

**Mark Your
Calendar**

Support Meetings

First Saturday
of the Month
(no meetings in August and
September)

When:

October 6, 2012
November 3, 2012

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:

August 11, 2012
FXAM Picnic & 5K
Clarkston, MI

September 8, 2012
13th Annual Golf
Outing, Wesburn
South Rockwood, MI

September 21, 2012
Hansen 6th Annual
Golf Outing
Kent City, MI

October 13, 2012
What About You
Walk, Ypsilanti, MI

**Fragile X Association of
Michigan**

313-381-2834

FXAM.org

Three Cheers for...



Our Graduate - Natalie Nantais

Roosevelt High School, Wyandotte
Favorite Subject: English
Future Plans: Henry Ford Community
College, Physical Therapy Assistant

Wrinkle Free for Fragile X The Silverton
Skin Institute in Grand Blanc hosted "Wrinkle
Free for Fragile X" for the 11th year in a row
during June, raising thousands of dollars for
Fragile X research. *Continued on page 5.*



Andrew Young just completed his sophomore year at
Waterford Kettering High School and his second year on the
track team. Andrew runs the 100m and 200m dashes. Even
with his sensory issues related to unexpected, loud noises, he
has no problem getting set up on the blocks and waiting for
the start gun! He was awarded the Athletic Participation
Award at a picnic on June 8th.

**FXAM's Special Friend
Hannah Moreno**

see page 3



Drug Trials - On the Front Line with our Families

Family: Lang

Study/Location: AFQ056, Rush University, Chicago, IL

Start Date: 2012

End Date: Unknown, still active.

Age of Child/Adult when he/she began the study: 16

Negatives/Positives: We completed the study and have been on the actual drug for a month or so. First of all, we gave our son the capsules with either apple sauce or yogurt. They're rather large capsules, but he had no trouble (particularly with the apple sauce, which is thin). I position the capsule on the tip of the full spoon, so it has a straight shot down the throat, and give him plenty more after each capsule to make sure it goes down. We rarely had any trouble with this aspect, but then he's used to stuffing his mouth and big swallows!

Also, involvement in the study requires lots of visits to Dr. Berry-Kravis's office, several blood tests and other testing. Our son is calm during such visits, and they put a cream on his arm to numb the area for the blood draw, so we haven't had issues on this regard - but it is a fairly demanding obligation to make all of the appointments.

We were either on a placebo or a very low dose the entire time we were in the study. We assume this for two reasons. One, there was absolutely no improvement in our son's behavior/cognition during the entire study. Two, once we ended the study and received the real drug, we noticed an almost immediate change.

The changes were not all positive, but we've seen enough positive to keep going. First let me tell you our son is on the very lowest functional level. He is nearly 17 but still functions a little above a two-year-old in most areas. (He makes up for this by being very sweet, no aggression.) We were told the lower functioning kids usually don't show much improvement for a while. How long that will be, we really don't know yet.

We noticed that after he receives the drug he's quite a bit more active, starting about a half hour after receiving the drug and lasting at least a couple of hours. It's a good thing he's out of school as his body adjusts to this, because he makes quite a bit more noise and has a hard time sitting still. It hasn't been a problem for him at summer day camp, since they keep him pretty busy. They've also noticed his improved language.

We learned we could not give him the second dose of the day in the evening; when we started out doing that, his sleep pattern was unpredictable and interrupted. He would either get up in the middle of the night or just not want to go to bed at all. We've found giving him the second dose in the late afternoon, after he's had a few hours for that initial activity-burst to wear off, works much better.

On the positive side, he is using more words. As I mentioned, he functions a bit over the 2-year-old level - but he does have some words, and he understands a lot more than he can express. However, after having been on the drug for several weeks, we've noticed he is more receptive to instruction (somewhat) and is even using names on occasion. For example, someone came to the house who always brings DVDs for him and he said "Kim, I want Tales." (Dragon Tales) A whole unsolicited sentence, using her name! He also actually closed the refrigerator door on his own the other day, after looking inside for something. He has never, ever closed that door without me or someone else in the family telling him to do so.

Has the drug met your overall expectations? The results so far are certainly not instant or dramatic for us, and they are a mix of positives and negatives. It's my hope, however, that as the brain responds to this drug the positives will outweigh the negatives. I have to remind myself he's never been capable of great learning, and even small advances will take time. But time is all we have. If there is gradual improvement as his brain function increases, even just a little bit, this would be a miracle for us.

