

Mark Your Calendar

Support Meetings

First Saturday of the Month
(no meetings in July, August and September)

When:

May 5, 2012
June 2, 2012

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:

June 3, 2012

FXAM Family
Friendship Circle
Playdate! See page 3.

June 23, 2012

University of Michigan
Fragile X Clinic
Grand Opening
See back cover.

July 25-29, 2012

13th International FX
Conference, Miami

August 11, 2012

FXAM Picnic & 5K
Clarkston, MI

Fragile X Association of Michigan

313-381-2834
FXAM.org

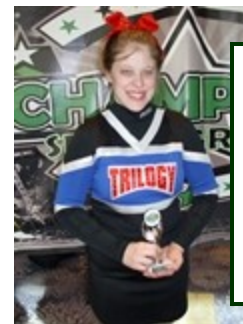
Three Cheers for...



Nora and Antonio!
See article on page 6.



Maggie! See **A Star is Born** on page 7.



Darienne! Her cheer team, Pride of Trilogy, came in first place in the National Championships.

Our Michigan Advocates that went to DC!
(see page 5 for the Price Family's review of the trip).



Drug Trials - On the Front Line with our Families

A number of FXAM families participate in clinical trials for new medications targeting Fragile X. Here is the first recap from a member family.

Family: Nantais

Study/Location: STX209 (Arbaclofen), Rush University, Chicago, IL

Start Date: April 2009

End Date: Unknown, still active.

Age of Child/Adult when he/she began the study: 17

Positives: When we started we were in the initial project which was intended to only look at improving challenging behavior, it was a double/blind process of placebo and med, our family and Dr. Berry-Kravis not knowing what was given when. After the first cycle, there were moments of great ability but one must keep in mind, my son, Austin, at times has very, very good days. By the end of this round I simply decided that if we were on the med it really wasn't a wonder med for us, no "Wow" factor. In July 2009, when we began the 2nd phase, I noticed an immediate improvement (Austin responded positively right from the start). We, in the past, have often had problems with unexpected transitions and we got stuck in a traffic jam five miles from home on our return trip from Chicago, I expected the worst. Typically this may have resulted in a meltdown, the meltdown never happened. That month Austin did very well, he happened to be enrolled in the Extended School Year (ESY) program and in his progress report at the end of that month he improved in eleven different areas. Since we've been enrolled in the study we've eliminated two of the medications Austin was taking and we cut his Abilify dose in half, now he only takes 15 mgs a day. Just the changes in the meds he's on is a HUGE positive for me. I like the fact that STX209 is based on a drug that has been on the market for years with a very good safety and tolerability record. I trust the organization that sponsors this trial, Seaside Therapeutics, Inc., I've been following Dr. Bear's work for over a decade.

Negatives: For our family, for Austin, there are really no negatives, we've had no serious side effects but I'd like to remind families to be vigilante. Medications for improving symptoms/behaviors will only go so far, the environment for the child is still very critical, for example you could be doing all the right things and be on a right mix of meds but if the environment is not a good fit for the child/adult you could still have problems unless you correct what's wrong in the environment.

Has the drug met you overall expectations: Yes, I wasn't looking for a cure, I was looking for something that would improve the overall quality of Austin and our family's life and STX209 has more than met our expectations.

"Even if you're on the right track, you'll get run over if you just sit there."

~ Will Rogers.

Have you participated in a Trial?

Does your child have a favorite game, app, PC software that you believe other children/adults might enjoy?

Please share and send your story/review to the editors for inclusion in a future newsletter.

Mary Beth - mblangan@hotmail.com Sally - sallyn423@wyan.org

Apps for iDevices (iPhone, iPod, iPad) by Romy Patterson

We have two favorite Handwriting Apps. They aren't free, but have been well worth the money. They both offer different features, which make both worth taking a look at.

