

**Mark Your
Calendar**

Support Meetings

First Saturday
of the Month

When:

October 4, 2014
November 1, 2014
(no meetings in July,
August & September)

Business Meeting

6 - 7 p.m.

Support Meeting

7 - 9 p.m.

Where:

Beaumont Hospital
Royal Oak Campus
Administration Bldg
Private Dining Room

Special Events:

July 16-20, 2014

14th International
FX Conference
Anaheim, CA

August 9, 2014

FXAM Family Picnic
See page 5.

September 6, 2014

15th Annual
FXAM Golf Outing
South Rockwood,
See page 4 and
fxam.org/Events.html

**Fragile X Association of
Michigan**

Contact Information:
313-381-2834
FXAM.org

Three Cheers for... Our Graduates

Andrew Young

Waterford Kettering High School
Favorite Subject: Gym
Future Plans: Attending Life Tracks in
the fall. Wants to work for a professional
sports team.



Susanne Melekian

Jardon Vocational School
See page 3.

July is Fragile X Awareness Month

Share your Fragile X story with at
least one new person this month!

The beginning of
knowledge is the
discovery of something
we do not understand.

~ Frank Herbert



Between the Lines - Featured Book

Becoming Mrs. Rogers

by Cindi Rogers

Reviewed by Cortney AbouElSeoud and Mary Beth Langan

Cindi Rogers shares her family's navigation into the world of Fragile X Syndrome in *Becoming Mrs. Rogers*. This is a comprehensive book of their journey - the surprise Fragile X diagnosis of their sons Jake and Joe all the way through to the hope they continue to have utilizing an important toolbox in their adult sons' daily lives.

Many of you will see your own families in the early chapters of this book. The years before realizing something was unique about your family, the confusing diagnosis journey, hitting survival mode post diagnosis. Families affected by Fragile X and also autism spectrum and other disorders will find comfort that their journeys have many

similarities with the Rogers family's journey.

Becoming Mrs. Rogers is segmented into three parts and 46 short chapters. This is a great thing for busy families affected by Fragile X. You can definitely find time to read this book, even if it needs to be done in small chunks. If you're not as interested in the most emotional sections about searching for a diagnosis and coming to grips with it, you can skip to the areas where the tools and hope are carefully laid out for you.

Cindi's toolbox is one that is unique to her family just as each family's journey is especially unique. She meticulously lays her tools out with explanations for each one. Her

straightforward instructions on using them makes it easy to take one or all and add them to your own toolbox! This section of the book is not just for families though, anyone who works with individuals with a Fragile X diagnosis can benefit from these tools as well.

This book is a must have, not just for families affected by Fragile X and similar disorders, but also for extended family members and all persons supporting Fragile X families. As parents of children with Fragile X, we have already been putting some of Mrs. Rogers' tools to good use and plan to implement more. Come become a part of Mrs. Rogers' neighborhood!

Through the Maze - Featured Facebook Page

Autism Discussion Page

facebook.com/autismdiscussionpage/info

This page was developed by Bill Nason, MS, LLP to discuss tools that help children on the spectrum feel safe, accepted and competent. Although each child is different, with their unique strengths and challenges, there are some common strategies that can strengthen the social, emotion, and cognitive security for most children on the spectrum. Come learn, share, and support.

This discussion page will present a tool box of strategies for helping

your child/adult to succeed in many aspects of their life. Bill provides the presentations in a series of power point presentations represented in photo albums. If you are joining the page mid way through you can easily get at each power point from the photos section. When you go to the photo section, you will see only the latest six albums. There will be more hidden. Just click on the "see all photo" link to see the earlier ones.

Please take time to review the power point presentations, comments and comment yourself.

Bill's tool box consist of many topics with strategies to assist your child to feel safe, accepted and competent.

If you're looking for assistance in reducing confusion, handling sensory overload, or defining boundaries and expectations, this page will help. Nason's Autism Discussion Page will become one of your best resources.

