

Mark Your Calendar

Support Meetings

First Saturday
of the Month

When:

February 2, 2019
March 2, 2019
April 6, 2019

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: February 18, 2019

FXAM Playdate
See page 5.

February 25-26, 2019

Advocacy Day
Washington, D.C.
See page 5.

March 24, 2019

Noodles & Co.
FXAM Fundraiser
See page 5.

Fragile X Association
of Michigan

FXAM.org

Contact Information:

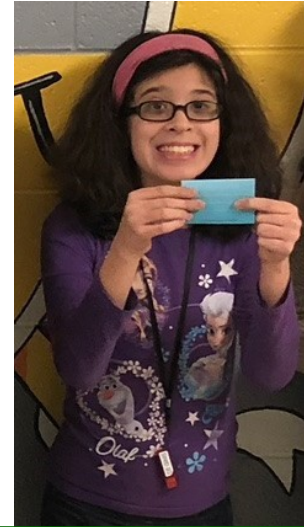
313-881-3340

contact@fxam.org

Three Cheers for...



The Windsor Spitfires and Keegan - While spreading some cheer at a Windsor hospital, the junior hockey team The Spitfires paid Keegan a visit and left him a cute stuffed bear and a Spitfire program.



Charlotte - won a \$10 DQ gift card for turning in the most Box Tops for Education in the 7th grade at Smith Middle School during November



Santa Helper Susanne, Ron and Santa Shea.

Easy Opportunity to Raise Money for FXAM

Once again it's tax time and you may be looking for someone to do your taxes for you. For every **new** client who files their taxes with H&R Block or Block Advisors, \$20 will be donated to FXAM.

The flyer with a code you'll need to take to H&R Block can be downloaded at FXAM.org and on the FXAM Facebook page or email mblangan@hotmail.com for the flyer and share it!

FXAM families and their friends and family all over the state can easily be a part of this fundraiser if this works for them.

Thanks for participating AND thank you to FXAM parent Alexia Weber for setting this up for us!

From the President's Desk *by Heather Van Dam*

Are you looking to make some new friends in 2019? You're in luck! The FXAM board is accepting nominations in February and will be voting on the new board of directors in March. If you would like to have a direct impact on the decisions that are made, please nominate yourself! We meet for one hour before the support meeting and for an annual board meeting (for a few hours). There are five executive board positions. You can nominate yourself for any position or as a general board member, but we have open positions for Vice President, Treasurer and Recording Secretary. The new board will begin in April. To be on the board, you should plan to regularly attend meetings regularly. Email me at heather@stylrite.com.

Many, many thanks to those stepping down from the board: **Laine Cyplik, Sheryl Roman and Kim Young**. A special thanks to **Elina Gelfand** who is stepping down as Vice President but staying on the board. Although these four have had different

positions and terms of service, they've all given much of themselves for FXAM. We are grateful for their exemplary service. Thank you to them and all of our board members for serving our Michigan Fragile X families!

I'm so glad our family made it through the break! This is the hardest break for me. Two weeks off school, cold weather, lots of work, shopping, wrapping, decorating, cooking, cleaning and a constant lack of routine. Thankfully, we made it and no one got sick. Last year, I started an adventure to try new things and say yes to fun! Even if it made me uncomfortable. I tried new foods and drinks. I went paddle boarding. I went on a bike ride with no destination in mind, just like when I was a kid. I got lost and found my way back. I worked at being more present. I took time to myself. I read books. I danced alone. I worked on being a better friend. I laughed hard and cried hard too. I ran down the beach in my swim suit like a

Baywatch babe! I pushed myself to be more open to life. Guess what? I liked it so much I'm continuing it this year. For me, having kids that require the level of energy and care that our kids do is just another reason to make the most of every day. I am thankful for all I have and all that my kids achieve. Hope you take the time to make the most of every day in 2019 too – in whatever way works for you!

Officers:

Heather Van Dam – President
 One nominee – Vice President
 O P E N – Treasurer
 One nominee – Recording Secretary
 Mary Beth Langan – Corresponding Secretary

General Board Members:

Cortney AbouElSeoud
 Elina Gelfand
 Joyce Kreger
 Frank Liberati
 Nina Liberati
 Laureen Majeske
 Kailey Owens
 Tiah Solway
 Sulie Tyler

University of Michigan Fragile X Clinic *by Joe Jacher*

Happy New Year from the University of Michigan Fragile X Clinic!

