# FRAGILE X ASSOCIATION OF MICHIGAN

eXtra, eXtra

Volume XIII, Issue 2, April 2017

## Mark Your Calendar

### Support Meetings

First Saturday of the Month

*When*:

**May 6, 2017**
**June 3, 2017**
*(No meetings in July, August & September)*

Free Childcare in May.
See page 5.

***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:

**June 16, 2017**
**Wrinkle Free for a Cure**
See page 5.

**August 5, 2017**
**FXAM Family Picnic**
White Lake
Save the date.

**Fragile X Association of Michigan**

**FXAM.org**

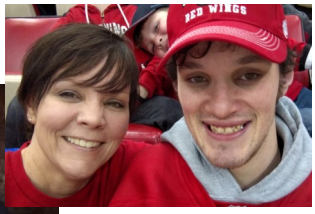
**313-881-3340**

southeastMI@fragilex.org

## Three Cheers for…

## 50 Issues of the FXAM Newsletter

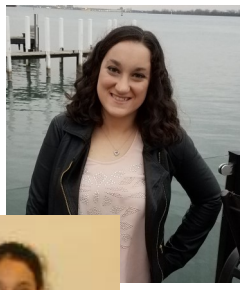
**2005** - On our first cover page, FXAM members participating in NFXF's Advocacy Day in Washington, D.C. on June 24, 2004.



**2005** - Kim and Andrew talked about IEPs.



**2006** - Yes, There Really is a Best Buddies The Best Buddies Program and What it Can Do for You by Stephanie Dillworth.
bestbuddies.org/



**2005** - Jordan and Natalie were SibShop participants.
siblingsupport.org/

**2005** - Life 101 Graduate - Meet Jason Zarycki by Evelyn Zarycki. See page 7.

**2005** - Life is Different Now… Not Necessarily Better or Worse. See page 3.
**2006** - Grief can be a Gift. See page 6.

**Mary Beth**

**Sally**

# 50 Issues of the FXAM Newsletter

## We have loved lists:

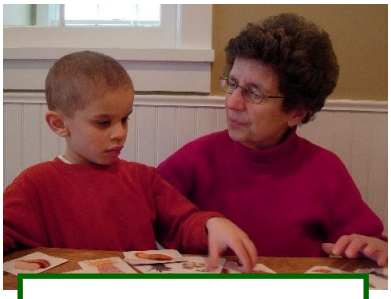
**April 2006** - The Top Ten Things You Should Know about FXTAS
**July 2006** - 5 Things to Consider Doing in Honor of National Fragile X Awareness Day on July 22
**April 2013** - Top 10 Things a Teacher Should Know About Fragile X Syndrome
**April 2017 -** The Top Ten Things You Should Know About Fragile X-associated Primary Ovarian Insufficiency (FXPOI). See page 4.

Alli & Darienne January 2010


Nathan July 2007

Sammi & Jake January 2009

Kyle & Roger April 2007



Andrew & Emma April 2007

Nicholas October 2006

Embracing Fragile X
by Cortney AbouElSeoud
April 2013


Welcome to the "D"
The Popejoy Family April 2010

# 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.

We have often had a quote in each of our newsletters, it even used to be titled "Quote of the Quarter", but over the last twelve years, the last 49 issues, there does seem to be one quote that still resonates today and will still hold true tomorrow:

**"We cannot change the cards we are dealt, just how we play the hand."**

***~ Randy Pausch, The Last Lecture***

# Recognize your Graduate in the July newsletter!

Send the following information to Sally at Sallyn423@wyan.org by **June 10**:

