

Mark Your Calendar

Support Meetings

First Saturday of the Month

When: October, November

Business Meeting 6 p.m.

Support Meeting 7 - 9 p.m.

Where:

Beaumont Hospital
Royal Oak Campus
Administration Bldg
Private Dining Room

Special Events:

July 21-25, 2010

Internat'l Fragile X Conference
Hyatt Regency

August 21, 2010

FXAM Picnic & 5K
Clarkston, MI
Details on page 2

September 11, 2010

11th Annual Golf Outing, Wesburn Golf & Country Club
Details on page 8

September 17, 2010

Hansen 4th Annual FX Golf Outing, The Falls at Barber Creek
Details on page 8

Fragile X Association of Michigan

Contact Information:
313-381-2834

fraxmich@hotmail.com

FXAM.org

Three Cheers for ...



During the fifth month, third day of each year **Fifth Third Bank** celebrates Fifth Third Day. The Bank honors their communities, customers and colleagues in a weeklong celebration called the "Fifth Third Week of Giving." Thank you Fifth Third Bank for selecting FXAM to receive your Fifth Third Employee Involvement Grant! Special thanks to Kim Young for providing the opportunity for the Fragile X Association of Michigan (FXAM) to be recognized.

Byna Elliott (Fifth Third Director of Community Affairs),

Kim Young (Fifth Third Customer Service Manager/FXAM Treasurer) and **Laureen Majeske** (FXAM President)

Ryan Love - Reeths-Puffer High School Class of 2010

North Muskegon, Michigan

Ryan graduated from Reeths-Puffer High School on June 8, 2010. Ryan was in a specialized classroom from 6th-12th grade, going out for Vocational Education work and some inclusion classes like Theater Production. Ryan's favorite part of school was the bus ride - which he has done since he was 3 years old, and he's now 20! Continued on page 3.

Kim Love-Hall and Ray Hall with the proud graduate



Aidan Silverton, Brendel Elementary School

Grand Blanc, Michigan



Aidan graduated 5th grade from Brendel Elementary school on June 17, 2010. Aidan was a proud Brendel Bulldog and participated in Special Olympics all year long. He heads to Grand Blanc Middle School West, where he will enter the sixth grade. Aidan will spend the summer riding horses, playing tennis, swimming on the club swim team and heading to overnight camp, at Tamarack Camp, for the second summer in a row. Congratulations little buddy! You make us proud everyday with all the abilities that you have!

Love, Mom and Dad (Jennifer & Kimball)

From the Presidents Desk by *Laureen Majeske*



Well, two years of conference planning has come to an end. We've had meetings. We've had fundraisers. We've stuffed bags. We've collected donations. We've made shirts and bags and booklets. We've planned and planned and planned. And we've had more meetings.

We've done it. And we've done it all for you. We've done it for you because you are our Fragile X family, a part of our community, a part of our life. And we want you to know how much we appreciate you.

As you look through these pages, you will see the fun we've had, the hard work we've done, the hours it took to get us here. You'll see families and how proud we are of their accomplishments. You'll see information we want you to have to

make your life easier. You'll see the volunteers that gave so generously of their time so that this conference would be ready for you, our friends. You'll see a world filled with Fragile X and yet a world so real because it's the world in which we live.

While you are here, just remember, there "Ain't No Mountain High Enough", because we will walk with you all the way to the top, and all the way back down the other side.

For those of you who are visiting us in Michigan, don't forget to check out The Henry Ford, which is comprised of three attractions - the museum (where we will be having our off-site event), Greenfield Village (an extraordinary walk back in time), and the Rouge Factory Tour (here's your chance to see how a car is really made!). The Henry Ford is one of the premier attractions in Michigan and

an incredible piece of Detroit and Michigan and innovation history. While you are at The Henry Ford on Thursday evening, be sure to check out the PLAY exhibit, where visitors can become a game piece in a life-size version of backgammon, billiards, foosball and more. The exhibit is meant to prompt thoughts about social interaction, collaboration and teamwork. For more info, visit thehenryford.org and come see us at the Welcome Area to see how to get a \$2 coupon if you want to go to one of the attractions on your own.