As part of working in the Pediatric Genetics Clinic, I am constantly searching for different organizations to connect my families with. As I reflect upon the last two years of being the Fragile X Clinic Coordinator, I continue to be inspired by the passion and altruism of FXAM. There is no other group in Michigan or the Midwest as strong and supportive as you all. From everyone at the University of Michigan, thank you for all that you do.

If you are interested in signing up for the FXCRC FORWARD Registry and Database, or would like to make an appointment for any other reason, please contact us at **734-764-0579**. More information on the Registry and Database can be found online at forwardfx.org/.

Joe Jacher, MS, CGC
 Genetic Counselor
 Fragile X Clinic Coordinator

2019 Fragile X Clinic Dates

February 28

May 2

June 13

August 1



Do you have a child with Fragile X Syndrome?

If so, your child may be eligible to participate in a research study at Rush University Medical Center.

We want to learn about a new medication for Fragile X Syndrome.

Would the study be a good fit for your child?

- Yes, if your child has a diagnosis of Fragile X Syndrome
- Yes, if your child is between 32 months to 6 years old (up to 7th birthday)
- Yes, if your child is able to swallow a liquid medication
(please ask your doctor for other eligibility requirements)

What will happen if your child takes part in this research study?

Your child will be in the study for 21 months and:

- Have 15 in-person study visits
- Be given medication or a placebo (dummy medication)
- Be given language intervention
- Have blood and laboratory sampling
- Have heart activity monitored
- Have a physical, neurological and eye exam
- Participate in activities involving:
 - Tests of cognitive abilities
 - Viewing pictures of people on a computer
 - Language tasks like answering questions and telling a story from a picture book
 - Interactive play sessions with study staff
 - Brain wave test to measure sound processing

You will also be asked to participate in several activities including:

- Frequent visits over phone/video
- Language Intervention sessions
- Complete questionnaires regarding your child's language, behavior and overall function development and also their sleep habits.

You may receive \$34 for each visit and up to \$510 if you attend all visits in the study.

Participation comes at no cost to the family.

Research is always voluntary!

FOR MORE INFORMATION CONTACT:

Anna De Sonia
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Katie Friedmann, RN
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Katherine.I.Friedmann@rush.edu

Information can also be found on <https://clinicaltrials.gov/show/NCT02920892>

What is an ABLÉ account?

by Alexia Weber, FX Parent and H&R Block Master Tax Advisor

An ABLÉ account is a tax-advantaged savings account maintained for the benefit of an eligible individual with disabilities to pay his or her qualified disability expenses. It is not to be confused with a special needs trust.

Who is an Eligible Disabled Individual

The individual must either:

- be entitled to social security disability insurance (SSDI) or Supplemental Security Income (SSI) benefits because of a disability or blindness that began before he or she attained the age of 26, or
- have a disability certification regarding a medically determinable physical or mental impairment that began before he or she attained the age of 26. A disability certification is a certification signed under penalties of perjury by the individual or the parent or guardian of the individual that certifies that:
 - the individual has a medically determinable physical or mental impairment, which results in marked and severe functional limitations, which:
 - can be expected to result in death, or
 - which has lasted or can be expected to last for a continuous period of not less than 12 months, or
 - is blind; and
 - such blindness or disability occurred before the date on which the individual attained age 26, and
 - includes a copy of the individual's diagnosis relating to the individual's relevant impairment or impairments, signed by a physician meeting the criteria of section 1861(r)(1) of the Social Security Act.

What are the Benefits of an ABLÉ Account

- Income earned by the accounts would be tax-free if used for qualified expenses.
- ABLÉ account distributions that are used for qualified disability expenses are completely tax-free.
- Qualified expenses are those paid for the benefit of the eligible individual to help him or her maintain health, independence, and quality of life. Examples include expenses of education, housing, transportation, employment training, medical equipment, and financial and legal services.
- Account funds would generally not impact eligibility for federal means-tested programs and benefits, such as Medicaid, if the funds remain under \$100,000