**School** **Favorite subject** **Future plans** and **A recent photo**

# The Top Ten Things You Should Know About Fragile X-associated Primary Ovarian Insufficiency (FXPOI)

*By Sally Nantais*

1. It's **genetic**.
2. The exact number of females who carry the fragile X premutation is unknown. It is estimated that 1 in 151 females may be affected by the fragile X premutation. *
3. FXPOI occurs in about 20-25 percent of adult female fragile X (FMR1) premutation carriers. It has also been reported in teenagers who are carriers, though it is less common in that population.
4. Fragile X-Associated Primary Ovarian Insufficiency (**FXPOI**) is a cause of infertility and early menopause among adult women. Women with a condition called primary ovarian insufficiency stop having menstrual cycles and have symptoms of menopause before 40 years of age. Women who have a premutation in their FMR1 gene are at higher risk for primary ovarian insufficiency and are at higher risk for having children who have FXS.
5. Even though women with FXPOI may develop symptoms similar to those of menopause, such as hot flashes and vaginal dryness, FXPOI differs from menopause in some important ways:
   - Women with FXPOI can still get pregnant in some cases because their ovaries may occasionally function to release viable eggs. Women who have completed menopause cannot get pregnant because their ovaries no longer release eggs.
   - Women with FXPOI can experience a return of menstrual periods. Women who have completed menopause will not have menstrual periods again.
   - FMR1 premutation carriers can have normal ovarian function, but can still go through early menopause, which is menopause occurring between 40 and 45 years of age (menopause normally occurs between 45-55).
6. Women who are concerned that they might have FXPOI can get their levels of follicle-stimulating hormone (FSH) tested. FSH levels are higher in women whose ovaries are not working properly, compared with other women of the same age whose ovaries are functioning normally.
7. Women with FXPOI may experience osteoporosis, a loss of bone tissue causing bones to get thinner and weaker, increasing the risk of bone fractures.
8. Women with FXPOI report higher levels of thyroid problems, depression, and anxiety. However, no studies have solidly linked these conditions with FXPOI.
9. "Menopause is a period of women's life characterized by the cessation of menses in a definitive way. The mean age for menopause is approximately 51 years. Primary ovarian insufficiency (POI) refers to ovarian dysfunction defined as irregular menses and elevated gonadotrophin levels before or at the age of 40 years. The etiology of POI is unknown but several genes have been reported as being of significance. The fragile X mental retardation 1 gene (FMR1) is one of the most important genes associated with POI." **
10. Where to go for more information on FXPOI:
    - National Fragile X Foundation - **fragilex.org/fragile-x/fxpoi/**
    - Co-occurring diagnoses among *FMR1* premutation allele carriers **ncbi.nlm.nih.gov/pmc/articles/PMC3696492/**

* Prevalence of CGG Expansions of the FMR1 Gene in a US Population-Based Sample, **ncbi.nlm.nih.gov/pmc/articles/PMC3391968/**

** Study of the Genetic Etiology of Primary Ovarian Insufficiency: FMR1 Gene **ncbi.nlm.nih.gov/pmc/articles/PMC5192499/**

# What's going on ...

## Free Childcare at the meeting on May 6!

6 - 9 p.m.

Free childcare available

6 p.m. Business meeting

7 p.m. Support meeting

**RSVP** by **May 1** to mblangan@hotmail.com with your children's names and ages.

We'll have pizza and salad in the childcare room and for the adults at the meeting.

Please bring something fun to share (game, toy, etc).

Hope to see your whole family in May!

## Wrinkle Free for Fragile X! Friday, June 16, 2017

If you want to smooth your wrinkles away AND donate to a good cause, mark your calendars for June 16 when the 16th annual "Wrinkle Free for Fragile X" will take place at the Silverton Skin Institute in Grand Blanc. Each year, Jennifer and Kimball Silverton, of Grand Blanc, host an event, offering patients an opportunity to receive injections of a wrinkle smoothing product such as Botox at a charitably priced rate with all money going towards research. Participants will have the opportunity to learn about Fragile X, learn about smoothing away wrinkles and be able to enjoy delicious food! The Silvertons' son, 19-year-old, Aidan, has FX. The event has raised more then $300,000 over the years. Dr. Kimball Silverton is a board certified dermatologist and fellowship-trained cosmetic surgeon.