Welcome to the D! We're so glad you're here with us.

Thank You Conference Chairs!

Local Conference Chairperson: Laureen Majeske

Auction: Peggy Branch/Don Price

Welcome: Mary Beth Langan/Malinda Popejoy

Entertainment: Arlene Cohen

Sponsorships/Grants: Mike Makris

Wreck Room (recreation room for all ages):

Elina Gelfand/Nina Liberati

Volunteers: Kim Young/Tina Makris

Publicity: Ted Coutilish

Volunteer Hospitality: Karen Dacey

Photographer: Mike Young

CEUs: Jeff Cohen

A warm thank you also goes to the following FXAM members who helped make this happen (we apologize if you helped but are not listed here!):

- | | | |
|---------------|----------------|-------------------|
| Greg Barr | Janet Brushman | Karen Fodor |
| Tony Gelfand | Cassie Hale | Michele Jankowski |
| Ban Kassab | Joyce Kreger | Roger Laske |
| Sally Nantais | Romy Patterson | Mark Popejoy |
| Tricia Price | | |

4th Annual Family Picnic and Fragile X 5K Run & Walk

Save the date, **August 21, 2010**, marks our 4th annual event!

Independence Oaks County Park
Twin Chimneys Shelter
9501 Sashabaw Road

www.destinationoakland.com

Go to the events page at **FXAM.org** to get the registration form or to follow a link (for **gorecego.com**) to register online with a credit card.

This year the run will be a sanctioned run with a professional time-keeper.

FXAM will be selling items at the picnic (and also the golf outing):

- FXAM playing cards (\$5)
- FXAM t-shirts (\$15)
- FXAM hoodies (\$30)

And, so much more! We can accept cash or checks.

The picnic will follow the run. There is no cost to attend the picnic, except for the park gate fee. Attending the Picnic? Please RSVP to Kim, bring a

dish to pass and your own refreshments. Don't forget your sunscreen, bug spray and that socks are required for the Bounce Houses.



Questions? Contact Kim Young
248-396-0315 or young4mi@comcast.net
Registration form at
fxam.org/uploads/Fragile_X5K_2010.pdf

The William and Enid Rosen Research Fund

The William and Enid Rosen Research Fund was established by the National Fragile X Foundation (NFXF) in recognition of William's passing in 1997 and the donation by his family of his vital organ tissue for Fragile X research. Following Enid's passing in 2004, the fund was renamed in recognition of her and her husband's

dedication and support of the foundation. Bill and Enid were the parents of NFXF and Fragile X Association of Michigan (FXAM) Board member Arlene Cohen. Arlene and Jeffrey Cohen are still active on the boards of the Fragile X Association of Michigan and the National Fragile X Foundation. Jeffrey is a past president of the NFXF.



Summertime, Summertime, Sum, Sum, Summertime!

Have your camera in the ready position, in the next couple of issues we'd like to focus on what your kids did during the summer! So take those pictures and send them along to Mary Beth (mblangan@hotmail.com) or Sally (sallyn423@wyan.org) with a small recap describing their activity.

Ryan Love *(continued from page 1)*

Ryan will be going on to the Wesley School Transition Program in Muskegon, which will allow him to continue to work on his Vocational Skills, going out to work sites like Big Lots and Plumb's Grocery Store. He is excited to be moving on to "College", although a bit apprehensive because it's something new and out of his normal routine. Thankfully he'll still be

able to ride the bus so that routine will continue. Life will be exciting and challenging for our family over the next few months, but we're happy and so proud of all of Ryan's accomplishments. He was originally misdiagnosed with Soto Syndrome as a toddler and we were told he would never walk or talk. Eighteen years later,

not ONLY is he walking and talking, but he's graduating from high school! What more could we ask? He is a blessing every day and we are so lucky he's our son!

We cannot always build the future for our youth, but we can build our youth for the future.

