Fragile X
Association of Michigan

extra, extra
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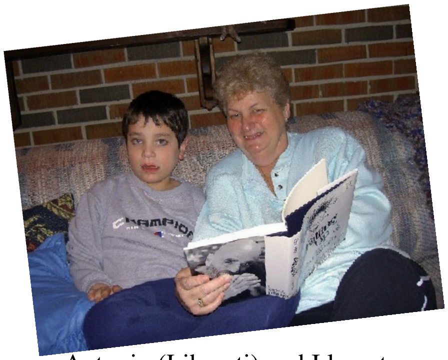
Three Cheers for Grandparents



Antonio (Liberati) and I love to read, sing and look at family pictures together.
Florence Coleman

I enjoy playing flashcards with Andrew (Coutilish). It's one of his favorite things to do. *Emma Langan*

I enjoy spending time with Darienne. She is always so happy!
Peggy Majeske

My best birthday ever was when Darienne helped by blowing out the candles, Sean gave me a big birthday kiss and Shea practiced his birthday song for Susanne and all the grandchildren to sing to me. *Marlene Sienko*

Austin (Nantais) and I love having fun together
Joann Poe

My Buddy, Kyle

by Grandpa Roger Laske

My grandson and "Buddy", Kyle, is now six years old and is attending an inclusion kindergarten. Where has the time gone? As they say "time flies when you are having fun". And we have been having fun!

We were fortunate that Kyle’s mother, Michelle, was using the same pediatrician as Laureen Majeske who had three children with Fragile X. The doctor saw Kyle’s head-banging and asked if Kyle had genetic testing. It was my eldest daughter, living out-of-state, that researched online for Fragile X as a possible diagnosis for the issues we were experiencing with Kyle as an infant. He was missing his milestones. He did not want to hug. But, as usual, we had to convince the “Child Development Specialist” to do a blood test for Fragile X. He was “sure” that it was not Fragile X.

Once we had a name for the issues, we had to find information and the internet did have a few sites that were informative. Most important, we found the location of a support group at Royal Oak Beaumont Hospital. Not only did we learn about the Fragile X, we learned the personal experiences of other families that had children with similar issues and how they were handling them. They also helped us with the everyday trials and tribulations. We also learned of many resources to help us start Kyle on the long road to being his best self.

With Kyle’s mother, Michelle, having to work everyday, it was left up to Grandpa to take Kyle to his many therapy sessions. Grandpa learned so much about the many disciplines that are used by dedicated therapists to help Kyle learn the very basic things, like walking and talking. Physical therapy, occupational therapy, speech and language therapy, signing, sensory integration therapy, behavioral therapy and then on to toilet training – so much to learn and share with each other.

Next came Early Intervention at the Royal Oak Learning Center. Dedicated teachers, aids and therapists also applied their skills and watched Kyle grow into something greater. Then came the Early Childhood Program and another set of wonderful dedicated teachers that left their imprint on Kyle’s life. Even Kyle’s daycares, Happy House and PB&J, guided Kyle by attending our Fragile X seminars and attempting to learn more about Kyle’s issues and how to handle them the proper way. And now his paraprofessional in kindergarten has also attended a seminar – what wonderful people!

He has grown so much now that when I look at him, it is hard to remember all the time we had together. Babysitting him after his therapies and on other days so Momma could go grocery shopping and get the laundry done also gave me precious time to enjoy and teach Kyle.

Kyle is a fixture in my little cul-de-sac. My neighbors also watch out for him and see him grow. We are a team, learning to ride a Big Wheel, a tricycle and finally a two-wheeler (with training wheels). Our walks through the neighborhood, getting the mail and sitting on the big rocks along the street were a time to share each other’s love. He knew he had to hold my hand if we left my cul-de-sac to walk in the street in my subdivision.

One of Kyle’s great pleasures is riding in my 1956 Chevrolet. I had to put in a seat belt to hold the car seat in place. Belts were not available back then. He sits in back, up high and looks at the world going by like a king on his throne. Another joy of Kyle’s is going to the beach and swimming in Saginaw Bay in summer. He simply loves it. We will continue this sharing time with Grandma and Grandpa as long as Kyle loves to go.

My orthopedic doctor has a saying on his wall – *“A hundred years from now it will matter not what my bank account is or the car I drove… Because I was important in the life of a child”.* This statement is so true because I know what Kyle does to my heart as we learn together to write his name, count up to 30, and draw flowers. Now he is reading words. Oh, how I hope it doesn’t stop.

