

**Mark Your
Calendar**

Support Meetings

First Saturday
of the Month

When:

February 5, 2011
March 5, 2011
April 2, 2011

Where:

Beaumont Hospital
Royal Oak Campus
Administration Bldg
Private Dining Room

Special Events:

March 1-2, 2011

National Fragile X
Foundation (NFXF)
Advocacy on The
Hill (see page 2)

**Fragile X Association
of Michigan**

Contact Information:

313-381-2834

fraxmich

@hotlinemail.com

FXAM.org

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

Three Cheers for...



Peter Todd, MD, PhD,
Donna Martin, MD, PhD and
Jeffrey Innis, MD, PhD of
the proposed Michigan
Fragile X Clinic (see page 5).

Chris Bappert, age 39, was "Worker of the Year" at his workshop, Peckham Vocational Industries. Chris has a sewing job at Peckham. He received his award at a lovely ceremony in November 2010. Chris, his mother Carol and brother Tom (age 43, who attends a day program), live in Haslett, Michigan.

A GIANT THANK YOU to Dennis Lee Darrow, State Farm Insurance of Clarkston, MI for his donation/work on our International Conference! Mr. Darrow donated a eXtra large amount of popcorn for the Wii tournament in the Wreck Room and we wanted to (belatedly) thank him.

Twenty-five issues of eXtra, eXtra!



From the President's Desk by Laureen Majeske

Dear FXAM Members and Friends,

Can you believe we've already had 25 issues of eXtra, eXtra from the Fragile X Association of Michigan? It shows you how much we've grown over the last 6 years and the dedication of the families who participate. While many families come and go, more and more stay to help make a difference in our community. Our newsletter is our lifeline to those of you who are not able to make it to meetings or events due to distance or just busy lives. Our editors do their best to keep you informed of everything that is going on within FXAM as well as

up-to-date information in the rest of fragile X world. If you have a topic that you would like to see covered within the newsletter, please let Sally or Mary Beth know. Here's looking forward to the next 6 years!

Another way we try to stay connected is through **our FXAM directory**. It's a great way to connect with folks in your area or families with children the same age as your own, etc. If your information has changed over the past 5 years and Mary Beth has not yet contacted you by email or phone, please contact her at mblangan@hotmail.com or 313-881-

3340 to make sure we have your accurate information and that you are staying in the loop!



Our general elections are approaching. If you are interested in sitting on the Executive Board or the Board of Directors, please let us know by the February meeting so that we can put your name on the voting roster. You can email me at lmajeske1@comcast.net. Wishing you a very prosperous and healthy New Year!

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

University of Michigan researcher, Peter K. Todd, MD, PhD, reported in a journal article published in the *Public Library of Science (PLOS) Genetics* that the expression of the toxic RNA that leads to Fragile X-associated Tremor/Ataxia Syndrome (FXTAS) is modifiable by genetic or pharmacologic means. Read more about this FXTAS research at:

www2.med.umich.edu/prmc/media/newsroom/details.cfm?ID=1864

Study Shows Promise for New Drug to Treat Fragile X - The first drug to treat the underlying disorder instead of the symptoms of Fragile X, shows some promise according to a new study published in the January issue of *Science Translational Medicine*. Researchers from Rush University Medical Center helped design the study and are now participating in the larger follow-up clinical trial. The data from the early trial of 30 fragile X patients, found the drug, called AFQ056, made by Novartis Pharmaceuticals, helped improve symptoms in some patients. Read more about AFQ056 research at:

www.rush.edu/webapps/MEDREL/servlet/NewsRelease?id=1458

Study on Family Adaptation to Fragile X Syndrome - Report 1: Overview of the Study and Shared Experiences from Mothers

www.fragilex.org/pdf/Report1FragileX1.pdf

Advocacy Day Scholarship

FXAM offers a scholarship to help ease your budget if you'd like to participate in the NFXF Advocacy Day in Washington, D.C. This year, the event is March 1-2.

If you are interested in attending and would like to apply for the

scholarship, please contact Laureen Majeske at

lmajeske1@comcast.net or
586-978-9079

by **Saturday, February 5**, stating your intention to apply for the scholarship.

"The future depends
on what we do in
the present."

Mahatma Gandhi

Twenty-five issues of e tra, e tra!

In January 2005, Mary Beth Langan and Sally Nantais produced the very first issue of the Fragile X Association of Michigan (FXAM) quarterly newsletter. We've covered a lot of topics in the course of six years. Many of the newsletters are available online at FXAM.org on the support page.

