

**Mark Your
Calendar**

Support Meetings

First Saturday
of the Month
(no summer meetings)

When:

October 5, 2013
November 2, 2013

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:

July 21, 2013

A Day at the Park
Holt, see page 2.

July 28, 2013

FXAM Picnic & 5K
Clarkston, see page 2.

September 7, 2013

**14th Annual Golf
Outing, South**
Rockwood, see page 4.

September 20, 2013

**Hansen 7th Annual
Golf Outing,**
Kent City, see page 3.

**Fragile X Association of
Michigan**

Contact Information:

313-381-2834

FXAM.org

Three Cheers for... Our Graduates



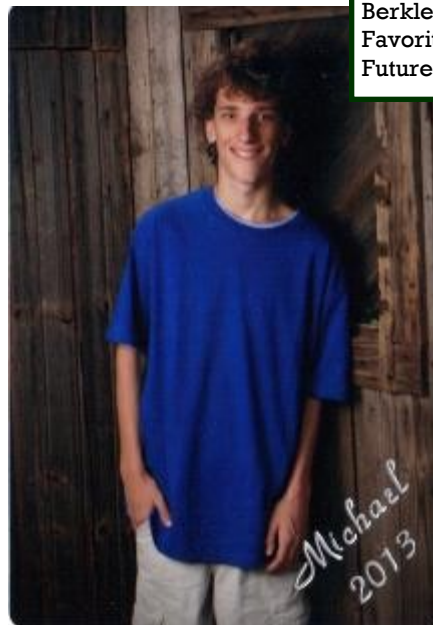
Ayden Abouelseoud

Kindergarten @ Elliot Elementary, Holt
Favorite Subject: Reading
Future Plans: Play Plants vs. Zombies with
Daddy!



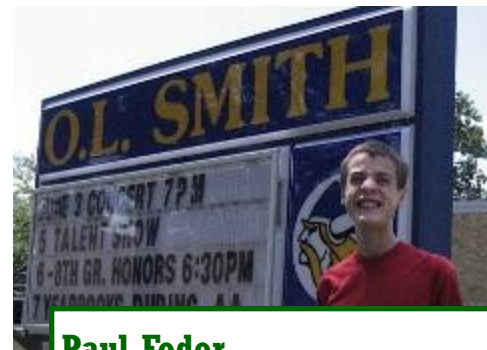
Maggie Branch

Berkshire Middle School
Favorite Class: Theatre Arts
Future Plans: Working as a sous chef



Michael Vickey

Berkley High School
Favorite Subject: Ceramics & PE
Future Plans: Sleeping Everyday!



Paul Fodor

O. L. Smith Middle School, Dearborn
Favorite Subject: Swimming in Gym
Future Plans: Spending lots of time in the pool



Andrew Langan Coutilish

Ferry Elementary, Grosse Pointe Woods
Favorite Subjects: Music & Speech
Future Plans: Detroit RiverWalk time!



Genevieve Nantais

Wilson Middle School, Wyandotte
Favorite Subject: Science
Future Plans: Attend college and play hockey

A Day at the Park - Fragile X Awareness/Fundraiser Event

Sponsored by Michigan Miller Mutual Insurance Company

delhitownship.com/parks-parkinfo.htm

Sunday, July 21, 2013

2 to 5 p.m.

Valhalla Park
4000 Keller Rd
Holt, MI 48842

A Day At The Park is an event to raise awareness and money for Fragile X.

This is Courtney and Sherief Abouelseoud's first fundraiser/awareness event for Fragile X in Mid-Michigan!

The fundraiser will coincide with National Fragile X Awareness Day which occurs on July 22 each year.

The day of the event, there will be a bake sale as well as a raffle. There will be an online thirty-one fundraiser running the month of July as well. For more details visit

fxam.org/Events.html

All proceeds from the event will benefit the Fragile X Association of Michigan and the National Fragile X Foundation.



Fragile X 5K Fun Run/Walk and Picnic

destinationoakland.com/parksandtrails/parks/independenceoaks/

Sunday, July 28, 2013

RUN/WALK

10:00 Registration Opens

11:00 Race Starts

\$20 Pre-registration

\$25 Day of the Race

\$10 Children under 15 &

Individuals with fragile X

Register at:

fxam.org/Events.html

PICNIC

12:00 Food Served

1:00 iPad Mini Raffle

1:00-3:00 Fun Day Games

3:00 Raffle Drawings

Picnic RSVP by

July 23, 2013

Independence Oaks
Twin Chimneys Shelter
9501 Sashabaw Road
Clarkston, Michigan

The picnic follows the Fragile X 5K Fun Run/Walk Registrations accepted the day of the race for the run. One does not have to participate in the 5K to attend the picnic.

There is no charge to attend the picnic, however, there is a \$5 vehicle entry fee to be paid at the park's entry gate and FXAM families are asked to bring a dish to pass.

Families last name beginning with **A-M** please bring a side dish.

Families last name beginning with **N-Z** please bring a dessert.

Let 'Em Know 5K

Virtual Run, Walk or Stroll for Fragile X

National Fragile X Awareness Month

July 2013

<http://www.fxam.org/Fundraising.html>

Girls Night Out - Chicago - Research Study

Do you need a little respite in July, August or September?

Here's the perfect opportunity. A Fragile X Female Carrier Study is being conducted in Chicago and not only do they need female carriers but they need control subjects as well. A control subject is an individual who is not a carrier of fragile X.

Grab a friend, drive in on Tuesday and enjoy Chicago before participating in needed research! The study visits are **only** on Wednesdays.