Between the Lines

Featured Book

What's Happening to Grandpa?

by Maria Shriver

This children's picture book looks at a difficult transition that nearly all children must face - the aging of loved ones. *What's Happening to Grandpa?* gently guides a child to an understanding of Alzheimer's Disease in her grandfather, yet the book could certainly be used if a child has a loved one with FXTAS or any condition that includes dementia issues.

This is Shriver's third children's book. She has also written *What's Heaven?* which explores death, specifically death of a grandparent and *What's Wrong With Timmy?* which is about a boy with developmental disabilities.

All three books by Shriver can help parents explain certain issues to their children in a delicate, respectful manner.

The Top Ten Things You Should Know About Fragile X-associated Tremor/Ataxia Syndrome (FXTAS)

By Drs. Randi and Paul Hagerman

1. It's genetic.
2. Fragile X-associated Tremor/Ataxia Syndrome (FXTAS), first reported in 2001, is an adult-onset neurological disorder that is caused by the same (fragile X) gene that causes fragile X syndrome, although FXTAS appears to be restricted to carriers of smaller (premutation) expansions of the gene than the full mutations that cause fragile X syndrome. FXTAS typically develops after the age of 50, with either tremor or ataxia, and it's usually gradually progressive.
3. One in 800 men is a carrier, it's estimated that nearly one-half of male carriers in families with known fragile X syndrome will develop FXTAS, a smaller number of carrier men in the general population will develop FXTAS. Approximately 10,000 to 20,000 men in the United States over 50 may have FXTAS, associated with carrying the premutation.
4. Approximately one in 130 females is a carrier, a small percentage of women with the permutation compared to males may develop FXTAS.
5. FXTAS can involve tremors, problems with balance/walking (called ataxia), and/or dementia, and is often misdiagnosed as Parkinson's and/or Alzheimer's disease.
6. Men and women, 50 years of age and older who have ataxia (walking/balance problems), and/or late-onset tremor, parkinsonism, or dementia along with a family history of developmental delay, autism, mental retardation, or premature ovarian failure, should be tested.
7. Testing for FXTAS is the same as testing for Fragile X Syndrome, a blood test of the FMR1 gene, which gives a CGG repeat number. The test should include both a "Southern blot" and "PCR" test for FXTAS to obtain a diagnosis or to rule it out.
8. Treatment – course of treatment can include SSRIs or Effexor XR for the psychiatric problems including anxiety, depression and moodiness, gabapentin for neuropathic pain in legs, and a variety of medication for the tremor. Hypertension can also occur with FXTAS and should be treated because it can worsen the brain changes associated with FXTAS. Treatment information is still anecdotal and treatment studies have not yet been carried out for FXTAS.
9. The premutation and early FXTAS symptoms may be exacerbated by other neurological diseases such as multiple sclerosis, Alzheimer's Disease and Parkinson's Disease or chemotherapy in cancer patients.
10. Where to go for the most accurate and up-to-date information on FXTAS:
    a. National Fragile X Foundation, **www.fragilex.org/html/fxtas.htm**
    b. Fragile X and company: Finding the right diagnosis, Patient Page, **www.neurology.org**
    c. American Academy of Neurology (AAN), Date: July 19, 2005, **http://www.newswise.com/articles/view/513235/**
    d. The U.C. Davis M.I.N.D. Institute, **www.ucdmc.ucdavis.edu/mindinstitute/research/fxrtc.html**

General Hospital, Daytime soap has a character who has Fragile X.

Episode aired January 16, 2006. Plot evolved around Sam, character's sister.

Sam went through Fragile X testing on the episode to determine if she was a carrier.

To comment on FX being on GH:
ABC, Inc.
500 S. Buena Vista Street
Burbank, CA 91521-4551

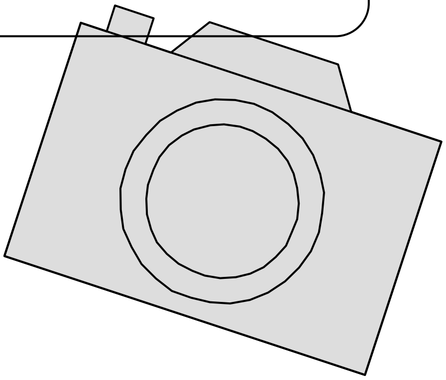
On the web...

http://abc.go.com/site/contactus.html

Calling All Graduates

"Three Cheers for" in July will focus on our Grads.

If you have a kindergarten, high school, center-based or college Grad, please contact Sally or Mary Beth to contribute a picture.