January 2005

Three Cheers for: Samantha Herron
Life is Different Now... Not
Necessarily Better or Worse
Through the Maze - The National
Fragile X Foundation
Between the Lines - Children with
Fragile X Syndrome A Parents'
Guide
NFXF Quarterly Feature, Braden on
Behavior, *Putting the "I" back
into the BIP*

April 2005

Three Cheers for Bowling &
SibShops
Navigating your way through
Individualized Education Plans
(IEPs)
Stress Management for Parents
Through the Maze - Wrightslaw
Between the Lines - From Emotions
to Advocacy

July 2005

Three Cheers for Our Graduates
Life 101 Graduate - Meet Jason
Zarycki
Workshop Review - The Out-of-
Sync Child
Fragile X and Sensory Integration
Through the Maze - Developmental
FX
Between the Lines - The Out-of-
Sync Child has Fun

October 2005

Three Cheers for the 6th Annual
Golf Outing
Our Golf Sponsors
Speech, Language &
Communication
The Scope of Speech and
Communication with Fragile X
(sample from our families)
Through the Maze - Speechfun
Between the Lines - Words are not
for Hurting

January 2006

Three Cheers for Tyler Sutherby
Yes, There really is a Best Buddies,
The Best Buddies Program and
What it can do for you.
Through the Maze - Bridges4Kids
Between the Lines - You Will Dream
New Dreams

April 2006

Three Cheers for Grandparents
My Buddy Kyle
The Top Ten Things You Should
Know about FXTAS
Advocacy Day, Giving Fragile X a
Voice
Between the Lines - What's
Happening to Grandpa

July 2006

Three Cheers for our Graduates
Three Cheers for Andrew Young
Our Experience with a Fragile X
Clinic
Clinic information for Akron,
Chicago, Indianapolis and
Sacramento
5 Things to consider doing in honor
of National Fragile X Awareness
Day on July 22
Through the Maze - The Arc
Michigan

October 2006

Three Cheers for Golf, the Liberatis
and their Family and Friends
Three Cheers for Nicholas Weber
Our Golf Sponsors
Grief can be a gift
Fragile X: A Family Affair (member
notes from the conference)
Between the Lines - Fragile Handle
with Care
Through the Maze -
MarciaBraden.com

January 2007

Three Cheers for the Holiday Party
and Ms. Candace Shay
National FX Advocacy Day
Emory and Waisman Center Fragile
X Studies
Between the Lines - Fragile X
Syndrome: Diagnosis, Treatment
and Research

April 2007

Alex and Jacob Louk and Friendship
Circle
Students with Fragile X syndrome,
What Teachers Need to Know.

July 2007

Nathan Fischer and the Golden
Grizzly Band
Research News

October 2007

Three Cheers for Golf
Don Bailey, Ph.D.
Our Golf Sponsors

Twenty-five issues of e tra, e tra!

Continued from page 3

January 2008

9 to 4 with Eric Zachary Wagar
Fragile X Advocacy Day
Diagnosis Experiences of Women
with Premature Ovarian Failure
Wayne State University Research
Study.
Fragile X Research News

April 2008

Earning Our Wings
Fragile X Advocacy
Scholarship Opportunity for 2008
International Conference

July 2008

Three Cheers for our Graduates
Fragile X hits the newsstands in
Time's article *Fragile X:
Unraveling Autism's Secrets*

October 2008

What I did on Summer Vacation
The FXAM Store
Our Golf Sponsors

January 2009

Three Cheers for Sammi & Jake
Fragile X Advocacy Day
Waisman Center Research Study
Research Registries - Are You
Connected?
What's the Deal? Do you have your
Fragile X card deck?

April 2009

Three Cheers for
little sisters
Nicholas Weber
Achieving a Better Life Experience
Fundraising what I can do
Research Studies - Get Involved

July 2009

Three Cheers for our graduates
The Who, What & Where of Fragile
X Clinics (Akron, Chicago,
Sacramento)


October 2009

Three Cheers for Golf Outings
FXAM 10th Annual
Hansen's 3rd Annual
Never give up! Thank you Grandpa!
Our Golf Sponsors
PrettyFavors.com
The Gift of Giving

January 2010

Three Cheers for Mike Bobbit & the
Holiday Party
Have you never attended an
International Fragile X
Conference?
NFXF Advocacy Day
Top Ten Reasons to Come to Detroit

April 2010

Three Cheers for
Our Michigan Advocates
Austin Nantais
Advocacy Day 2010 - One Hundred
for One Million
12th International Fragile X
Conference Sponsorship
Opportunities
Fragile X Studies - Emory Study of
Child Learning
Welcome to the 

e tra

e tra

July 2010

Three Cheers for
Fifth Third Bank
Our Graduates
Thank You Conference Chairs
The William and Enid Rosen
Research Fund
The Making of a Newsletter
If a Picture is Worth 1,000 Words,
here's our Fragile X Fundraising
Novel
Silverton Skin Institute 7th Annual
Botox Benefit
First Giving, With a Cup of Joe, a
Pumpkin Patch and Art!
What a Favor, Pretty Favors with
Joyce Kreger
Through the Maze - Hagerman Lab
and FXTAS.org
Between the Lines - Visual
Strategies for Improving
Communication
What Every Parent Should Know
About Supplemental Security
Income (SSI) and Your Child
Turning 18

