

**Mark Your
Calendar**

Support Meetings

First Saturday
of the Month

When:

November 6, 2010
February 5, 2011

*No Meetings in
December and
January!*

Where:

Beaumont Hospital
Royal Oak Campus
Administration Bldg
Private Dining Room

Special Events:

December 4, 2010

Holiday Party
see page 3

**Fragile X Association of
Michigan**

Contact Information:

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fraxmich
@hotlinemail.com

FXAM.org

A member of the
NFXF LINKS Network
(Linking Individuals
Nationally in Knowledge
and Support)

Three Cheers for...

Mike Stockdale, Plant Chairman, Local 900, Ford Wayne Stamping & Assembly Plant, hosted a Poker Run which benefited Fragile X! Poker Run attendees met at Local 900 and went to five bars/restaurants to have some refreshments and pick up a card for our poker hand. We ended at Stockdale's on the Avenue where prizes were awarded to the top poker hands plus raffle prizes were drawn. Many thanks for the monetary gifts that were given from the UAW and Ford Motor Co for the event. Special thanks to all those who attended. In the end, \$6,500 was donated to the Fragile X Association of Michigan! You're a **Royal Flush** in our eyes Mike!



Hansen 4th Annual Fragile X Golf Outing - Delivery anyone? John and Nick Hansen had fun keeping golfers hydrated and fed.



**FXAM 11th
Annual Golf
Outing -**

Many thanks to all the golfers who supported this event despite the weather!



Lauren Majeske was awarded the National Fragile X Foundation Education & Awareness Award for significant contributions to the awareness of Fragile X.

The Artist named Grant!



Grant, son of FXAM family members Romy & Mike Patterson, won a nationwide FRAXA contest for his snowman to be featured on a holiday card to raise money for Fragile X research.

Way to go Grant!

The Eleventh Annual FXAM Golf Outing

The 11th Annual Fragile X Association of Michigan Golf Outing was once again a huge success. As soon as the horn blew for the scramble to start, the rain started as well. Even though the rain was constant through all 18 holes, it did not deter anyone from having a great time. The rain finally stopped just in time for the golfers to enjoy a delicious barbecued steak dinner under the big tent.

Donations were readily given to those who entered all Par 3, closest-to-the-pin contests and winners of the 10 raffle items that were donated. FXAM would like to thank all our donators and golfers who make our outing a success every year. Even though money is tight during this tough economic time, our attendees and donators were very generous to our Fragile X cause. Thank you to everyone!!

Nina Liberati

The Mickelson (\$1,300+)

Kenwal Steel Corporation

The Palmer (\$500+)

**Mike & Stella Banich
Steven J. Lebowski, PC**

The Watson (\$250+)

**Adams Holdings, LLC
C. Hawker & Associates
Evelyn Kosch-Mannino
H. Ross**

The Player (\$150+)

Arnaldo's Banquet Center
Jerry & Karen Bishop
Jeffrey Cohen JD, PC
Florence Coleman
Dearborn Brand
Sandy & Peggy Domonkos
Fontanini Meats
Innovative Interiors, Inc.
Italia Bakery
Kiwanis Club of Allen Park
Lakeshore Utility
Langan-Coutilish Family
Liberati & Sons Construction
Papa & Mama Rose Liberati
Liberati's Italian Deli & Bakery
Lincoln Park Community Credit Union
The Breakfast Club (Friends Of Bob Mannino)
Mascari Sales and Marketing, LLC
McInerney's Chrysler Dodge Jeep Ram
Mr. Joe's Sport Bar - Southfield
J. R. Mitchell Inc.
Austin, Natalie & Genevieve Nantais
Pomponio Construction
Mark & Malinda Popejoy
Preferred Brands
Rivers Edge Community Credit Union
Charlie & Inez Roy
Sue Shannon
Sorrento Cheese Co.
Theresa Sternicki
John & Susan Sturock
UAW - Ford Local 900
Kenneth Vance & Associates, PC
James & Cindy Vickey
Weed Eraser, Inc.
David Wujczyk
The Wurth Family

We would also like to thank the following businesses, organizations and individuals for their donations:

