



FRAGILE X ASSOCIATION OF MICHIGAN

Mark Your Calendar

eXtra, eXtra

Volume XI, Issue 1; January 2015

Support Meetings

First Saturday
of the Month

When:

February 7, 2015

The ABLE Act
See back page.

March 7, 2015

April 11, 2015

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 16, 2015

FXAM Winter Break
Playdate
See page 3.

March 3-4, 2015

Advocacy Day
Washington, D.C.
See page 3.

March 21, 2015

FXAM Moms:
Let's Do Lunch!
See page 3.

Fragile X Association of Michigan

(a member of the
NFXF Community
Support Network)

Contact Information:

313-381-2834

southeastMI@fragilex.org

FXAM.org

Three Cheers for...



Our Holiday Party

Emma and 63 other FXAM family members enjoyed the holiday gathering in Thanksgiving for our Fragile X Family on December 6. Much fun was had by all!



Noah's Ark and The Pattersons

See page 2.

Noah's Ark at Sterling Civic Theatre *by Romy Patterson*

So often we want our children to play among their same-age peers, but they may not have the coordination or social skills to fully participate in activities. Even though they are welcome to attend events, it's obvious to all that they are different. I have finally found an outlet where my Fragile Xer can interact and be accepted among his peers and others.

It is no secret that imitating is a strength for many with Fragile X. My son is no exception and is quite the performer at home. Years ago, I came across an article that talked about including special needs children in theatre. I did some research, and came across the Sterling Civic Theatre (soon being renamed Macomb Civic Theatre) in Sterling Heights. I took my son and daughter to see the theatre's performance of *Shrek the Musical* this past summer. The theatre's executive producer gave my family a backstage tour before the show. My son was able to walk on stage, touch props, see costumes and makeup, and talk to Shrek. At first, my son hesitated, then absorbed himself in everything around him. He was so happy. When the winter production of *Beauty and the Beast Junior* was announced, I knew I had to get my kids involved.

The Sterling Civic Theatre has a program called Noah's Ark. It was named after their first special performer, who approached the theatre asking if he could join. The theatre offers complete inclusion and has zero tolerance for the R-word and bullying. The kids are welcome to act, sing, dance, work backstage or just be social. One boy's only interest is holding the stage door for performers. One child wanted to be on stage, but couldn't bring herself to walk out. Therefore, they dressed her as a bird & she sat on the shoulder of a performer who was dressed as a

tree. They have experienced volunteers that work with parents to understand each child's strengths and challenges. The one complaint the producer always heard was that the junior productions were at such a fast pace that the kids didn't have time to get to know each other. Therefore, the theatre launched their first StageGeeks Theatre Camp for K-12 students in October 2014. There were approximately 80 kids in camp. They learned how a show comes together, special effects, choreography, vocals and did many activities in following directions and even improv. Following the eight weeks of StageGeeks camp, all the kids auditioned for *Beauty and the Beast Junior*. Theatre policy is that everyone that auditions is in the show!! There are no paid performers and they rotate directors, choreographers, etc. to give local talent a chance to keep things original. They partner with local schools to share props and costumes. Throughout the year, they also do various fundraiser performances to raise money for college scholarships for local high school seniors in theatre.

My son (FX) and daughter (non-FX) loved the StageGeeks camp. I gave the director a Positive Student Profile that I usually give my son's teachers. He had never seen such a document and asked his other Noah's Ark parents to do the same. It was neat to see the director taking advantage of my suggestions from the profile. Before I knew it, my son was doing improv scenes, dancing to Michael Jackson's *Thriller*, acting out charades and performing in the StageGeek talent show. The director made a point of making sure the Noah's Ark kids were participating in all the activities. Over Thanksgiving weekend, the theatre group had their best performers sing popular

Broadway songs for their "Night of Broadway" fundraiser. He asked the Noah's Ark kids and anyone else that wanted to perform to join the show. My kids and three others did a song from *Peter Pan*. Before going on stage my son said, "Mom, do I get to take a bow?" I told him that I thought he could. The song finished and everyone left the stage except my son. He went center stage and took a bow then walked off. It was the sweetest thing ever.

The cast for *Beauty and the Beast Junior* was announced, and both of my kids are in the chorus. My son was cast in a role that says one line during a song. He is so excited to see his name in print. All the performers will rehearse two nights a week with a third night set aside to give extra help to the Noah's Ark kids. My kids are meeting so many new people and getting a chance to develop socially and creatively. For the first time, my son is a participant and not an observer. I get the chance to meet new people outside of a doctor's office and help make sets, costumes, etc. while the kids rehearse. It's so nice to do something "normal" and not spend our evenings in speech and occupational therapy.

