

Mark Your Calendar

Support Meetings

First Saturday
of the Month

When:

May 2, 2009

June 6, 2009

Time:

Business Meeting:
5 – 7 p.m.

Support Meeting:
7 – 9 p.m.

Where:

Beaumont Hospital
Royal Oak Campus
Administration Bldg
Private Dining Room

Special Events:

July 18, 2009

Annual picnic and
Fragile X 5K Fun Run
& Walk
Independence Oaks
Clarkston, MI

Fragile X Association of Michigan

Contact Information:

313-381-2834

fraxmich

@hotlinemail.com

Fragilex.org/html/
michigan.htm

Three Cheers for Little Sisters who always look out for us:



Abigail Gelfand, of West Bloomfield, lends a helping hand to her brother Sam.



On the podium, Austin, Natalie & Genevieve Nantais of Wyandotte. Natalie performed an exhibition skate during the Adults for Autism Figure Skating Competition in Taylor during April. She skated for her brother, introducing many to Fragile X, and her coach's son Sammy who has autism



Nicholas Weber of South Lyon proudly displays his Special Olympics medal. In snowshoeing, he placed 2nd in the 50 meter and 5th in the 75 meter events. Winter 2009 Games were in Traverse City.

Think Spring!



Ryan Love of Montague and his favorite set of wheels!



Andrew Coutilish of Grosse Pointe and Hayden Makris of Harper Woods having fun at the park.

Achieving a Better Life Experience - S. 493/H.R. 1205

Introduced in February 2009, the Achieving a Better Life Experience Act of 2009 (aka the ABLE Act of 2009) ABLE accounts for individuals with a disability to pay for certain expenses of such individuals, including expenses for education, housing, transportation, employment support, medical care and certain life necessities.

The bill defines "individual with a disability" as an individual who is eligible to receive certain supplemental security income (SSI) benefits under the Social Security Act.

It is a bill that will not limit coverage because of a diagnosis. It won't matter if the diagnosis is one of autism, fragile X syndrome Angelman syndrome or cerebral palsy, it only matters if the individual receives SSI.

ABLE allows individual taxpayers a tax deduction, up to \$2,000 per year, for contributions to an ABLE account (similar to contributing to a 529 account for education). It requires the Secretary of the Treasury to study and report to Congress on the use of ABLE accounts and the effect of the tax deduction for contributions to such accounts.

ABLE accounts would be disregarded in determining eligibility for Medicaid benefits and for purposes of determining eligibility for other means-tested federal programs.

In plain English, funds in the accounts and expenditures which meet the requirements of the bills would not affect the individuals' eligibility for federal benefits. Under the current law individuals can't have more than \$2,000 in their name (unless it's through a special needs trust) or they risk losing benefits such as SSI or Medicaid.

Fundraising - What Can I Do?

Restaurant Fundraiser

Many restaurants, including fast food restaurants, will donate a percentage of a certain day's (or evening's) profits to an organization. You need to book a date and time, provide FXAM's Tax ID, advertise to FXAM members, family and friends, and attend! Some restaurants may require participants to submit a flyer for the event.

Casual Fridays

Some places of employment and schools have casual days in which participants must pay \$1 to dress casually or in jeans for the day. The funds collected are then donated to a designated charity... and what better charity than the Fragile X Association of Michigan, host of the 2010 International Fragile X Conference!

Penny Drive

If your place of employment or your child's school permits, have a Penny Drive on Fragile X Awareness Day (July 22) or Fragile X Research Day (October 5).

Vendor Party

Host an open house with one vendor (such as Party Lite or Pampered Chef) or multiple vendors (as many as will fit in your home with their samples)! Tell the vendors you are forfeiting your hostess gifts/free merchandise for the night, but would like your organization to receive a percentage of the total sales for the event (10% was earned at a past event). Some vendors will even allow online and outside catalog sales count toward the fundraiser profits. A great event for folks who like to chat and shop!

Bakeless Bake Sale

No fuss, easy to do with family and friends. You don't bake anything but friends can make donations based on baked items, that they don't receive, for example:

- ☞ One Dozen Cookies \$2
- ☞ One Dozen Brownies \$3
- ☞ Apple pie \$5
- ☞ Cheesecake \$10
- ☞ Chocolate Trifle \$15

You make the list, have a little fun and set the prices.

Bowling Fundraiser

Many bowling alleys will rent lanes or the entire alley for fundraising events. They charge a set rate for bowlers, i.e. \$9 for three games and shoes, you sell tickets for \$20, conduct a 50/50 raffle and, if you like, create a couple of basket raffles.

