



FRAGILE X ASSOCIATION OF MICHIGAN

eXtra, eXtra

Volume XI, Issue 2; April 2015

Mark Your Calendar

Three Cheers for...

Support Meetings

First Saturday of the Month

When:

- May 2, 2015**
Free Childcare
See page 4.
- June 6, 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:

May 9, 2015

FXAM Dads
Dining Out
See page 4.

June 5, 2015

Wrinkle Free for a Cure
See back page.

June 7, 2015

FXAM Family Friendship
Circle Playdate!
See page 4.

Fragile X Association of Michigan

(a member of the
NFXF Community
Support Network)

Contact Information:

313-381-2834

southeastMI@fragilex.org

FXAM.org



Heather Van Dam

Pictured with Congressman Dave Trott of Michigan's 11th District. See Heather's story on page 2.



Jeffrey Cohen

who led the most attended Advocacy Day in NFXF history earlier this month! This required countless hours planning and coordinating schedules with legislative offices. From this year's event, Jeff is pictured with FXAM member Aidan Silverton.



Bobby

who turned 26 on April 6. He lives in Cadillac, Michigan with his sister and brother-in-law who are his guardians and his three silly nephews.

My Perspective of Advocacy Day *By Heather Van Dam*

In life, we are given many opportunities. We don't always notice them because fear holds us back. I was recently given the opportunity to go to Washington, D.C. in March for my first National Fragile X Foundation Advocacy Day. Unlike many Fragile X carriers, I don't have a lot of anxiety. Mostly because I really love adventure! But this was totally different. I was going without my husband Derek who is always with me on my adventures. I was scared! I was also rooming with someone I had never met before and I was joining 200 other people and only knew a handful of them. All of my worry was overpowered by the chance to go and talk to Members of Congress. To say I was excited would be a major understatement. I was JACKED UP!! I had a million things I wanted to tell them about what needed to be done to help not just kids with Fragile X, but all kids. I wanted to point my finger and tell them what they needed to do to make the world a better place! My mind was a tornado of ideas. Upon my arrival at the hotel, I was greeted by many familiar faces I had never met in person but had only seen on Facebook. A few I had met at the 2014 NFXF conference in California. It was a little weird to meet strangers with whom I had an instant connection. They were all so welcoming and friendly. I was instantly reminded that I was a member of a special club. I arrived on Tuesday for training that afternoon. The training they provided gave me a feel for what was to come the next day. There

was a lot of talk about how we should tell our story and the kind of information that we should include. It was great to be given direction. I sat at a table with other Michigan advocates. I had met all of them before and it was so great to know they had done this before and would have my back if I froze. We went over the K.A.S.S. Act and the T.I.M.E. Act which we would be discussing the next day with Members of Congress. They also gave us leave-behind folders with all of the necessary information about the Acts, Fragile X syndrome and who they could contact at the NFXF if they had questions. When the training was over, I felt ready for the next day. On the day of our visit to Capitol Hill, we all boarded busses that would take us to the Hill. We stood on the steps of the Capitol building for a BIG group picture. We then went into the Capitol building where Congressman Gregg Harper gave us a tour of the House of Representatives and told us about his son who has Fragile X. After the tour, we split up into groups and went to our meetings with Members of Congress from our state. The day was like a marathon: rushing from a meeting in one building to a meeting in the next building. Each meeting left me feeling more prepared for the next. I just sat back at the first ones to see how it went and what I could add. I was so fortunate to spend the day with the Price Family. They have been to Advocacy Day every year for many years. They were pros. Dave Trott is the Representative from



Alli Cohen with Heather in D.C.

my district. Luckily, it was the last meeting of the day so I had a lot of time to go over what I wanted to say. When we arrived for the meeting, Representative Trott was on the House floor for a vote. We met with a member of his staff. She was so kind and really seemed to genuinely care and have concern for what we had to say. I felt like I was really being heard. When the meeting was over and we were leaving we ran into Representative Trott in the hallway. He was apologetic for having missed our meeting. We spoke with him in the hall for several minutes and told him our

**"Don't go through life,
grow through life."**

~ Eric Butterworth

My Perspective of Advocacy Day *continued from page 2*

story and asked if he would support the Acts. He said he would have a look at the folders we left and see what he could do to help. Besides the birth of my children, I have never felt so powerful in all my life. It made me feel as if I could do anything. I

had the amazing opportunity to meet face to face with Members of Congress! How many people can say that?! I had the chance to be a lobbyist for a day. I told them what we wanted and how it would help all kids. Not just kids with special needs. I felt like a real life

super hero. The Members of Congress were all very kind and listened closely to everything we said. The more people who go, the more things will begin to change. If you have never done it... I say DO IT! Your words and actions have POWER!

Fragile X-Associated Disorders: Emory's new study to identify risk factors of severity

The National Fragile X Center at Emory University has an exciting new study to discover genes that affect the risk and severity of three fragile X-associated disorders:

Seizures in Fragile X Syndrome
Fragile X-associated Tremor/Ataxia Syndrome (FXTAS)
Fragile X-associated Primary Ovarian Insufficiency (FXPOI)

The goal of the study is to discover genes that work with the fragile X mutation (FMR1) to increase severity of these three fragile X-associated disorders. They hope the results from this study will help find new avenues for potential treatments.

If you would like more information, please contact Krista Charen at:
404-778-8479 or Krista.Charen@emory.edu.

New Clinical Trial sponsored by Neuren Pharmaceuticals

Neuren Pharmaceuticals (neurenpharma.com) 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.

