



# FRAGILE X ASSOCIATION OF MICHIGAN

eXtra, eXtra

Volume XI, Issue 3, July 2015

## Mark Your Calendar

### Support Meetings

First Saturday  
of the Month

#### When:

**October 3, 2015**  
**November 7, 2015**  
(no meetings in July,  
August & September)

#### 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 1, 2015

**FXAM Family Picnic**  
See page 4.

#### August 17, 2015

**FXAM Summer Playdate**  
See page 4

#### September 12, 2015

**16th Annual  
FXAM Golf Outing**  
See page 3

#### September 19, 2015

**FXAM Moms:  
Let's Do Lunch!**  
See page 4.

#### October 10, 2015

**FXAM Fragile X  
Conference**  
Marcia Braden in MI!  
Details will follow on the  
website and Facebook.

**Fragile X Association  
of Michigan**

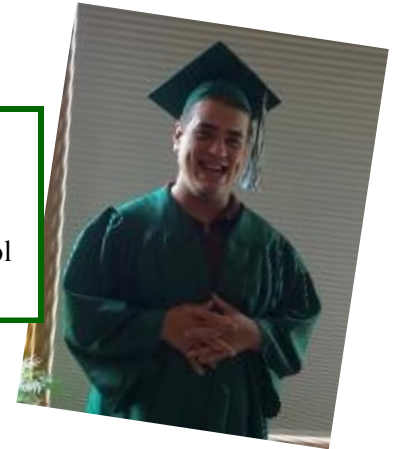
**FXAM.org**

## Three Cheers for...

### Our Graduates

#### Antonio Liberati - High School

Allen Park High School  
Favorite Subject: Spelling/English  
Future Plans: Attending Allen Park High School  
in their new vocational training program.



#### Grant Patterson - 6th Grade

Bruce Collins Elementary  
Favorite Subject: Music  
Future Plans: Be a star on stage.

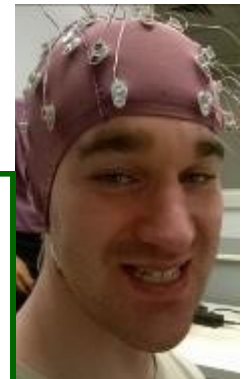


#### Adam Popejoy - High School

Plymouth High School  
Favorite Subject: Cooking  
Future Plans: Western Wayne Skill Center,  
he hopes to find a job and work with  
people.

### Research

Austin Nantais has been very busy participating in four different research studies at Rush University. See page 2 to learn more about some of the active studies.



## Research Studies at Rush University in Chicago

### Enhancement of Literacy Skills in Fragile X Syndrome

Ages 12-45, males and females with diagnosis of FXS

This study examines the use of three different reading interventions spanning all reading abilities with individuals with FXS. Individuals will be placed in a reading intervention at their baseline visit, caregivers will be trained in the administration of the intervention. Individuals will need to participate in the reading intervention four times a week for 15-20 minutes at home/school.

3 visits total: baseline visit, 3-month visit, 6-month visit

**Contact information/learn more:** Anne Hoffmann at [anne\\_hoffmann@rush.edu](mailto:anne_hoffmann@rush.edu)

### The Expressive Language Sampling Project

This study is being done to learn about the spoken language of individuals with fragile X syndrome and how this ability may change over time. The project is seeking to develop and validate expressive language sampling as a way of measuring objectively whether the language of a person with fragile X syndrome is improving in a clinical trial of medication or with an intervention or therapy. About 300 children, teens, and young adults between the ages of **6 and 23 years** will participate in this study at five different sites around the U.S. About 60 participants will have their study visits at the Rush University Medical Center.

