

**Mark Your
Calendar**

Support Meetings

First Saturday
of the Month

When:

May 3, 2014

June 7, 2014

(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:

May 10, 2014

FXAM Moms:

Let's Do Lunch!

See page 2.

May 25, 2014

FXAM Family

Friendship Circle

Playdate See page 3.

June 6, 2014

Wrinkle Free for a Cure

See back page.

July 16-20, 2014

14th International

FX Conference

Anaheim, CA

August 9, 2014

FXAM Family Picnic

Watch for more details!

FXAM Contact Information:

313-381-2834

FXAM.org

Three Cheers for...

Douglas Rich - Harry Scott and Hillary Rich married June 2012 at a beautiful outdoor wedding near Grand Rapids. Everyone was impressed with him - including his parents. Douglas greeted the guests with a handshake and a huge smile!



Maggie and Wish Upon A Teen - See page 4 for more info.



Kevin McLean - He's become successful in seeing movies at the theater! See page 4 to learn what helped.



Paul Fodor - Look at that proud smile! He was so happy with his silver medal for Special Olympics Basketball Regionals, he wanted to sleep with it. Congratulations Paul!

Between the Lines - Featured Book

Behavior Solutions for the Inclusive Classroom: A Handy Reference Guide that Explains Behaviors Associated with Autism, Asperger's, ADHD, Sensory Processing Disorder, and other Special Needs

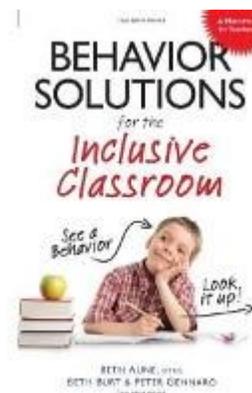
by Beth Aune, Beth Burt and Peter Gennaro

Reviewed by Heather Van Dam

I received the book Behavior Solutions for the Inclusive Classroom as a gift. I found it to be very easy to read. Each chapter gives solutions for a different behavior. This makes it possible to read and specifically focus on the sections that apply to your child. After reading the book, I gave it to his teachers to read. Our son Mason - who is 8 years old and is

affected by Fragile X - spends time in an inclusive class room as well as a resource room and both of his teachers were excited to read about how they could help him to have better days.

Regardless of their classroom placement, I believe Behavior Solutions for the Inclusive Classroom could be helpful for all students.



The Cheesecake Factory

FXAM Moms: Let's Do Lunch!

Cortney & Mary Beth would like to meet up with awesome FXAM moms for lunch.

Saturday, May 10, 2014 at 11:00 am

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

27679 Novi Road

Novi, MI 48377

313-305-7500

thecheesecakefactory.com

Come join us for some Mom-only time on Mother's Day weekend!

Email cabouelseoud@gmail.com and mblangan@hotmail.com so we know to expect you for lunch and can keep you up to date with our lunch plans.

Shopping and mall walking are post-lunch options.

Please note: this is not one of our free events. Each FXAM mom will be paying for her own food/drinks.



Conference Registration is already open!

Visit fragilex.org for more info on the conference and to register. As long as you register by May 16, 2014, you will receive the early bird discount.

The Fragile X Association of Michigan will once again be granting scholarships to help our FXAM members attend the National Fragile X Foundation's biennial International Fragile X conference! We will decide the exact amount of the FXAM conference scholarships after we have the final number of scholarship applicants, but each member's scholarship will be a minimum of \$350. **To apply for the FXAM conference scholarship**, you need to contact Lauren Majeske at lmajeskel@comcast.net or

586-978-9079 to let her know you are interested in the scholarship. Apply to Lauren by April 30, 2014. By May 5, Lauren will confirm that you'll receive the scholarship and the amount for which you'll be eligible. In late July, you'll verify that you attended the conference by submitting receipts (hotel, etc) and, after verification, will be paid the scholarship money in early August.

Please note: *The FXAM scholarship is different than the NFXF scholarship or the Rogers Neighborhood Family Fund scholarship. Both of those deadlines have passed. If you've received one of those scholarships, you may still apply for the FXAM conference scholarship.*

FXAM Family Friendship Circle Playdate!

Sunday, May 25, 2014

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/weinberg-village/ and the amazing rooms of The Activity Wing friendshipcircle.org/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, May 20** with the # of adults and # of children attending this FXAM event.

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.

Sharing our eXcellent resource info

Do you have a program that your family member absolutely loves? Do you have a resource that you have used that has helped you help your child be their best? Have you had an experience that you could share with

others that may assist others in our FXAM family? What are your tips and tricks? You might have resource info based on a specific age group (Early Development, Elementary, Middle School, High School, 18 & over) or a

specific topic which may or may not span different age groups (sensory needs, homework, sleep issues). Please share your knowledge!

Wish Upon A Teen



Wish Upon A Teen has been a great organization for Oakland County FXAM family member Maggie Branch. Maggie's participated with them in a number of ways over the past six months. Among other things, she's enjoying learning to cook with friends at Sur La Table and being a part of a cool

Tech Teens group. Her brother Patrick has even enjoyed an event with Wish Upon A Teen as they have sibling support events and he bowled with some new friends at a recent event. Check out wishuponateen.org for more scoop on this innovative organization!