October 2010

Three Cheers for
Mike Stockdale
Laureen Majeske
FXAM 11th Annual Golf Outing
Hansen's 4th Annual Golf Outing
The Artist Named Grant
Our Golf Sponsors
New Fragile X Registry
On the Research Front - Progress
4th Annual Fragile X 5K Fun Run &
Walk and FXAM Family Picnic
Through the Maze - Individualized
Education Program (IEP)
Development Process
Between the Lines - From Emotions
to Advocacy

A little eXtra Michigan news ...

Lowell bowler Jacob Nawrocki rolls 300 in Special Olympics tournament

Nawrocki used his old favorite to bowl a perfect 300 game recently during a non-sanctioned Area 11 Special Olympics Tournament at Park Center Lanes.

Nawrocki, who has a mental impairment known as Fragile X Syndrome, rolled games of 205-200-300 for a 705 series.

Just copy the title above into Google or Yahoo as a search to read the full story online.

We wish Jacob the best of luck in obtaining his next goal, bowling an 800 series.

Check this out!

fragilex.org/html/foundation.htm

You'll see a couple new but familiar faces on the National Fragile X Foundation (NFXF) Board of

Directors. Our hats are off to Theodore Coutilish and Jennifer Silverton for taking an active role in fragile X awareness, advocacy and support.

Michigan Fragile X Clinic

We had four special guests at our FXAM 2010 Holiday Party at the Langan-Coutilish house - four doctors who are interested in learning more about our families and how the Fragile X gene affects our daily lives. The three doctors pictured on page one were from the University of Michigan Health System: Peter Todd, MD, PhD (neurology; read about his research on page 2), Donna Martin, MD, PhD (genetics) and Jeffrey Innis, MD, PhD (genetics). Also at the party was David Stockton, MD (genetics at Children's Hospital of Michigan). Many of us had great

conversations with each of them, discussing FXS, FXTAS, FXPOI, the great food we all shared and even football. We also enjoyed learning a little about the plans for a Michigan Fragile X Clinic. Discussions are continuing and the hope is that we'll soon have an official Michigan Fragile X Clinic in the NFXF's Fragile X Clinical & Research Consortium (FXCRC). The FXCRC allows clinicians/researchers all over the United States to stay connected and share info to help their patients and families and advance research. We look forward to a FXCRC clinic in Michigan. We hope to have a clinic representative attend one of our Spring 2011 meetings.

Stay tuned for more info on a Michigan clinic!

Through the Maze Featured Website

Michigan Alliance for Families *michiganallianceforfamilies.org*

800-552-4821

Michigan Alliance for Families provides information, support and education to families of children and young adults with disabilities from birth to age 26. Michigan Alliance connects families to resources in their own community. In established geographic areas, the groups also help facilitate parent involvement as a means of improving services and results for children with disabilities. The efforts of Michigan Alliance align with the Individuals with Disabilities Education Act (IDEA) to help improve results for children with disabilities. Michigan Alliance can assist you in knowing your rights, effectively communicating your child's needs, and advising how to help your child develop and learn.



Check their calendar often for workshops in your area, the *Content of the IEP* workshop gets two thumbs up from Sally!

Between the Lines Featured Book

House Rules *by Jodi Picoult*

The main character of the novel - Jacob Hunt - has Asperger's Syndrome. Jodi always weaves a great story where the ending is not usually what you expect and this one is no different. But in addition to an excellent read, you will hear many familiar threads about communication issues, sensory issues (including obsessions with foods), meltdowns and other parts of Jacob's life. Jodi grew up with a cousin on the autism spectrum and also interviewed dozens of teenagers with Asperger's Syndrome. She does an excellent job including many aspects of autism spectrum disorders into the novel which add an interesting extra hook for readers who have a family member with autism and/or Fragile X Syndrome.

Warning: you may find it hard to put this book down!

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.

Electronic copies of our newsletter are available on our website. If you would like to share them with family, friends or professionals, please share our web address with them.

FXAM.org



On The Cover/Top Stories

Mark Bear's Fight To Decode Autism

Mark Bear, 53, has been fixated on understanding the brain since he was 6--when he saw news commentators speculating about John F. Kennedy's brain functioning after the shooting. He later became a neuroscientist, now at the Massachusetts Institute of Technology, spending most of his career doing basic research on how the brain's cells form connections during learning. Read more about Mark and his importance in the world of Fragile X at:

forbes.com/forbes/2010/1206/features-mark-bear-mit-health-care-decoding-autism.html



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