LETTER SCHOOL by Borreal (Lite is FREE / Full App \$2.99)

If you're just starting handwriting, this is a wonderful app. This app teaches a 3-step approach to writing numbers and letters (upper and lowercase), and uses fun animations to keep you interested. Step 1 wants you to tap touch-points, and the app draws the letter for you. Step 2 provides the touch points, and you have to perform the strokes

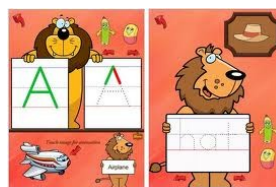


going dot-to-dot. Step 3 gives you the starting dot, and you have to write the letter yourself. If you are struggling, it does provide additional prompting with directional arrows to show you which way to go. In addition to the multi-step approach, each letter is drawn with a cute animation (ie. Train tracks), and when the letter is complete a train runs the tracks for reward.

The difference between the two versions is that the Lite only provides a subset of the letters.

ABC TRACER by App-Zoo (Lite is FREE / Full App \$1.99)

This app demonstrates the correct way to write numbers and letters (both upper & lowercase). You can then draw the letter any way



you want, but until you do it correctly (indicated by a green line) you don't get

the applause reward. There is a graphic on each page, that you tap and it will do an animation. In addition, it has basic words you can write, and an ABC sequencing game. My kids are fascinated with letters & numbers, so this is a fun game for them.

The difference between the two versions is that the Lite only provides a subset of the letters.

Our school OT loves both of these apps as well. She uses *Letter School* for her younger students, and *ABC Tracer* for the older ones.

FXAM Family Friendship Circle Playdate!



Sunday, June 3, 2012

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 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. Also included will be light refreshments.

Please RSVP to Elina Gelfand by Tues., **May 29** 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!

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.

Fragile X on Facebook by Mary Beth Langan



A month after my son Andrew was diagnosed in Fall 2002, I joined the FRAXA Family Listserv and connected with Fragile X parents from Michigan and around the globe. I learned most of my Fragile X-related info from these friends, who quickly became my Fragile X family. I could read about their experiences, share my own – the good and the not-so-good – and know I wasn't alone.

In 2012, the listserv posts few emails most weeks, but Facebook groups have exploded, including ones linking folks connected by the FMR1 gene.

Cortney AbouElSeoud from Holt, Michigan is a part of our FXAM family, but Cortney, Sherief and their three beautiful children haven't been able to make it to any FXAM events yet (though they still hope to do so). Cortney describes some pretty great Fragile X connections for someone who doesn't have the opportunity to easily attend a FXAM meeting:

I've found the Fragile X Facebook group extremely helpful since I joined in 2010. Not only have I met countless parents who are going the same things as our family, but also other women who are carriers facing the same health issues. Often someone will pose a question to the group that I haven't ever considered, but it makes sense with something that is happening health-wise with me or someone in my family. It has really opened my eyes to being proactive about testing and keeping my health in check so I can better care for my children. All that aside, the support that I've received from the group with two of my children being diagnosed is just invaluable. Both times people have taken the time to talk to me and just listen - they've been there before so they understand more than anyone else can. I was even connected with a geneticist from the National Fragile X Foundation who answered all my questions and called the lab that ran my daughter's test so she could answer questions about the confusing results.

Perhaps our words have sparked an interest. Here are some specifics about the most common Fragile X-related Facebook groups. The number in parentheses is group members as of 3/30/2012; the numbers grow daily.

Fragile X Association of Michigan (109) – The official Facebook group for our NFXF Michigan LINKS group. It's a great place to ask regional/state-related questions and share Michigan and FXAM news.

Fragile X (706) – This is where you will connect with the most Fragile X parents. People share their highs and lows, their questions and answers, their failures and successes here. It's an excellent place to ask anything related to Fragile X in some way and find someone who'll understand and be there to support you.

Fantastically Fragile X – The FX Brag Room (598) – Seven friends knew “how important it is to focus on the positive, encourage others to stay positive and how contagious that spirit is.” They decided they wanted “a place where ONLY the positive is celebrated.” These are all folks active in other groups too, but they wanted a separate place where you only share and read about the positive aspects of our Fragile X family. It can be very uplifting to read the posts!

Fragile XPress Learning (365) – The group's page states: “Our mission was to assist one another in helping each and every one of our children to reach their fullest potential within the educational environment and into adulthood.” Discussions mostly focus on education, whether homeschool, public, private or afterschool.

