

**Mark Your  
Calendar**

**Support Meetings**

First Saturday  
of the Month

**When:**

February 6, 2010

March 6, 2010

April 10, 2010

*2nd Sat due to Easter*

**Business Meeting**

4:30 - 7 p.m.

**Support Meeting**

7 - 9 p.m.

**Where:**

Beaumont Hospital  
Royal Oak Campus  
Administration Bldg  
Private Dining Room

**Special Events:**

**February 13, 2010**

Do-Wops  
Retirement Tour  
St. Clair Shores, MI  
(details on page 3)

**Fragile X Association of  
Michigan**

Contact Information:

**313-381-2834**

fraxmich  
@hotlinemail.com

FXAM.org

**Three Cheers for...**

Pictured (L to R)  
Laureen Majeske,  
Bryan Sienko  
(Laureen's brother),  
Lesley Braden  
(Roastmaster) and  
Mike Bobbit



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Comic had a gig, all he needed was a charity. He chose the Fragile X Association of Michigan (FXAM) to receive the proceeds from the night which were \$810. Mike Bobbitt, funnyman from Hazel Park, and twenty something of his comedic friends roasted Santa Claus at Joey's Comedy Club (Livonia) in December. Fun was had by all who attended! They also put together a one-hour DVD for us of the top moments of the night which you can purchase for \$10. The charity event was mentioned in both The Detroit News and The Detroit Free Press where we got a nice little plug and a small opportunity to introduce others to Fragile X. Thank you, Mike, for a wonderful evening!

**The Holiday Party**



## Have you never attended an international Fragile X conference?

Want to know why some from your state think it's an event you don't want to miss?

Here are some of their thoughts on the subject (and the number of international conferences they have attended prior to attending this year)...

"Our son was diagnosed in October 2007. Fortunately there was a conference the next summer and we were able to attend. It was a life-changing experience. To have it in our own backyard this year makes it that much more important for everyone in Michigan to attend. The wonderful speakers and presenters, the life-long friendships you will make and just knowing you are not alone is definitely worth it."

*Mike & Tina, Harper Woods (1)*

"You have never felt as much support as you feel when you're surrounded by 800 people who will never ask you 'fragile WHAT?' It's amazing to see the fragile x gurus presenting all week, chatting with you between sessions and dancing with you at the Saturday night's dinner/dance/auction event! After my first conference, even my anxiety over traveling could not stop me from attending the next ones."

*Mary Beth, Grosse Pointe (3)*

"I leave every conference with new energy and hope to help my son achieve more than we had even dreamed of. It's a re-charge to face all that life brings."

*Kim, Waterford (5)*

"The chance to sit and chat in the hotel lobby with a researcher from The Netherlands, a doctor from England, a professor from Stanford and families from other states and countries is priceless."

*Laureen, Sterling Heights (5)*

"The first conference I attended changed my life (and my kids'). I gained knowledge that I desperately needed and made life-long friends that are among my best. I've been back to every conference since and wouldn't think of missing one. Having a conference in your hometown is the opportunity of a lifetime; don't miss it."

*Jeffrey, West Bloomfield (8)*

## NFXF Advocacy Day March 2-3, 2010 Washington, D.C. by Jeffrey Cohen

There is no one single thing an individual can do to better advance the cause of Fragile X research, treatment and programming than to attend an NFXF Advocacy Day in Washington D.C. Michigan has always been well represented at NFXF Advocacy Days and we should be! Our Senator, Debbie Stabenow, has led the effort for increased funding for FX in the US Senate for the last 4 years. Please don't assume that others from Michigan will attend and make the case for you and your family. If you've never attended Advocacy Day this is the year for you. More information can be found at [fragilex.org](http://fragilex.org). Select Public Policy and Legislative Advocacy and follow the links for information and to register. Questions? E-mail [j.cohen@fragilex.org](mailto:j.cohen@fragilex.org) or call **313-806-1190**. As you may know, there is now a member of Congress who has a son living with Fragile X. Gregg Harper represents District 3 in Mississippi. He is working very hard for all of us but he needs your help. Here's his personal message to us all:

*"Like many of you, Fragile X is not just a concept to me; it is something that is very personal to my family. My son, Livingston and my family deal with the joys and the challenges of Fragile X every single day of our lives. And after almost a year of serving as a new congressman from Mississippi, I now know first-hand the incredible impact constituents can have on an issue such as Fragile X by taking the time to come to Washington and make their voices heard. Lawmakers need to hear directly from you. They need to understand the conditions commonly related to this genetic disorder, they need to hear about your victories, your challenges, and what is needed to make life more meaningful for your loved one and for your family. Come to Washington, D.C. in March. Join me in strengthening our voice of awareness as we continue to search for better treatments and a cure for Fragile X. Your participation will make a difference."*

—Representative Gregg Harper (R-MS)

From the President: We have a \$400 stipend available for Advocacy Day. Anyone who is interested should contact Laureen by February 5th at [lmajeske1@comcast.net](mailto:lmajeske1@comcast.net) or **586-978-9079**. The \$400 will be split between all who apply, to help them advocate for Fragile X in Washington, D.C.

