



FRAGILE X ASSOCIATION OF MICHIGAN

eXtra, eXtra

Volume XII, Issue 3, July 2016

Mark Your Calendar

Support Meetings

First Saturday of the Month
(No meetings in July, August & September)

When:

October 1, 2016
November 5, 2016

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:

Happy Fragile X Awareness Month!

July 20-24, 2016

15th International Fragile X Conference
San Antonio, Texas

August 6, 2016

FXAM Family Picnic
See page 5.

September 10, 2016

17th Annual FXAM Golf Outing
See page 3.

Fragile X Association of Michigan

FXAM.org

Contact Information:

313-381-2834

southeastMI@fragilex.org

Three Cheers for...

Our Graduates



Andrew Langan Coutilish

School: Parcels Middle School
(Grosse Pointe Woods)

Favorite subject: PE (only on swim days)

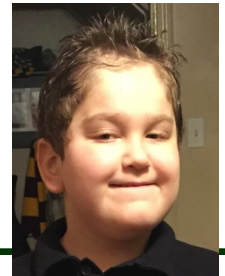
Future plans: Attending Dad's alma mater, Grosse Pointe North High School

Nicholas Weber

School: South Lyon High School

Favorite subject: Band

Future plans: Annoying my sisters all summer and the post-secondary program at SLHS. See page 4.



Nick Hansen

School: Newaygo High School

Favorite subject: Work Study, Oil & Lube

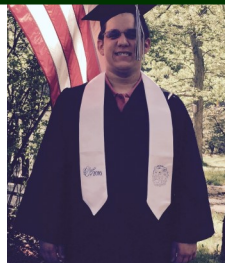
Future plans: Will attend a community based program in the fall.

Riddick Martin

School: Washington Elementary

Favorite subject: Writing/Art

Future plans: Attending Wilson Middle School (Wyandotte) in the fall.



The Popejoy Family and their journey to independence. See page 2.

Melissa Morrison, author of *My Journey with Mickey*, will be doing a book signing and fragile X awareness event at the Lone Ranger Day Parade in downtown Oxford on August 6 from 10 am to 4 pm.



Journey to Independence *by Malinda Popejoy*

When my son Adam turned 19, I was at my wit's end and needed help. For some reason, it was hard for me to reach out for help, but it is what we all needed. He is very moody and sometimes mean to me and his sister Amber. I chose Managed Care Network and a couple of people came out to the house for some visits with the family. The case manager was very prompt in getting us an agency to get a staff member to look after Adam. We ended up going through five different staff members in six months. That was challenging - having someone in your home most evenings. Then I asked for housing for Adam. Our case manager gave me some options to look at but I

could not find anywhere that I would feel comfortable leaving him. So we heard of apartments in Westland that have an agency that works with some other adults with disabilities and it was only 15 minutes from our home. We went and checked out the apartments and liked them. Now we needed a roommate for Adam so it could work with his budget. This was the hardest part. I called the school social worker, the case manager was looking, I talked with my church, prayed and a few months later Adam came home and told me he found a friend to live with. I called the young man, talked with him and met with his mother. We all got along well and I could just feel

that we all fit. So Adam moved into the apartment first and his roommate will be moving in August. It is going well and we are all very happy. Now when we see Adam he misses us and is nicer to us. We took Adam out for dinner and before we left, we gave hugs. My heart melted when Adam and Amber were hugging each other! We are all growing from this experience and it feels really good to have made the hard choices that needed to be made.



From the President's Desk *by Laureen Majeske*

I'd like to start by saying congratulations to all of our graduates, from the youngest to the oldest. It has been amazing to see how far all of you have come and all of the wonderful things you are doing. If you can dream it, you can reach it. We are so proud of all of your accomplishments.

We have had some really fun events over the past few months, from creating pottery, to trying gymnastics, to meeting up with the moms, to some awesome support group meetings and more. Over the last couple of years we have been putting a stronger emphasis on family fun, offering many different activities for groups of all ages for little to no

cost to the families. We are pleased to see so many people taking advantage of these opportunities while also having the chance to encourage and support each other. We are always open to new ideas so let us know what else you would like to see. Still coming up for this summer is our popular Family Picnic hosted by Sulie Tyler and Jeff Buikema. Our wonderful members have been opening their homes to us to offer a safe and calmer environment for our kids during this annual event. If you have previously attended the picnic when we held it at a park and it was too much for your child, I encourage you to try again this year in this different format. It is

the one place you can go and be completely accepted by the people who understand the most.

Our Annual Golf Fundraiser is just around the corner as well. This is such a fun time, whether you golf or not. We are also looking for prize table additions (fun little prizes, gift cards, golf paraphernalia, etc.) and for larger raffle items (BBQ grill, sports memorabilia, TV, bicycles, higher end items). Let me know if there are any items you would like to donate. We always appreciate the help!

Enjoy your summer and keep us on the calendar!



Let 'Em Know

FRAGILE X AWARENESS MONTH

crowdrise.com/michigan---lek-2016/fundraiser/fragile-x-association-of-michigan/join



**FRAGILE X ASSOCIATION
OF MICHIGAN**



17TH ANNUAL GOLF OUTING GOLF & DINNER REGISTRATION FORM

Where: **Wesburn Golf & Country Club**

5617 S. Huron River Drive, South Rockwood, (one mile west of I-75, exit 26)

When: Saturday, September 10, 2016

12:15 p.m. registration, shotgun start at 1:15 p.m. (four-person scramble)

Cost: \$95 per person includes: open driving range before the start, hotdogs and refreshments before and during the round, golf and cart fees, dinner, participation gift, and door prizes.