We will ask parents to accompany their son/daughter to Rush University Medical Center for **three visits**. Your child will complete several tests and activities that will help us learn more about his/her language and problem-solving abilities. We also will ask you some questions about how your child takes care of himself/herself on a daily basis. We also will ask you to complete a questionnaire about your child's behavior. Your visit to the Rush University Medical Center will last most of one day and we will ask you to return for another visit after one month and again two years later. During the second and third visits, we will repeat some of the same activities. For more information about this study, please contact:

**Clinical Research Coordinators:** Meraj Baig/ Melissa Baer at 312.563.6636 or [meraj\\_baig@rush.edu](mailto:meraj_baig@rush.edu)

### : ERP Study or Event Related Potential Study

**Age/Diagnosis/Inclusion Criteria:** Fragile X females: any age, for a total of 10 subjects. Fragile X males: two groups: **a)** 12 years old or greater, total of 10 subjects, **b)** 3 years old to 12 years old, total of 10 subjects Controls (typically developing): any age, total of 10 subjects.

**Number of visits:** two

**Study Description:** to determine if ERP, a specific type of EEG recording can become a biomarker for Fragile X Syndrome, i.e. an objective, direct, reliable, quantitative measurement of neurological improvement after some type of treatment/intervention (e.g. medication).

**Contact information/learn more:** Jeremy Kraff M.D. at [Jeremy\\_Kraff@rush.edu](mailto:Jeremy_Kraff@rush.edu)

### Toolbox Cognitive Battery (TCB) Validation Research Study

(enrollment begins in January 2016)

Inclusion Criteria:

1. Male or Female between the ages of 6-25yrs
2. Diagnosis of Intellectual disability associated with Fragile X Syndrome, Down Syndrome, or from other undetermined causes.
3. IQ less than or equal to 79 measured by the Stanford Binet-5th edition
4. Mental age equal to or above 3 years 0 months
5. Fluent in English or at least has phrase speech and clear ability to understand and follow directions

Exclusion Criteria:

1. Uncorrectable vision impairment
2. Significant motor impairment preventing touch screen or keypad responses
3. History of head injury, brain infection, stroke, or other neurological problems such as uncontrolled seizures or excessive sedation from medication that would interfere with testing sessions
4. Any changes in medication 6 weeks prior to study.

(continued on page 5)

# 16TH ANNUAL GOLF OUTING GOLF & DINNER REGISTRATION FORM

- Where:** **Wesburn Golf & Country Club**  
5617 S. Huron River Drive, South Rockwood, (one mile west of I-75, exit 26)
- When:** Saturday, September 12, 2015  
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**



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

For more information on the Golf Outing visit: [fxam.org/events.html](http://fxam.org/events.html)

# What's going on ...

## FXAM Family Picnic



**Saturday, August 1, 2015  
1 - 3 pm**



Our annual picnic will be at the Van Dam home  
**Heather, Derek, Alison & Mason**

FXAM will provide hotdogs, drinks and a bounce house. Families are invited to bring a side dish or dessert to share. RSVP to Heather via text/phone to 248-343-2077 or [fab4fam@comcast.net](mailto:fab4fam@comcast.net) by Friday, July 24 with the # of adults & children attending and what you'd like to add to the table!

**Hope to see you at the FXAM Family Picnic!**

## FXAM Summer Playdate

**Monday, August 17, 2015 at 10:15 am**

Come to Andrew's house for lunch and fun!  
Langan-Coutilish Home, Grosse Pointe, MI  
More info closer to the date on the FXAM Facebook page  
or contact Mary Beth at [mblangan@hotmail.com](mailto:mblangan@hotmail.com) or 313-881-3340.

## FXAM Moms: Let's Do Lunch!

**Saturday, September 19, 2015 at 11:00 am**

The Cheesecake Factory at Twelve Oaks Mall in Novi  
(on the lower level near Nordstrom)

[thecheesecakefactory.com](http://thecheesecakefactory.com)

Come join this mom-only event!

RSVP to [cabouelseoud@gmail.com](mailto:cabouelseoud@gmail.com) and [mblangan@hotmail.com](mailto:mblangan@hotmail.com)

Shopping and mall walking are post-lunch options.