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 at this time 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.

U of M is working toward being a participating site in the future. Stay tuned!

For more information on Neuren's NNZ-2566 clinical benefit in Rett syndrome Phase 2 trial visit: neurenpharma.com/IRM/Company/ShowPage.aspx/PDFs/1448-1000000/NeurensuccessfulinRettsyndromePhase2trial

What's going on ...

Free Childcare at our May 2nd Meeting!

6 - 9 p.m.

Free childcare available

6 p.m. Business meeting

7 p.m. Support meeting

RSVP by April 28 to
mblangan@hotmail.com with
your children's names and ages.

We'll have food & fun caregivers
for them!

Please bring something fun to
share (game, toy, coloring
book...).

Hope to see your whole family in
May!

FXAM Dads Dining Out

Saturday, May 9, 2015 at 6 p.m.

Churchill's

churchillscigarbar.com

116 S. Old Woodward

Birmingham, MI 48009

Bistro menu, beverages and cigars in addition to an opportunity to
gather with other Fragile X Dads at our first FXAM Dads' event.

Mary Beth will be taking reservations at mblangan@hotmail.com or 313-881-3340.

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

FXAM Family Friendship Circle Playdate!



Sunday, June 7, 2015

2:00 - 4:00 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 friendshipcircle.org/facility/weinberg-village
and the amazing rooms of The Activity Wing friendshipcircle.org/facility/activity-wing

Free event includes time for fun, frolic, food and friendship. Appropriate for kids of all ages.
Pizza, salad and water will be served.

Please RSVP to Elina Gelfand at

elina.gelfand@yahoo.com or 248-470-3311 by **Tuesday, June 2**,
with the # of adults and # of children attending this FXAM event.

See you at the FXAM Family Friendship Circle Playdate!

From the President's Desk by *Laureen Majeske*



Yesterday I thought it was Spring, but today as I sit here writing this I am looking out the window at a lawn covered with snow. This kind of mirrors our lives -- very unpredictable, we never know what's going to happen from day to day. That's why we are here to offer support in many different ways. Read through the newsletter, peruse our website, meet others at a support group meeting, attend a FXAM event, connect with others on our FXAM Facebook page or check out the many other things available. We are here for you!

Thanks again to all the members who do work for the volunteer-run Fragile X Association of Michigan. We are still looking for a member to fill the position of Recording Secretary. Duties include being a part of the FXAM Board of Directors, taking notes at our seven business meetings during the year and at the annual board meeting, and distributing the

minutes via email to all board members. If you cannot make a meeting, another board member takes notes for you. If you are interested or would like to learn more, please contact me at lmajeske1@comcast.net. Thanks for considering this! We are always looking for new faces, ideas and inspiration. This is YOUR group and YOU can make a difference!

In an effort to reach more families across the state, we held a satellite meeting in February in the Lansing area where families met at the AbouElSeoud home and Skyped into our Royal Oak meeting where Jeffrey Cohen was speaking about the ABLE Act. While we have a few small kinks to work out, the event was a success and our out-state families were excited to participate. We are looking forward to holding more satellite meetings to make our support group available to more of

you and will spread the word when we have another one scheduled. Coming up in May, we have free childcare available at our Royal Oak meeting. Twice a year we offer this service, so take advantage of this Spring session! There will be pizza and salad on May 2 for both adults and children.

The 2015 Let 'Em Know virtual 5K campaign has now been launched by the National Fragile X Foundation for this year's Fragile X Awareness Day in July. We have a goal of raising \$2,500 which will be split evenly between the NFXF and FXAM. Don't forget to sign up under the Fragile X Association of Michigan's page so that the funds you raise count toward our goal. Copy the link below to access the Fragile X Association of Michigan page. Let's walk it out this July!

Let 'Em Know 5K 2015

crowdrise.com/FragileXAssociationofMI/fundraiser/FragileXAssociationofMI

Greetings from the University of Michigan Fragile X Clinic!

By Kailey Owens, Clinic Coordinator

Please join us in congratulating Kate Partynski on her upcoming graduation from the University of Michigan Genetic Counseling Program! Kate has accepted a position in Pediatric Genetics in Orange County, California. Thank you again to all of the FXAM dads who participated in Kate's study. We hope to share the results at a national meeting in the future!

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

May 14 and 21 (A2)	September 23-24 (MARQ)
June 11 (A2)	October 15 and 29 (A2)
June 25-26 (MARQ)	November 5 and 19 (A2)
July 9 and 23 (A2)	November 5-6 (TC)
August 20 and 27 (A2)	December 10 and 17 (A2)
September 10 and 17 (A2)	December 10-11 (MARQ)



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FXAM.org

Wrinkle Free for Fragile X!

For the 14th year, the Silverton Skin Institute of Grand Blanc, Michigan will be hosting **Wrinkle Free for Fragile X and Autism**. This annual event is hosted by Dr. Kimball Silverton, board certified dermatologist and fellowship trained cosmetic surgeon, and his wife Jennifer, President of the National Fragile X Foundation Board of Directors. The event offers patients an opportunity to receive injections of a wrinkle relaxer such as botox at a significantly reduced price with all proceeds going toward research. The Silvertons have a 17-year-old son Aidan who is affected by Fragile X and a 15-year-old unaffected daughter, Camryn. The event will be June 5, beginning at 9 am at the Silverton Skin Institute. More details are available at FXAM.org or visit silvertonskininstitute.net to learn about the institute's procedures. For more information, contact the institute at 810-606-7500.



Fragile X Association of Michigan

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