****If you can't make it for golf, please come for dinner about 6:00 p.m. Dinner, refreshments, door prizes, and a participation gift included for \$50.**

ALL PROCEEDS WILL GO TOWARDS RAISING AWARENESS, SUPPORTING RESEARCH AND AIDING LOCAL FAMILIES AFFECTED BY FRAGILE X



Please list members of your foursome below, along with their shirt sizes.

****If you are a single golfer or do not have a complete foursome, we will match you up.**

1. _____
Name Size

2. _____
Name Size

3. _____
Name Size

4. _____
Name Size

Please mail payment/donation payable to the **Fragile X Association of Michigan** to:

Nina & Frank Liberati
9068 Quandt, Allen Park, MI 48101
313-381-2834/nliberati@yahoo.com

Nicholas by Alexia (aka Mom)



You, my son, have led us on quite an adventure. In the past 20 years, you have taught us all some important life lessons. I've learned to take things one at a time; one day at a time. You did not come with a program guide. Every time I thought I had you figured out, you would change gears lest I get too comfortable. From the day you were born through graduation there were lots of highs and lows with a few curve balls thrown in. Life has not been boring as you kept everyone on their toes trying to get through each day. So proud to see you walk across

that graduation stage. There were times I wondered if we would get that far. I have learned to manage every emotion and to expect the unexpected. From the day I cried proudly as I put my two oldest kiddos on the bus on the same day to the proud tears watching my youngest two cross that stage. There have been many, many, tears over the years. Tears of sadness (diagnosis day), tears of laughter (lots of those), tears of anger (IEP days), tears of pride (milestones met, Special Olympics, just being you).

A quote from your sister on your birthday: "This is my brother, he is autistic and has fragile x syndrome; but most importantly my best friend. I hold nothing from him. Moments

such as learning new words or remembering corny jokes are huge improvements. People may see his disability but I see a bright young man and that's all that matters. I am so proud of all he has accomplished in his life."

You have grown into a beautiful young man I am proud to call 'son'. Even though some days seemed to drag on forever, these 20 years have flown by. I miss my little guy, but love the man you've become. Continue to grow and learn. Pass me an outline of the plan along the way so I can keep up. The stars and moon are yours for the taking. Soar away!



NIH RESEARCH STUDY

This research seeks to understand how protein formation in the brain is affected in fragile X syndrome (FXS). Researchers will measure the rate at which the brain makes proteins (protein synthesis) and will identify specific parts of the brain affected in FXS. In the future, measurement of protein synthesis in FXS may help us to develop and test new therapies.

The study enrolls eligible young men with FXS, ages 18-24, from around the world, and includes:

- One visit, lasting several days, to the NIH Clinical Center, in Bethesda, Maryland.

- Assessment by physicians

- Blood draw, Two brain scans (PET & MRI), possible sedation

- Travel, food, and lodging are covered and include the patient and one or two accompanying family members.

- Compensation is paid for your time and assistance.

Please consider enrolling your child in our clinical research study of FXS. If you would like to participate, be on our mailing list, be contacted in case of future studies, or would simply like to have more information: Please call Inna Loutaev, +1 301 496 4707, or E-mail loutaev.inna@nih.gov, or visit our website: <http://patientinfo.nimh.nih.gov/>

Department of Health & Human Services, National Institutes of Health, National Institute of Mental Health, www.clinicaltrials.gov 06-M-0214

What's going on ...

FXAM Family Picnic



Saturday, August 6, 2016
12 - 3 p.m.



Our annual picnic will be at the Tyler-Buikema home
Sulie, Jeff, Indigo, (Jarrett will be out of town) and Keir

FXAM will provide hotdogs, drinks and a bounce house. Jeff and Sulie will provide smoked pulled pork, mac and cheese, and baked beans. We suggest you bring an appetizer, side dish, salad (any kind, potato, tossed, coleslaw, fruit, etc.) OR a dessert. As you respond YES, you'll be able to write a message saying what you're adding to the picnic. Also welcome are chairs (we'll have some, but more would be good), picnic blankets and, if desired, your choice of adult beverage.

Here is a link to an Evite we created, which we can use for potluck sign up: <http://evite.me/FNDv9rAxqC>
or RSVP to suliet@wideopenwest.com and I will add your email to the evite.

Hope to see you at the picnic!

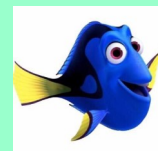
Through the Maze - Featured Website

Help your Child Cope with Fireworks Displays

families.com/blog/help-your-child-cope-with-fireworks-displays

This might be a little late for this year but if you think ahead, based on your recent experiences this is an excellent resource for future events. The 4th of July can be very threatening for a child or adult with sensory issues related to noise. The Nantais family is fortunate enough to have an escape plan, our summer mobile home is in a park which doesn't allow fireworks of any kind. Yet I still vividly remember the sheer panic that ensued one year when we didn't have this escape option. Mama Bear came out and read a few neighbors the riot act after more than 1.5 hours of an assault on Austin's well being. Visit fxam.org/resources.html for helpful strategies for numerous holidays.

"When life gets you down, do you wanna know what you've gotta do? JUST KEEP SWIMMING, JUST KEEP SWIMMING, JUST KEEP SWIMMING!" ~ Dory



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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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FXAM.org



Jacob Price participated on his North Farmington High School swim team this past year. Some of the events he swam included 50 freestyle, 50 breaststroke and 100 freestyle. Jake was even in a 200 freestyle relay! Here he is shown with two of his biggest fans, Grandma and Grandpa Price.



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