

**Mark Your  
Calendar**

**Support Meetings**

First Saturday  
of the Month  
(no meeting in December  
and January)

*When:*

**November 2, 2013**  
**February 1, 2014**

**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:**

**December 7, 2013**

**FXAM Holiday Party**  
See page 4.

**March 4 - 5, 2014**

**Advocacy Day**  
Washington, D.C.

**Fragile X Association of  
Michigan**

Contact Information:

**313-381-2834**

**FXAM.org**

A member of the

**NFXF LINKS Network**

(Linking Individuals  
Nationally in  
Knowledge and  
Support)

**Three Cheers for...**



**A Day at the Park**  
See page 2.



**Picnic & 5K Fun Run/Walk**  
See page 2.



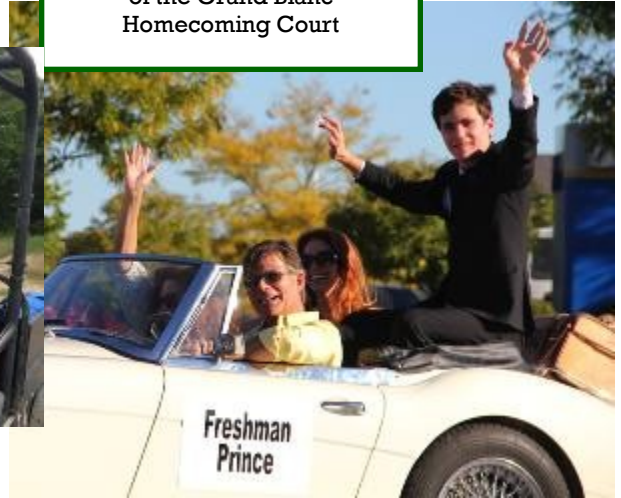
**14th Annual FXAM Golf  
Outing** See page 3.



**7th Annual Hansen Golf  
Outing** See page 4.



**Prince Aidan Silverton**  
of the Grand Blanc  
Homecoming Court



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

Sponsored by Michigan Miller Mutual Insurance Company

On July 21, 2013, Cortney and Sherief Abouelseoud hosted the first mid-Michigan Fragile X Awareness Day event called A Day at the Park.

The weather was beautiful and we had a great time talking about and sharing Fragile X with those in the community. The kids spent their time eating popsicles and playing on the park equipment while the adults mostly just chatted and relaxed. At the end of the afternoon, we had a raffle where we had so many generous

donations that at least one person from each family was able to go home with a raffle item! Overall we had between 50-75 people attend throughout the day and were able to get a group shot of most of them near the end. The event was very generously sponsored by Michigan Miller Insurance Company. We were really excited to meet our fundraising goal for our first year and split the donations between the National Fragile X Foundation and FXAM!



## Fragile X 5K Fun Run/Walk and Picnic

By Kim Young

"As we work to create light for others, we naturally light our own way."

~ Mary Anne Radmacher

Summer flew by in a flash and so did the participants at this year's Fragile X 5K Fun Run/Walk and Family Picnic. We had record attendance this year, drawing from many of the local high school cross country teams! 95 runners and walkers came out to race through the wooded trails of

Independence Oaks County Park, in Clarkston. My better half, Mike, manned the grill again this year cooking for a record wrap-around line. The weather always seems to threaten us each year, but it managed to hold off until after all of the festivities. A great day was had by all again this year!

## Moving Forward: Meet the NFXF's Interim Executive Director

Jeffrey Cohen, FXAM member, is the new interim executive director of the National Fragile X Foundation. Cohen, who succeeds Robby Miller, has a long association with the Foundation. He joined the NFXF Board of Directors in 1996 and served until 2010. During that time, he was board president from 1997-2003

and was chair of the Public Policy Committee from 2003-10. Since 2011, he has served as the NFXF Director of Government Affairs and Advocacy. Cohen earned degrees in business administration and law from Wayne State University. He lives with his wife, Arlene; son, Josh; and daughter, Alli; in West Bloomfield. Both of

their children are affected by fragile X syndrome.