Quiet on the Set!

Going to the movies might seem like a small feat for some, but recently it was a huge success for Kevin McLean. It had been six years since Kevin had seen a movie in a theater. In the past, his anxiety would take hold and he'd have to leave before the opening credits ended. Kevin put that behind him and he managed an early viewing time for *Frozen*. Mom, Marie Weaver, believes, the time and sitting in the front row with no one around him helped. Now he's a regular moviegoer with *The Lego Movie* under his belt as well. The next step will be a family outing to the movies. Way to go Kevin!

Welcome Abigail Deppen, MS, CGC

Abigail Deppen recently moved to Michigan from Miami where she was working as a genetic counselor in the South Florida Fragile X clinic. She loved working in the clinic and hopes she'll be able to continue seeing patients affected by the Fragile X gene in her new position in Detroit.

She is working in the genetics clinic at Henry Ford Health System and would be happy to see carriers before or during pregnancy, newly diagnosed

families, carriers with FXPOI or FXTAS, etc. Abby knows that there is a Fragile X Clinic at the University of Michigan and would not want to take away referrals from them. However, if you or family members are seeking genetic services in Detroit, feel free to contact Abby at:

Henry Ford Genetics
313-916-1439

From the President's Desk by *Laureen Majeske*



In the freshness of spring, we have decided to freshen up the Fragile X Association of Michigan as well! Come and experience our newly rejuvenated support meetings. The business meeting is still from 6:00 - 7:00 p.m. - unless the reminder says otherwise - and everyone is welcomed and encouraged to attend. Kailey Owens, Genetic Counselor from our Fragile X Clinic, attended the last one and it was great to get an update of all the new things that are going on at the clinic, including a new Fragile X "Supergroup" dedicated to sharing information and research from multiple research groups within the University of Michigan Hospitals. The support meeting will become a time of sharing, supporting and socializing. From 7:00 to 7:15 p.m., we will update you on all of the things going on at FXAM. 7:15 until 8:30 p.m.

will be a time of sharing and support where you can share your version of Fragile X and/or get all the answers you need in a relaxed setting. At 8:30 p.m., we will have a half hour of socializing and smaller group conversations. This is a great time to build friendships and have one-on-one discussions without having to talk in front of the entire group. We know that the best support is having a friend by your side. As always, refreshments are served at our meetings. We are also planning to have a meeting with childcare in the spring and one in the fall so those of you who have difficulty getting babysitters can have a chance to attend. Pre-registration will be required at those meetings. We'll let you know when those are scheduled. We are also still working with Beaumont Hospital to have electronic access to allow

you to call into the meeting for those who live too far to travel. You are important too and we haven't forgotten about you!

Make sure to mark your calendar with all of the upcoming events. This year our annual FXAM golf outing celebrates its FIFTEENTH year! The day promises to be full of fun and celebration. After 8 years of our family picnic and 5K Fun Run/Walk, we are going back to just the family picnic. Look for more details as summer draws nearer. The FXAM picnic is a great opportunity to meet and reconnect with other families affected by Fragile X.

Have a great spring - we all deserve it after the long winter!

Greetings from the University of Michigan Fragile X Clinic!

By Kailey Owens, Clinic Coordinator

Happy Spring! Hopefully warm weather is on the way. I enjoyed meeting with families at the March FXAM meeting and I hope to attend these meetings regularly. I am also excited to report that I will be attending my first Fragile X Conference this year and I look forward to seeing familiar faces there! We have had a good turnout in our clinic so far this year and we still have several available dates, so please come and meet with us! Listed here is the our Fragile X Clinic schedule for the remainder of 2014. Also, please consider joining the FXCRC FORWARD Registry and Database. More information on the Registry and Database can be found online at <http://www.fxrc.org>. If you are interested in scheduling an appointment in our clinic for yourself or a family member with Fragile X or FXTAS, please contact us at 734-615-3591.

2014 U of M Fragile X Clinic Schedule

May 1 and 15	September 4 and 11
June 5 and 19	October 2 and 16
July 10 and 24	November 6 and 20
August 7 and 21	December 4 and 11

*There are two ways to live your life.
One is as though nothing is a miracle.
The other is as though everything is a miracle.*

~ Albert Einstein

e tra, e tra

Editors:

Mary Beth Langan 313-881-3340

mblangan@hotmail.com

Sally Nantais 734-282-7910

sallyn423@wyan.org

This newsletter is published quarterly and sent to all members and supporters of FXAM. Permission is granted to reproduce and distribute this newsletter for noncommercial purposes.

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

Wrinkle Free for Fragile X!

For the 13th 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, Vice-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 16-year-old son Aidan who is affected by Fragile X and a 14-year-old daughter Camryn. The event will be June 6, beginning at 9 am at the Silverton Skin Institute. Registration info will be announced shortly. Visit silvertonskininstitute.net to learn about the institute's procedures. For more information, contact the institute at 810-606-7500.



P.O. Box 1414

Troy, MI 48099-1414