From the President's Desk by Laureen Majeske

We need your help! We need all members who are interested in helping out on a committee for the 12th International Fragile X Conference, right here in our backyard, in Detroit (Dearborn) in 2010, to get involved. The enthusiasm is building here in Detroit as we begin planning the conference. There is so much to do! It is going to be a *lot* of work, and a *lot* of fun! AND, we'll get so much more done if you can pitch in!



Committees have been set (see page 4) and we are looking for volunteers to join committees and work with the chairpersons to make our Michigan-hosted conference a success! We really want to give this event a true Michigan flavor so we are hoping to have volunteers from all over the state. If you are not local to the Detroit/Southeast Michigan area, we understand that you would not be able to make monthly meetings, but there are numerous committees in which you can contribute. Check out the committees and see where you will best fit in. For those that are local, your committee chair will set a committee meeting schedule. We need your expertise, input and creativity. The chairperson will be relying on his/her committee to follow through, no task can be left undone.

Whether or not you are able to sit on a committee, there are plenty of other ways you can help. We are also looking for:

Auction/Raffle Items

High-end items will be needed to be auctioned off at the Saturday banquet. Perhaps a weekend at the Grand Hotel on Mackinac Island or a private dinner with Kid Rock. Many other items will be needed for silent auction and raffle items. Michigan-themed baskets. Sensory item-themed baskets. Sporting event ticket packages. Jewelry. Gift certificates for restaurants, spas, etc - consider companies that are national chains to entice our out-of-town guests.

General Donations

Items to be put in the welcome bags (1200 count), snacks to supply to our volunteers, teen/youth room or child care, fidget toys, paper or notebooks, etc. These could be promotional items donated by your company or any other organization, for example potato chips from Better Made or Frito Lay, stress balls with the Compuware logo, etc. We are also looking for cardboard cutouts/posters of automobiles and race car drivers (past or present).

Service Donations

Signage, theater lighting, transportation (car/bus service), printing, etc.

Sponsorships

You may work for a company or know of an organization that would like to be a conference sponsor at any level, perhaps sponsor a certain portion of the conference (coffee break, child care, family night, etc) or make a donation. Please contact Mike Makris for more information (contact info on page 4), to request a sponsorship packet to share with a company or to give us contact information if you would like us to make the connection.

Grants

Does your company give out grants for educational events held in Michigan? Let us know and we'll work together on obtaining the grant. Please contact Mike Makris.

Other

If you have something special to offer that we haven't mentioned, please let us know.

We will be sending out additional requests as we get them. Thank you so much to all of you for your help in making this conference a success. Please contact me or a committee chairperson to sign up for the committee that is the right fit for you!

Laureen Majeske
Local Committee Chairperson
12th International Fragile X Conference
586-978-9079, lmajeske1@comcast.net

The Committee List - What Catches Your Eye?

Auction

Chairperson **TBD**

Solicits and organizes live/silent auction and raffle items; plans overall event including display, auctioneer, bidder registration and checkout procedures.

Welcome Committee

Chairpersons: **Mary Beth Langan/Malinda Popejoy**

Organizes welcome area and information for attendees. Recruits and coordinates volunteer staff for coverage.

Mary Beth Langan, 313-689-3340
mblangan@hotmail.com

Malinda Popejoy, 734-414-0371
mmpopejoy4@att.net

Entertainment

Chairperson: **Arlene Cohen**

Identifies and negotiates contract for local talent for Saturday banquet dinner; organizes decorations for stage and tables.

Arlene Cohen, 248-568-1236
a.cohen@fragilex.org

Sponsorships/Grants

Chairperson: **Mike Makris**

Identify, recruit and close local sponsorship opportunities. (This is currently our most urgent need.)

Mike Makris, 248-804-7963
mmakris.fx@gmail.com

Teen/Young Adult Program

Chairpersons: **Elina Gelfand/Nina Liberati**

Organize program to involve older individuals affected w/FXS and their siblings to keep them engaged and entertained while parents attend sessions.

Elina Gelfand, 248-970-3311
elina.gelfand@yahoo.com

Nina Liberati, 313-381-2834
nliberati@yahoo.com

Volunteers

Chairpersons : **Kim Young/Tina Makris**

Recruits, schedules and orients on-site volunteers. There are a wide variety of volunteers needed; including room monitors, teen/youth room assistants, set-up and much, much more.

Kim Young, 248-674-2147
young4mi@comcast.net

Tina Makris, 313-372-0503
turtlesmom318@comcast.net

Publicity

Chairperson: **Ted Coutilish**

Identifies and coordinates local media opportunities.

