



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



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

3340 to make we have sure your accurate information and you that are staving 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

eXtra, eXtra



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.

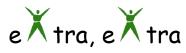
July 2007

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 eXtra, eXtra!

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 D



Continued from page 3

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



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

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!

A little eXtra Michigan news ...

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.

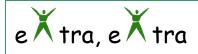
Stay tuned for more info on a Michigan clinic!

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 She does an excellent job Asperger's Syndrome. 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!



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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



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