## From the President's Desk by Laureen Majeske

**G**reased Lightning! We are sliding into the New Year with a bang and starting the countdown of the last six months until the conference! Committees are gearing up and we still need your help. Please consider volunteering on a committee. You can find the list of committees on our website at FXAM.org, contact the committee chair or contact Kim Young at [young4mi@comcast.net](mailto:young4mi@comcast.net) or 248-674-2147. Auction donations and sponsorships are still needed. Call Peggy Branch at 248-647-4010 to donate an auction item. Check with your company to see if they offer grant opportunities, contact Mike

Makris at 248-804-7963 or [mike.makris@fxam.org](mailto:mike.makris@fxam.org) and he will take care of the rest.

Thank you to Mike Bobbitt, comedian extraordinaire, for a fabulous night at Joey's Comedy Club and for helping us spread the word about Fragile X. We appreciate having you on our team!

We are all looking forward to the Do Wop concert in February benefitting Fragile X. It



is our last big fundraiser before the conference and we hope to see you all there.

Don't forget to support our group by purchasing Fragile X playing cards, t-shirts, hooded sweatshirts, party favors at [www.prettyfavors.com](http://www.prettyfavors.com) and coffee and hot chocolate at [www.jakeandsams.com](http://www.jakeandsams.com). The proceeds will help offset the conference and benefit all of us.

Looking forward to a wonderful New Year as we go forward together to make the world a better place for those affected by Fragile X.

### The Fabulous Do-Wops Retirement Tour

A percentage of the proceeds to benefit Fragile X!

**SATURDAY, FEBRUARY 13th**

Lakeland Manor  
26211 Harper Ave.  
St Clair Shores, MI

Doors Open @ 7:00 pm  
Dinner @ 7:30 pm  
Open Bar  
Dancing with DJ~John Ray

\$45 Per Person  
**Advance Tickets Only!**

For tickets contact Mike Makris at  
248-804-7963 or  
[mike.makris@fxam.org](mailto:mike.makris@fxam.org)

### Thank You!

Our appreciation goes to **Jim Karakashian** CPA, CVA of Cusmano & Co, PC of Troy

3001 W Big Beaver Road, Suite 402  
Troy, MI 48084-3105  
(248) 649-1166

[jim.karakashian@cusmanoandcompany.com](mailto:jim.karakashian@cusmanoandcompany.com)

Jim donated his services, completing our 990

- the tax form for a non-profit organization -  
free-of-charge to FXAM.

**We are grateful for Jim and his donation!**

### On the Cover

Holiday Party Pictures, (clockwise from left to right)

Darienne Majeske, Sandi McClennen,  
Frank and Nina Liberati

Mike and Hayden Makris

Roger Laske

Arlene Cohen and Darienne

Allison Cohen and Darienne

## Top Ten Reasons To Come To Detroit

1. Detroit is a city that knows how to survive and thrive through tough times. At the conference you'll learn to survive and thrive with Fragile X in your life.
2. You will be within 30 minutes of one of our five Great Lakes in a state that has more than 11,000 inland lakes with plenty of fishing and water sports.
3. At the Henry Ford Museum you'll see the monumental impact that Henry Ford made on all our lives. The conference itself will have an equal impact on yours.
4. You may gamble some money away at our Detroit casinos, but you'll leave the conference much richer with your bags full of new ideas.
5. Bridge the gaps in your knowledge of Fragile X; take a bridge to another country on the same trip (we're the only major U.S. city north of Canada, and they have a casino too!)
6. Greenfield Village will make you glad to be an American as you bear witness to her pioneering history, just as we are all pioneers of Fragile X.
7. The ballpark is brand new and spectacular. Walk the ground level concourse that surrounds the entire field and still be able to watch the game from every angle as you stroll because there are no walls. Throw Fragile X a curve and have a grand slam time with the Detroit Tigers!
8. You'll feel a lot better about your own football team.
9. Michigan has almost more golf courses than any other state, with many being within a 30 minute drive of the conference.
10. We 'Ain't Too Proud To Beg! Come on over to see everything else we have to offer – The Detroit Institute of Arts, the Detroit Science Museum, the Museum of African American History, Belle Isle, Motown, the Riverwalk, Corktown, Greektown, Mexicantown and more! We're proud of our city, and we can't wait to show it to you and have planned the best conference yet!