Congratulations to Jeffrey and the NFXF!



## Fourteenth Annual FXAM Golf Outing

The 14th Annual Fragile X Association of Michigan Golf Outing on September 7 was once again a huge success! The **121** golfers (a record number) teed off at approximately 1 p.m. and everyone had a great time during the 4-person scramble. Afterwards **153** 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** as organizers of this event each year. The 14th Annual Golf Outing raised approximately **\$16,300** 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!

**The Mickelson (\$1,300+)**  
**Kenwal Steel Corporation**  
**Bob Mannino**

**The Nicklaus (\$1,000+)**  
**UAW - Ford Local 900**

**The Palmer (\$500+)**  
**Mike & Stella Banich**  
**Jeff Meltzer/Jem Industries**  
**Men's Wearhouse**  
**John & Nancy Warneck**  
**Watson Engineering**

**The Watson (\$250+)**  
**C. Hawker & Associates**  
**Evelyn Kosch-Mannino**  
**Mr. Joe's Sports Bar**  
**OK Foods**

**The Player (\$150+)**  
**Advantage/Waypoint**

**Arnaldo's Banquet Center**  
**Jerry & Karen Bishop**  
**Florence Coleman (In Honor Of Richard)**

**Dearborn Brand**  
**Family Dentistry PC**  
**Father Saylor K of C #3774**  
**Green Lantern Pizzeria LLC**

**John & Kate Hansen**  
**International Paper**  
**Kiwanis Club of Allen Park**  
**Lakeshore Utility**  
**Law Offices of Miller & Miller, PC**

**Liberati's Italian Deli & Bakery**  
**Liberati & Sons Construction**  
**Papa & Mama Rose Liberati**  
**Lincoln Park Community Credit Union**

**McInerney's Chrysler Dodge Jeep**  
**Austin, Natalie & Genevieve Nantais**

**Nichols Ski & Snowboard**  
**Pomponio Construction**  
**Rony's Body Shop**  
**Charlie & Inez Roy**  
**Sartori Company**  
**Sue Shannon**

**Silverton Skin Institute**  
**Sorrento Cheese Company**  
**Southfield Chrysler, Dodge, Jeep, Ram**

**Theresa Sternicki**  
**Frank Urban**  
**James & Cindy Vickey**  
**Weed Eraser, Inc**  
**The Wurth Family**  
**Judith Zarkis**

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

**Agemy & Sons Market**  
**Anthony Aratari**

**Bob & Pat Asmussen**  
**Jim & Julie Bademian**  
**Cathy Bartolotta**  
**Brennan Jewelry**  
**Nick & Kelsey Coleman**  
**Rosalea Colucci**  
**Escalon Premier Brand Tomatoes**  
**Tyler Fabrey**  
**Karen, Paul & Katie Fodor**  
**Joann Forde**  
**Lori Friesner**  
**J. Goulasarian Contracting**  
**Joan Grab**  
**Rosalie Guerra**  
**Mary Hancock**  
**William & Kim Holdsworth**  
**George & Barbara Jakubik**  
**Levon & Gloria King**  
**Kelly Koson**  
**Mary Beth Langan**  
**Deborah Lee**  
**Susan Leigh**  
**Angelo & Nick Liberati**  
**Tullio Liberati Jr.**  
**Tullio Liberati III**  
**Len & Peggy Majeske**  
**Tony & Dora Mangiapane**  
**Nancy Marosi**  
**Stella Marzano**  
**Jeannette McMillan**  
**Marty & Lesa Melhorn**  
**Nolan Muzzin**  
**Sally Nantais**  
**The Orchards Golf Club**  
**Jerome & Jeannette Pearsons**  
**Pia's Restaurant**  
**Felice Piroli**  
**Grace & Sam Pizzo**  
**Virginio & Anna Reale**  
**Sheryl & Rachael Roman**  
**Roselli Foods**  
**Lester & Lisa Voutsos**  
**Kevin & Laura Weston**  
**Mitch & Fran Wolski**  
**Nazar & Sue Zain**

## Greetings from the University of Michigan Fragile X Clinic!

By Kailey Owens, Clinic Coordinator

It was wonderful to talk with so many families at the FXAM Annual Golf Outing and spread the word about the FXCRC FORWARD Registry and Database that our clinic is participating in.

