



FRAGILE X ASSOCIATION OF MICHIGAN

eXtra, eXtra

Volume XIII, Issue 4, October 2017

Mark Your Calendar

Support Meetings

First Saturday of the Month

When:

November 4, 2017

February 3, 2018

(no meetings in December & January)

Free Childcare in Nov and Feb
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, 2017

Annual Board Meeting
11 am - more details to be sent to Board.

December 2, 2017

FXAM Holiday Party
See page 4.

February 3, 2018

Guest speaker
See page 4.

March 5-6, 2018

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

Fragile X Association of Michigan

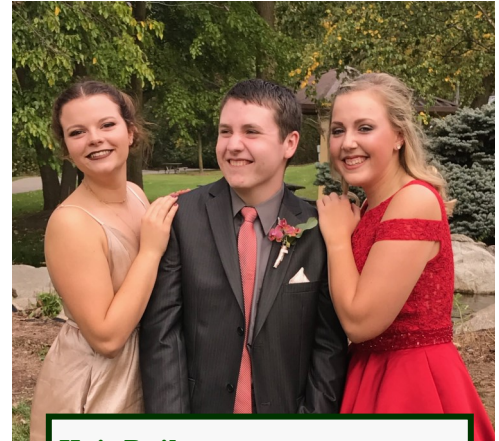
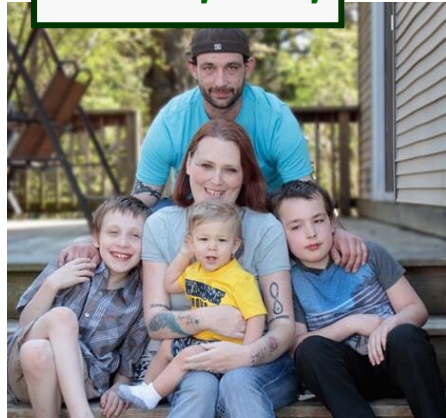
FXAM.org

Contact Information:
313-381-2834

Three Cheers for...

FXAM Families!

The McKay Family



Keir Buikema had an awesome homecoming with friends.

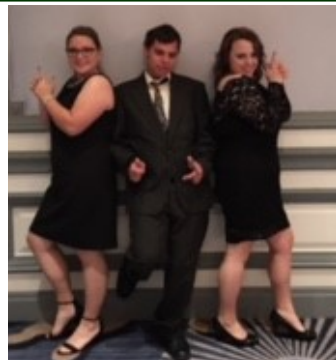
The Liberati Family



Austin Nantais believes if you're in the hospital for days, you might as well grow a beard and be a pirate!



Unstoppable
Meghan, Nicholas and Katelynn Weber



Sam and Jacob Gelfand

Eighteenth Annual FXAM Golf Outing

The 18th Annual Fragile X Association of Michigan Golf Outing on September 10th was once again a huge success! The **103** golfers teed off at approximately 1:00 p.m. and everyone had a great time during the four-person scramble. Afterwards, **131** 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 Laureen Majeske** as organizers of this event each year. The 18th Annual Golf Outing raised approximately **\$29,696** 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, longest drive contest 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+)

Steven Lebowski
Bob & Evelyn Mannino
John & Nancy Warneck

The Nicklaus (\$1,000+)

Farbman Group
Kenwal Steel Corporation

The Palmer (\$500+)

Mike & Stella Banich
DBI Services
Anthony Iaquinto
Tony Kleczynsky
Martin Seward
Theresa Sternicki

The Watson (\$250+)

Castella Products
D.V.M. Enterprise
Escalon Premier Brand
Tomatoes
Robert J. Finkel
C. Hawker & Associates
Mr. Joe's Sports Bar
Richard Lambert
Roselli Foods
Silverton Skin Institute

The Player (\$150+)

Advantage/Waypoint
Allen Park Kiwanis
Armour-Swift Products
Arnaldo's Banquet Center
Florence Coleman (*In Honor of Richard*)
Epicurean Sales & Marketing
Fairway Packing Co.
Family Dentistry, PC
Steven Fellows
Green Lantern Pizzeria LLC
The Hansen Family
Jeffrey Innis, MD
Father Saylor K of C #3774
Law Offices of Miller & Miller, PC
Liberati & Sons Construction
Litehouse Dressings
Mcinerney's Chrysler Dodge Jeep
Mercedes-Benz of St. Clair Shores
Austin, Natalie & Genevieve Nantais
NAPA, J & B Motor Supply, Inc.
Pomponio Construction
Russ & Danielle Rodriguez
Rony's Body Shop, Inc.
Sartori Company
Sue Shannon
Sorrento Cheese
Turri's Italian Foods
James & Cindy Vickey
Weed Eraser Inc.
The Wurth Family

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

Anthony Aratari
Bob Asmussen
Jim Bademian
Marie Beahn
Daniel & Beverly Buckley
Shirley Cavataio
Rick Coleman
Joan Ford
Bob & JoAnn Forde
Joann Forde & Caleigh
Tony & Elina Gelfand
George & Barbara Jakubik
Kelly Koson
Deborah Lee
Tullio Liberati, Jr
Tullio Liberati, III
Peggy & Len Majeske
Tony & Dora Mangiapane
Bob Mannino
Stella Marzano
Mr. & Mrs. Milewski
Sally Nantais
Kailey Owens
Malinda Popejoy
Pia's Restaurant
Grace Pizzo
Austin Sienko
Marlene & Ed Sienko
James & Tiah Solway
Dr & Mrs Lester Voutsos
Debbie & Hank Willard

"It's not how
much we give
but how much
love we put
into giving."

