

**Mark Your
Calendar**

Support Meetings

First Saturday
of the Month
(no summer meetings)

When:

May 4, 2013
June 1, 2013
October 5, 2013

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:

April 27, 2013
Fragile X Fundraiser
See back page &
FXAM.org

June 30, 2013
FXAM Playdate!
See page 5.

July 28, 2013
FXAM Picnic & 5K
Clarkston, MI

September 7, 2013
**14th Annual Golf
Outing, Wesburn**
South Rockwood, MI

**Fragile X Association of
Michigan**

Contact Information:

313-381-2834

FXAM.org

Three Cheers for...



Darienne Majeske and the Pride of Trilogy Cheerleading Team, after winning first place in the Champion Spirit Group National Championships, in Chicago, during March 2013. Cheerleading Training Center of Michigan - www.ctcofmi.com



Josh See page 3.

Trevor Pribac - Grandma Amy Pribac is very proud of Trevor for successfully attending Grandpa Bill's Big 80th Birthday Bash in Michigan. Trevor's family came in from Maryland for the occasion. Affected by Fragile X, Trevor doesn't always love attending parties. Trevor celebrated with 40 family members and friends with no meltdowns, both at Sajo's Restaurant and back at the house! Three Cheers for Trevor and the Pribacs!



Embracing Fragile X

by Cortney AbouEISEoud

I'm a 31-year-old mom of three children ages five and under - two of those with full mutation Fragile X. The astounded looks from strangers followed by "How do you DO it?!" are as familiar to me as my face in the mirror and always greeted with the same smile and shoulder shrug that answers nothing but closes down a conversation that would ultimately end in me being extremely rude. Because how do I not? These are my kids. My family.

My story begins much differently than most others in the Fragile X world. I found out I was a carrier when I was in high school. My carrier dad is the youngest of five. His mother passed her affected X to at least three boys including my dad; subsequently seven female cousins are Fragile X carriers. While I was enjoying high school, three significantly older cousins were getting married and having children. One cousin had a

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Embracing Fragile X (continued from page 1)

son with delays and his eventual diagnosis led to the discovery of Fragile X in our family. I've known I was a carrier for so long now, I can't even say what it felt like to be told. I certainly didn't understand the scope at the time and wouldn't for quite a while. I eventually went to college, fell in love and got married. My husband was aware before we were married that I was a carrier. We went into marriage and made the decision to have children with that information. I thought at the time we were completely informed with that decision, but I know now we actually were not.

After I became pregnant, we requested genetic counseling from my doctor. I'd never actually been tested - though I knew I must have been a carrier - so we went through that process as well. The counseling was not what I expected. Our genetic counselor had never even heard of fragile x syndrome so the information she gave us was printed from the internet. As most genetic counselors, she painted a worst-case scenario for us. It was fairly traumatic to essentially be told the child you are carrying has no hope. They offered to test the baby and informed us we had options; we vehemently declined. My husband and I were quite shocked by the information we were given. It took a few days, but we took a step back and then moved forward with a new resolve. Our baby was still our baby and nothing else mattered. We searched for a local pediatrician who knew about Fragile X, planning for what we were told was inevitable should I have passed on my expanded X. We only found one in our area that even knew anything about it, so the decision was not too difficult. Our son Ayden arrived early, but very healthy. When our pediatrician came in to see him, we asked about the Fragile X testing. We were told he had no physical features of Fragile X and she saw no reason to test him. As new parents who didn't know better, we took comfort in her words and followed her advice.

When Ayden was around one year old, we decided we were ready for another baby. At the time, we were told his delays were very minimal and that "he would catch up" so we assumed we had nothing more to think about. I became pregnant very quickly; looking back, that was a very good thing because our worst age with Ayden started around age 18 months. He was enrolled in early intervention at that time where he was given a full developmental assessment. His delays were much more significant than we realized and he easily qualified for services. It was after his first IFSP, just after the birth of our second son, when I finally admitted to myself that Ayden must have Fragile X Syndrome.