We still have openings for clinic appointments through the end of 2013, so please give me a call if you would like to schedule a time to meet with our doctors in the clinic. Our

schedule for 2014 is in progress, so look for a future announcement regarding dates for next year.

We are thrilled to announce that we have been in talks with a pharmaceutical company and have applied to be a site for an upcoming clinical drug trial. Stay tuned for further announcements regarding recruitment if we are chosen to participate!

### FXCRC FORWARD Registry and Database

If you haven't joined and are interested, please contact me at:

(734) 615-3591

More information on the Registry and Database can be found online at [fxcrc.org](http://fxcrc.org)

### Holiday Party

**Saturday, December 7, 2013 at 5 pm**

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

**Cohen Family Home**

**West Bloomfield, MI**

More info will arrive via email and FXAM Facebook Page or contact Arlene at [arjsc@comcast.net](mailto:arjsc@comcast.net) or 248-568-1236

### 7th Annual Hansen Golf Outing

The Hansen 7th Annual Fragile X Golf Classic at The Falls at Barber Creek, in Kent City, was a big success!

We ended up with 62 golfers and with a donation from Verizon, we have raised \$5,100 which was donated directly to FXAM.

Thank You to all those who donated, participated, and were otherwise involved in making it a fun day. A special thanks to the Liberati Family for making the trip to golf with us!

### Aidan Silverton *(see cover photo)*

Read the real-life fairy tale of  
**Prince Aidan Silverton  
and Princess Hannah Abdelkader**  
at

[mlive.com/news/flint/index.ssf/2013/09/  
grand\\_blanc\\_homecoming\\_to\\_reme.html](http://mlive.com/news/flint/index.ssf/2013/09/grand_blanc_homecoming_to_reme.html)

**It has a happy ending  
everyone will love!**

## From the President's Desk *by Lauren Majeske*

Such a wonderful summer; I'm sad to see it end. We had so much fun at our family picnic with the largest turnout of walkers/runners we've ever had with a total of 95! The young lady who won the iPad mini found us through the extensive advertising we did this year and came out to support fragile x. She was very excited to win! Soon after that was our annual golf outing. Next year we will be celebrating the fifteenth year of golf having raised well over \$150,000 toward serving Michigan families! We

are so appreciative of the families and businesses who support us year after year so that we can bring you fun family events, current medical information and speakers, and support in numerous ways.

Make sure to read this issue's update from our Michigan Fragile X Clinic. As they meet and treat more Michigan families, they are getting stronger and stronger as a clinic serving people with fragile x-associated disorders. I encourage you to join the fragile x

registry because clinical trials will be available in the not-too-distant future.

Please remember to send all updated home addresses, email addresses and phone numbers to

Mary Beth Langan  
mblangan@hotmail.com



so that you will not miss out on any important news!

See you at one of our upcoming FXAM events!



## Back to School... Fragile X Style!



e  tra, e  tra

Editors:

Mary Beth Langan 313-881-3340

mblangan@hotmail.com

Sally Nantais 734-282-7910

sallyn423@wyam.org

This newsletter is published quarterly and sent to all members and supporters of FXAM. Permission is granted to reproduce and distribute this newsletter for noncommercial purposes.

Electronic copies of our newsletter are available on our website. If you would like to share them with family, friends or professionals, please share our web address with them.

[FXAM.org](http://FXAM.org)



 **Fragile X**  
Association of Michigan

P.O. Box 1414

Troy, MI 48099-1414