

From the President's Desk by Laureen Majeske

A Newsletter from the Fragile X Association of Michigan?

What an eXceptional idea!

We're pleased to provide you with our first

edition of eXtra, eXtra, a quarterly publication of the Fragile X Association of Michigan. There are many other exciting developments at the FXAM, not the least of which is our formal incorporation and recognition by the IRS as a 501(c)(3) nonprofit organization. While we will continue our close affiliation, collaboration and support of the National Fragile X Foundation, our new structure will allow us to play a much expanded role in raising awareness and helping families touched by fragile X right here in Michigan.

We now have a fully functioning, all-volunteer board of directors that will meet quarterly or more frequently as the need arises. At our recent meeting we set out to establish a strategic plan for the coming year and beyond. Exciting projects we have agreed to explore include:

Inviting prominent local speakers of interest to our monthly support meetings

Sponsoring additional family fun/fundraising events

Distribution of education materials to all pediatricians in the tri-county area

Sponsorship of a yearly rotating medical/educational conference

Funding research grants through the National Fragile X Foundation

If you've attended local support meetings in the past but haven't recently, it's time to come back! If you're new to the fragile X

community, we look forward to welcoming you. We still meet the first Saturday of each month at the Beaumont Administration Building in Royal Oak, but the look and the feel and the energy are new and improved. We look forward to seeing you at an upcoming meeting.

Thank you to all of the families who have worked diligently over the past year to make our group eXceptional!"



FXAM members participating in NFXF's
Advocacy Day in Washington, D.C.
on June 24, 2004.

Three Cheers for

Samantha Herron. In Samantha's high school Child Development class they were asked to choose from a list of topics to do a report and presentation. Samantha instead asked her teacher if she could do her report on fragile X. The teacher agreed. Samantha worked on her report while away at a hockey tournament. Not only did she herself learn about fragile X, her teammates became interested and she was able to educate both them and their parents. Way to go Samantha!

Samantha learned about fragile X through brief encounters with the Majeske Family.

Parent's Venue

Life is different now... not necessarily better or worse

By Theodore G. Coutilish and Mary Beth

Langan, PUBLISHED: June 24, 2004, The Grosse Pointe News

10-10-02.

That was our family's D-Day.

In this instance, D-Day means "Diagnosis Day."

It's an easy date to remember. The day Mary Beth took the call that informed us that the blood test came back positive. "Andrew has Fragile X Syndrome."

It's so easy to remember the date because Mary Beth had to tell Ted about their son's diagnosis on her husband's 38th birthday.

Looking back now, life seemed pretty chaotic for a while. Well, more chaotic than the normal chaos!

More doctors to see. Research to do. Books to read. FX groups to join. The frenzy hadn't really stopped. The frenzy simply changed from finding a diagnosis to finding out more about the specific diagnosis. And dealing with it.

It all seemed so sad for a while. Tears came very easily. Dreams seemed shattered. Plans seemed obliterated.

But it really did improve. New dreams replaced the old ones. Little achievements became more exciting to watch. The good times seem more fulfilling than before.

Life is just different now... not necessarily better or worse.

It's still easy to remember those first weeks of stumbling through a diagnosis, especially when you hear of a family going through a similar process. Or you read their first post on a listserv. Or hear them ask you jumbled questions in a school hallway.

You want to say, "It'll be okay. Just take a breath. You'll get through this and keep going."

We still have a long road ahead of us, but, in a relatively short time, we have already

learned that "the diagnosis" was not the end of the road. It just brought us down a different road than what we had mapped out for ourselves.

Depending on printing schedules, you will probably receive this column on a day that Mary Beth is participating in Fragile X Syndrome Advocacy Day on Capitol Hill. She'll be sharing our story of FX. And explaining how money would help with FX education and research.

Advocacy Day is part of this year's International Fragile X Conference in Washington, D.C. Mary Beth is going in order to gather more information about how to help Andrew be his best. She'll be attending for the first time and learning from FX experts – the professionals and the parents.