Even though I had admitted to myself that Ayden's delays were a cause of Fragile X, we still didn't have him tested. By the time I thought it needed to happen, we knew a lot more about Ayden's sensory issues and that his aversion to touch was actually tactile defensiveness. We again looked to the professionals that worked with Ayden for advice. Should we get him tested? Would a diagnosis matter? We were ultimately talked out of testing for the second time. We were told his services with early intervention would not change and that medically speaking it made no difference either. To us, putting him through the blood draw for the test when we were told it was unnecessary just wasn't worth it. At that point, we decided to have him tested when a diagnosis would matter or if he needed blood work for something else. It wasn't until two years later that we had him tested and - not surprisingly - received his Fragile X diagnosis when he was age 3.5

It was at this point something clicked in me and I dove headfirst into finding out everything I could about Fragile X. Somewhere along the way, my eyes and ears had closed to the simple truth of what Fragile X really was and what it could mean. As I scoured the internet for any bit of information that could help Ayden, it didn't take very long for me to find out all the advice that we had received over the previous 3 1/2 years was not very good. That was when I got angry. Angry at all those professionals that had been giving us poor advice. Angry that we were put in this situation. Most of all though, I was angry at myself. I was angry that I let almost four years of my son's life slip through the cracks when I should have been advocating for him instead of letting people comfort me by saying things like "It will be okay," "He'll grow out of it," "He's a boy, they just are slower sometimes". It was at that point I knew I needed to share our story. I didn't want one more family to have to go through what we did. I didn't want another family to hear what we did and make the same mistakes we did. I didn't want another mother to have to question how much better off her son would be if he would have had intervention from an earlier age. So my blog - A Day At A Time - was born. A place where information for newly diagnosed families can be found, where people can be pointed in the right direction for accurate information. A place where people can learn not only that they are their child's advocate, but how to be an advocate.

I still forget sometimes. To be an advocate. Fragile X carriers are often blessed with varying degrees of issues to overcome and anxiety is at the top of my list. I forget to be an advocate sometimes because I let my anxiety guide me. I

Embracing Fragile X (continued from page 2)

find it easier to sit in my house and type on the computer than to have an actual conversation with someone. Meet someone new. Do something different. While Fragile X is most definitely behind that, it's also the driving force behind overcoming it. I had the pleasure of attending Fragile X Advocacy Day in Washington, D.C. in March. For the first time since my plunge into everything fragile x, I met people not in my family that were affected by Fragile X. At the beginning of training, we had to introduce ourselves five different times to different people in specific, different ways. By the end of the exercise, I thought I was going to vomit from anxiety overload. As we headed back to our seats, I did some quick breathing exercises and reminded myself why I was there. I also made a promise to venture out of my comfort zone for the next day and a half, even when I thought it was too much. I kept that promise and had the most amazing time!

While I've been aware of Fragile X for 15 years, I've only been an active part of the online community since Ayden was diagnosed in 2011. I've since been through the diagnosis of my daughter when she was born and also the news that my second son does not have Fragile X. I've learned through it all that this Fragile X life is constantly changing, but the thing that remains the same is the people. The ones we advocate for and the ones we advocate with. Whether you're advocating at school, in a doctor's office, at the grocery store, or on Capitol Hill. We each do the best we can for our families - with the support of our extended Fragile X family - each decision building the framework for those lives we are charged with and helping them to become the best they can be.

Cortney lives with her husband and three children in mid Michigan. Read more of her story at:

<http://fxsadayatime.blogspot.com>

Josh *by Arlene Cohen*

What I've learned during my 24 years as Josh's mom is that timelines mean nothing. I'm constantly surprised at his achievements. At 24, he is now reading more than he did during his years in school. He still gets tutored once a week because "school" at this point

is working on life skills. In addition to reading the written word, he can now read music. I always knew music was a motivator for him, but it wasn't until the last couple of years that I felt he could be a meaningful participant in a piano lesson.

He has a lesson once a week and can now translate notes to his fingers. I will never stop believing in him. My advice to parents is just because your child may be struggling today, does not mean those same struggles will be there tomorrow.

2013 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

Courage isn't having the strength to go on - it is going on when you don't have strength."

~ *Napoleon Bonaparte*

Top 10 Things a Teacher Should Know About Fragile X Syndrome

by Laurie Yankowitz, Ed.D.

Students with Fragile X Syndrome can often be like the proverbial girl with the curl in the middle of her forehead – when they're good, they're very, very good, and when they are bad they are horrid.

Knowing these 10 things will help bring out the good and minimize the horrid!

The #1 thing teachers should know about students with FXS is that they are prone to hyperarousal and anxiety.