Fragile X Advocates (142) – This group just started in March 2012 with advocates discussing their journey to Washington, D.C. and advocacy efforts. All interested in the national advocacy agenda of the NFXF may join.

Fragile X Healthy Body and Mind (78) – Mostly female carriers participate in this group. Discussions may involve carrier issues such as early menopause, thyroid issues or FXTAS or simply sharing ideas regarding keeping ourselves healthy in the midst of our busy lives. You can't be a quality caregiver if you're not taking care of yourself!

Fragile X Man Cave (71) – I do not have a Y chromosome so I had my husband Ted count the members of this group. You must have a Y chromosome to join. It's a place where Dads can share with other Dads. I'll bet there's daily chatter about hair, nails and shoes plus what loving caregivers they each have as a significant other... but I can only guess! (continued on page 5)

Fragile X on Facebook (continued from page 4)

Search for these closed groups on Facebook and send a request to join. When you can't sleep and have a question, sometimes there's a mom from the other side of the globe who is awake and has the answer!

Being Facebook friends with other Fragile X parents is also a great thing. You can then have real-time Facebook chats or private message a parent (or parents) outside of a group for more individual connection.

You should definitely Friend Request Holly Roos. She's a LINKS Program Assistant for the National Fragile X Foundation and an active parent in Illinois with connections all over the world. She currently has approximately 1,200 Fragile X family members as FB friends. Who better to connect you with more parents just like yourself?

If you have questions about these groups, email me at mblangan@hotmail.com or send me a friend request. I'd love to connect with you on Facebook!

Advocacy with the Price Family

After many hours in the car, we finally arrived in DC to be greeted by unseasonably warm weather, blue skies, and lots of sunshine. It only got better from there. After our four-hour training session, we felt like pros and were confident we would have success this year as advocates.

If you have not been to DC as part of NFXF Advocacy Day, then we encourage you to consider it next year. The day is quite intense, but you leave with a feeling of accomplishment and pride. Pride, not only because of your own efforts, but because we live in a country that allows ALL of it's citizens full, free and equal access to our elected leaders.

What does an Advocacy Day trip look like? The first day begins with an afternoon training session where you are briefed on the legislative agenda that all advocates will discuss in the meetings with their elected officials. The Public Policy group at the NFXF pulls together all of the pertinent information that you'll need in order to speak intelligently about the NFXF

agenda. This agenda includes requests for continued, and increased funding, for Fragile X research and the passage of Bills specific to enriching the lives of individuals with disabilities.

The information pertaining to the Bills and Legislation that you are asked to speak about, however, can often leave you feeling overwhelmed and intimidated. The idea of sitting across the table from your Congressional leader and asking him or her to support our requests can be quite daunting. This was our second year participating in Advocacy Day and we really felt like pros this time around! You have to keep it all in perspective and remember that it is their job to be in DC to represent you and your child. Remember that we, as citizens, all have the right to be in their office to discuss pending legislation that can positively impact the quality of life for our children for many generations.

So the million dollar questions are "Will my efforts really have an impact? Can little ol' me make a difference?" The answer is a surprising "Yes!" You won't go to

DC and move mountains the first year and probably not even the second year. But if you add up the 150 families that traveled to DC this year and the over 400 face-to-face meetings that occurred that day on Capitol Hill, then you will see how the effort of one individual is multiplied many times over having a positive impact on Washington and more importantly on our families.

Why do we go? We go because it is the opinion of the Price Family that the laws today were written a long time ago when our society did not embrace inclusion and independent living. We go because the laws today make it difficult and expensive for a family to save for a loved one with a disability. We go because the research community has made too much progress in the area of Fragile X research and Autism to have the door closed because of funding cuts. We go to ensure Congress that we have been and will continue to be good stewards for federal funding for FXS research and Fragile X Clinics. Those are our reasons. What are yours?

