

**Mark Your Calendar**

**Support Meetings**

First Saturday of the Month

*When:*

November 3, 2012  
February 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:**

**November 11, 2012**



Dine out for Fragile X!  
See page 3.

**December 1, 2012**

**FXAM Holiday Party**  
See page 3.

**March 5-6, 2013**

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

**Fragile X Association of Michigan**

**313-381-2834**

**FXAM.org**

**contact@fxam.org**

**Three Cheers for...**



**Mary Beth and Ted** - On July 27, at the 13th Annual International Fragile X Conference in Miami, FXAM's own Jeff Cohen presented Mary Beth Langan and Ted Coutilish with the Halstead-Bresnahan Family Award. NFXF presents this award every two years recognizing those who make a profound difference to families affected by Fragile X Syndrome.

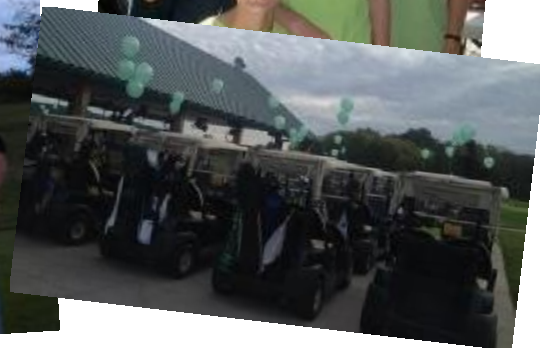
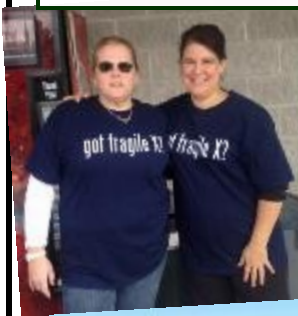
**Participants of the Fragile X 5K Fun Run/Walk & Family Picnic**

- Jeff and Ryan Roman kick up their heels for Fragile X. Charlie and Amy Lund cross the finish line with Andrew Young close behind.

See page 5.



**Golfers for Fragile X across the state**



## Apps for iDevices (iPhone, iPod, iPad) by Bonnie Korman



### Choiceworks

by Bee Visual, LLC (\$9.99)

I have long known the need to have a picture schedule system for my two (currently seven-year-old) boys with Fragile X. I've tried more than once to use handmade PECS pictures, either in a binder or up on a board. The pictures constantly get lost, chewed on, vacuumed, or otherwise mysteriously destroyed. I end up having to make more and more images. I get paper cuts and have recurring nightmares about my fingers being sucked into the laminator.

Then, we got an iPad. And I saw the possibilities. If I could find a good schedule app to use with the boys, I could eliminate the hassle of creating and then losing all those little cards.

Somehow I stumbled upon Choiceworks. I honestly don't remember if it happened to find it in a search in the App Store, or whether I heard about it elsewhere. I follow Moms With Apps and Free App of the Day, so I may have found it through there.

Choiceworks is very simple to use, which is nice if you don't want to spend a great deal of time setting up schedules. And who does? You can

create as many schedule boards as you like. Each schedule board you create will have the same, familiar, vertical layout, with the list of activities on the left and an "all done" column on the right. When my sons complete an activity, they can come over and touch the screen to move the activity over to the "all done" column. Sliding the activities over to the "all done" column is great fun and extremely satisfying for my boys. In fact it's so fun, I have to stop them from going ahead and sliding all the items over to the "all done" column first thing every morning.



There are several aspects of Choiceworks that I really like:

1. Using my own pictures. I love that I can upload my own photos to the app, name them whatever I like, and then use them in the schedules. I had to add images for Target, Doritos, and Grandma and Grandpa right away.
2. Creating as many schedules as I need. I can have a different one for every day of the week. Some days we have speech therapy after school. Some days we drive sister to her dance class. Every day is different, and the changes I have to make are minimal since I can have them set up for each individual day.
3. The number of steps you can put into a schedule is limited to eight. At

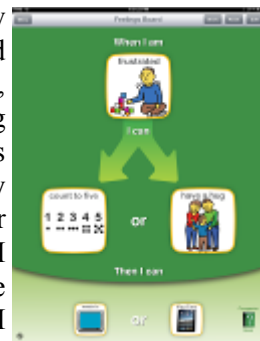
first I was annoyed by that, but it turned out to be a very great blessing in disguise. I have a tendency to get bogged down in the details of the day, and when you think about it, can't even the busiest day be simplified to eight small steps? It forced me to break down our days into more general steps, which was good for both the boys and for me.

