



FRAGILE X ASSOCIATION OF MICHIGAN

eXtra, eXtra

Volume XII, Issue 4, October 2016

Mark Your Calendar

Support Meetings

First Saturday of the Month

When:

November 5, 2016
February 4, 2017
(no meetings in December & January)

Free Childcare in November. See page 4.

Business Meeting

6 - 7 p.m.

Support Meeting

7 - 9 p.m.

Where:

Beaumont Hospital
Royal Oak Campus
Administration Bldg.
Private Dining Room

Special Events:

November 19, 2016

FXAM Moms: Let's Do Lunch!
See page 4.

December 3, 2016

FXAM Holiday Party
See page 4.

Feb 28-March 1, 2017

Advocacy Day
More details in our January newsletter
Washington, D.C.

Fragile X Association of Michigan

FXAM.org

Contact Information:

313-381-2834

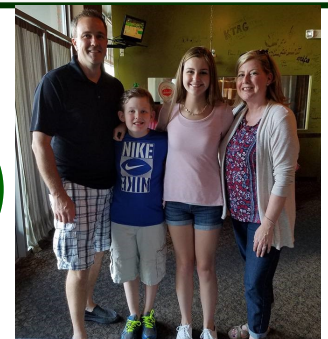
southeastMI@fragilex.org

Three Cheers for...

Come Dance with us in Memory of Lillian and Ken Chesney, Sr. Dancers, thank you for honoring Lillian and Ken and for raising funds for FXAM.



Sherwood Brewing Company and Lisa Nassar Sherwood for hosting a fundraiser for the Fragile X Association of Michigan on August 18, with the Utica Unicorns. Thank you to the Ohnui Family for the connection!



The Jankowski Family - Gerard, Matthew, Alexa and Michele enjoyed the fundraiser at the Sherwood Brewing Co.



The Branch Family - Peggy, Maggie and Patrick, photo op during Maggie's homecoming.

The Weber Family
Top Row: Eric, Ron, Nicholas
Bottom Row: Katelynn, Lexi, Meghan



Seventeenth Annual FXAM Golf Outing

The 17th Annual Fragile X Association of Michigan Golf Outing on September 10th was once again a huge success! The **109** golfers teed off at approximately 1:00 p.m. and everyone had a great time during the four-person scramble. Afterwards, **143** people enjoyed steaks, potatoes, mostaccioli and more under the tent.

The Fragile X Association of Michigan continues to be very grateful to **Nina and Frank Liberati and Lauren Majeske** as organizers of this event each year. The 17th Annual Golf Outing raised approximately **\$25,000** for the Fragile X cause. Way to go Nina and Frank!

We would like to thank all those who came out to golf, sponsored holes, made donations and all those who helped in setting up, working the par-3 closest-to-the-pin contests and clean up. We couldn't have done it without you!

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

The Mickelson (\$1,300+)

Kenwal Steel Corporation
 Bob & Evelyn Mannino
 Christopher M. Wouters
 Family Foundation
 Steven Lebowski
 John & Nancy Warneck

The Nicklaus (\$1,000+)

Adam Holdings, LLC
 Kenwal Steel Corporation

The Palmer (\$500+)

Mike & Stella Banich
 Anthony Iaquinto
 Gary & Donna Lebowski
 Watson Engineering

The Watson (\$250+)

Castella Products
 Escalon Premier Brand
 Tomatoes
 Robert J. Finkel
 C. Hawker & Associates
 Mr. Joe's Sports Bar
 Mark Kontry, P.C.
 Die Hard Lambert
 Roselli Foods
 Martin Seward
 Sorrento Cheese Company
 Southfield Chrysler

The Player (\$150+)

Advantage/Waypoint
 Allen Park Kiwanis
 Arnaldo's Banquet Center
 Daniel & Beverly Buckley
 Chesney/Laske Family (In
 Memory of Kenneth Sr. &
 Lillian Chesney)
 Epicurean Sales & Marketing
 Fairway Packing Co.
 Florence Coleman (In Honor of
 Richard)
 Family Dentistry, PC
 Fontanini Meats
 Green Lantern Pizzeria
 The Hansen Family
 Lakeshore Utility
 Liberati & Sons Construction
 The Liberati Families (In
 Memory of
 Tullio & Rose)
 Lighthouse Dressings
 McNerney's Chrysler Dodge Jeep
 Mercedes-Benz of St. Clair
 Shores
 Austin, Natalie & Genevieve
 Nantais
 Pia's Restaurant
 Pomponio Construction
 Preferred Brands
 Russ & Danielle Rodriguez
 Rony's Body Shop, Inc.
 Charlie & Inez Roy
 Sartori Company
 Sue Shannon
 Silverton Skin Institute
 Stephanie Sosinski
 Theresa Sternicki

