

Mark Your Calendar

Support Meetings

Take a break for the Summer. See you in fall!

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

July 22, 2009

**Fragile X Awareness
Day!** Spread the word
to family, friends and
colleagues.

Sept 12, 2009

**Tenth Annual Golf
Outing**, Wesburn Golf
& Country Club

Fragile X Association of Michigan

Contact Information:

313-381-2834

fraxmich
@hotlinemail.com

Fragilex.org/html/
michigan.htm

FXAM.org

Three Cheers for our graduates...



Kevin McLean

Anchor Bay Middle School-South,
Chesterfield/New Baltimore Schools

Favorite Subject: Cooking Class

Future Plans: Chef

Grant Patterson

Morgan Elementary, Utica Schools
Favorite Subject: Reading, Writing and 5th
grade girls

Future Plans: Movie Critic



Sean Dacey

North Hill Elementary, Rochester Schools

Favorite Subject: Science or Recess

Future Plans: Basketball Player, Police
Officer and Guitar Hero Expert

Michael Suriano

Congregation Beth Shalom, Oak Park

Favorite Subject: Art

Future Plans: Own a Pizza store, make all of the
pizzas, and give kids ice cream.



From the President's Desk by Lauren Majeske

Only one more year until the 12th International Conference in Detroit! I hope everyone has had a chance to look at all of the opportunities to volunteer in our April newsletter; we need your help. We hope you consider joining us to make this the best conference experience possible.

On another note, it has really been a pleasure to see all of the families who are enjoying extracurricular events over the summer. Many families have participated in workshops and research projects both in and out of state. There are several children attending different types of summer camps -- horseback riding, soccer, baseball and swimming. Groups are also being gathered to walk in our third annual Fun Run & Walk to raise money for the conference. And of course, don't forget our annual golf outing in September.

Enjoy your summer, your children, your families. If anyone needs a little extra support, someone to talk to or just some information, you can always pick up the phone and call any one of us.



The Who, What & Where of Fragile X Clinics

Some of the following information is from the National Fragile X Foundation site. Also listed is contact information from FXAM members who have visited three of the Fragile X clinics. Visit fragilex.org/html/clinics.htm for the full listing of Fragile X Clinics and more details.

What is a Fragile X Clinic?

A Fragile X clinic provides individuals and families affected by one or more of the Fragile X-associated Disorders with evaluation and care supported by the latest medical, educational, and research knowledge available. All of the clinics provide medical services (including medication evaluation and consultation) supervised by a MD. Multidisciplinary services and/or referrals such as occupational therapy, speech and language therapy, behavioral therapy and genetic counseling are available within the institutions. Many of the clinics also participate in collaborative research efforts with other Fragile X clinics and professionals. All of the clinics have an emphasis on fragile X syndrome while also providing services and/or referrals for fragile X-associated tremor/ataxia syndrome (FXTAS) and fragile X-associated primary ovarian insufficiency (FXPOI).

What is the Fragile X Clinical & Research Consortium?

In 2006, the National Fragile X Foundation organized all of the US and Canadian clinics into a "Fragile X Clinical & Research Consortium." The Consortium has many purposes including the development of a knowledge base for treatment of difficult cases and the establishment of a structure for collaborative research efforts, including drug trials. The National Fragile X Foundation is also working hard to establish additional clinics throughout the U.S. and to help existing clinics become more comprehensive in the delivery of their services.

Here are three clinics that have been visited by FXAM members:

**Akron Children's Hospital
NeuroDevelopmental Center
Fragile X Program**

Considine Prof. Bldg., Suite 4400
1 Perkins Square
Akron, OH 44308-1062

Medical Director: Carol Delahunty, MD

Clinic Coordinator: Cindy King, LISW

Email: cking@chmca.org

Phone: 330-543-6015

akronchildrens.org

FXAM Contact: Romy Patterson

Email: rcmp62@yahoo.com

"In 2007, we made a visit to the Fragile X Clinic in Akron to have evaluations for our boys, ages two and four years old at the time. We met with Dr. Carol Delahunty, developmental pediatrician and clinic director, along with Dr. Ethan Benore, behavioral psychologist. After a busy day of evaluations and exams, they gave us an action plan of things we should consider to help the boys maximize their potential. Over the past two years, the Akron team has continued to assist us and help guide our local pediatrician. Later this summer, we will make another trip to Akron to see Drs. Delahunty and Benore and the clinic's occupational therapist and speech pathologist."

The Who, What & Where of Fragile X Clinics (continued from page 2)

Rush University Medical Center

Fragile X Clinic

1725 West Harrison St., Suite 718
Chicago, IL 60612
Established in 1991

Medical Director: Elizabeth Berry-Kravis, MD
Clinic Coordinator: Dorothy Malecki
Email: Dorothy_Malecki@rush.edu
Phone: 312-942-4036
rush.edu

FXAM Contact: Mary Beth Langan

Email: mblangan@hotmail.com

Phone: 313-881-3340

“Having our first appointment with a professional who knew more about Fragile X than we did was a life-changing day! Our 8-year-old son with Fragile X and my father with FXTAS have now been to Rush five times. Being able to contact Dr. Berry-Kravis, who knows Andrew and knows the intricacies of Fragile X, has made us feel much more at ease regarding Andrew’s care. I’d be happy to answer questions about visiting the clinic at Rush, including where to stay and eat and so on.”

U.C. Davis M.I.N.D. Institute Fragile X Research and Treatment Center

2825 50th Street, Room 2282
Sacramento, CA 95817
Established in 2001

Medical Director: Randi Hagerman, MD
Clinic Coordinator: Louise Gane, MS
Email: louise.gane@ucdmc.ucdavis.edu
Phone: 916-703-0238
mindinstitute.org

FXAM Contact: Elina Gelfand



Email: elina.gelfand@yahoo.com

Phone: 248-470-3311

We first heard of the M.I.N.D. Institute just after my twin boys were diagnosed with Fragile X syndrome. They were not even three years old when we took them, along with my parents, to see Dr Hagerman and her team for a full evaluation. What we learned there and the amount of support that we received cannot be expressed in a few words. I left the M.I.N.D. Institute with the strong confidence that I could do it. When I lose that feeling, I know that their support is just a phone call or email away. Knowing that I can contact them at any time is priceless. We have since visited them one more time and are planning to see them again soon. Each time I see the team I leave with lots of advice and pointers on how to make the lives of my boys and all of our lives easier.

There is no need to go to India or anywhere else to find peace. You will find that deep place of silence right in your room, your garden or even your bathtub.

Elisabeth Kubler-Ross

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Fragilex.org/html/michigan.htm

Tenth Annual Golf Outing

Saturday, September 12, 2009

Wesburn Golf and Country Club

5617 S. Huron River Drive
South Rockwood, Michigan



All proceeds go towards
SUPPORTING the 2010 international
conference in Detroit,
SUPPORTING research and
ASSISTING local families.

Contact Nina or Frank Liberati for
tickets, donations (cash or door
prizes) or more information at

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