If you are in the metro Detroit area, I encourage you to check out *Beauty and the Beast Junior*, March 6-8 at Sterling Heights Stevenson High School. If you have a local theatre group in your neighborhood, I encourage you to ask about including your child in a show. The theatre's producer welcomes any opportunity to answer questions about his program and would love to see more groups including special kids.

To get more information visit sterlingcivic.org or contact Larry O'Grady at larry@sterlingcivic.org.

What's going on ...



**NATIONAL FRAGILE X
ADVOCACY DAY**

MARCH 3-4, 2015

Learn more and register at:

fragilex.org/advocacy/advocacy-day/registration/

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 3-4.

If you would like to apply for the scholarship or for more

information, please contact
Laureen Majeske at

lmajeske1@comcast.net or
586-978-9079

by **Friday, February 6**, stating
your intention to apply for the
scholarship.

ad·vo·ca·cy

the act or process of supporting
a cause or proposal. She was
known for her advocacy of the
Fragile X agenda.

FXAM Winter Playdate

Monday, February 16, 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 group
or contact Mary Beth at mblangan@hotmail.com or 313-881-3340.

FXAM Moms: Let's Do Lunch!

Saturday, March 21, 2015 at 11:00 am

Crispelli's
28939 Woodward Ave., Berkley, MI
(SW corner at 12 Mile Rd.)
248-591-3300 crispellis.com

Come join us for some Mom-only time! Hope to see you on March 21!

Email cabouelseoud@gmail.com and mblangan@hotmail.com so we know to expect you for lunch.

We can then keep you updated if there are any changes in plans.

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

Please note: This is not a free FXAM event. Each FXAM mom will be paying for her own food/drinks.

Fragile X Syndrome: NIH RESEARCH STUDY

This research seeks to understand how protein formation in the brain is affected in Fragile X syndrome (FXS). Researchers will measure the rate at which the brain makes proteins (protein synthesis) and will identify specific parts of the brain affected in FXS. In the future, measurement of protein synthesis in FXS may help us to develop and test new therapies.

The study enrolls eligible young men with FXS, ages 18-24, from around the world, and includes:

- One visit, lasting several days, to the NIH Clinical Center, in Bethesda, Maryland.
- Assessment by physicians
- Blood draw, two brain scans (PET & MRI), possible sedation
- Travel, food, and lodging are covered and include the patient and one or two accompanying family members.
- Compensation is paid for your time and assistance.

Please consider enrolling your child in our clinical research study of FXS. If you would like to participate, be on our mailing list, be contacted in case of future studies, or would simply like to have more information contact Inna Loutaev at loutaev.inna@nih.gov or 301-496-4707.

Department of Health & Human Services, National Institutes of Health, National Institute of Mental Health, clinicaltrials.gov 06-M-0214

New Clinical Trial sponsored by Neuren Pharmaceuticals

Neuren Pharmaceuticals is pleased to inform you of an opportunity to participate in a clinical trial for adolescents and adults with Fragile X syndrome. This clinical trial is testing an investigational medication, NNZ-2566, as a targeted treatment for Fragile X syndrome (FXS). The purpose of this study is to assess the safety and efficacy of two doses of NNZ-2566 when compared to placebo in adolescent and adult males who have been diagnosed with FXS.

This trial is currently enrolling participants and will include 60 participants between the ages of 14-40. Taking part in this study will involve 8 visits to the doctor's office over a 10-week period. The study medication and all study-related evaluations will be provided at no cost to participants. Some support for travel will also be available.

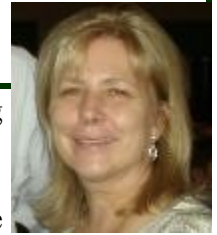
NNZ-2566 has an entirely novel mechanism of action compared with other drugs that have been tested for Fragile X syndrome. NNZ-2566 is a modified version of a biologically active part of Insulin-like Growth Factor (IGF-1). IGF-1 is a protein in the human body that helps cells grow and respond to stress or damage. In the brain, IGF-1 contributes to the growth of brain cells and the connections between them (synapses). The biologically active part of IGF-1 is called glypromate or GPE and supports the function of brain cells in a different way than IGF-1. GPE occurs naturally in the brain. NNZ-2566 is a version of GPE modified to make it available to take as an oral medication. NNZ-2566 may help improve brain function by enhancing functions normally performed by GPE and by increasing IGF-1 levels in the brain. NNZ-2566 has been shown in animal models of Fragile X to improve performance in tests of behavior and cognition.