Linking students for a positive impact on everyone

by Nina Liberati

My youngest son, Antonio, has Fragile X. He is currently a freshman at Allen Park High School in Allen Park, Michigan. This school year his high school implemented a new program called the Link Program. High school seniors are able to take one Link class per semester and receive one half credit for their participation in the Link Program. This class links them with a student in the ASD class for one of their class hours.

Antonio has five Link leaders this semester; a different student for each of his classes, except one. They give Antonio the one-on-one attention and support that he needs to excel in his classes. Antonio has bonded with each of his Link leaders and loves seeing them every day. This program has not only benefitted Antonio, but it has had a huge impact on all the students, teachers and staff at the high school.

Below is a write-up about the program from Nora, who is one of Antonio's Link leaders.

The Link program is a program in which each student who is on the Autism Spectrum is paired with a student who is not. The Link leader helps the student with autism to stay on task and to attempt to make them more social. Each Link leader is required to blog on a daily basis, attend a weekly lunch meeting, and read and complete packets that explore autism and the special education process. The school

social worker and the teacher of individuals with autism are available for consultation whenever needed.

This past summer, I worked at a camp for children and adults with impairments. I worked with adults ranging from the ages of 18-22. I developed a passion for people with disabilities. When I returned, I had the privilege of continuing my work, only this time with my peers.

I was paired up with Antonio, a 15-year-old student with Fragile X and autism. He is nonverbal. During my first semester, I attended gym with Antonio. He did all the things the other students did and the majority of the time he worked harder than the others. This semester, I'm working with Antonio in the classroom. I read and write with him. He shows improvement on a daily basis.

From this experience, I have considered career choices I had never thought of before. In just a couple months, I will be graduating and I have recently decided that I will attend Wayne State University. So far, I have not chosen a major that seems to fit what I want to do. Antonio has made me rethink my future entirely. He has showed me an immense amount of patience, and every day I look forward to creating more memories with him.

The link leaders are not the only

ones affected by this wonderful program. The students have shown very much improvement since the beginning of the year. Today, Antonio and another student with autism sit with me in the senior section at lunch. Antonio used to sit at a table with other kids and had no interaction with them at all. Now Antonio laughs and enjoys himself at lunch. Also, the students here at my high school have become much more accepting of the kids with disabilities.

In conclusion, the Link program is a fantastic program that I feel should be implemented at all other schools. It has positively affected Allen Park High School, and has created diversity in the relationships between students at the high school. It has changed my life for the positive, and has potential to do the same for many others.

Nora

Senior at Allen Park High School
Allen Park, Michigan



A Star is Born! by Peggy Branch

Maggie Branch, a twelve-and-a-half-year-old 7th grader at Berkshire Middle School, has become quite the thespian. Last year as a sixth grader, she participated in the 2011 Spring Musical "Thoroughly Modern Millie, Jr." (see photo on cover). And although initially a bit overwhelmed, after just a few rehearsals she had memorized all the songs and had a good grasp of the storyline. Rehearsals typically begin in mid-March and are three days a week right after school for two and a half hours - but nary a

complaint was heard from her! She had to memorize several songs as part of the chorus and had to complete several costume changes.

Mom volunteered to help during rehearsals and was backstage at all four performances, but found that, other than assisting with her make-up and fixing her wig, Maggie needed very little help. It was very empowering for her and she really blossomed at the performances - and made some new friends along the way.

Like many with fragile X, Maggie sometimes has a hard time looking you in the eye, but put her on a stage and she has no fear! We discovered she is a real "ham" at heart!

She is currently involved in her second musical "Once on this Island" and is enjoying the experience again. As a matter of fact, after seeing Maggie's success in last year's musical, several of her "typical" friends decided to participate this year. Maggie was an inspiration!



Fragile X 5K Fun Run & Walk

Saturday, August 11, 2012
Independence Oaks County Park, Twin Chimneys Shelter
9501 Sashabaw Road, Clarkston, Michigan
oakgov.com/parksrec/ppark/independence.html



The Fragile X Association of Michigan will be hosting our annual family picnic following the race. We will have hot dogs and assorted snacks. More details on the web at: fxam.org/Events.html

LeapPad Explorer Tablet by Sally Nantais

Linda Hodgdon's piece "*A Great Alternative to the iPad for Autism*" in our January newsletter really sparked my interest in this device. We took the plunge in March and purchased a LeapPad Explorer.