And if the day can't be planned with only eight images, you could have a "Morning" schedule, an "Afternoon" and an "Evening."

And as far as that goes, you could have a special schedules for trips to the dentist, cleaning up a bedroom, getting dressed, going to church - just about anything you need to get a child through in a day.

Choiceworks has two other types of boards you can personalize - Feelings boards, for describing how a child is feeling and how to cope, and Waiting boards, for planning specific activities to keep busy while waiting for something. I haven't made use of those boards. I can see where they might come in handy someday, and I don't rule out ever using them. I just haven't made that part of our routine. But the schedule boards do go a long way toward helping my boys see the process of our routines and get through them step by step.

*Bonnie Korman is the LINKS leader of Fragile X of Minnesota. She's the mother of three children, including twin boys with Fragile X. In her spare time, she blogs about life including Fragile X at [www.fragilexfiles.com](http://www.fragilexfiles.com).*



## From the President's Desk by Lauren Majeske



There is a chill in the air, but not for us! FXAM is on fire! In August we had a great turnout for our 5K and family picnic. It sprinkled a little and then cleared up for a great day. Lots of new faces this year, we loved meeting you! Thanks to Kim Young for all of your hard work.

September brought us our annual golf fundraiser hosted by the Liberatis. We had a full roster this year, with only room enough for one or two more teams; (Register early next year) this event filled up fast this year. The weather was great, the people are always wonderful, and we had some really great prizes. It doesn't get any better than this, and to top it off, we raised over \$17,000! We appreciate all of our supporters; we couldn't do it without you. SO many families are helped during the year; your money is put to good use! The Hansen family also hosted their

own annual Kent City golf outing. Some of us went up to golf with them and it was a super fun time! They have lots of fun games and prizes at the holes. Trying to hit the row boat in the middle of the lake is ADDICTING. I just know I'll hit it next year! And hot chili out on the course - what a brilliant idea on a cool day! Thanks so much for your support, Hansen family and friends!

And by the time you read this we will have participated in the Healthy Edge Non-Profit Health Expo and What About You Walk at Eastern Michigan University. I can tell you that this is a great event, highly organized by Christie Clipper, along with the talents of our own Ted Coutilish. This year we are giving out "got fragile x?" backpacks to all of the participants and I am looking forward to seeing these orange bags all over campus! Funds from this

event are going to support the fragile x clinic at the University of Michigan. The more we raise, the sooner we'll be able to hire a research coordinator for the clinic and begin having Fragile X drug trials in Michigan.

We are working with Warren Global Conferencing to try to set up a system where you can call into our meetings if you live too far away to attend. We want everyone who needs support to get it! Stay posted for more information. Make sure you're on our email list; contact Mary Beth to be added.

I look forward to seeing you at our next support group meeting on November 3 and at our December 1 FXAM holiday party!

### Dine out for Fragile X!

Sunday, November 11, 2012

Dine out with friends and family. Mention Fragile X at the register and 25% goes to FXAM!

**Noodles & Company**  
470 S. Main Street  
Royal Oak, MI 48067  
248-548-7700

Fundraising hours are from 4 - 9 p.m.  
Check out directions, menu and more at [noodles.com/RoyalOak](http://noodles.com/RoyalOak)

Download the flyer at [fxam.org](http://fxam.org) or make copies of the flyer between pages 4 and 5. Share the info with friends, family, colleagues, neighbors, etc via email, Facebook, phone calls, Twitter or a text.