AFQ056 is a study sponsored by Novartis Pharmaceuticals. The drug is involved in numerous clinical trials not limited to adult/adolescent patients with Fragile X Syndrome, such as: Parkinson's patients with L-dopa Induced Dyskinesias, subjects with Hepatic Impairment, and subjects with Renal Impairment, to name just a few.

Apps for iDevices (iPhone, iPod, iPad) by Marciel Maurer



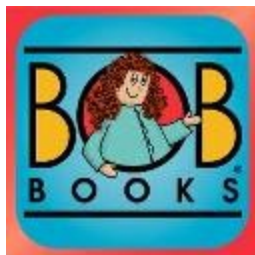
Monkey Math School Sunshine

by THUP Games (\$.99)

Our Jacob loves this game! This is one game that he will play on his own. He loves being able to earn a reward after completing a couple of tasks. It teaches many different math skills. He also likes the happy little monkey character a lot. Seeing the monkey jump and dance and flip is very rewarding to him.

Word Bingo by ABCya.com (\$.99)

Word Bingo is another great app we use. It includes four games and uses Dolch Sight Words.



Bob Books #1 - Reading Magic

by Learning Touch (\$1.99)

We are working on reading BOB books at home. This gives us a way to connect reading his books with something that he enjoys much more... using the iPad! I usually have to sit and work on this one with him directly. Reading Magic teaches the sounds of letters and uses word repetition with the illustrations. One feature that I like is how it will grab his attention by shaking an object until he notices it. It is a great intro to reading three

letter words and learning the sounds of the letters.

Teach Me: Kindergarten

by 24x7digital LLC

(currently on sale for \$.99)

This is another great app that teaches a variety of subjects, including Dolch sight words, spelling, addition and subtraction. It also has a reward system using coins to buy different items from their virtual stores. Both of our kids really like this app.

“Success is to be measured not so much by the position that one has reached in life as by the obstacles which he has overcome.”

Booker T. Washington

FXAM's Special Friend Hannah Moreno

Without any ties to Fragile X, Hannah Moreno chose FXAM for her Bat Mitzvah project and has been a part of our FXAM family for more than a year as she prepared for her project, raised awareness in person and in the media and exceeded her goal of \$1,000 collected for FXAM. Again, FXAM was in Hannah's thoughts during her Bat Mitzvah candle-lighting ceremony and we are grateful for her:

"This candle is for my Fragile X friends. When I started working on this project, I thought I'd raise awareness and some money and be done with it. I didn't expect to receive more than I gave. Over the past year, I learned that the world was far bigger than my cluster of friends and that, what I considered easy and took for granted, for others was an accomplishment or even a milestone. As my understanding of the world around me grew, so did my desire to help as much as possible. You guys are an inspiration for me and I feel honored to stand in front of you and light this candle in the hope that there will soon be a cure for Fragile X. Can I please ask Abbie, Alli, and Josh to come up here and light this candle with me?"

Thank you again Hannah from your Fragile X family!

Have you participated in a Drug Trial or Research Study?

Does your child have a favorite game, app, PC software that you believe other children/adults might enjoy?

Please share and send your story/review to the editors for inclusion in a future newsletter.

Mary Beth - mblangan@hotmail.com Sally - sallyn423@wyan.org



Fragile X 5K Fun Run & Walk and Family Picnic



Saturday, August 11, 2012
 Independence Oaks County Park, Twin Chimneys Shelter
 9501 Sashabaw Road, Clarkston, Michigan
oakgov.com/parksrec/ppark/independence.html

The Fragile X Association of Michigan will be hosting our annual family picnic following the race. We will have hot dogs and assorted snacks.

Reminder to all that the Sixth Annual Fragile X 5K Fun Run & Walk and family picnic are fast approaching! A few things to keep in mind:

- Registration form and fee is due by August 4, 2012, in order to guarantee a shirt
- Don't feel intimidated to participate if you are not a runner. Plenty of participants walk the event on the beautiful wooded trails
- If you are unable to attend, please consider being a t-shirt sponsor for as little as \$25 and have your name or your family's name on the shirt
- Encourage your families, friends and colleagues to attend and/or be t-shirt sponsors
- Create a Facebook event of your own to see if you can spread the word for participation
- You don't need to attend the run to attend the picnic but you do need to **RSVP** to Kim Young at young4mi@comcast.net to help with the head count for food. Please do so by August 8th. The park has a \$5 Vehicle Entry Fee (*No Charge for County Parks Pass Holders*)
- Fragile X Families are asked to bring a dish to pass for the picnic
- Last minute attendees will be accepted for both events
- This will be a great opportunity to connect with our FX family members who will have just attended the International Conference and hear all of the latest & greatest happening in our the FX Community!

