Fragile X Association of Michigan

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Volume VII, Issue 2; April 2011

Mark Your Calendar

Support Meetings

First Saturday of the Month

(no meetings in July, August and September)

When:

May 7, 2011
June 4, 2011

Where:

Beaumont Hospital
Royal Oak Campus
Administration Bldg
Private Dining Room

Special Events:

May 7, 2011

Dr. Peter Todd, U of M neurologist, will be speaking at our FXAM meeting.

July 22, 2011

Fragile X Awareness Day

August 20, 2011

FXAM Picnic & 5K
Clarkston, MI

Fragile X Association of Michigan

Contact Information:

313-381-2834

fraxmich@hotlinemail.com

FXAM.org

A member of the NFXF LINKS Network (Linking Individuals Nationally in Knowledge and Support)

Three Cheers for New Members!

Melissa Morrison is a new FXAM member living in Stevensville (SW Michigan). She and her daughter Amanda attended the Fragile X conference last July and Advocacy Day last month in DC. Here she is with her three brothers - from left - Donnie, David & her twin Mickey. David and Mickey are both affected by Fragile X and live in group homes in Ohio.

Nearly seven-year-old Jacob lives in Auburn (between Midland and Bay City) with his parents, Marciel & Brent, and his little sister Olivia. Jacob loves music and sports and is a big fan of the Tigers. He's very proud that he learned how to write his full name this year!

Ayden, age 3 1/2, lives with his parents Cortney & Sherief and his 2-year-old brother Issac. The AbouElSeoud family lives in Holt, which is just south of Lansing. Ayden lives for his next chance to play Angry Birds!

Noah (on right) is 11 years old. He lives and plays with his family (parents Robyn & Kevin, brothers Jacob & Adam) in Farmington Hills.

Jonathan is 3 1/2 and lives with his parents, Tiah & James, and his baby sister Isabelle in Essex, Ontario. Tiah and James already attended their first FXAM meeting in March. Jonathan wakes up each morning eager to watch The Mickey Mouse Clubhouse.

For those who didn't know: we have a few international FXAM members from Ontario, Canada plus a few just-across-the-other-border FXAM members from Ohio and then members from the U.P. and all over the lower peninsula.

From the President's Desk by Laureen Majeske

Exciting news: our new Fragile X Clinic at the University of Michigan will be up and running soon! This clinic, a part of the Fragile X Clinical and Research Consortium (FXCRC) and funded by the CDC, will offer comprehensive services on site, as well as coordinate with your own local service providers.

Dr. Peter Todd, one of the clinic directors, will be at our next support group meeting on Saturday, May 7, to present information about what our clinic will have to offer and to answer any questions you may have. The Fragile X Association of Michigan and our members will be an active partner with this clinic as we move forward. There will be many opportunities to volunteer or to participate in upcoming research. Please come to show your support and to meet Dr. Todd (or meet with again, if you met Dr. Todd at the FXAM Holiday Party in December). Light refreshments will be served.

Also, it has been some time since we last updated our FXAM Directory, so **please take the time to update your personal information** on the enclosed form and share with us your favorite, most knowledgeable professionals who help support your family members who are affected by Fragile X. Thanks! Hope to see you at the May meeting.

On the Research Front - Progress, Progress, Progress!

New Clue Found for Fragile X Syndrome-Epilepsy Link

ScienceDaily (Apr. 12, 2011) — Individuals with fragile X syndrome, the most common inherited form of intellectual disability, often develop epilepsy, but so far the underlying causes are unknown. Researchers have now discovered a potential mechanism that may contribute to the link between epilepsy and fragile X syndrome.

Read more at: **sciencedaily.com/releases/2011/04/110412171202.htm**

Marinus Pharmaceuticals Announces U.S. Department of Defense Grant to Study Ganaxolone in Fragile-X Syndrome

NEW HAVEN, Conn., April 13, 2011 /PRNewswire/ -- Marinus Pharmaceuticals, Inc., the leader in the development of neurosteroids for central nervous system disorders, today announced the award of a $3 million grant by the U.S. Department of Defense to study its lead candidate ganaxolone for the treatment of Fragile-X Syndrome (FXS). Ganaxolone modulates GABA-A ion channels by selective binding to the neurosteroid receptor. Early research suggests that normalizing neurosteroid levels with ganaxolone treatment may eliminate the behavioral symptoms associated with FXS.

Read more at: **finance.yahoo.com/news/Marinus-Pharmaceuticals-prnews-2602789386.html?x=0&.v=1**

2011 Graduates

Do you have a graduate you'd like us to spotlight in July?

(kindergarten, elementary school, high school...)

Contact Mary Beth at mblangan@hotmail.com or 313-881-3340

"Where flowers bloom so does hope."

Lady Bird Johnson

Please help with a project that will assist all families affected by Fragile X!

We're looking for Fragile X-friendly professionals and other referrals that you have found in your area. We'll be sharing this information with the new Michigan Fragile X Clinic, as well as other Fragile X Clinics who see Michigan families. We also may have this information at FXAM.org and/or share it with new FXAM member families.

We also need to update your member information (other side of page)!

Please get us this important information to us in one of these ways:

- send Mary Beth Langan an email with all of this info in the body of the email to mblangan@hotmail.com
- complete the two-sided form, resave it and email the new document back to Mary Beth
- complete the two-sided form, scan it and email it to Mary Beth
- complete the two-sided form and mail it to:

Mary Beth Langan
851 Washington Road
Grosse Pointe, MI 48230

List professionals (pediatricians, geneticists, neurologists, speech pathologists, occupational therapists, educational advocates, special needs attorneys, etc) and extracurricular programs that you have found were knowledgeable/helpful (or willing to learn!) with your family member with Fragile X. We will assume you mean for a family member with Fragile X Syndrome, unless you note FXTAS or FXPOI next to the referral.