### Holiday Party

#### Annual Potluck Gathering

Saturday, December 1, 2012

5 - 9 pm

Langan-Coutilish Home  
Grosse Pointe, MI

More info will arrive via email and FXAM Facebook page or contact Mary Beth at [mblangan@hotmail.com](mailto:mblangan@hotmail.com) or 313-881-3340

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

## The Thirteenth Annual FXAM Golf Outing

The 13th Annual Fragile X Association of Michigan Golf Outing on September 8 was once again a huge success! The rain stopped a couple of hours before the 116 golfers teed off, so everyone was able to have a great time during the 4-person scramble. Afterwards 140 people enjoyed steaks, potatoes, mostaccioli and side dishes under the tent. Door prizes and raffle items were distributed after dinner. 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 Fragile X Association of Michigan continues to be very grateful to **Nina and Frank Liberati** as organizers of this event each year. The 13th Annual Golf Outing raised approximately \$17,500 for the Fragile X cause. Way to go Nina and Frank!

Thank you to everyone who contributed to our success!

The Mickelson (\$1,300+)

**Kenwal Steel Corporation**  
**Steven Lebowski**  
**Bob Mannino**

The Nicklaus (\$1,000+)

The Palmer (\$500+)

**Mike & Stella Banich**  
**Liberty Union**  
**Watson Engineering**

The Watson (\$250+)

**C. Hawker & Associates**  
**Evelyn Kosch-Mannino**  
**Martin Seward**  
**John & Nancy Warneck**

The Player (\$150+)

Adam Holdings LLC  
Architectural Door and  
Millwork  
Arnaldo's Banquet Center  
Jerry & Karen Bishop  
Blue Marlin II, LLC  
Mr & Mrs Dennis Brown

Florence Coleman (In Honor  
of Richard)

Commerce Holdings, LLC  
Cranbrook Partners and Co.  
Dearborn Brand  
Green Lantern Pizzeria, LLC  
H & L Holdings, LLC  
William & Kim Holdsworth  
Anthony Iaquinto  
International Paper  
Father Saylor K of C #3774  
Kiwanis Club of Allen Park  
Mark Kontry P.C.  
Kelly Koson  
Lakeshore Utility  
Law Offices of Miller &  
Miller, PC  
Gary & Donna Lebowski  
Liberati's Italian Deli & Bakery  
Liberati & Sons Construction  
Papa & Mama Rose Liberati  
Lincoln Park Community  
Credit Union  
Mascari Sales and  
Marketing, LLC  
McInerney's Chrysler Dodge  
Jeep  
Mr. Joe's Sport Bar - Southfield  
The Nantais Family  
Pia's, Inc.  
Pierce & Pierce, PC  
Pomponio Construction  
Mark & Malinda Popejoy  
Preferred Brands  
Charlie & Inez Roy  
Sue Shannon  
Silverton Skin Institute  
Mr & Mrs Darcy Smith  
Telegraph Chrysler Dodge  
Jeep Ram  
Theresa Sternicki  
UAW - Ford Local 900  
Kenneth Vance &  
Associates, P.C. James & Cindy  
Vickey  
Weed Eraser, Inc  
Wolff Group, LLC  
The Wurth Family  
Weed Eraser, Inc

David Wujczyk  
The Wurth Family

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  
Mr & Mrs Malcolm Beaton  
Jeffrey Cohen JD, PC  
Nick & Kelsey Coleman  
Mr. Patrick Duerr, JR  
JoAnn Forde  
Fraternal Order of Police,  
Lodge #110  
Lori Friesner  
J. Goulasarian Contracting  
Chrissy Grybel  
Rosalie Guerra  
Mr. & Mrs. M. Hall  
John & Kate Hansen  
Italia Bakery  
George & Barbara Jakubik  
Levon & Gloria King  
Paul Klenczar  
Mary Beth Langan  
Tony & Maria Lalli  
Deborah Lee  
M-Den  
Len & Peggy Majeske  
Tony & Dora Mangiapane  
Jeannette McMillan  
Jerry & Sally Nantais  
The Orchards Golf Club  
Jerome & Jeannette Pearsons  
Virginio & Anna Reale  
Rony's Body Shop, Inc  
Susan Stearns  
John & Susan Sturock  
Lester & Lisa Voutsos  
Mitch & Fran Wolski  
Weight Watchers  
Sheryl Fellows  
Judith Zarkis, The Country  
Store, Romeo

## Fragile X 5K Fun Run/Walk & Family Picnic

All of us living in the fragile X world know all too well about overcoming challenges. The annual Fragile X 5K Run/walk & Family Picnic this past August was no exception! Mother Nature definitely gave us a few weather challenges to overcome. Fortunately, the rain stopped during the run just long enough for us all to breeze through the

wooded trails and return to the shelter for a cozy lunch with friends. Despite the chilly day everyone had a great time and the event was a success.