What are Some of the Hiccups to the ABLÉ Account

- The maximum annual contribution amount is the current gift tax exclusion amount, which is \$15,000 for 2018/2019.
- After death, ABLÉ funds may be used to pay outstanding payments of qualified disability expenses of the designated beneficiary. Then, a special rule allows the state to recoup Medicaid expenses after the designated beneficiary's death. For this purpose, the state may file a claim for the amount of the total medical assistance paid for the designated beneficiary under the state's Medicaid plan after the establishment of the ABLÉ account.
- Contributions to the account would not be tax deductible.
- Earnings attributable to non-qualified distributions are taxable and subject to a 10% additional tax.
- Excess contributions not removed by the beneficiary's tax return due date will incur a 6% penalty.
- Generally, ABLÉ accounts will not affect the account holder's eligibility for federal means-tested programs or benefits. However, special considerations apply for Supplemental Security Income (SSI) purposes.
 - If the individual is receiving SSI, a distribution for housing expenses will be countable income for SSI purposes. In other words, the housing costs will be treated as paid by outside sources.
 - If the individual is receiving SSI, the first \$100,000 in the ABLÉ account is exempted from the SSI individual resource limit. However, if the ABLÉ account exceeds \$100,000, the individual will be suspended from eligibility for SSI benefits. Even so, the individual could continue to be eligible for Medicaid.

For more information, feel free to email me at: alexia.weber@blockadvisors.com

What's going on ...



NATIONAL FRAGILE X *FEBRUARY 25-26, 2019*
ADVOCACY DAY

Learn more and register at:

fragilex.org/get-involved/advocacy

FXAM offers a scholarship to help ease your budget if you'd like to participate in the NFXF Advocacy Day in Washington, D.C. This year, the event is February 25-26.

If you would like to apply for the

scholarship, please contact Heather Van Dam at:

heather@stylrite.com

248-343-2077

by **Saturday, February 2,** stating your intention to apply for the scholarship.

ad·vo·ca·cy

the act or process of supporting a cause or proposal. She was known for her advocacy of the Fragile X agenda.

FXAM School Break Playdate

Monday, February 18, 2018

Andrew, Keir and Paul are arranging a playdate/lunch. Meeting in the community or at Andrew's house. Watch for a discussion on our FXAM Facebook page or contact Andrew's mom Mary Beth at mblangan@hotmail.com or 313-881-3340.

Fragile X + Noodles & Co. = Win-Win

It's a win-win for those who like Noodles & Co. and supporting Fragile X! When you dine at:

Noodles & Co.

470 S. Main St.

Royal Oak, MI 48067

Sunday, March 24, 2019, 4:30 - 7:30 p.m.

50% goes to FXAM when you mention Fragile X Association of Michigan at the cash register! We'll soon have a flyer with details. Available at the February meeting, at FXAM.org, on our FXAM FB page OR email mblangan@hotmail.com to have one emailed to you.

Please share with family and friends who might like to support us in the easy way!

eXtra, eXtra

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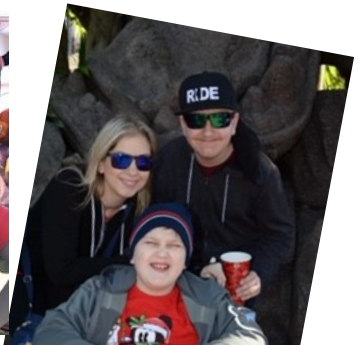
Electronic copies of our newsletter are available on our website.

If you would like to share them with family, friends or professionals, please share our web address with them.

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contact@fxam.org

FXAM.org



Jay's Juniors 100.3 WNIC and Riddick Martin - Riddick was diagnosed with Fragile X at the age of two. In 2014, he was diagnosed with Craniopharyngioma, a benign tumor that grew from his pituitary gland and connected to his optic nerve. The tumor resulted in Riddick having three brain surgeries and 30 days of radiation treatment.

We applied for a trip called Jay's Juniors. Jay Towers and his staff take chronically and terminally ill children to Disney World to give them a relief from all the doctor visits. On October 25, I got a call from Jay, Allyson and Chelsea saying to pack our bags, we were going with them to Disney, along with his brother, Grandma and Papa. Riddick had a blast meeting Mickey Mouse, riding Buzz Lightyear Spin and going shopping. Riddick's brother, Xander, loved doing the radio interviews that were played on 100.3. Jay Towers and all the staff that helped us during the trip were so wonderful and helpful. We were fortunate to get selected for this all-paid/no-worries vacation. The memories will last forever.

 **Fragile X**
Association of Michigan

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