Fragile X
Association of Michigan

eXtra, eXtra
Volume I, Issue 1; Jan 2005

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.

From the National Fragile X Foundation

Letter from Robby Miller to the Fragile X Association of Michigan

To the Board of Directors of the Fragile X Association of Michigan,

I recently learned that the National Fragile X Foundation will be the beneficiary of a $6,000 donation from your just concluded golf outing. This represents an increase over your 2003 donation of 20% and on behalf of our entire staff, board of directors and all of the families we serve, let me express our sincere appreciation and thanks.

We at the NFXF have enjoyed a long and productive relationship with our members, friends and supporters in Michigan and we were pleased to learn that the Fragile X Association of Michigan recently incorporated and has now secured its federal 501(c)(3) non-profit status. We look forward to working with you and supporting your efforts.

The NFXF continues to enhance our support, awareness and education activities while substantially increasing our direct funding of both basic science and clinical research, and our legislative advocacy efforts. We know that these are all areas of interest for the members of your group and also wanted you to know that your continued support helps to make this all possible.

The staff and Board appreciate the continued support from the wonderful families in Michigan and we look forward to collaborating with you on the many exciting projects you have planned.

Please let me know how we can help and contact me anytime with your feedback and suggestions.

Robby Miller
Executive Director
National Fragile X Foundation

NFXF Quarterly Feature

Braden on Behavior

Putting the "I" Back Into the "BIP."

Winter 2004

The Behavior Intervention Plan (BIP) is included in the 1997 amendments to the Individuals with Disabilities Education Act (IDEA). In general, the amendments include:

- More collaboration with relevant education personnel to resolve behavior problems that may interfere with academic progress.
- Team exploration of strategies and support systems to address any behavior that may impede the learning of the child with the disability or the learning of his peers.
- If a disciplinary action is leveled, the IEP team meets within 10 days to perform a behavioral assessment to collect data necessary to formulate a Behavior Intervention Plan or if one already exists to review and revise as necessary.
- Additional inservice and preservice to learn how to develop

The need to properly assess behavior of those with special needs was driven by the fact that behavior often interfered with the ability of one with special needs to be educated in the least restrictive environment.

When the special needs student becomes disruptive, noncompliant or avoidant he can become estranged from his peers and isolated from the social interaction necessary for meaningful inclusion. The behavior becomes a discipline issue which in reality is more likely a manifestation of the disability.

Disciplining the behavior out of a challenged student is impossible, especially if it is a manifestation of the disability. IDEA requires that the IEP include a BIP in lieu of a traditional school discipline policy when behavior impedes learning and is a manifestation of the child's disability.

In order to properly design a good BIP, a number of preliminary steps must be taken. Creating an effective BIP for individuals with fragile X syndrome is similar to designing a sound instructional program. **Recognizing that the environment plays a major role in the way a student with fragile X syndrome learns and behaves is critical.** Identifying overt behaviors (physical aggression, yelling out, destruction, etc.) although important, does not identify the cause of the aggression. It is my contention that if the behavior reaches an aggressive level it is most likely due to a weakness in the behavioral support system. **There are usually antecedents (triggers) that when unaddressed contribute to the behavioral escalation.** For example; if a child becomes silly when presented with a transition and is simply admonished without any modification, the behavior will continue, because the function of the behavior has not been addressed. **The student's behavioral repertoire will change to meet his need to avoid. Without modifications, the behavior will escalate to an aggressive form (hitting, kicking, yelling). When the level of aberration is increased, it can no longer be ignored and the behavior serves the ultimate purpose; to make the transition stop.**

This above example highlights the need for a **Functional Behavior Assessment (FBA).** This assessment is designed to identify the contextual factors that contribute to the behavior. When properly conducted, the FBA identifies the conditions under which the student is successful or unsuccessful. In the example given it may initially appear that the student is oppositional whenever asked to comply, but the student may anticipate a fearful experience created by the unknown. Because the student lacks the ability to express the affective nature of his behavior, he must act it out. Often with students with fragile X syndrome anxiety becomes the driver for aberrant behaviors. The underlying fear must be addressed in order to effectively intervene.

Because students with fragile X syndrome demonstrate a **behavioral delay**— the behavior does not always immediately follow the antecedent—the FBA should be conducted over several days and should utilize a team of professionals from a number of disciplines. When a team approach is used, the assessment gains perspective. The educator may be able to determine that a skill deficit is the antecedent, while an occupational therapist might identify an environmental antecedent that has sensory implications (loud sounds, proximity or crowded conditions) and a speech therapist might identify an expressive language deficit that causes embarrassment that results in aggressive outburst.

After assessing the function of the behavior the intervention begins. Often, a student with fragile X syndrome has habituated a behavioral response so a prosocial response needs to be taught. This is the true essence of the BIP; teaching an **intervention** that replaces the maladaptive behavior.

The reason for writing this article is to highlight the importance of the intervention portion of the BIP. Without the focus on "I", the BIP is simply a piece of paper to document behavioral episodes. Designing an intervention requires careful consideration. It is necessary to identify the antecedent, but equally important is finding ways to teach the student new coping strategies. With proper support the student gains benefit from the intervention and becomes more prosocial in his reactions.

Plan to be proactive and understand that IDEA provides ways to keep the student with fragile X syndrome viable and included with typical peers.

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EDITOR'S NOTE: Marcia Braden, PhD, is a psychologist and a longtime advisor to the National Fragile X Foundation. She is also the author of the acclaimed book, "Fragile, Handle With Care", *and a nationally known lecturer on fragile X. Her sessions at the NFXF's International Conferences are always "standing room only".*

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 Dinning 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 McGillivary, 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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