~ Mother Teresa

Research is Key in the Race for Better Meds for Fragile X

by Mary Beth Langan

We read about Fragile X research. Many of us participate in research studies. This past summer, the FXAM board was honored to help fan the flame of a woman's love of research and open her eyes wider to the opportunities in the field of neurodegenerative and neurodevelopmental disorders research, specifically for FXTAS and Fragile X Syndrome.

Years ago, Veronica Towianski met our Past President Laureen when the Majeske family joined Lakeside Bible Church. Veronica met the three Majeske children and didn't know at the time that the genetic disorder that affects them would affect her own life. In Summer 2015, Laureen helped coordinate an opportunity for Veronica to job shadow at the Todd Lab at the University of Michigan School of Medicine. Dr. Peter Todd co-directs the Michigan Fragile X Clinic and does Fragile X-related research in the neurology lab that he leads.



Veronica may have only job shadowed for a few days, but those days were a turning point for her. She worked with Katelyn Green, a graduate student in Cell and Molecular Biology who joined the lab that year. Veronica assisted Katelyn on experiments with cells and learned how much she loved the field of biology and wanted to work in research.

Veronica returned to school – she's been a student at Macomb Community College and is now in her second year at the University of Detroit Mercy.

As Summer 2017 approached, she knew she wanted more experience with research. Laureen helped again by coordinating a six-week experience at the Todd Lab made possible by a grant from FXAM (a small stipend plus room and board with extended FXAM family member Therese Langan). Veronica got to work again with Katelyn Green and take those 2015 cell experiments much further. They worked with cells with certain repeat levels in their DNA, adding different concentrations of various drugs to study the effects on the cells. Veronica even had the chance to experiment a bit within the experiments during her time in the lab. She started the experience with an open mind, just wanting to learn all that she could. Veronica is so happy that she was offered this opportunity by FXAM. It helped solidify her love of research and expand her knowledge in the world of neurodegenerative disorders.

Back at Detroit Mercy, she has switched her undergraduate program from Biology to Mechanical Engineering. After her Engineering degree, she hopes to do graduate work furthering her knowledge of Biology and research, specifically disease research in the field of cancer or neurodegenerative disease. As a Biotech Engineer, Veronica would like to do research on living organisms in order to understand more in depth how diseases work. This should help to figure out more efficient ways of diagnosing disease and engineering ways to curb their effects and possibly cure the disease.

She's a Titan cross country runner and is now in a better position to go the distance in the field of research. How rewarding for our group to have played a part in her journey!

How wonderful it is that nobody need wait a single moment before starting to improve the world. ~ Anne Frank

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 **October 30** 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 Holiday Party Our Annual Potluck Gathering

Saturday, December 2, 2017 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 27 and share what you'll be adding
to the gathering by contacting

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

Special Guest FXAM February Support Meeting

FX Guru at February meeting!
Save the Date - February, 3, 2018

Dr. Elizabeth Berry-Kravis from the Chicago FX Clinic
will be our special guest.

Childcare will be available. See our January newsletter for details.

From the President's Desk by Heather Van Dam

As I write this, I am preparing to travel to Minneapolis to take part in the National Fragile X Foundation Leadership Summit. Community Support Network leaders from around the country will be connecting, collaborating and discussing plans for the upcoming year, including what we can do to on the national, state and local levels to help families and individuals who are affected by Fragile X every day. This includes Advocacy Day in Washington, D.C. in March 2018 and the 2018 NFXF International Fragile X Conference in Cincinnati in July 2018 (how lucky for our group that this year's conference is only a short drive from Michigan!). I'm excited to learn what the NFXF has planned for the

upcoming year.

I'm also looking forward to the Fragile X Association of Michigan annual board meeting in November. We will be looking ahead and planning for 2018. We will be considering what to host that would be beneficial to our families, from fun family gatherings and playdates to local educational speakers and scholarships to help families attend the Cincinnati NFXF Conference next July. We'll also be looking at ways to extend our reach and impact more families throughout Michigan. Our goals are to "enrich lives through educational and emotional support, promote public and professional awareness, advance research toward improved treatments

and a cure for Fragile X and its associated disorders." I and all of the FXAM board members are committed to meeting these goals. We want to hear from our Michigan families. Please email me at fab4fam@comcast.net and let me know your ideas!

I hope to see many of you at upcoming FXAM meetings and events, including our Holiday Gathering on December 2. It's a fun party and a great way to toast the end of 2017 in celebration with our FXAM family.



University of Michigan Fragile X Clinic by Joe Jacher

Hello from the University of Michigan Fragile X Clinic!

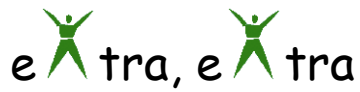
I would like to first commend all of the individuals who helped organize the golf outing in September! We had a wonderful time and were inspired by the dedication and passion from all of families in FXAM. We still have several clinic appointments available through the end of 2017 and we have already set up a partial schedule for 2018. If you are interested in signing up for the FXCRC FORWARD Registry and Database, or would like to make an appointment for any other reason, please contact us at 734-764-0579. More information on the Registry and Database can be found online at <http://forwardfx.org/>.

Joe Jacher, MS, CGC
Genetic Counselor
Fragile X Clinic Coordinator

Our upcoming clinic schedule is listed below:

2017/18 Fragile X Clinic Dates

November 2	November 16
December 7	December 21
January 4	January 18
February 1	February 22
March 1	March 15



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FXAM.org



**Thank You
to all who
supported our**



**18th Annual
Golf Outing**



FRAGILE X ASSOCIATION
OF MICHIGAN

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