Ted will be taking a few vacation days to parent Andrew full time while she's out of town.

Perhaps some dads take vacation days so the mom and dad can take their child to Disney World or some place like that. Andrew would detest the sensory overload of such a place at this point of his life. He would much rather stay home and do his usual routine of therapies and have regular ol' roughhousing and play time with his daddy.

Life is simply different now... not necessarily better or worse.

The power of the pen!

Theodore G. Coutilish and Mary Beth Langan write a bi-monthly column in their local newspaper on their experiences of having a child with fragile X syndrome.

Sally Nantais writes a monthly column for her local newspaper, The News-Herald, sometimes using it as a means to educate readers about fragile X.

Do you have a talent for writing? It's an excellent way to create awareness and advocate for our children, and children like them.

Through the Maze Featured Website

National Fragile X Foundation
www.fragileX.org

What is the first website most people visit after receiving a diagnosis of Fragile X in their family, has the easiest web address to remember, and has a full spectrum of FX info?

FragileX.org, of course!

The web site of the National Fragile X Foundation (NFXF) has so much information that you could not possibly take it all in during one visit. The site has numerous topics, from "What Is Fragile X?" to information on testing, education, support links, membership of NFXF and much, much more. At fragileX.org there is so much to read, recommend and share with family members, medical and educational professionals, and therapists working with your family. In addition, much of this information is also available by speaking with a live person via the NFXF toll-free number.

FXTAS is a recently identified condition present in some older FX carriers, usually in males but rarely in females. FXTAS can involve tremors, balance irregularities and dementia and is often misdiagnosed as Parkinson's. This website is one of the few places to find information that carriers can share with their doctors if they believe that FXTAS could be a possible diagnosis.

There is much to learn at fragileX.org. Although it's the first place you may turn for information, it certainly will be the place to turn time and time again.

Looking for answers? Need Help?

Check out the
National Fragile X Foundation

Phone: 800-688-8765
E-mail: NATLFX@FragileX.org
Internet: www.fragilex.org

Want to contribute? Have a story you'd like to share? Contact Mary Beth Langan at 313-881-3340 or mblangan@hotmail.com; or Sally Nantais at 734-282-7910 or sally_nada@juno.com

Quote for the Quarter

"You miss 100 percent of the shots you never take." Wayne Gretzky

Between the Lines Featured Book

Children with Fragile X Syndrome – A Parents' Guide

Edited by Jayne Dixon Weber
Published in 2000 by Woodbine House

This book is a wonderfully helpful first book to read about FX, but it's also one to which you may return time and again, long after the FX diagnosis. We shared it with family members and friends who wanted to know more about FX.

Weber's book discusses a variety of topics, from the genetics of FX, to education, legal rights, estate planning, advocacy, and more. Each chapter ends with movingly honest statements from parents. You will feel you are not alone as you read this book. You realize there are many others dealing with the same issues you have in your world. The book ends with an excellent resource guide.

If you would like to borrow the book and your library does not have it, ask your librarian about an inter-library loan as many other libraries have it. Or you can buy it for \$18 at www.fragilex.org or many local bookstores.

For a free catalog of the Woodbine House Special Needs Collection, call 800-843-7323 or visit www.woodbinehouse.com.

Calendar of Events

Support Meetings:

When: February, March, April
First Saturday of the month.

Time: Business Meeting: 6 – 7 p.m.
Support Meeting: 7 – 9 p.m.

Where: Beaumont Hospital, Royal Oak
Admin Building, Private Dining Room

Guest Speakers:

Feb 5: Stress in the lives of Parents of Children
with Special Needs
Pamela McCaskill, Ph.D.

Mar 5: Educational Strategies
Sandra McClennen, Ph.D.

Apr 2: Behavioral Interventions
Jamie McGillivray, M.S., B.C.B.A.

Bowling Party/Fund Raiser

March 20, 2005, 2 – 5 p.m.
Langan's Bowling (no relation to Mary Beth)

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