Please include as much info as you are able for the referral: professional, name of the clinic/practice/program, address, phone number, email address, website and comments. Use additional paper if you have more referrals than fit below.

Fragile X
Association of Michigan

Member Information Form

Member Name(s): _____

Address: _____

City: _____ **State:** _____ **ZIP + 4:** _____

Telephone (home): _____ **Telephone (cell):** _____

E-mail Address(es): _____

_____

Would you like to be included in our member directory? ☐ **Yes** ☐ **No**
Please X one

This is a great tool for connecting with members in the same area and/or those with children within the same age group, etc. We only send the directory to other FXAM families; it is not public.

All FXAM members will be mailed copies of our FXAM quarterly newsletters (Jan, Apr, July & Oct) plus other event info and materials. Our newsletters list upcoming meetings and events. Emails are sent with meeting reminders and information. If you ever need to update your info, please contact Mary Beth Langan at mblangan@hotmail.com or 313-881-3340.

Type of Membership:
Is your membership? ☐ **Family** ☐ **Professional**
Please X whichever applies

If professional, please specify your field: _____

_____

If family, please provide information on your children:

Name	Date of Birth *(mm/dd/yyyy)*	Do they have FX?	Male	Female
_____	_____	☐ Yes ☐ No ☐ ?	☐	☐
_____	_____	☐ Yes ☐ No ☐ ?	☐	☐
_____	_____	☐ Yes ☐ No ☐ ?	☐	☐
_____	_____	☐ Yes ☐ No ☐ ?	☐	☐
_____	_____	☐ Yes ☐ No ☐ ?	☐	☐

May we include children's information in our member directory? ☐ **Yes** ☐ **No**
If you'd like, we will only use birth year if you note "birth year only". *Please X one*

Additional comments: _____

_____

Research Studies Actively Recruiting

ADOLESCENTS & ADULTS
with **social, emotional, and/or communication difficulties**

Individuals aged 15-30 years who have diagnosed developmental, psychiatric or genetic conditions (e.g., ASD, ID, ADHD, FASD, Down Syndrome) and their parents/caregivers are invited to participate in a study improving diagnostic measures for use with adolescents and adults with Autism Spectrum Disorders. $25 gift cards for participant and parent/caregiver ($50/ family).

For more information, please contact:

Vanessa Hus Bal, MSc at
University of Michigan Autism and Communication Disorders Center
734-936-8781

FIRST WORDS Project

The FIRST WORDS research project represents a collaborative effort between the University of Michigan Autism and Communication Disorders Center (UMACC) and the Florida State University (FSU) Department of Communication Disorders. The goal of this research study is to identify tools that will improve the screening and referral processes of very young children with communication delays or autism spectrum disorders.

We are recruiting families with children between the ages of 12 months to 24 months of all abilities to participate in this research project.

For more information, please contact:

Dinette Morrison at
734-764-3328 or
dnettem@umich.edu

Rush University, Chicago, IL
Dr. Berry-Kravis

Trials of new medications targeted to brain mechanisms in FXS.

- Novartis AFQ056 trial (mGluR5 blocker) for adolescents age 12-17 as of May 2, placebo-controlled for 4 months, followed by an option for an extension.
- Rush will open recruiting up for two Seaside STX209 (arbaclofen) studies in May (age 12-25) and June (age 5-11) both placebo controlled for 2 months, followed by an option for an extension.

Full information on studies are available at clinicaltrials.gov.

Dr. Berry-Kravis is helping recruit for two studies involving FXS PET scans, one of which is in our own backyard.

- Measuring protein synthesis in 12 -17 year olds, is it increased over controls like in the mouse models? Wayne State University.
- Measuring the number of mGluR5 receptors in brain in males age 18 and over. Must be able to do the scan without anesthesia. Cannot be in other medication trials and must tolerate blood draws. This study will help with selecting the best dose for clinical trials of these drugs in FXS. Yale University, ALL expenses paid.

For more info on Rush study recruitment, please contact:

Crystal Hervey at 312-942-7250

Through the Maze - Featured Website

Our Fragile X World
ourfragilexworld.org
866-214-2044

Our Fragile X World is a community of families and researchers dedicated to providing practical information about the world of fragile X. Through use of the telephone and internet they will conduct periodic surveys of families, providing important information for policy and practice.

Families enrolled in ***Our Fragile X World*** agree that researchers at RTI International may invite them to participate in voluntary, confidential surveys about their experiences with fragile X. RTI International is one of the world's leading research institutes, dedicated to improving the human condition by turning knowledge into practice. If your family has been touched by fragile X, we hope you take the opportunity to join ***Our Fragile X World.***

If you're already enrolled in ***Our Fragile X World***, you should have recently received a letter and brochure asking you to login and update your information. This photo made it into the brochure and is an excellent example of how the FMR1 gene affects more than one generation in families. It's a photo of FXAM member Andrew Langan Coutilish (affected by FXS) kissing his grandpa, Jack Langan (affected by FXTAS).

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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

Fragile X Advocacy Day: 2011

From Grand Blanc to Grosse Pointe to Stevensville, the Michigan Fragile X Family was well represented on The Hill on March 2 for the NFXF-sponsored Advocacy Day. Part of the Michigan advocates' schedule included visiting Senator Hansen Clarke. Present were - back row, from left: Elina Gelfand, Joshua Cohen, Ted Coutilish, Clarke, Melissa Morrison, Amanda Morrison, Jeffrey Cohen; front row: Jennifer Silverton, Don Price, Samantha Price, Jacob Price, Tricia Price. Thanks to the team - and those from all over the U.S. - for representing our Fragile X cause in Washington, D.C.!

Fragile X
Association of Michigan

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