.Last minute texts/questions? Mary Beth's cell: 313-689-3340

*Please note: this is not one of our free events*

*Each FXAM mom will be paying for her own food/drinks.*

**From the President's Desk** by *Laureen Majeske*



I hope everyone is enjoying their summer! And I hope you have been able to participate in some of our recent family activities, it's been so nice to see so many families making real connections with each other. So much more coming up (as you can see in our newsletter), and we hope you take advantage of the many opportunities. Our members spend a

lot of time planning these events for you because they want to make sure that we have something for everyone. Always remember to check our FXAM Facebook page for updates and other information. And if you aren't a member yet of that group, please consider becoming one!

Make sure to check out the updates from the Fragile X Clinic for exciting

news of the ongoing research study and information on how you, too, can participate.

Hope to see you at the Family Picnic which will be held this year at the Van Dam home. Have a great summer!

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

*By Kailey Owens, Clinic Coordinator*

We are excited to be participating in the Neuren NNZ-2566 drug trial! Thank you to everyone who contacted us to express interest in participating. We received our IRB approval to participate near the end of the open window for enrollment, which is July 17th. This unfortunately limits the number of participants for our site. We hope to be eligible for additional drug trials in the future where we can enroll a larger number of Michigan participants. Please stay tuned!

As a reminder, in addition to appointments in Ann Arbor (A2), we also hold clinics in Marquette (MARQ) and Traverse City (TC). The upcoming clinic schedule is listed, to schedule an appointment, please contact me at 734-615-3591.

**U of M Fragile X Clinic Schedule**

July 9 and 23 (A2)	November 5 and 19 (A2)
August 20 and 27 (A2)	November 5-6 (TC)
September 10 and 17 (A2)	December 10 and 17 (A2)
September 23-24 (MARQ)	December 10-11 (MARQ)
October 15 and 29 (A2)	

**Toolbox Cognitive Battery (TCB) Validation Research Study**  
(Continued from page 2)

The purpose of this research is to explore whether certain types of intellectual or cognitive tests are reliable, valid, and sensitive to improvement in evaluating treatment responses among individuals with intellectual disability. This newer cognitive test administered on the Apple iPad, TCB, has been shown to accurately measure various cognitive skills across a wide age range, but has yet to be adapted and tested among individuals with intellectual disabilities. This is what we are doing with the TCB study.

Participation in the study involved two-three visits here at Rush University Medical Center. The first visit lasts approximately 3.5-4 hours and is scheduled over a two day period. The second visit is scheduled approximately 4 weeks later and will be much shorter, only lasting about an hour. These visits will include cognitive testing for your son/daughter and you will be asked to full out questionnaires about him/her as well. Some participants will be asked to return for a third visit. The schedule for the third visit is the same as the first visit and will take place approximately two years later. We will compensate \$30 for the completion of visit 1, \$20 for visit 2, and \$50 for visit 3. We will also validate your parking sticker for all visits, and reimburse you for your lodging and mileage.

As you can imagine, there are some questions that we need to go through to help determine whether your son/daughter is eligible to participate in this study. Feel free to email me at the email address below if you're interested or have any further questions about the study.

**Clinical Research Coordinator: Merve Senalan at [Merve\\_senalan@rush.edu](mailto:Merve_senalan@rush.edu) or 312.563.6559**



eXtra, eXtra

Editors:

Mary Beth Langan 313-881-3340

[mblangan@hotmail.com](mailto:mblangan@hotmail.com)

Sally Nantais 734-282-7910

[sallyn423@wyan.org](mailto:sallyn423@wyan.org)

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If you would like to share them with family, friends or professionals, please share our web address with them.

**Contact Information:**

**313-381-2834**

[southeastMI@fragilex.org](mailto:southeastMI@fragilex.org)

**FXAM.org**



Paul Fodor (L) and Aidan Silverton (R) were torch bearers in the Special Olympics Unified Relay Across America in June.



## **Fragile X Association of Michigan**

PO Box 1414

Troy, MI 48099-1414