Troy Chamber of Commerce

by Michelle Laske

The Fragile X Association of Michigan has joined the Troy Chamber of Commerce (TCC) and its Non-profit Network (NPN)!

FXAM members are automatically TCC members and entitled to all TCC benefits, such as, Member2Member discounts, discounted educational seminars and social events.

Check out the website www.troychamber.com for a calendar of events and to learn more. Membership will provide us with another avenue for informing the public about Fragile X, networking with over 750 companies and fundraising.

The Non-profit Network consists of approximately 25 community groups and charitable organizations that meet every other month to explore partnership opportunities and share information with each other.

Our first partnership opportunity was the Troy Supper Bowl. This was a family event that took place in January at Somerset Mall. It featured football films, NFL player and alumni appearances, live entertainment, auctions, skills contests, kid zone, and tailgate-style cuisine. Over 600 tickets were sold, collecting $8,000 for distribution to the Non-profit Network. Donations to each organization were based on the number of volunteers. We had one FXAM member volunteer and received $100. There were 90 volunteers in total. In the future, we will send out a member notification of future fundraisers put on by the Non-profit Network in case you're interested in volunteering to raise funds for FXAM.

From the President's Desk

By Laureen Majeske

Not having a meeting in January and being "snowed out" in February, parents were happy to get together in March for the first time since last year. We would like to welcome the new families we have met over the past few months and say welcome back to the Maracles who have returned to Michigan after living in Tennessee for a few years.

Our new Board was elected in February. Congratulations to Laureen Majeske (President), Nina Liberati (Vice President), Kim Young (Treasurer), Michelle Laske (Recording Secretary) and Mary Beth Langan (Corresponding Secretary). While this Board remained similar to the last Board, we encourage all those interested to participate on a committee or at a business meeting. It is a wonderful way to get to know people on a more personal basis as well as an excellent chance to serve the community. We are continuously branching out and we are now a new member of the Troy Chamber of Commerce.

Being "IEP Season", I wish everyone good luck during the next few months!

Advocacy Day: Giving Fragile X a Voice

by Kim Young

Kim Young, Laureen Majeske, Senator Debbie Stabenow and Jeffrey and Arlene Cohen

For the past three years, I have been fortunate to be part of a movement in Washington, D.C., created by goals and passions at the National Fragile X Foundation (NFXF). At the 2004 International Conference, over 200 families lobbied on Capitol Hill seeking federal funding for Fragile X. Although the number of families attending each year has become smaller, the momentum created in Washington has grown larger. It's exciting to see what a group of people can accomplish together.

The Fragile X Association of Michigan has created an Advocacy Day stipend for those able to attend the annual event, in order to help defray some of the costs. It is a very empowering experience to visit with elected officials and then see results in the Federal Budget as a result of those meetings. In 2004 and 2005, the NFXF sought $1 million in federal funding through the Center for Disease Control (CDC) and sought requests, through the National Institute of Health (NIH), which could amount to as much as $25 million to help provide awareness and educational and medical supports. Of that $2 million sought over the last two years, $1.8 million has been awarded! That is a great success, one on which to build. Our own Senator Debbie Stabenow is the Democratic lead on the letter circulating the Senate for the 2007 Federal Budget. The letter is asking Congress to support all of the requests of the NFXF because of the importance of our cause. It has been wonderful to see an increase in interest and support in all of the Michigan elected officials' offices each year I return.

For those of you who participated in Advocacy Day 2004, please consider rejoining the cause and attending next year's efforts. If it's something you've never participated in before, it is an exciting and empowering process, which really does make a difference – a difference in the lives of everyone affected by Fragile X.

Quote for the Quarter

My grandkids believe I'm the oldest thing in the world. And after two or three hours with them, I believe it, too.

Gene Perret

Mark Your Calendar

Support Meetings:

When: June
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

No Support meeting in May

Special Events:

Apr 30: **Bowling Party/Fund Raiser**
4 – 6 p.m., Langan's Bowling
(no relation to Mary Beth)

Jul 19-23: **International Conference, Atlanta**

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.

Aug 6: **Picnic, Boulan Park, Troy**
www.ci.troy.mi.us/ParksRec/parks/Boulan.asp

Sep 9: **Annual Golf/Dinner Fundraiser**
Wesburn Golf & Country Club
South Rockwood, Michigan

Contact Information:

Phone: 313-381-2834
E-Mail**:** **fraxmich@hotlinemail.com**
Web: **www.Fragilex.org/html/michigan.htm**

eXtra, eXtra

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