Ted Coutilish, 734-320-7981
tcoutilish@live.com

Volunteer Hospitality

Chairperson: **Karen Dacey**

Coordinate volunteer hospitality room; maintain refreshments for volunteers. Obtain childcare snacks by donor or purchase. This committee does most of its work closer to the conference.

Karen Dacey, 248-601-1995
karendacey@hotmail.com

Photographer

Chairperson: **Mike Young**

Responsible for visually recording all conference events and coordinating w/AV staff for display.

Mike Young, 248-674-2147
young4mi@comcast.net

CMEs/CEUs

Chairperson: **JeffreyCohen**

Initiate and oversee application process through accredited university program.

Jeffrey Cohen, 313-806-1190
j.cohen@fragilex.org

Together We Can Get it Done!

Research Studies - Get Involved! by Sally Nantais

Austin's diagnosis in 1997 when he was almost five), gave us a *reason* for his challenges, his disability. The test was not subjective, but concrete; observations from a parent or professional didn't make a difference. There are no gray areas - it's black and white, measured accurately and scientifically, by a simple blood test.

With his diagnosis came the discovery that I was a carrier of Fragile X Syndrome. I never really felt guilty (well no more than a fleeting moment or two) about being a carrier of a genetic condition. It was something beyond my control, I compare it to being in a car accident where I was hit from behind, I didn't see it coming and there is nothing I could have done to change it.

In some ways I've been thankful to have a diagnosis for Austin's challenges. Due to knowing a name for his issues, I've been able to follow the research and the advances made in understanding Fragile X, on a physical, biological and daily living skills level. What I realized from the beginning is that any research project will only be successful if there are participants.

Through participation in research, our family has had the opportunity to do something that may make a difference for others navigating a world with a few extra challenges, living a different

kind of normal. Participating in research makes us feel like we will be part of a solution for a better tomorrow for our son and others affected by Fragile X Syndrome.

We embarked on our first study in April 2004 and since then have participated in **over twenty studies**. That number surprised even me, I never really counted them before, and it doesn't include all the various online surveys we've done related to Fragile X or autism or simply being a caregiver.

If you're unfamiliar with research, you've got a few great resources within our group - folks who are active on the research front. We've had members who have travelled to the following research facilities or had researchers travel from these facilities to see them: Stanford, Palo Alto, California; U.C. Davis M.I.N.D. Institute, Sacramento, California; the Waisman Center, Madison, Wisconsin; Rush University, Chicago, Illinois; and University of North Carolina - Chapel Hill, to name just a few.

Each study will differ. The one thing you won't usually do is make money by participating in research studies, in some cases you may accumulate many out-of-pocket expenses, some studies will cover all costs related to travel, lodging, meals, some studies may not cover travel, lodging or meals at all.

Some studies may provide a stipend for participating. You may even have a researcher come to your home or have you visit them at a local hotel (this may occur when there is a group of people, willing to participate and they are centrally located).

You will work hard, you will learn a little more about your child through the process and maybe even yourself. You will probably love connecting with researchers who know more about Fragile X than most people you meet. You'll definitely have a few experiences that would have never occurred if you didn't participate and in the end you may be surprised by the sense of accomplishment you'll walk away with after participation.

For our group, Mary Beth and I are going to create a "Research Central". If you have or will be participating in a study and would be willing to share your experiences, let one of us know. If you are considering participating in a study and would like to talk with another Michigan parent who has traveled to visit the same research team, or worked with that organization, contact me or Mary Beth.

Sally, 734-282-7910
SallyN423@wyan.org

Mary Beth, 313-881-3340
mblangan@hotmail.com

FXAM Annual Family Picnic and Fragile X 5K Run & Walk

Save the date, July 18, more details will follow at a later date.

Independence Oaks County Park

Twin Chimneys Shelter
9501 Sashabaw Road

oakgov.com/parksrec/ppark/independence.html

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 (\$10)
- FXAM t-shirts (\$15)
- FXAM hoodies (\$30)

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

Questions?
Contact Kim Young
248-396-0315
fraxmich@hotmail.com



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Fragilex.org/html/michigan.htm



Fragile X Advocacy Day, March 3 - 4, 2009, Washington D.C.

Taking a step in the right direction, Fragile X Association of Michigan members, Arlene and Jeffrey Cohen, Kim Young and Mike Makris participated in Advocacy Day with fellow advocates from 34 other states. Advocates made the case for increased funding for Fragile X research and programming at the Centers for Disease Control and Prevention (CDC) and National Institutes of Health (NIH). Advocates also urged their members of Congress to co-sponsor and support the Achieving a Better Life Experience Act of 2009 -ABLE.

More details on ABLÉ on page 2



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