Agemy & Sons Market
Nick Coleman
Family Dentistry, PC
Joan Grab
Rosalie Guerra
J. Goulasarian Contracting, Inc.
Laurence & Jan Jacobs
George & Barbara Jakubik
Julian & Wanda Joseph
Levon & Gloria King
Deborah Lee
M-Den
Bob Mannino
Paula Marsh
Jeannette McMillan
Jim Morrin
Jerry & Sally Nantais
Francis & Mary Jane Nazareno
Jerome & Jeannette Pearsons
Pia's Restaurant
Rony's Body Shop
Roselli Food Co.
Sadie Selafani
This is ZIP Printing
Rose Tripepi
Lester & Lisa Voutsos
Charlotte Westbrook
Weight Watchers

Once again, the Fragile X Association of Michigan (FXAM) is very grateful to **Nina and Frank Liberati** as organizers of this event. And we extend our gratitude to their family, friends and other FXAM members who assisted in many ways to make this event a success! The **ELEVEN** Liberati FXAM Golf Outings have raised over \$110,000 for the Fragile X cause! Way to go Nina and Frank!

New Fragile X Research Registry

In the past, the University of Wisconsin and the University of North Carolina have each maintained a fragile X registry which has been critical to the success of research on FXS, enabling each group to quickly identify possible participants to meet research studies needs. They have merged their registries to expand and strengthen this resource.

Who can join?

Children and adults with fragile X-associated disorders may join. The Registry needs to reflect the general population of the United States. We encourage individuals of all races and ethnic groups to sign up.

Don't sit back and just **READ** about research, **BE A PART** of the research. **Join TODAY!** *

The Registry is for families who have individuals with:

- ☛ Fragile X syndrome - full mutation or mosaic
- ☛ Fragile X premutation
- ☛ Fragile X-associated primary ovarian insufficiency (FXPOI)
- ☛ Fragile X-associated tremor/ataxia syndrome (FXTAS)

www.fragilexregistry.org/join/

or

call toll-free: 1-866-744-7879

** current members of the old Wisconsin or North Carolina registries need to re-enroll in the new registry.*

Our annual potluck holiday party is set!

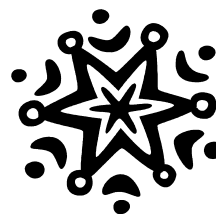
Saturday, December 4, 2010

5:00 - 9:00 pm

Langan-Coutilish Home
of Mary Beth, Ted & Andrew

851 Washington Road
Grosse Pointe, MI 48230

Mapquest or contact Mary Beth
for directions!



Please contact Mary Beth by
Monday, November 29 at
313-881-3340 or
mblangan@hotmail.com



Let her know what holiday food you'd like to add to the festivities of the evening and how many from your family will be attending! You are invited to bring the whole family or have a "date night" and attend without children.

The Hansen 4th Annual Fragile X Golf Outing By Kate Hansen

On September 17, 2010, our Fourth Annual Fragile X Golf Outing was held at The Falls in Kent City, Michigan. It was a beautiful day! We had 72 golfers and raised \$4750, for the Fragile X Association of Michigan. Nick attended the outing and had a blast riding around the course serving snacks and beverages. He also was a big help reading off the winning numbers for door prizes. All in all it was a great day and we are all looking forward to the Fifth Annual Fragile X Golf Outing next year!!

Special thanks to the 2010 Hole Sponsors!

Al & Carolyn Spangenberg
 Bill & Lori Spangenberg
 Cedar Auto Service
 Chad Vansyckle
 Freedom Chevrolet
 Fremont Ford
 Grand Rapids NAPA
 Distribution Center
 Hoffman's Garage
 Independent Bank

John & Helen DeJager
 Larry & Elaine Hansen
 Majestic Lawn Service
 Ottawa Kent Insurance
 Outback Steakhouse
 Scot Cave
 Sparta Bowling Alley
 Ted & Cheryl Corrigan
 Tire Wholesaler's Plus
 Trini's Restaurant
 Truck Repair Service
 Verizon Wireless
 WCFX-FM 95.3

On the Research Front - Progress, Progress, Progress! By Sally Nantais

Seaside Therapeutics released positive results in July (fragile X study) and September (autism study) on the Phase 2 study of STX209 (Arbaclofen). The fragile X study was a double-blind placebo controlled study with 63 enrollees, including a few from FXAM families.