It is how their nervous systems are wired. Most recommendations that follow are geared to maximizing focus and cooperation by minimizing hyperarousal and anxiety:

1. **Don't force eye contact.** Eye contact will come naturally as the student becomes more comfortable with you.
2. **Expect inconsistency.** Engagement and performance is likely to vary greatly; it can be difficult to discern why. Try to accept this to avoid frustration; your student will pick up on frustrated energy and that will exacerbate anxiety.
3. **Students are “simultaneous” vs “sequential” learners.** FX'ers are motivated by the end result, and impatient with the process. Use backward rather than forward chaining; use checklists to show progress toward an end result.
4. **Allow frequent breaks.** Accommodate attention deficits by keeping tasks brief.
5. **Verbal expression is cognitively taxing.** Provide some non-verbal alternatives for students to show what they know, such as following directions and pointing to visual representations.
6. **Think “INDIRECT.”** There are times when FX'ers enjoy attention, but most often they are adverse to the limelight. Give compliments in the 3rd person about the student to others within earshot; use incidental learning; include the student in a small group while directing instruction to a peer; avoid direct, open-ended questioning: prompt “The President of the United States is.....” vs. “Who is the President of the United States?”
7. **Prepare for transitions.** Give 10 and 5 minute prompts. Allow to be at the head or back of the line. Use social stories about routine transitions. Provide a purposeful errand so the focus is on the outcome (e.g. delivering an envelope) rather than moving from one place to another.
8. **Work with an OT knowledgeable about sensory integration and embed SI strategies into the school day.** FX'ers are prone to hyperarousal and anxiety which undermines focusing ability- learn what SI techniques are calming for your student – heavy work like re-arranging desks, cleaning windows, moving stacks of books? Vestibular input, like going for a walk, doing wall push-ups, swinging, using a skateboard?
9. **Notice environmental triggers.** FXer's often have sensory sensitivities to sound, light, textures, taste, and smell that provoke hyperarousal. Make adjustments to the environment (dim lighting, allow use of muting headphones) as much as possible.
10. **Know FXS strengths.** Common strengths associated with FXS are a good visual memory, sense of humor, desire to be helpful, empathic nature, and gift for mimicry. Use visual cues, make learning fun, provide opportunities to be of assistance, encourage providing emotional support to peers, use modeling as a primary teaching technique – and **ENJOY YOUR STUDENT WITH FXS!**

From the President's Desk *by Lauren Majeske*

After a long winter, it is nice to finally see Spring arriving and everything becoming fresh and revitalized. And FXAM is on the move too - with an evening of dinner and dancing at the Palace of Auburn Hills to raise money for FXAM and the NFXF's Rosen and Weingarten Research Funds, which help fund vital Fragile X research.

Plan for summer with the dates for our 5K and FXAM family picnic and our annual golf outings all

listed in this newsletter. Start getting your teams together now to maximize your fun later! Get ready for another playdate at the Friendship Circle in June. All ages welcome to come enjoy themselves! And don't forget our monthly support group meetings. It's a place not only to get support, but to visit with friends, renew old acquaintances, learn new things, share your experiences, have questions answered and just have a good time.

Have an idea for something you would like to see our group do? Come early for the business meetings and share your ideas or just give us your input on things already going on. If you can't make the meetings, share your input via email or phone. You can make a difference!



News Briefs

Fragile X Clinic - University of Michigan - Dr. Peter Todd

My research group has recently had a paper on FXTAS accepted at Neuron, which is a prestigious research journal. This paper describes a new way in which CGG repeats in the Fragile X gene contribute to human disease and suggests some ways in which we might be able to correct these problems in patients.

Update on Children's Hospital Seaside Research

We'd like to follow up on our January 2013 article on the Children's Hospital of Michigan STX209 research study. Children's Hospital did everything they needed to get ready for the study. Unfortunately, Michigan folks won't be able to partake in this specific study here because Seaside Therapeutics has filled all spots in the study at other sites. Fortunately, that may mean that STX209 will get to the pharmacy shelves quicker AND it means that Children's is ready to possibly participate in other future studies. Stay tuned!

FXAM Family Friendship Circle Playdate!

Sunday, June 30, 2013

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

Free event includes time for fun, frolic and friendship! Appropriate for kids of all ages. Refreshments will be served. Come join in the fun!

Please RSVP to Elina Gelfand by **Tuesday, June 25**, with the # of adults and # of children attending at elina.gelfand@yahoo.com or 248-470-3311

See you at the FXAM Family Friendship Circle Playdate!

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FXAM.org



PLEASE JOIN THE TEAM

TO HELP THOSE IMPACTED BY FRAGILE X

APRIL 27, 2013

AT THE PALACE OF AUBURN HILLS VIP CLUB

DETROIT PISTONS

Team Member:

\$120 per person

Captain:

\$170 per person (on-court free throw)

MVP:

\$220 per person (locker room tour)

The evening will feature cocktails, dinner, DJ, raffle and a half-time appearance from Dr. Elizabeth Berry-Kravis.

Contact Elina for more information and to RSVP: elina.gelfand@yahoo.com

All proceeds benefit the National Fragile X Foundation's Rosen/Weingarden Research Fund and the Fragile X Association of Michigan.

 **Fragile X**
Association of Michigan

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