Franklin D. Roosevelt

e tra, e tra - The Making of a Newsletter

The inaugural issue of the newsletter was produced in January 2005, created by FXAM board members Mary Beth Langan and Sally Nantais. In January 2011, we will produce our **25th** newsletter.

The purpose of the newsletter is, and always will be, to provide

support and networking opportunities to families in Michigan, many of whom don't live close enough to attend FXAM meetings and events.

The success of our newsletter is a result of the contribution of many members, near and far. We hope to continue to produce the newsletter for many years to come, but its success

will depend on the members of our group. We encourage all to participate by sharing your photos, events, family adventures and success stories with us. We're only a few finger taps away! Most of the issues are available on our website. Check them out at:

fxam.org/Support_Group.html

If a picture is worth 1,000 words, here's our Fragile X Conference Fundraising Novel



Mom-To-Mom Sale



We Golfed! Fore Fragile X



We put our kids to work as well!



Comedy for a Cause!



We laughed! More than once! Comedy with the Popejoys!



We ran and walked!



What a DEAL!



We planned & planned & planned



There was Art and Music!
Park West Gallery, Southfield, MI



Working at the carwash!



Silverton Skin Institute 7th Annual Botox Benefit

Dr. Kimball and Jennifer Silverton, of Grand Blanc, held their 7th Annual Botox Benefit at the Silverton Skin Institute, raising nearly \$15,000 for Fragile X Syndrome research. The Silvertons' 12-year-old son, Aidan, has Fragile X.

Dermatology patients received Botox injections at a greatly reduced price with

ALL monies going toward research.

Botox is injected into facial muscles where wrinkles form. The muscles are then relaxed, smoothing away the wrinkles for several months.

Dr. Silverton is a board-certified dermatologist and fellow-trained cosmetic surgeon. The event has proven very popular as patients call year-round

inquiring about the next date for the Botox Benefit. All office staff donate their time for the event and the Botox product is provided through an educational grant from the product manufacturer.

silvertonskininstitute.net
810-606-9600

First Giving, with a Cup of Joe, a Pumpkin Patch and Art! The Price is Right!

Don and Trish Price along with their children, Samantha and Jacob make fundraising for Fragile X a part of their family life.

Through their First Giving website, raising money for FX, they have exceeded \$2,000!

Their annual Pumpkin Sale begins with a summer pumpkin patch at Don's parents' house and ends with the whole family selling pumpkins in October.

Jake & Sam's is their e-business and the

names of their children. The site sells gourmet coffee and cocoa. FXAM is one of their organizations that can benefit from a sale from their site!

Trish & Don also organized a FXAM fundraiser on June 25 at the well-known Park West Gallery in Southfield. Folks came to view art, listen to music, eat and drink, all on a Friday night for the Fragile X cause.

The family keeps busy working together for Fragile X!



What a Favor! Pretty Favors with Joyce Kreger!



Joyce's favored son Michael!

We all have occasions where we need party favors, whether it is for a wedding, baby shower, graduation, or milestone birthday. Why not buy favors from a site where 100% of the profits go towards Fragile X research and education?

In cooperation with a leading party favor manufacturer, Kate Aspen, we now have a website, called prettyfavors.com, devoted to Fragile X.

In addition, all products are 10% off the regular retail price. Please spread the word to family and friends about prettyfavors.com.

It is hard to find money for charitable causes in this economy. People who care and would like to provide support can buy discount favors while helping the Fragile X community. A win-win for both!

Monthly Support Meetings Are Taking a Holiday

The monthly support group meetings are taking a holiday. They will resume on Saturday, October 2, 2010.

FXAM Board of Directors are:

Laureen Majeske - President
Nina Liberati - Vice President
Kim Young - Treasurer

Mary Beth Langan - Corresponding Secretary

Elina Gelfand - Recording Secretary

Arlene Cohen
Jeffrey Cohen
Karen Dacey
Frank Liberati
Malinda Popejoy
Mark Popejoy

Please take the opportunity to recognize our directors for all the hard work, effort and hours they've dedicated to not only bringing the International Conference to Detroit but making it a conference to remember by all who attend.

