

**Mark Your
Calendar**

Support Meetings

First Saturday
of the Month

When:

February 2, 2013

March 2, 2013

April 6, 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:

February 3, 2013

**FXAM Family
Friendship Circle
Playdate!**

See page 5.

March 5-6, 2013

Advocacy Day

See page 4.

**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...

Al Cataldi, wood carver extraordinaire. Al has carved and donated many items to FXAM for us to use as raffle prizes. His items at the golf outing brought in several hundred dollars. He is currently working on a sailboat with "fragile x" on the bow. Al, many thanks for your support!

Fragile X Awareness

Jessica Harris for inviting Sally Nantais to do a presentation on Fragile X at Baker College in Allen Park.

Natalie Nantais for doing a presentation on Fragile X for her Public Speaking class at Henry Ford Community College in Dearborn.

**Some of the 54 Friendly Faces at
our 2012 FXAM Holiday Party**



Apps for iDevices (iPhone, iPod, iPad) by Sally Nantais

Apps for Students with Autism Spectrum Disorders

Download at: autismhandbook.org/images/4/4c/Appwheel.pdf

So you've got a tablet/device, where do you start? Sometimes starting is the most difficult task of all.

Mark Coppin developed an "Apps for Students with Autism Spectrum Disorders" wheel that might have just the start you need.

The wheel is divided into six Common Learning Characteristics:

- ◆ Social Skills
- ◆ Need for Sameness or Routine
- ◆ Sensory Sensitivity
- ◆ Difficulty with Traditional Learning Methods
- ◆ Behavior
- ◆ Communication

Each common learning characteristic is then defined by Common Learning Traits. We will focus on the "Behavior" characteristic. The learning traits are:

- ◆ Hyperactive
- ◆ Easily Frustrated

- ◆ Generalization
- ◆ Impulsive
- ◆ Self Control
- ◆ Explosive
- ◆ Difficulty with Personal Management.

The next level then defines App Categories. Once again focusing on the "Behavior" characteristic the App Categories could be:

- ◆ Behavior Tracking
- ◆ Visual Schedules
- ◆ Behavior Management
- ◆ Video Modeling
- ◆ Reward System
- ◆ Visual Timer
- ◆ Self Management

The final level then defines apps that might fit the characteristics or traits you wish to address through your tablet/device. With the "Behavior" characteristic that may be:

- ◆ Behavior Tracker Pro
- ◆ Chore Pad HD

- ◆ Time Timer iPad Edition
- ◆ iReward
- ◆ Choiceworks
- ◆ iEarned That
- ◆ Behavior Lens
- ◆ Video Scheduler
- ◆ Win a Spin HD
- ◆ iChoose

As noted on the apps wheel, this is only a sampling of apps; it is only intended to give you a starting point. Keep in mind no two children are the same. What will be important is that you address what's needed for your child and their learning style.

Your apps wheel may not contain all six of the Common Learning Characteristics listed in Mark's sample. You might only want to address three specific characteristics; use Mark's wheel as a template and go from there. When you're done, please share your version of apps wheel with our FXAM Family

Through the Maze (kid friendly) - Cool Math Games by Joyce Kreger

coolmath-games.com

Filled with fear that my son was watching another "Annoying Orange" YouTube video or something equally annoying, I got a delightful surprise last year. Michael was on the website coolmath-games.com. The site deserves its name because the games are really cool. With a variety of levels, you can find anything from shapes, colors and patterns to jigsaw puzzles and logic games. What makes these games especially solid is that they all involve strategy, yet your child will just have fun.

Michael started playing Bloxorz, which is a simple strategy game of moving a block from point A to point B without the block falling into space. He would delight in getting to the next, more difficult level. He is now loving anything with the word Papa's in front of it, like Papa's Freezeria, Papa's Burgeria, Papa's Wingeria, and more. They are all fast food restaurant games where customers place an order and you fill it. This involves all phases of cooking and/or assembling the food in the right order to ensure the customer gets exactly what he or she wants. The customer reacts and gives a tip based on the accuracy. Most importantly, it is enjoyable. There are hundreds of games, so your child is sure to find something that will be enjoyable.