Austin sometimes struggles at adapting to new technology and he hasn't quite mastered the family's HP tablet. When we travel to Chicago for our study visits I need devices he can easily navigate on his own, while I drive, with no assistance from me. With the family's HP tablet he hasn't mastered moving between games and movies with the existing menu

structure. I felt the LeapPad Explorer would assist him in mastering the techniques used in tablets and other mobile devices, such as swiping, a feature not used when he uses his Nintendo or entertains himself on the computer.

What I really like about the product is:

- It's durable, made to be handled by a child who may not always treat it with kindness.
- It's one piece (we've had Nintendo DSs broken in half).

- Unlike other LeapPad products we can eliminate the need for cartridges or books that could be lost or damaged.
- It's more kid friendly for a child who has often struggled with fine motor activities.
- It's not just limited to games, it's a camera, it's an eReader, and it plays videos.

What Austin really likes about the explorer: the three Blue's Clues videos mom purchased and downloaded to the tablet. He's ready for the treasure hunt!

Walt Disney World - Just a few tips by Sally Nantais

Plan, Plan, Plan.

Do visit Disney's Disabilities website:

<http://disneyworld.disney.go.com/guests-with-disabilities/>

The printable guides pamphlet, geared towards those visiting Disney with individuals with disabilities, will explain the rides in the park, duration, noise, do you need to be mobile, etc. It will assist you in planning your trip, the guest assistance card worked very well at "Fast Pass - FP" rides, and we found it worked best if we did the non-FP rides early in the morning when the park wasn't at its busiest. My list of things to consider, or at least think about, is below. Good luck and have fun!

- Has your child traveled by plane before? If not, plan a field trip to the airport, park where you would park, ride the shuttle in, at the ticket counter ask for a special pass to go through security, expose him/her to as many of the unknowns as possible.
- Do a social story about the plane ride, the rules of the plane, certain times when he can't have his/her DS/iPod or DVD player on.
- Prior to our trip, we had experience with hotel stays. If your child has never stayed at a hotel, plan a trip to a local hotel to gain some experience and exposure before a big Disney vacation.
- If traveling by plane I've found sour candy works well to clear the ears. Austin doesn't chew gum long enough to have it help, but sour patches or sour gummy worms work well.
- Bring your leapster, iPod, DS, portable DVD player.
- When traveling by plane we try to get our seats as close to the main exit as possible, he struggles with waiting, and waiting to get off is hard. Sour candy at this time serves as redirection, what's going on with his taste buds creates a distraction.
- Austin and I always board early, once he's seated on the plane he does well, avoids the waiting to get to your seat.
- We didn't go to more than one park in one day and decided which park to go to based on which one had extended hours that day.
- We stayed on site, more expensive, but if at any time my son needed a break I could take him back to the hotel and pool without disrupting the entire family's day.
- Guest Assistance Card (Pass) is a must. Your first stop should be at the City Hall in the Magic Kingdom to request one. If you don't start with the Magic Kingdom and start at another park ask the person at the gate where you need to go to obtain a guest assistance card.
- Rides with the Fast Pass symbol will allow you to easily use the Guest Assistance Card. Some rides don't have a fast lane. We hit the rides that didn't have a Fast Pass lane early before the park got busy which reduced our wait times.
- If your child/adult is sensitive to sounds, I recommend ear protection headphones (we just used a simple pair we bought at Lowe's). Midway through our trip our son would tell us when he wanted them and when he didn't. Some of the shows would have been too much for him without them.
- Be prepared, many rides will dump you into a gift shop. Our only minor melt was after we left the Star Wars ride. We purchased gifts and had our gifts sent back to our hotel (he didn't understand why he had to give up his purchase. It was early in the day) we didn't want to carry around packages all day.
- We typically started at 8 or 9 am and ended around 3 pm. During one day, I knew Austin was growing close to needing a break, so we used a little manipulative. We told Austin we could go on two more rides or three, it was his choice. Of course, he picked two which was exactly what we wanted to do, but it gave him a sense of control, and also he could easily measure when we would return to our hotel room.
- We got the meal option, but I don't know if I'd do that again, the size of the meals were large. If I did get the meal option again we might have a couple of kids share one meal. Even though you're flying bring along as much as you can, snacks, popcorn, poptarts, pretzels, etc., food is very expensive at Disney.
- Austin went on every ride we did, except the Tower of Terror, only dad and Natalie did that ride and they were still able to use the special pass because the rest of our family was waiting on them.
- Bring disposable rain ponchos.
- We didn't get the park hopper pass, that would have been too much for Austin, we picked one park a day (depending on which one opened early or stayed open late). We were only there for four days, not enough time to do everything but we did do Magic Kingdom, Animal Kingdom, MGM and Downtown Disney.
- We only lost one child, :-), Genevieve, in Animal Kingdom Dinosaur Land. In an enclosed playscape. There is an area away from the playscape (still within the enclosure) where children can go and dig for dinosaur bones. One of us was always positioned at the exit, so we know she didn't leave the area. When we mentioned to a park person we couldn't find her they replied that most missing children in the playscape are in the dig area, and there she was, digging away.
- The ride everyone hated - It's a Small World - was at the top of the list, long lines, problems along the way, and the song going over, and over, and over again.
- **Have FUN!**