Through the Maze - Featured Websites - FXTAS

Hagerman Lab wizard1.ucdavis.edu/index.cfm



The Hagerman laboratory is engaged in basic (molecular genetic) and treatment-related research for the Fragile X family of disorders.

Their goal is the development of effective therapies for those disorders.

Under the *For Families* tab you'll find a wealth of information in areas such as:

- Anatomy of a Gene
- Fragile X Syndrome
- FXTAS
- Reason for Hope
- Research Participation
- Tissue Donations

An interesting part of the tissue donation program involves carrier women as they give birth. The lab places great value on the umbilical cords themselves (not cord blood), which would otherwise be discarded. If you can help with any tissue donations, please contact the lab :

Hagerman Lab

Lisa Makhoul, Exec. Asst.

Phone: 530-754-7270

Fax: 530-754-7269

Email: Use form at website under *Contact Us* tab.

Fragile X-associated Tremor/Ataxia Syndrome (FXTAS)

FXTAS.org

The National Fragile X Foundation (NFXF) launched a new website dedicated solely to Fragile X-associated Tremor/Ataxia Syndrome (FXTAS) this year.

The website is designed with the individual family, the doctor and the genetic counselor in mind, with easy navigation panes, specific to each audience. This is the site to visit to learn more about FXTAS, stay abreast of what we know and what we are learning about the conditions.

FXTAS is one of three disorders that results from changes in the Fragile X gene. NFXF has produced an informational brochure about FXTAS that is available for free on the website or by calling 800-688-8765.

Between the Lines - Featured Book

Visual Strategies for Improving Communication by Linda Hodgdon

J loved this book! When I was first introduced to the PECS/visual support concept I immediately bought a couple of books on the topic. This one was by far my favorite and the only one I needed! It is an amazing communication tool for children who are not verbal. The strategy is explained in a very easy-to-read manner and gives visual examples of what you need to do with example situations in which they would be helpful. It also helps you avoid

common errors and explains things like: What is too small? How close do you take the picture? How much is too much?

We used this approach with our son and found it very helpful. When he was less verbal we used it to give him choices regarding food and activities. We also used it to create a visual daily schedule. As a three-year-old he was in two different programs and had three different daycare providers throughout the week. This schedule helped him transition from one to the other with ease.

Currently we don't use it daily since he is more verbal, however he still likes to look at the pictures of various people and comment on them. On the days when we don't know "what to do?" we still pull out the stack of cards with activities/toys for ideas. Twice we have gone on international trips with many flights and used this picture approach to help him visualize how many more flights we had until the end.



Reviewed by Stephanie,
Fragile X Mom from Minnesota

What Every Parent Should Know About Supplemental Security Income (SSI) and Your Child Turning 18

The Social Security Administration (SSA) manages TWO different programs: Supplemental Security Income (SSI) and Social Security Disability Insurance (SSDI).