Go to coolmath-games.com and remember to place the dash between the words math and games to get to the right website. Hope your child enjoys this as much as my son does!

STX209 Studies at Children's Hospital of Michigan

STX209 (Arbaclofen) is a selective gamma-amino butyric acid type B (GABA-B) receptor agonist. Arbaclofen is a modification of Baclofen, a medication that has been on the market for decades with a solid safety record.

Research suggests that individuals with autism and fragile X syndrome have abnormalities in synaptic transmission. Through the GABA-B receptor, STX209 may serve to restore the normal balance at the synapse and correct abnormalities associated with these disorders. In layman's terms, let's say the transmission is at warp speed and what Arbaclofen does is it has the ability to slow down the transmissions, more or less put the brakes on.

Seaside Therapeutics currently has over 25 locations across the US participating in studies on the use of STX209 (Arbaclofen) and shortly they will be adding the Children's Hospital of Michigan to the list.

Children's Hospital of Michigan is located at 3901 Beaubien Street in Detroit, near I-75 and Mack Avenue.

This study's goal is to figure out if STX209 can improve social function. The study in the older age group has completed and so only

the **ages 5-11** study is open right now. Children with fragile X syndrome who have issues with social function - as compared to typically developing peers - may be eligible. Examples include children who like to be by themselves, have emotional outbursts, don't react well to social situations, are difficult to reach, don't respond to affection, etc.

Only children with fragile X syndrome, the full FMR1 mutation can enroll. These individuals may or may not also be diagnosed with an Autism Spectrum Disorder.

They hope to enroll participants and start the study as soon as possible and hope for it to be open in early February. The study will likely be enrolling until May of this year. Enrollment will last approximately three months. Families who participate may be eligible for the longer-term extension study.

The primary investigator will be Dr. David Stockton; he will be assisted by Dr. Flore and Dr. Misra.

David W. Stockton, MD. Dr. Stockton is a Professor in the Departments of Pediatrics and Internal Medicine at Wayne State University. Dr. Stockton is Chief of the Division of Genetic and Metabolic Disorders in the Department of Pediatrics and

coordinates patient care in the genetics clinics of the Detroit Medical Center.

Leigh Anne Flore, MD, MS. Dr. Flore is a recent addition to our clinical geneticists at Children's Hospital of Michigan and Wayne State University. Her clinical and research interests include autism/developmental disorders, dysmorphology, and medical genetics education.

Vinod Misra, MD, PhD. Dr. Misra is also a clinical geneticist at Children's Hospital of Michigan and Wayne State University. He sees a range of patients and has expertise in management of patients with dysmorphology, congenital anomalies, inborn errors of metabolism, and other genetic disorders.

For more detailed bios on the staff and the Genetics Department at Wayne State University visit:

<http://www.childrensdmc.org/geneticandmetabolicdisorders>

Stay tuned to FXAM.org as study details are finalized we will keep our families up-to-date through the website and our e-mail lists. If we don't have your current e-mail, please connect with Mary Beth at:

mblangan@hotmail.com

Visit seasidetherapeutics.com for more on their ongoing fragile X research.

Did you know that Dr. Paul Wang - Vice President, Clinical Development, at Seaside - has Michigan roots? He grew up in Michigan and attended University of Detroit Jesuit High School.

University of Michigan Fragile X Clinic Schedule 2013

Clinics are scheduled on Thursday mornings, with two time slots available for each date. Additional dates/times may be available on a limited basis if needed due to scheduling conflicts for patients and their families. Anyone interested in scheduling an evaluation, please contact Rob Owens at 734-232-6750.

January 3 and 17	May 2 and 16	September 5 and 19
February 14 and 21	June 6 and 20	October 3 and 17
March 7 and 28	July 11 and 18	November 7 and 21
April 4 and 18	August 1 and 15	December 5 and 12

University of Michigan and the FXCRC FORWARD Registry and Database

The University of Michigan has received full approval to enroll participants in the FORWARD Registry and Database. The Registry is open to all individuals with a Fragile X premutation or full mutation and includes basic patient demographic information as well as questions regarding interest in potential future research studies. The Database is open to all individuals with a full mutation only (up to age 24 years) and includes questions about development, education, medical health, and behavioral problems.

