! This year, we changed from being campers to boaters. Initially, Mason was apprehensive to get on the boat and once on the boat did NOT want to go any faster than no wake! After a few outings, he became very comfortable and only wanted to go full speed around the lake. He even asked to learn to ski. Although he never

got in the water, he did put on the lifejacket and get close to the ski. HAHA! Maybe next year or the year after or never. As long as he asks, we will continue to encourage him try.

Alison, who will be 20 in March, applied for a job in September. She asked me to review her application and I only made a few minor punctuation/grammar changes. She got an interview and asked my advice on how to dress. She did great at the interview and even told them about some of the challenges she has. They hired her on the SPOT! She is now employed full time. We are so proud of her. She stepped out of her comfort zone even though it was very difficult for her. She has been recognized for her hard work and featured on the company's employee page. She has gained a sense of independence and the value of money.

Know that I am thinking of all of our FXAM families and how hard the changes have been for so many of us. May your 2020 end with unique and positive holiday experiences. Sending peace to you and your families!

University of Michigan Fragile X Clinic

We are happy to announce that we have received a \$50,000 grant from the Toni Wisne Sabina Foundation for ongoing research at Dr. Peter Todd's lab at the University of Michigan. As you know, money has been tight for everyone during this pandemic, including foundations, so for us to receive a grant this year was pretty special. It was nice to know that they considered fragile x research to be an important investment in the future for those who have fragile x and it's related disorders. The money has been passed on to Dr. Todd's lab and they are extremely appreciative of our work on their behalf!

For more information on the Fragile X Clinic or to make an appointment:

fragile-x-clinic.med.umich.edu/

734-764-0579.

Twenty-First Annual Golf Outing

The 21st Annual Fragile X Association of Michigan (FXAM) Golf Outing was on a sunny September 12th this year. The "Covid-19 day of golf" went well. We had 76 golfers. No bells and whistles, but everyone had a great day. It was one of the nicest days we have had weather wise.

We would like to thank all those who came out to golf, sponsored holes and made donations. We couldn't have done it without you!

The golf outing was unique and the proceeds from our generous donors will be shared in three ways by these wonderful organizations that support special needs communities: FXAM, Supporting Independence in Michigan and LIFE Communities.

Our sincere gratitude goes to the following businesses, organizations and individuals for their generous donations:

The Mickelson (\$1,300+)

Steven Lebowski
Bob Mannino

The Palmer (\$500+)

Mike & Stella Banich
Daniel & Beverly Buckley
RCI Property Management
LLC

The Palmer (\$500+)

Martin Seward
Theresa Sternicki

The Watson (\$250+)

Escalon Premier Brand
Tomatoes
Robert J. Finkel
C. Hawker & Associates
Mr. Joe's Sports Bar
Kiwanis Club of Allen Park
Richard Lambert
Evelyn Kosch-Mannino
Roak Brewing Company
Roselli Foods

The Player (\$150+)

Fairway Packing Company
Family Dentistry, PC
Father Saylor K of C #3774
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Fontanini Meats
Green Lantern Pizzeria LLC
J & B Motor Supply, Inc.
Lakeshore Utility
Gary & Donna Lebowski
Liberati & Sons Construction
Litehouse Dressings
Sally Nantais (Austin, Natalie
& Genevieve)
Pomponio Construction
Joseph Procopio
Russ, Danielle & Giovanni
Rodriguez
Rony's Body Shop
Sartori Cheese
Silverton Skin Institute
Smithfield Meats
Sorrento Cheese
James & Cindy Vickey
Greg & Felicia Wurth

We would also like to thank the following businesses, organizations and individuals for their donations:

Agemy & Sons, Inc.
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Bob & Joann Forde
Roger Laske
Deborah Lee
Dora Mangiapane
Sheldon & Jeanie Miller
Sally Nantais
Rich Ortiz
Kailey Owens
Frank Savona
Marguerite Sclafani
Sue Shannon
Dr. & Mrs. Lester Voutsos
Mike Zaker

"The ultimate measure of a man is not where he stands in moments of comfort and convenience, but where he stands at times of challenge and controversy."

~Martin Luther King, Jr.

eXtra, eXtra

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**Thank You
to all who
supported our
21st Annual
Golf Outing!**