Celebrating my Sister

By Danielle Melekian

Susanne Melekian was born on November 15, 1988. On June 5, 2014, she graduated from Jardon Vocational School. While at Jardon, Susanne learned the skills necessary to succeed in the work place, to take care of herself, and to care for a home. Her mom, Michele, once asked if Susanne could be placed in a more challenging class. The counselor looked at her and said, "Susanne is already in the most challenging class."

Susanne came to Jardon in 2007 after graduating from West Bloomfield High School that same year. She started in the Community Advantage Program 1 or CAP 1. In CAP 1, Susanne learned how to take care of herself, a house, and how to keep a job. While in CAP 1, Susanne got her first job, working at Kohl's. While there, Susanne learned what it was like to be in the work place. She had to

interact with customers as well as stay on task with her duties, such as keeping the clothing organized. In 2008, Susanne continued her employment career with her job at PetCo. These jobs weren't glamorous, but they helped Susanne build the foundation that would benefit her in future careers.

In 2009, Susanne moved into CAP 2. She worked at Target, Beaumont Hospital, Pizza Depot, and JoAnn Fabrics. No matter what the job, Susanne was able to excel. The job experience and ability to work well in various environments has helped Susanne qualify for Project SEARCH. Project SEARCH is housed at Henry Ford Hospital. Susanne hopes to intern either in Labor and Delivery or in an office putting her computer skills to work entering patient information.

Though Susanne is a great worker,

she cannot be defined by her work ethic. Susanne has an excellent memory. She is great at remembering people's birth dates, phone numbers, even what happened on a specific day. My mom, Susanne, our sister Laura, and I were at Sears and my mom couldn't remember the phone number that went with her Sears card. We named all the numbers we could think of and we're about to give up when Susanne recites a phone number. It was my dad's old work number that was at least twenty years old. Not surprisingly, it was the number.

Susanne continues to experience life outside of school. She goes out with her friends for lunch, out shopping, and to the movies. She hosts parties and keeps in touch with friends through Facebook. On the outside, Susanne looks like any other twenty-five year old but she is more than that. She's my big sister who has accomplished a lot.

Upcoming Fragile X Research Opportunity for Fragile X Dads!

Kate Partynski is a second-year, genetic counseling graduate student at the University of Michigan. She has chosen to focus her research project on Fragile X syndrome. Her study will explore fathers' experiences with Fragile X syndrome in an effort to better understand family adaptation to a child's diagnosis. Previous studies have suggested that mothers and fathers have different experiences in parenting

a child with Fragile X, but no published research has investigated specifically how fathers' parenting experiences and resilience may impact overall family dynamics, such as family communication, marital satisfaction, and quality of life. Kate's study hopes to identify coping strategies and paternal factors that help families positively adapt to a new diagnosis of FXS. Her study will

be an online survey that will likely be available in early fall.

When the survey link is ready, we'll send it to the FXAM corresponding secretary, Mary Beth Langan, to share via email and on the FXAM Facebook page.

If you are not connected via either of those methods with FXAM, please get connected by contacting Mary Beth at:

mblangan@hotmail.com



Fragile X
Association of Michigan



15TH ANNUAL GOLF OUTING GOLF & DINNER REGISTRATION FORM

- Where:** 5617 S. Huron River Drive, South Rockwood, (one mile west of I-75, exit 26)
- When:** Saturday, September 6, 2014
12:15 p.m. registration, shotgun start at 1:15 p.m. (four-person scramble)
- Cost:** \$95 per person includes: open driving range before the start, hotdogs and refreshments before and during the round, golf and cart fees, dinner, participation gift, and door prizes.

**If you can't make it for golf, please come for dinner about 6:00 p.m. Dinner, refreshments, door prizes, and a participation gift included for \$50.

ALL PROCEEDS WILL GO TOWARDS RAISING AWARENESS, SUPPORTING RESEARCH AND AIDING LOCAL FAMILIES AFFECTED BY FRAGILE X



Please list members of your foursome below, along with their shirt sizes.
**If you are a single golfer or do not have a complete foursome, we will match you up.