If it's impossible for you to get away but you have a friend, who is not a fragile X carrier, and they would like to participate in research please share this information.

The goal of the study is to find out whether certain medical illnesses are more common in female Fragile X carriers compared to women who are not carriers. They will screen for neurologic problems (for example tremor or walking difficulties) and endocrine problems (like thyroid disease). They are also looking at what might be causing these symptoms by studying the fragile X gene and protein in blood and skin cells.

The study visit itself will begin at 8 a.m. and last approximately 5 hours including a few breaks. You would meet a neurologist, a neuropsychologist and an endocrinologist, along with filling out some questionnaires.

If you are interested and/or would like to learn more, please contact Tracy Waliczek at 312-563-2848.

Hansen 7th Annual Fragile X Golf Outing



Friday, September 20, 2013

The Falls at Barber Creek
16030 Barber Creek Avenue
Kent City, Michigan
thefallsatbarbercreek.com

Four person, 18 hole
scramble.

Registration: 8 a.m.

Shotgun start: 9 a.m.

Dinner and awards: 3 p.m.

Player registration: \$50

Hole sponsorship: \$50

For more info contact

Kate Hansen at

kathrynh1129@yahoo.com or
231-519-2349

Between the Lines - Featured Book

Perfect Game by Fred Bowen

Isaac is a serious pitcher who wants a perfect game. But he loses his cool and can't get his head back in the game. Then Isaac learns about a Special Olympics Unified Sports team and meets an interesting athlete who shows him a whole new way to think about perfect.

The interesting athlete is Kevin, who has fragile X syndrome. Written for "middle readers" but a great story for the whole family!

**The game isn't over
until it's over.**

~ Yogi Berra



14TH ANNUAL GOLF OUTING GOLF & DINNER REGISTRATION FORM

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

When: Saturday, September 7, 2013
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

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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. _____ | _____ | 2. _____ | _____ |
| Name | Size | Name | Size |
| 3. _____ | _____ | 4. _____ | _____ |
| Name | Size | Name | Size |

____ I/We cannot make it for golf, but please include us for dinner. (Please fill in names and shirt sizes above and enclose \$50 per person.)

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

From the President's Desk *by Laureen Majeske*

FINALLY summer is in full swing and so are we! Our next big event is the family picnic and 5K. Come on out and walk or run the beautiful course around the lake at Independence Oaks. There is even a short cut for the walkers if you don't want to do the whole course! Every participant gets a run shirt and one free raffle ticket for an iPad mini. (Additional tickets can be purchased as well.) Then stop over to the pavilion for lunch and family fun. The picnic is a great opportunity to meet other families and make new friends. We are planning many fun activities and games for both children and adults this year. You do not want to miss it! Check the newsletter and the FXAM website for registration information. We'd love to see you at the picnic even if you choose to skip the 5K!

It's also time to register for our annual Golf Fundraiser. You DO NOT have to be a golfer to participate! There are many people who are first timers. It is just a fun day to get together, hang out on the golf course, have hot dogs for lunch and a steak dinner later, win prizes and have a lot of laughs. Even our seasoned golfers say it is one of the best charity fundraisers they've ever attended and come back year after year. You can also help by sponsoring a hole or getting your company to sponsor a hole. See registration form for more information. This event helps us to provide scholarships for families to attend the International FX Conferences and financing for the many events we put on during the year.



Please check this newsletter for Mid-Michigan and West Michigan events. Fragile X is all over our state!

Thank you to all of the families who attended our fundraiser at The Palace. It was fun to shoot baskets on the Pistons' court, and equally fun to watch Dr. Liz Berry-Kravis shoot baskets too! Many thanks to the Cohens and the Gelfands for their hard work to host this fun event! The money is being split between the Rosen-Weingarten Research Fund and the Fragile X Association of Michigan.

Enjoy your summer!

Through the Maze - Featured Website Fragile X and Autism Families for STX209 Our stories ~ Our hopes stx209stories.com



What happens when a clinical drug trial terminates early? For me, Sally Nantais, it created devastation and shattered dreams. Like many, I soon discovered I was not alone. So we do what we do best, we band together and become the advocates our children and our community need us to be.

Arbaclofen (STX209) was in Phase III testing for fragile X syndrome and Phase II testing for autism. Both of these clinical trials had optional extensions if families found success with use of the drug.

On May 15, 2013 Seaside Therapeutics, Inc., the sponsor of Arbaclofen, sent a communication to the clinics involved in the administration of Arbaclofen stating the following: "We regret to inform you that Study 209FX303 [An Open-Label Extension Study to Evaluate the Safety, Tolerability, and Pharmacokinetics of STX209 (arbaclofen) in subjects with Fragile X Syndrome] is being terminated immediately. The closure of the study is due to resource limitations at Seaside Therapeutics, Inc., and is not related to any known safety issues in patients dosed with STX209."

Visit stx209stories.com where many families have shared their journeys.

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FXAM.org



Three Cheers for ...

Kevin McLean on his participation on the Anchor Bay Track Team and his graduation from Anchor Bay High School. Marie and Mark Weaver's proud smiles say it all! His favorite subject in school is building maintenance. He likes to clean and sweep and work for Mr. John and Mr. Earl. His favorite teacher is Mrs. Dolores Jones-Hoffmann. His plans for the future include attending life skills classes in Macomb county and hopefully working part-time independently as a cart wrangler for Kroger or washing dishes for a local restaurant.

 **Fragile X**
Association of Michigan

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