The Fragile X Association of Michigan would like to extend special thanks to these sponsors:

- Rotpac Racing - for providing our timing for the race every

year at a discount - Rotpac.com

- DVM Enterprises of Linden
- Albaugh Masonry Stone & Tile - Albaumasonry.com

Please think about coming out to join us next summer to enjoy a day of good food, good friends and fun!

**"Not what we have but what we enjoy constitutes our abundance."**

*~ Epicurus (Greek philosopher, BC 341-270)*

### Through the Maze Featured Websites

Ever feel like reading about how Fragile X is affecting another family's life? There are a number of Fragile X parents who blog, including about how daily life in their homes is affected by Fragile X. For some folks, reading about others on a Fragile X journey helps them feel not so alone and as if others understand their lives.

If this interests you... here are some of the Fragile X-related blogs. Enjoy!

**[www.fragilexfiles.com](http://www.fragilexfiles.com)**

**[thefascianos.com](http://thefascianos.com)**

**[ourfxjourney.blogspot.com](http://ourfxjourney.blogspot.com)**

**[mrsrogersfxneighborhood.blogspot.com](http://mrsrogersfxneighborhood.blogspot.com)**

**[basicallyfx.com](http://basicallyfx.com)**

**[lifewithmyxmen.blogspot.com](http://lifewithmyxmen.blogspot.com)**

**[marcandrachael.blogspot.com](http://marcandrachael.blogspot.com)**



### Hansen 6th Annual Fragile X Golf Outing

The Hansen 6th Annual Fragile X Golf Outing was held on September 21 at The Falls at Barber Creek in Kent City, MI. We had 62 golfers and raised approximately \$5,300. This year helium balloons were sold as mulligans. A team could buy up to four. Attached to each balloon was a card with the NFXF logo and their website. When a golfer used a mulligan, the balloon was released up into the air. Just doing our part to spread awareness! :o)

A close friend of Kate Hansen, Cyndi Reed, volunteered 50 hours to the golf outing. In turn, Cyndi's employer, Verizon, will be giving a \$750 grant to FXAM! YAY Cyndi - thank you so much for your hard work and dedication!! And thank you Verizon!!

We were once again blessed by golfers coming from our metro Detroit FXAM family - thank you Nina and Frank Liberati and Laureen Majeske for making the trip. Laureen spoke to the group during lunch and shared info about FXAM and some of the exciting news on the research front.

**Thank you Hansen Family!**

e  tra, e  tra

Editors:

Mary Beth Langan 313-881-3340  
mblangan@hotmail.com

Sally Nantais 734-282-7910  
sallyn423@wyan.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)



## Experimental drug gives hope for rare disease, autism

USA Today - September 20, 2012

For the first time, a drug has shown success in treating social withdrawal symptoms in children with a rare disorder called Fragile X Syndrome, leading scientists to hope that it might also help those with autism. Read the whole story at

<http://www.usatoday.com/news/nation/story/2012/09/20/fragile-x-and-autism/57808848/1>

## Progress in Identifying the Genetic Roots of Autism

The Wall Street Journal - September 24, 2012

One of the most agonizing questions that parents of children with autism ask is—why? Now, a growing number of genetic tests are providing some answers. Scientists say that roughly 20% of autism cases can be linked to known genetic abnormalities, and many more may be discovered. Read more at:

<http://online.wsj.com/article/SB10000872396390444813104578016280501020620.html>

THE WALL STREET JOURNAL.  
**WSJ**



P.O. Box 1414  
Troy, MI 48099-1414