For all individuals interested in participating in the FORWARD Registry and Database: If you or your family members have not yet been evaluated by the University of Michigan Fragile X Clinic, or if it has been more than 6 months since you were last seen in clinic, please call our office to set up an appointment to review your medical history and enroll in the study. If you or your family members have been evaluated in the University of Michigan Fragile X Clinic within the last 6 months, you can be enrolled in the study without a medical appointment (with no charge to your health insurance).

Anyone interested in participating in the FORWARD Registry and Database, please contact our clinic coordinator, Rob Owens, at 734-232-6750.

Advocacy Day Scholarship

FXAM offers a scholarship to help ease your budget if you'd like to participate in the NFXF Advocacy Day in Washington, D.C. This year, the event is March 5-6 (see back page).

If you are interested in attending and would like to apply for the

scholarship or for more information, please contact Lauren Majeske at

lmajeske1@comcast.net or
586-978-9079

by **Monday, February 4**, stating your intention to apply for the scholarship.

"If you think you're too small to have an impact, try going to sleep with a mosquito."

~ Anita Roddick

From the President's Desk *by Laureen Majeske*

As I look back over the last year, I am amazed at how much has been accomplished. You should be proud of how many families were supported, how many friendships were made, the awareness that we've spread both as a group and individually, the money raised and used for our Michigan families through scholarships to the International Conference, free family events, informational events, publications, the fragile x clinic and more!

We are looking forward to 2013 and watching our Fragile X clinic kick into high gear. In this newsletter, you will find information on registering with the Fragile X clinic database which will allow you to be on the cutting edge of research and studies coming into Michigan. In the future, look for another fragile x clinic to join our current one. The new clinic would serve adults with fragile x syndrome and those who have Fragile X-associated

Tremor/Ataxia
S y n d r o m e
(FXTAS).

Please let me know what else you would like to see happening in FXAM over the coming year.

Send your suggestions to lmajeske1@comcast.net. Be a part of our future! Happy 2013!



Through the Maze - cdc.gov/ncbddd/fxs/ by Sally Nantais

The Centers for Disease Control and Prevention recently updated their website on fragile X syndrome. If you haven't checked it out yet, it is worth taking a look. The site is easy to navigate and presents data in various media formats. Whether you're looking for some simple facts, data or statistics or want to review some of the latest research while not being overwhelmed. For families who are new to fragile X, I do recommend the video on the cause of fragile X.

FXAM Family Friendship Circle Playdate!

Sunday, February 3, 2013

12:30 - 2:30 pm at Friendship Circle

6892 West Maple Rd.

(between Halsted & Drake)

West Bloomfield, MI 48322



Check out their wonderful programs at friendshipcircle.org including Weinberg Village LifeTown's Lessons for Life www.friendshipcircle.org/weinberg-village/ and the amazing rooms of The Activity Wing www.friendshipcircle.org/activity-wing/

Free event includes time for fun, frolic and friendship! Appropriate for kids of all ages. Also included will be pizza and an activity of gingerbread cookie decorating. Come join in the fun!

Please RSVP to Elina Gelfand by Friday, January 28, with the # of adults and # of children attending at elina.gelfand@yahoo.com or 248-470-3311

See you at the FXAM Family Friendship Circle Playdate!

Friendship Circle of Michigan was founded on the idea that within each person is a soul, regardless of any limitations that may surround it, regardless of whatever natural gifts we may have or lack, regardless of what obstacles and challenges we may confront, our souls are sacred and worthy of boundless love.

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FXAM.org

ad·vo·ca·cy

/ˈæd və kə si/ Show Spelled [ad-vuh-kuh-see]

noun, plural ad·vo·ca·cies.

the act of pleading for, supporting, or recommending; active espousal: He was known for his advocacy of the Fragile X agenda.



Gregg Harper invites you to
Fragile X Advocacy Day 2013
youtube.com/watch?v=s3URq500DE4

To learn more and register:
fragilex.org/public-policy-and-legislative-advocacy



NFXF Advocacy Day
MARCH 5-6, 2013



P.O. Box 1414
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