### **The Henry Ford: America's Greatest History Attraction**

[www.hfmgv.org](http://www.hfmgv.org)

### **Detroit Tigers**

[detroit.tigers.mlb.com](http://detroit.tigers.mlb.com)

### **Oh Canada!**

If you're thinking about crossing the border, make sure you have the right documents!

[www.cbp.gov/xp/cgov/travel/vacation/ready\\_set\\_go/land\\_travel/](http://www.cbp.gov/xp/cgov/travel/vacation/ready_set_go/land_travel/)

Questions contact Sally at [Sallyn423@wyan.org](mailto:Sallyn423@wyan.org)

### **Pure Michigan!**

[www.michigan.org](http://www.michigan.org)

### **Detroit Metro Visitors and Convention Bureau**

[www.visitdetroit.com](http://www.visitdetroit.com)

## Support the Conference Auction

Bring your dancing shoes and your wallets to the 12th International Fragile X Conference July 21-25.

Shop Around Detroit, the city that put the World on Wheels and Motown Music in our souls, and bid on one-of-a-kind items during the conference auction Saturday, July 24.

YOU can make the auction even better by your contribution which will enable The National Fragile X Foundation to continue its work supporting families around the world who are affected by fragile x, along with the clinics, researchers and professionals that also support the same families.

We are looking for auction donations that will have our attendees Dancing In The Street. Items such as electronics, computer and gaming equipment, jewelry, sports



packages, equipment and major league tickets, golf packages, hotel and time-share

accommodations, vacation packages, airline tickets and other unique gifts on which you and others in our extended fragile x family would want to bid.

### Showcase your talent.

As a special addition to this year's auction, we are collecting artwork from friends and relatives of fragile x families, or by those affected by fragile x, to be auctioned off in an exclusive fragile x gallery within the auction. Original artwork can be pottery, glass, woodworking, dolls, paintings, photographic art, sculpture or any other priceless gem showcasing your talent. Because space is limited,

we may have to limit the amount of artwork we accept.

As always, we look to our dedicated LINKS groups to graciously put together packages of items unique to their states. We have a special way of showcasing them this year. Contact Peggy Branch for more information.

And remember, donations are tax deductible and all proceeds benefit fragile x.

To make a donation or for more information, contact Peggy Branch, 2010 Auction Co-Chair, at 248-647-4010 or [peggybranch@comcast.net](mailto:peggybranch@comcast.net).

**When we all give,  
there Ain't No  
Mountain High  
Enough!**

## Everyone is Extraordinary

**An auction to benefit EMU students with special needs.**

**When:** Thursday, February 18, 2010, 6-9 pm (doors open at 5:30)

**Where:** EMU Student Center Ballroom ([emich.edu/studentcenter](http://emich.edu/studentcenter))

**Why:** Create a scholarship for students with special needs to attend EMU

**MC:** Vic Faust, co-anchor of WXYZ-TV's Action News This Morning Weekend

**Auctioneer:** Steve Gross, Premier Auction Services

**Cost:** \$30 per person, \$50 per couple Heavy hors d'oeuvres and soft drinks included in ticket price.

**Cash bar for beer and wine.**

**Buy tickets today -**  
Online: [emutix.com](http://emutix.com)

By Phone: 734.487.2282

**More Details:**  
[emich.edu/specialneedsauction](http://emich.edu/specialneedsauction)

**Questions** 734.487.2483 or  
[speced\\_auction@emich.edu](mailto:speced_auction@emich.edu)

**Event Planned by**  
EMU employee Ted Coutilish, FXAM member and Publicity Chair for the 2010 International Fragile X Conference

**Eastern Michigan University  
Education First**

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Pound the Pavement for Fragile X  
Auction/Raffle Items Needed

**Any questions, please contact  
Peggy Branch @ [peggybranch@comcast.net](mailto:peggybranch@comcast.net)  
248-647-4010**

HOPE FOR THE FUTURE



The Prices 2nd annual  
Pumpkin Sale for Fragile  
X raised \$125 this year!  
Way to go Samantha &  
Jacob!



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