1. **When a child with a disability turns 18, they can file for Supplemental Security Income (SSI).**
 - At 18, when they apply, it's based on their income ALONE, not yours.
 - If your family exceeds the income cap, you cannot apply prior to 18, if you make an appointment prior to their 18th birthday YOUR income will be included.
 - If you make the appointment after their 18th birthday only the applicant's income counts.
2. **What is considered Income?** Savings and checking accounts, mutual funds, savings bonds, certificates of deposits, joint accounts, real estate and other resources in the applicant's name will come into play. Any earned or unearned income. Any asset in their name that could be sold and converted to cash will be counted as a resource, part of their income. Be cautious with trusts. Special needs trusts (not in the child's name, but designed to benefit the child) may provide an opportunity for additional funds outside of the income cap. If special needs trusts are not set up correctly, they can end up jeopardizing the person's ability to collect SSI and be eligible for Medicaid.
3. **How far back do they look at income during the application process?** In our case they went back three years; this could change. If you have savings bonds, mutual funds, college funds, and/or stocks in your child's name (even if they only have joint ownership) you may need to dissolve or move the accounts out of your child's name. Plan for this well in advance, this is not something you want to do a week or two before your appointment. It may be nice that relatives provide savings bonds at each birthday or Christmas, but keep in mind **these do add up**. They will be listed as income and when your child applies it could make them ineligible to receive SSI. Another thing to be aware of is any wills or beneficiaries your child is listed in, any large sum of money that goes to them directly (even in the future) will make them ineligible for SSI and may also impact their ability to receive Medicaid.
4. **Guardianship/Power of Attorney.** You will need to decide if you will obtain guardianship or have a durable power of attorney. This is a personal choice, you need to do what's right for you and your child. Guardianship from state to state, and in some cases county to county may vary. You may need to obtain legal assistance. Your local Arc or a neighboring Arc, or a parent advocate group may be able to assist you with this matter. Find your nearest Arc at thearc.org.
5. **Will your child/dependent pay rent or will they share in the household expenses?** If your child shall pay you rent/room and board, you need to report the amount they will pay. If you charge rent, you will need to account for this on your taxes. If your child will share in the household expenses, you need to be prepared at the Social Security appointment to list everyone who lives in the household, their SS number(s) and monthly household expenses (mortgage, gas, electric, water, cable, groceries, etc).
6. **Online application.** If you want to save time at the appointment, fill out the application online and make your own copies for your records and to submit at your appointment. Bring a printed copy of the application along with you, in our case all of the meds crossed over fine from the online form, but not all of the doctors information did (even when the meds they prescribed were listed, the doctor details were not.)
7. **Identification.** Apply for your child's State ID card long before your appointment. You will find this helpful in creating their financial account and setting up their SSI.
8. **Financial account.** If you want to use a direct deposit option, open your child's bank/credit union account prior to your appointment. Make sure you have the institution's routing number and your child's account number with you.
9. **Supports for your application.** Keep in mind, you/your child will grant the SSA access to all of their medical records but there are other pieces of information you may wish to include with your child's application, not available in the medical records, or available but you may wish for them to stand out. Bring copies of documents from throughout their lifespan. If you kept records of medications, doctors, therapies, evaluations, hospital stays, etc., throughout their lifetime it will be much easier to assemble your supports.
10. **Where to learn more:**
 - Social Security – Supplemental Security Income - www.ssa.gov/pubs/11000.pdf and www.ssa.gov/ssi/
 - Understanding SSI - www.socialsecurity.gov/ssi/USSI2007final.pdf
 - What to do when your child turns 18 - findarticles.com/p/articles/mi_go2827/is_11_38/ai_n31007640/
 - Alternatives to Guardianship, page 4 - www.arcmi.org/puff/December%202009%20Focus.pdf
 - Guardianship Alternative Information Network - www.thearcnw.org/gain.html
 - Still have questions? Call the Social Security Administration at 800-772-1213

Compiled by Sally Nantais through research and her own experience with a recently turned 18 year old

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.

Newsletters are available on the web at FXAM.org

Would you like to be on our E-mail list? Send your E-mail address to Mary Beth or Sally.

**Ain't No Mountain High Enough
To Keep Me From You!**



This issue is being mailed to our FXAM members and will be in the welcome bags of all attending the international conference. Our audience is a bit wider this time!

Golf for Fragile X

FXAM 11th Annual Golf Outing

Saturday, September 11, 2010

Wesburn Golf and Country Club

**5617 S. Huron River Drive
South Rockwood, Michigan**

Contact Nina or Frank Liberati for tickets, donations (cash or door prizes) or more information at:

313-381-2834 or nliberati@yahoo.com



Hansen 4th Annual Fragile X Golf Outing

Friday, September 17, 2010

The Falls at Barber Creek

**16030 Barber Creek Avenue
Kent City, Michigan**

thefallsatbarbercreek.com

Contact Kate Hansen for tickets & more info at: 231-519-2349



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