The improvements were statistically significant in patients with more severe impairments in sociability. In the fragile X study 41 patients are still active, including my son Austin. While we've been on STX209 we've eliminated two meds and we've cut Austin's Abilify dose in half, now he is only on STX209 and Abilify.

The autism study was an open label

trial. The patients were only given the STX209 medication (no placebo was given) and 32 patients were enrolled. Within the autism study statistically significant improvements were reported in the irritability and social withdrawal subscale in the study.

If you wish to follow this research, do so at SeasideTherapeutics.com or e-mail me at: Sallyn423@wyan.org.

A team of researchers at Emory University have identified a potential new strategy for treating fragile X syndrome, the most common inherited cause of intellectual disability.

The researchers have found that a class of drugs called

phosphoinositide-3 (PI3) kinase inhibitors can correct defects in the anatomy of neurons seen in a mouse model of fragile X syndrome.. Read more at:

physorg.com/news200670693.html

Dr. Randi Hagerman, U.C. Davis, reported positive results with patients using Minocycline. This was with a group of families who volunteered to try Minocycline, a drug used to treat acne. The study has moved to a double-blind placebo controlled study. The study of Minocycline originated in a trial which is ongoing and sponsored by the FRAXA Research Foundation.

More details on NFXF's study at: fragilex.org, search for **Minocycline**.

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

August 21 was a dreary day in Michigan and sadly it had a dismal impact on our 2010 Annual Fragile X 5K Fun Run & Walk and FXAM Family Picnic.

For those of you who braved the

elements, our most sincere gratitude is sent your way. We hope the 2011 annual event has more family members in attendance, along with some sunshine!

Stay tuned for info.

**“How beautiful a day
 can be when
 kindness touches it!”**

George Elliston

From the President's Desk *by Laureen Majeske*



How can we ever thank all of the Michigan families who came out to volunteer at the conference or came as attendees? You were outstanding representatives of our great state. The feedback from other attendees about how friendly and helpful the Michigan people were, made this an exceptional conference. Our world-wide fragile X family felt our warm welcome, the hospitality we strove for and received the most cutting-edge information there is on fragile X. To the volunteers who spent the last two years helping to prepare for the conference, your dedication was hugely appreciated by all those that worked on this great event and I hope that this was an experience you will cherish forever.

On to some other great news -- there is a Fragile X clinic in our future! Yes, Michigan will be getting it's first clinic, as a part of the Fragile X Clinical & Research Consortium, dedicated to families of those with fragile x syndrome and related disorders (FXTAS and FXPOI). Details are still being worked out, but by early next year it should be up and running. Stay tuned for exciting information in the very near future.

In another awesome piece of news, Mike Stockdale, Plant Chairman, Local 900, of the Ford Wayne Stamping Plant recently sponsored a Poker Run and donated a whopping \$6,500 to FXAM! Thank you to Mark and Malinda Popejoy for

being the terrific employees that inspired Mike to select our group to receive the proceeds. And a BIG thank you to Mike for being our newest fragile X advocate!

I hope to see all of you soon at an upcoming meeting to help move our group forward, to set the stage for all newly diagnosed families to have a place to get information and to gain support from families who understand fragile X offering our seasoned families fellowship and a chance to make a difference.

Through the Maze Featured Website

Individualized Education Program (IEP) Development Process

Go to Michigan.gov/mde
search for **IEP Development Process**

When you have your next IEP you are going to find that the IEP form has changed drastically. Don't let a simple form throw a wrench into the works, take the time now to familiarize yourself with the new form. A pdf version of the new IEP form is available at:

michigan.gov/documents/mde/IEPform_319500_7.pdf

Changes have been made to more than just the IEP form, on the IEP Development Process page you'll find links to all revised forms (Notice of Meeting, Reevaluation/Annual Review and Amendment Form).

There are Quick Reference Guides and Podcasts broken down by individual sections of the IEP. For example, a guide and podcast is available on **Section 2: Present Level of Academic Achievement and Functional Performance (PLAAFP)**, common to all IEPs, and one is available on **Section 3: Secondary Transition Considerations**, which is not included in young children's IEPs. Secondary transition services are required to be **in effect** when the student turns 16.