The Orchards Golf Club
 Turri's Italian Foods
 James & Cindy Vickey
 Weed Eraser Inc.
 David Wujczyk
 The Wurth Family

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

Terry Adams
 Anoir Agemy
 Bob Asmussen
 Jim Bademian
 Julie Bademian
 Cathy Bartolotta
 Shirley Cavataio
 Nick Coleman
 The Coleman Family
 Eric, Deborah & Connor Collis
 Brian & Antoinette Foley
 Joann Forde & Caleigh
 Joan Grab
 Mr. & Mrs. Hancock
 George & Barbara Jakubik
 Jerry from Westburn Golf &
 Country Club
 Levon & Gloria King
 Ray Lalli
 Tony & Maria Lalli
 David & Rose Anne Laske
 Roger Laske
 Deborah Lee
 Tullio Liberati, Jr.
 Tullio Liberati III
 M-Den
 Leonard & Peggy Majeske
 Tony & Dora Mangiapane
 Bob Mannino
 Stella Marazano
 Sally Nantais
 Kailey Owens
 Grace & Sam Pizzo
 Fred & Cookie Sclafani
 Ed & Marlene Sienko
 The Country Store - Romeo
 Dr. & Mrs. Lester Voutsos
 Weight Watchers
 Betty Woloszyk,

To The Person Who Taught Me Patience And Acceptance

**Because of you, my life has changed forever.
by Kelsey R. Weiss at Alma College**

If the last three years of high school taught me anything, it was the power of acceptance.

People may look at their peers with autism or any other type of cognitive impairment as something unfortunate. Granted, when I was fourteen I probably thought the same thing. Everything changed when I walked into my first Autism Spectrum Disorder classroom. This is usually a classroom tucked away from everyone else. Students are put in a corner so as to not bother any of the general education and mainstream students, but at my high school, they were put front and center. They were in the main hallway, right smack dab in the middle.

I am going to be honest. To the students that were in that classroom the first day I walked in, you all terrified me. Just like every other naive teenager, I did not know what I was getting myself into. There was a lot going on in that classroom. Trust me, I was about wetting myself because I had no clue what I walked into.

I was assigned to the most rambunctious and only nonverbal student in the program. He scared me; however, the first moment that kid smiled at me, I knew I was doing the right thing. He is what I needed in my life. Every day I would be greeted with a huge smile and crater-sized dimples. I was hooked instantly. I spent the next two years working with him and really getting to know him.

Let me enlighten you about the boy I am talking about. His name is Antonio, and he has Fragile X. For those of you who are thinking that he is some sort of gifted youngster (X-Men joke), let me explain what this means. Fragile X is a genetic condition that causes cognitive impairments. One-third of the people that have Fragile X also have autism, which this boy has. He is nonverbal but can say a few words; he can do some sign language. If you're thinking, "Oh gosh, he can't speak, how did you communicate?", you have little faith in both me and Tone. When you work with students like him, you develop your own way to communicate. Of course, this came after working with him for a while. I learned the sign language he knew, (things like "bathroom", "please", "yes", "no", etc.) and I learned that I could give him two options to pick from. Here is the kicker -- Antonio was and still is so much smarter than we give him credit for. The boy can finish a whole puzzle in only a few minutes.

My favorite thing to say when I talk about Tone is he is the biggest stinker I have met, but I mean it in the most loving way. Antonio enjoyed picking the wrong answer to get a rise out of someone, which he did to me multiple times. He was the most frustrating person I have ever met but by far my favorite person in the world.

Antonio knew what was going on. He could read and write; he just could not speak. He may have needed me to speak for him, but that never stopped him. Everyone that worked with him would agree that if he could talk, he would be cussing us all out. This wasn't because he was a bad kid. This was because just as he knew how to push our buttons, we knew how to push his.

As intimidating as he was, he is a giant teddy bear. One of the sweetest humans I have ever met, Antonio loves to laugh and give hugs and just love people.

And people love Antonio. During his senior year of high school, he was voted Homecoming King. That was one of the proudest moments I have ever felt. I, along with all the other people that worked with him, held hands as the winner was announced. I am not ashamed to admit that I cried. I felt like a proud mom.