From the President's Desk by Lauren Majeske

Dear Friends,

It's all about support -- you support me, I support you and we all support each other. We are always looking for new ways to keep us all connected.

You can see throughout this newsletter all of the different ways you can find the help you need through facebook, families and conferences. You can do it any way you want through advocacy, playdates, clinical trials, support meetings, and soon you'll be able to call in to our monthly meetings. Live too far away but want to attend or get advice? We are in the process of setting up phone conferencing and Skype so

you can be there, too! It will be a great way for you to get answers to your questions and hear familiar voices. We'll send out all of the details in the near future.

On June 23, we will be having the grand opening of the Fragile X Clinic at the University of Michigan C.S. Mott Children's Hospital in Ann Arbor. We will be serving light refreshments in the beautiful atrium which will be a perfect chance for you to mingle with the doctors and tour the space. In the future, the clinic will be hosting some of the many drug trials and research projects that are going on across the United States. This is an exciting time and we want you to be a part of it. Please

plan on attending!

Read through the newsletter and see what some of our members are up to! Let us know what you are doing and maybe we'll print it in the future. Your stories encourage many others, so please share them with us by sending them to one of our editors.

See you soon at one of our events!



Hello! Hello!

**What are you missing?
Do we have your correct
e-mail address?**

**Don't miss out on anything, send your
e-mail address, and any other contact
information updates, to:**

**Mary Beth
mblangan@hotmail.com**

It's time to PLAY BALL!

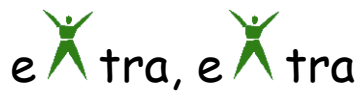
Challenger Division Little League Baseball
April 28 - June 30

2 games per week (1 weekday, 1 Saturday)
Heritage Park in Taylor

You have until **May 7** to sign up your child.
(for anyone age 6-18 or still in school with
any mental or physical challenges)

No sign-up fee - this is a **FREE** activity.
Your child will have a buddy while on the field.
We make this fun for everyone!

Contact Martin Drouillard at
just_e_nuff_99@yahoo.com
or
313-414-5405



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FXAM.org



Fragile X Syndrome Clinic

The Grand Opening of the Fragile X Syndrome Clinic at the University of Michigan will be
Saturday, June 23, from 12:00 to 2:00 p.m.

The reception will take place in conference rooms on the 12th floor in C.S. Mott Children's Hospital at U of M. These rooms have a great view of Ann Arbor and provide a great setting for this free event which will include light refreshments.

Stay tuned for future details outlining the Grand Opening through e-mail; now is a great time to make sure we have your updated e-mail address.



P.O. Box 1414
Troy, MI 48099-1414