Between the Lines Featured Book

From Emotions to Advocacy By Pete and Pam Wright

In the second issue of the FXAM newsletter, in April 2005, we featured this book. With new families having joined our group since 2005 and the 2nd edition of the book now in print, it is time for the spotlight to again be shining on the Wrights.

Pam & Pete Wright are an amazing husband-wife team who are educating those connected with the world of special education about the laws that affect our families.

From Emotions to Advocacy is a great staple for your home library. It'll guide you in planning and organizing how to have your child receive quality special education services. The Wrights will teach you how to be your child's special education project manager!

In addition to this important guidebook, the Wrights' knowledge is available to you via conferences, a free e-newsletter, information on their website and many other important books regarding the ins and outs of special education law.

Educate yourself to help educate your child. **Visit wrightslaw.com for more on the Wright info!**

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Editors:

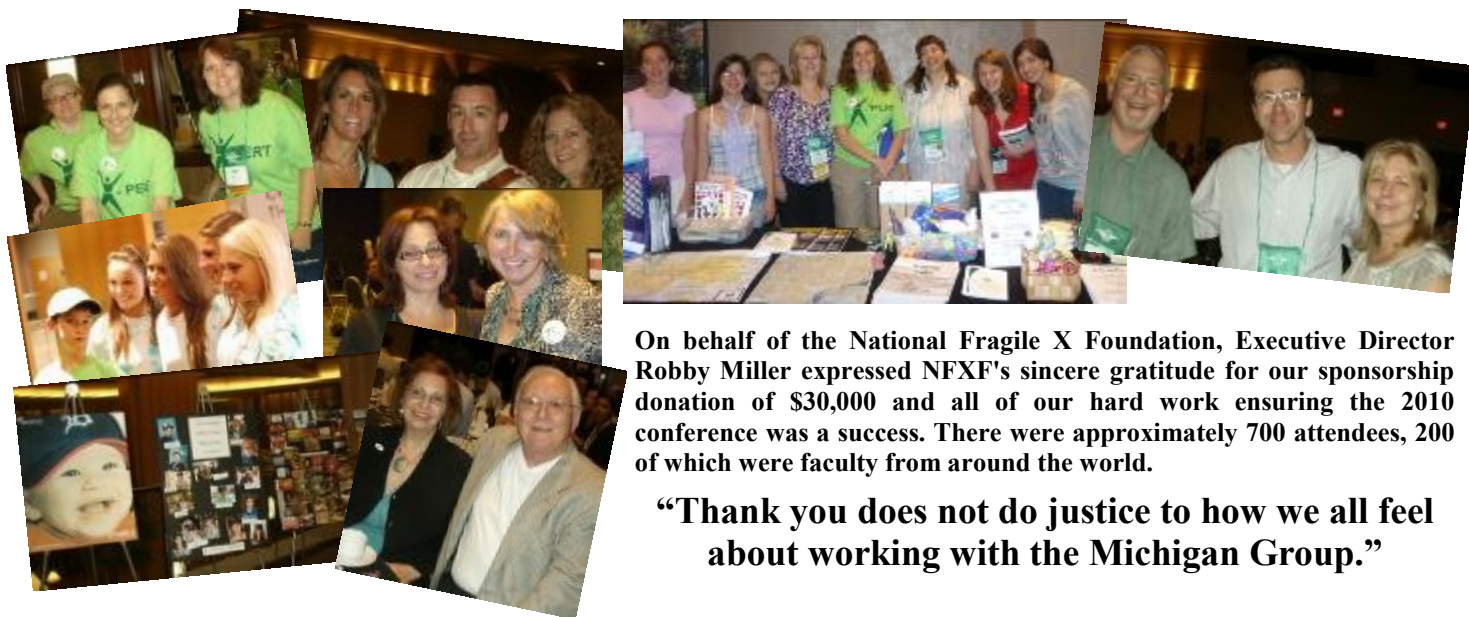
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FXAM.org



On behalf of the National Fragile X Foundation, Executive Director Robby Miller expressed NFXF's sincere gratitude for our sponsorship donation of \$30,000 and all of our hard work ensuring the 2010 conference was a success. There were approximately 700 attendees, 200 of which were faculty from around the world.

“Thank you does not do justice to how we all feel about working with the Michigan Group.”



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