Nearly four years after meeting Antonio, I can say one thing for sure. My life has not been the same since I met him. He has taught me how to accept and love people no matter what they are like. He has also taught me patience. Good gosh he has taught me patience. I would not change anything about him. I love that little meatball, and I hope he loves me too.

What's going on ...

Free Childcare at the meeting on November 5!

6 - 9 p.m.

Free childcare available

6 p.m. Business meeting

7 p.m. Support meeting

RSVP by **November 1** to mblangan@hotmail.com with your children's names and ages.

We'll have pizza and salad in the childcare room and for the adults at the meeting.

Please bring something fun to share (game, toy, etc).

Hope to see your whole family in November!

FXAM Moms: Let's Do Lunch!

Saturday, November 19, 2016

Place and time to be determined after we see who can join us for some Mom-only time!

Email mblangan@hotmail.com to say you're interested.

We'll look at the responses received by **November 11** and decide on a central location for our lunch.

Please note: This is not a free FXAM event. Each FXAM mom will be paying for her own food/drinks.

FXAM Holiday Party Our Annual Potluck Gathering

Saturday, December 3, 2016 at 5 pm

We will gather in Thanksgiving of our FXAM Family at our annual Holiday Potluck.

Langan-Coutilish Home, Grosse Pointe, MI

Please RSVP by November 29 and share what you'll be adding to the gathering by contacting

Mary Beth at mblangan@hotmail.com or 313-881-3340

If you're not on our email list, please send an email to Mary Beth so you won't miss out on our events!

From the President's Desk *by Laureen Majeske*

Happy Fall! What fun we've been having these last few months! Our events have included a fantastic FXAM Family Picnic at Sulie and Jeff's home, square dancing for Awareness in memory of the Chesneys, a fundraiser at Sherwood Brewing Co. put on by Lisa Nassar Sherwood (thanks to Lori and Rome Ohnui!) where we got to hang out with the Utica Unicorns, and our Annual Golf Fundraiser, which, while we still had a little rain, was a roaring success. Coming up is the popular Creative Arts Studio where attendees can make a ceramic

piece, a FXAM Moms Lunch and our FXAM Holiday Party, all before the end of the year. Whew! Look for more fun after the first of the year where we look forward to another fun event at the Michigan Center for Sports and Academics where they have added a Ninja Warrior obstacle course (we know the moms and dads will love it as much as the kids!) and Fragile X Advocacy Day in Washington, D.C.

We have loved sharing all of these fun times with you and we thank all of our wonderful families for your continued

support and friendship. We'd like to thank our members for thinking of us. We received many generous memorial donations in honor of Lillian Chesney, Kenneth Chesney, Sr., and Deloris Fraley. Many thanks to the Laske-Chesney and Cyplik-Goodell-Fraley families for spreading awareness and asking for donations in the names of their loved ones. We truly appreciate your kind gestures.

Enjoy the beautiful colors that Michigan has to offer this season.

ABLE Rollout is here

Michigan MiABLE account will open for enrollment on November 1, 2016.

The MiABLE account will allow individuals with disabilities to plan for their future by saving and investing up to \$100,000 without it having an impact on their benefits (i.e., Social Security and Medicaid). Currently Michigan has the highest level in the nation for maximum contributions, \$500,000. If the account exceeds \$100,000 benefits will be suspended until the account drops below that figure. "Spend down" describes the process of literally spending the excess money received by a benefits recipient down to the maximum allowable resource limits.

MiABLE is a 529 plan, like the 529 Education plan. A 529 plan is a tax-advantaged savings/investment plan designed to encourage saving for the future expenses of a designated beneficiary (typically one's child or grandchild).

Details at: michigan.gov/mistudentaid/0,4636,7-128-60921_74426---,00.html

Already announced on our FXAM Facebook page:

Creative Arts Studio Ceramic Painting Event
Saturday, November 12 from 4:00 to 6:00 p.m.

\$5 per artist. Adults are free. Pizza will be served.
Limit of 18 artists and adults.

Please connect with Joyce Kreger on our FB page (or if not on Facebook, email mblangan@hotmail.com) to see if there is still space available.

"Try to be a rainbow in someone's cloud."

~ Maya Angelou

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If you would like to share them with family, friends or professionals, please share our web address with them.

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**Thank You
to all who
supported our**



**17th Annual
Golf Outing**



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