FDA has granted two special designations for Neuren's development of NNZ-2566 in Fragile X: *Fast Track Designation* and *Orphan Drug Designation*. Both designations are important milestones in accelerating the development of viable treatments for Fragile X, and demonstrate a recognition of the critical unmet needs of individuals with Fragile X.

Closest participating sites are Rush University (Chicago) and Cincinnati Children's Hospital. For other current sites and more information, visit clinicaltrials.gov/ct2/show/NCT01894958 as well as at fraxa.org.

For more information about Neuren visit neurenpharma.com.

From the President's Desk by *Laureen Majeske*



This past month we held our Annual Board Meeting. This is our biggest business meeting of the year where we take everyone's input and map out the next year's plan. We also added these board members Cortney AbouElSeoud, Heather Van Dam, Sulie Tyler and Kailey Owens, Genetic Counselor from our Fragile X Clinic, as our new Clinical Adviser. Joyce Kreger stepped down as Recording Secretary but will remain an active board member. Below is the list of our entire board. If you are interested in running for a board position, let me know by February 15 for our March meeting biennial elections. To be eligible, you must have attended at least two meetings

in the past year. We're very excited to welcome these new members. I know their participation will make a positive impact to FXAM. Last year, we added childcare to two meetings, additional family events and streamlined our support meetings to offer a friendlier, more interactive experience. We can look forward to enhanced programming, an education seminar, as well as our annual events and support meetings.

In our effort to reach out to all of our Michigan families who aren't able to attend our meetings in Royal Oak, we are researching options for out-state meetings to be electronically connected to Royal Oak. We hope to share details soon

of a Lansing meeting on February 7.

You may live across the state, but we haven't forgotten you!

Soon you'll be able to order items from FXAM.org using PayPal. We hope this will help more of us sport FXAM swag to show our support!

If you have a great story to tell, information that would benefit our families, or a topic you would like to see, please email our newsletter editors. We are always looking for new things to share with our families.

Hope to see you soon!

Greetings from the University of Michigan Fragile X Clinic!

By Kailey Owens, Clinic Coordinator

Happy 2015! In 2014, we provided care for 17 families and we have seen a total of 36 different families since opening our clinic. Twenty-three of these families are enrolled in the FORWARD Registry. We hope to meet with many more families in 2015. Thanks to all the FXAM dads who participated in Kate Partynski's graduate research on coping styles and experiences in raising a child with Fragile X syndrome. We appreciate your assistance! For upcoming Fragile X clinic appointments, please contact me at 734-615-3591.

U of M Fragile X Clinic Schedule

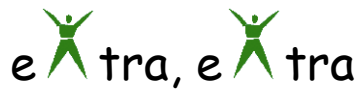
February 12, 2015	August 20 and 27, 2015
March 12 and 19, 2015	September 10 and 17, 2015
April 16, 2015	October 15 and 29, 2015
May 14 and 21, 2015	November 5 and 19, 2015
June 11, 2015	December 10 and 17, 2015
July 9 and 23, 2015	

Meet Your 2015 FXAM Board of Directors

Laureen Majeske – President, Elina Gelfand - Vice President
 Sheryl Roman – Treasurer, Mary Beth Langan - Corresponding Secretary
 Vacant - Recording Secretary

Cortney AbouElSeoud, Jeffrey Cohen, Karen Dacey, Joyce Kreger,
 Nina Liberati, Sulie Tyler, Heather Van Dam, and Kim Young.

Kailey Owens is Clinical Advisor to the FXAM Board.



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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

The ABLE Act

On December 19, 2014, The ABLE Act was signed into law by President Obama. The ABLE Act allows individuals with disabilities, like Fragile X, and their families to save money in ABLE accounts which will not be taxed. Attend our FXAM meeting on February 7 to learn more from Jeffrey Cohen, FXAM board member and NFXF director of government affairs and advocacy. Read Jeffrey's The ABLE Act Explained at:

<http://www.fragilex.org/2015/advocacy/advocacy-day-posts/the-able-act-explained/>

“In all things it is better to hope than to despair.”

~ Johann Wolfgang von Goethe

Fragile X Association of Michigan

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