1. _____	_____	2. _____	_____
Name	Size	Name	Size
3. _____	_____	4. _____	_____
Name	Size	Name	Size

____ I/We cannot make it for golf, but please include us for dinner. (Please fill in names and shirt sizes above and enclose \$50 per person.)



Please mail payment/donation payable to the **Fragile X Association of Michigan** to:

Nina & Frank Liberati
9068 Quandt, Allen Park, MI 48101
313-381-2834/nliberati@yahoo.com

From the President's Desk by Laureen Majeske



While you are reading this newsletter, many Fragile X families will be just returning from the 14th International Fragile X Conference held in Orange County, California. These are very exciting times with new medication trials on the horizon and many new research projects in various stages of completion. The information on fragile x is expanding ten-fold and we can't wait to share all of the news with you when we return. Congratulations to the Fragile X Association of Michigan family members that received FXAM conference scholarships. These funds help families take part in this incredible opportunity to learn more about our children, our families and ourselves.

Recently, I had the opportunity to meet all of the personnel and researchers from Dr. Peter Todd's lab at the University of Michigan. I wanted to share with you how passionate they are about helping families affected by fragile x. While they do have a lot of fun - teasing each other, naming the mice and putting fruit flies to sleep - they take their jobs very seriously and are so excited when they gather a new bit of information that helps propel the research forward. It was exciting to watch the enthusiasm of our university students talk about their upcoming plans and what the internships and jobs in Dr. Todd's Fragile X lab mean to them. Our future is in good hands!

Don't forget to sign up for our Fifteenth Annual FXAM Golf Fundraiser. You do not need to know how to golf to participate! Just come out and have some fun all day attending the event, attending the dinner or contact Nina Liberati at nliberati@yahoo.com to volunteer with set up or during the event.

From all of your FXAM board members, we hope you are having a wonderful, fun-filled summer! Hope to see you at the August FXAM family picnic, the September golf fundraiser and/or our first fall meeting in October.

Greetings from the University of Michigan Fragile X Clinic!

By Kailey Owens, Clinic Coordinator

I am excited to be attending my first International Conference in July and hope to see many familiar faces in California! Our clinic is in the process of updating our website on a new platform that will hopefully be more user-friendly, and we will send out the new link once it is up and ready. We have also made some adjustments to the phone call intake process for setting up appointments that we hope will be clearer and more efficient. **All requests for appointments in our clinic should now go to my direct phone line: 734-615-3591**

If you are interested in signing up for the FXCRC FORWARD Registry and Database, please let me know!

2014 U of M Fragile X Clinic Schedule

July 10 and 24	October 2 and 16
August 7 and 21	November 6 and 20
September 4 and 11	December 4 and 11

Fragile X Association of Michigan Family Picnic

August 9, 2014
Noon—3 pm

Our annual picnic will be at the home of
Mary Beth, Ted and Andrew

FXAM will provide a main dish, drinks and games. Families are invited to bring a side dish or dessert to share! **RSVP** to Mary Beth at mblangan@hotmail.com or 313-881-3340 by **Tuesday, August 5** with the # of adults and # of children who will be attending!



eXtra, eXtra

Editors:

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mblangan@hotmail.com

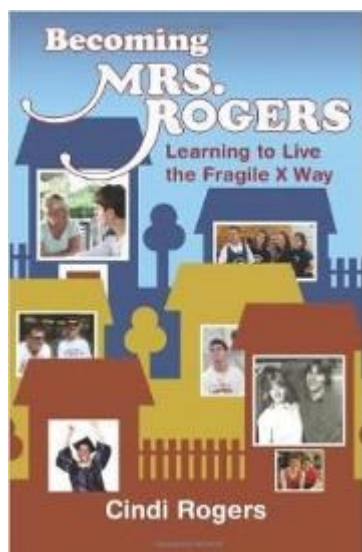
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FXAM.org



You can find *Becoming Mrs. Rogers* at amazon.com!

One lucky winner will leave the FXAM Family Picnic with a free copy.

Come on August 9 and enter the free raffle for *Becoming Mrs. Rogers*!



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