More details and registration forms on the web at: fxam.org/Events.html

13th Annual Fragile X Golf Outing

Saturday, September 8, 2012
Wesburn Golf and Country Club

5617 S. Huron River Drive
 South Rockwood, Michigan

12:15 p.m. Registration
 Shotgun start at 1:15 p.m.
(four-person scramble)

More details and forms on the web at:
fxam.org/Events.html

Hansen 6th Annual Fragile X Golf Outing

Friday, September 21, 2012
The Falls at Barber Creek

16030 Barber Creek Avenue
 Kent City, Michigan
thefallsatbarbercreek.com

Shotgun start at 9 a.m.
 Contact Kate Hansen for tickets and
 more info at:

231-519-2349
 or
kathrynh1129@yahoo.com

From the President's Desk by Lauren Majeske



I hope everyone in our Michigan Fragile X family is enjoying a wonderful summer!

We had a great turnout at the grand opening for the Fragile X Clinic at the University of Michigan C.S. Mott Children's Hospital, even though it was a little bit of a drive for some of our families. I know that the chance to speak one-on-one with the clinic directors and other physicians, and the opportunity to listen to the presentation on their model for the clinic was well worth the drive for many. They were generous hosts in providing us with nice lunch choices

and fabulous desserts. There was time for everyone to ask questions afterwards and some very interesting and important topics came up. Your input has made a difference as many changes have already been made to address the concerns of our families.

The Fragile X Association of Michigan is going into our busy season with the International Fragile X Conference in Miami at the end of July, our Fragile X 5K Fun Run & Walk and Family Picnic in August, annual golf outings in September (on the west and east sides of the state) and the What About You Walk in

October. Many of these events help raise money to support our Fragile X Clinic and FXAM families in various ways. You will find all the information you need within this issue. Come on out and have fun or sign up to volunteer. We'd love to see everyone at one or more of the events mentioned in this newsletter -- these are all for YOU!

Hope to see you all soon!

Wrinkle Free for Fragile X *(continued from page 1)*

Dr. Kimball Silverton and the Silverton Skin Institute offered patients an opportunity to purchase Botox injections at a fraction of the regular cost at a one-day-only event where all monies went towards Fragile X (FX) research. Botox is a product, injected to relax wrinkles and smooth the smooth. Botox is usually used between the eyes, in the forehead and next to the eyes where's crow's feet can appear. Patients arrived and received a brief lecture on Botox and on Fragile X, including the opportunity to ask questions and review FX literature provided. Dr Silverton is a board-certified dermatologist and fellowship-trained cosmetic surgeon. He and his wife, Jennifer, have a 14-year-old son, Aidan, with FX. They also have an unaffected 12-year-old daughter, Camryn. Donations from this event will be forwarded to the National Fragile X Foundation and the M.I.N.D. Institute at the University of California at Davis for Fragile X research.

2012 What About You Walk

presented by Eastern Michigan University

**Saturday, October 13, 2012
Ypsilanti, Michigan**

5K Walk/Run 1 Mile Walk/Run

In addition to the Walk/Run, event includes:

- Charity Expo
- Family Fun Activities
- Free Lunch
- Free Tickets to EMU vs. U-Toledo football after the walk/run

Updated info will soon be available at whataboutyouwalk.com and fxam.org plus we'll send out info via email.

Through the Maze

Featured Website

Fragile X Syndrome Clinic
sitemaker.umich.edu/um.fxs/home

The University of Michigan Fragile X Clinic website provides all the details you need to know to access clinic services and what to expect during a clinic visit.

Care providers are available at U of M for all of the critical clinical needs of patients with Fragile X Syndrome and associated disorders. Continued involvement of other non-UM providers for some patients may occur. For those who have insurance outside of the UM system, this will allow you to receive coordinated care from providers within your system if you wish. Check out the **Fragile X Friendly non-UM Providers** page on the website for a list of providers participating.