Cost: $290 *

Where: Silverton Skin Institute, 8245 N. Holly Road, Ste. #101

Grand Blanc, MI 48439, 810-606-7500 **

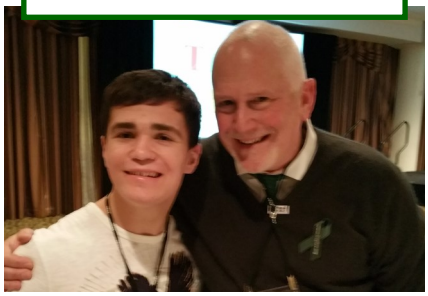
** $50 non-refundable deposit required ** must call in advance to secure a spot; space is limited*

## 50 Issues of the FXAM Newsletter

Maggie
April 2012

Darienne
April 2012

Advocates eXtraordinaire
Aidan and Jeffrey
April 2015



Prom King Antonio October 2014

# Grief can be a Gift

By Sally Nantais, PUBLISHED: August 1, 2004, *The News Herald*

With the dog days of summer upon us, I was sitting at this silly computer trying to find the direction for a column. My mind wandered far from summer to a personal experience. It's a unique experience that only a parent of a child with a disability can understand: the grief that one experiences with a diagnosis of a disability.

These thoughts were brought on by the images of Nancy Reagan having to be coaxed from her husband's coffin, so weary and grief-stricken. It's a vision some of us won't quickly forget.

It intensified with a column I read for the Grosse Pointe News by close friends Mary Beth Langan and Ted Coutilish on "D-Day," which had nothing to do with World War II. "D-Day" for them was "Diagnosis Day." Having a child with a disability is not something one ordinarily chooses. The beginning, the diagnosis stage, is one of the most difficult.

We all have dreams for our children that may be shattered with a diagnosis of a disability, be it physical or developmental.

With the loss of those dreams comes grief and all the emotions that go with it: denial, fear, guilt, blame, anger, sorrow and acceptance. Grief doesn't exclude things we can't see or touch.

Grief over our shattered dreams can be as intense as that for the death of a loved one.

Denial came first. "They can't be right, look at what he can do, at how bright he is?" Why do they measure our children on what they can't do and not by what they are capable of doing?

Fear of the unknown is always present. As a parent, you want to know as much as possible and have all the answers. Unfortunately, you quickly discover there are no answers for the important questions.

Will my child have friends? Will my child be happy? Will my child be able to live independently when he's older? What will happen to my child when I'm no longer able to care for him?

Guilt and blame quickly followed, which for me was an easy trap to fall into. After all, my son's disability, Fragile X syndrome, is genetic. Prior to his diagnosis (he was diagnosed when he was 4) I had no idea that I had a 50/50 chance of passing a developmental disability to my child.

Anger became apparent when I questioned why this happened to me. I wondered why I had to be the one to pass it on and not one of my sisters? It didn't seem fair, but is life ever fair? At times, my anger has been misdirected. My son has a condition that he was born with and he will die with. At least that's how one insurance company explained a denial of service to a parent of a child with Fragile X syndrome. At this time, it's not curable and it's not terminal.

There's no Make A Wish or Rainbow Connection for my child or other children like him. Sometimes it seems as though no one cares about the quality of his life, or others like him.

Sorrow was never as intense as it was in the beginning. It's difficult to explain the depth of your sorrow: It was, and at times still is, immeasurable. Surprisingly, sorrow didn't occur immediately, but happened a little later when hearing the words "mentally retarded" used to describe my son's disability.

Grief may never completely end, but its intensity can subside. From time to time it will resurface and I've learned to welcome it, as it gives me the opportunity to be reborn.

In the movie, "Harry Potter and the Chamber of Secrets" there is a special bird called a phoenix. The phoenix has some unusual characteristics.

When he reaches the end of his life, he bursts into flames and is reborn from his ashes. His tears can heal the wounded and he has the ability to carry incredible loads.

There are times when I feel like the phoenix. I need to burn up so I can start over. From the ash comes additional strength and courage to go on and never give up.

My tears may not heal the wounded, but they do heal me. Lastly, it feels as though the weight on my shoulders is almost unbearable, but I've managed to carry it.

With the passage of time my grief has become a gift. Another door has opened in which my life has become more meaningful. One day, my husband asked me to imagine our lives without our son.

I could describe it with a single word: "shallow." I've found you can live a "shallow" life just as easily as you can drown in shallow water. It's only a matter of choice.

Strangely, many years ago "perfect" was something I strived for. Now, I strive for less than perfect.

All because of a child who may never be "perfect," who may never be "normal," but who will simply love me with all his heart, no matter what. A lesson learned through the process of grief.

## Life 101 Graduate - Meet Jason Zarycki by Evelyn Zarycki, January 2005

Jason is 34 years old and is fully affected by Fragile X. He was not diagnosed until he was 19 years old when the gene was identified and testing became a little more common. Jason has lived in an apartment since he was 26 years old. This came after he graduated from the LESA Adult program in Howell, Michigan. Jason's apartment rent is subsidized and he is able to live in a very nice one-bedroom apartment on his own. This is possible with daily support supplied by his mother and staff who prompt him to take his medications, take him once a week grocery shopping, once a month to the barber and whatever necessary doctor and dentist appointments. Jason attends a daily program 3 days per week for 1/2 day. On Thursdays, he volunteers with the "Meals on Wheels" program, which he enjoys very much. This utilizes his positive personality traits of being compassionate, sociable and helpful. Among Jason's other passions are University of Michigan sports and all Detroit major league sports, of which he is VERY knowledgeable. He has participated in Special Olympics since childhood. This provides him with additional opportunities for being with friends and feeling successful and learning good sportsmanship. He loves all music and Playstation 2. Jason has an older brother to whom he is very attached, though unfortunately his brother lives 150 miles away with his growing family. Jason has a good sense of humor and his family is very proud of his progress.

### Update on Jason

Jason celebrates his 46th birthday on April 22. He has lived independently in his own apartment with minimal support since age 26. He has been in his present apartment for over 16 years! He still participates in Special Olympics Unified Basketball, Unified Golf and Soccer. Jason attends a day program 3 days per week where he is able to socialize, dine out and do various activities. He is a very knowledgeable sports fan and is a huge University of Michigan fan! All who know him love his smile and sense of humor.

## From the President's Desk *by Laureen Majeske*

After 14 years of having your support as FXAM President, I have decided to move forward with other endeavors in my life. I can't tell you what it's meant to me to work for our families in Michigan. When my three children were first diagnosed, information was pretty much non-existent. We didn't have anyone to help us through all of those first scary meetings, first IEPs, or navigating the system. I promised myself that I would not let any other family go through the same thing we did and I have worked to the best of my ability to help our families and to raise awareness and funds to benefit our cause. The Board of Directors of FXAM is an awesome group, and while members of the Board have changed over the years, one thing has stayed consistently the same. You are guaranteed that everyone on your Board works tirelessly for YOU. We are proud that we have brought you opportunities for social events (for both kids and adults), medical conferences, speakers, scholarships to help families attend the international conferences, quarterly newsletters, fundraisers, and so much more. And none of that will change.

I will remain on the Board because I know our work is never finished. Still in the works is our goal to bring our monthly meetings right to you in your home. Soon you will be able to call in to a support group meeting from anywhere in Michigan and ask questions, hear a friendly voice and know you are not alone. This is close to being done and should begin very soon. We are also expanding our reach into corporate donations by putting together materials that specifically address that goal and which we hope will make us stand out among non-profits vying for the same monies.

The proverbial gavel will be handed over at the May meeting to the 2017 version of the FXAM Board:

**President - Heather Van Dam**
**Vice President - Elina Gelfand**
**Treasurer - Sheryl Roman**
**Recording Secretary - Laine Cyplik**
**Corr. Secretary - Mary Beth Langan**
**Past President - Laureen Majeske**
**Cortney AbouElSeoud**
**Joyce Kreger**
**Frank Liberati**
**Nina Liberati**
**Kailey Owens**
**Tiah Solway**
**Sulie Tyler**
**Kim Young**

Thank you to all of our board members, past, present and future, for their work on behalf of our Michigan families.

I am looking forward to a less active role, while still supporting FXAM families and my family remaining a part of our Fragile X family!

# eXtra, eXtra

Editors:
Mary Beth Langan 313-881-3340
mblangan@hotmail.com
Sally Nantais 734-282-7910
sallyn423@wyan.org



Electronic copies of our newsletter are available on our website. If you would like to share them with family, friends or professionals, please share our web address with them.

**313-881-3340**

**southeastMI@fragilex.org**

**FXAM.org**

**FXAM Family Fun at the Gym!**

FRAGILE X ASSOCIATION OF MICHIGAN

**PO Box 1414**
**Troy, MI 48099-1414**