

## Mark Your Calendar

**Please see page 11 for a link to an important questionnaire!**

### Support Meetings

*When:*

**February 4, 2023**

*Business Meeting*

10 - 11 a.m.

*Support Meeting*

11 a.m. - 1 p.m.

*Where:*

Berkley Public Library  
3155 Coolidge Hwy  
Berkley, Michigan

Zoom option details will be on FXAM FB page and FXAM.org

### Special Events:

**February 27-28, 2023**

**Advocacy Day**

See last page.

Watch our FXAM FB page for upcoming event info!

If not on Facebook, email [mblangan@hotmail.com](mailto:mblangan@hotmail.com) to express your interest!

**Fragile X Association of Michigan**  
[FXAM.org](http://FXAM.org)

**Contact Information:**  
313-689-3340

PO Box 1414  
Troy, MI 48099-1414

## Three Cheers for...

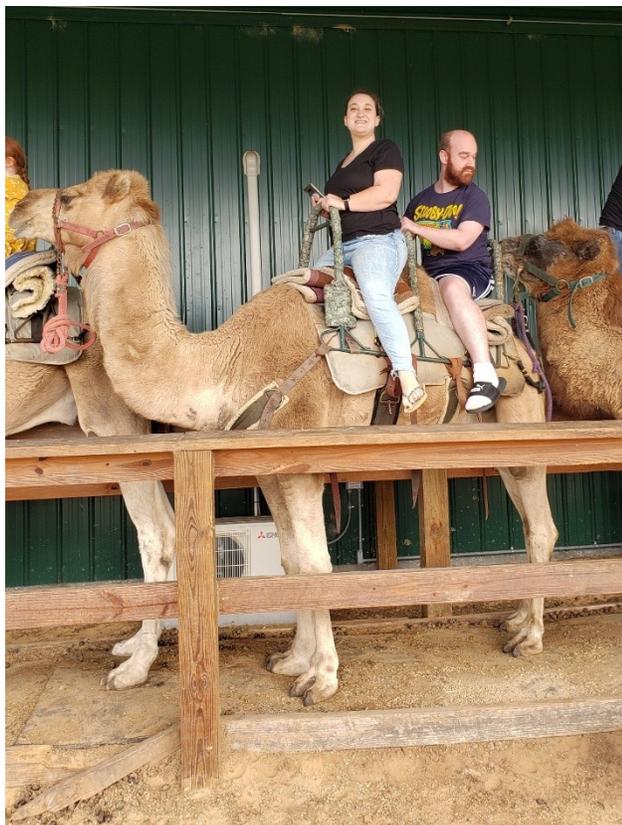


**Paul** - has been successfully walking dogs at the Dearborn animal shelter for a year and a half now. In November, we got brave enough to foster Maggie the One-Eyed Wonder Dog. The bond between Paul and Maggie is amazing. He spends hours talking to her, which she doesn't mind at all, especially since she's deaf.



**Roger and Kyle** - their Christmas get-together may have been a little delayed by a blizzard but they sure looked festive when it was time to celebrate!

## Three Cheers for...



**Austin** - really surprised his mom and sisters, begging to go on a camel ride at the end of our Giraffe Ranch Safari in Florida.

Mom still has giraffe spit on her car.

He finished his first 1,000-piece puzzle and he loved his group hug during our Universal Florida visit.



## Three Cheers for...



**Antonio** - was busy celebrating the Christmas season with his family. He enjoyed cutting down our Christmas tree. He also loved a penguin that he got for Christmas. His favorite Christmas gift was an Applebee's gift card. When he turns on his full smile, Antonio radiates joy!



## Three Cheers for...



**Mark** - recently celebrated his 8<sup>th</sup> work anniversary at Kroger. Mark is a Courtesy Clerk and also works in the bottle room and does a little stocking. Happy Anniversary to Mark! Hope you celebrated with your family, including your adorable nephew Elliot.



**Michael** - Busy and focused working at [Building Beds 4 Kids](#). Great job Michael!

## Three Cheers for...

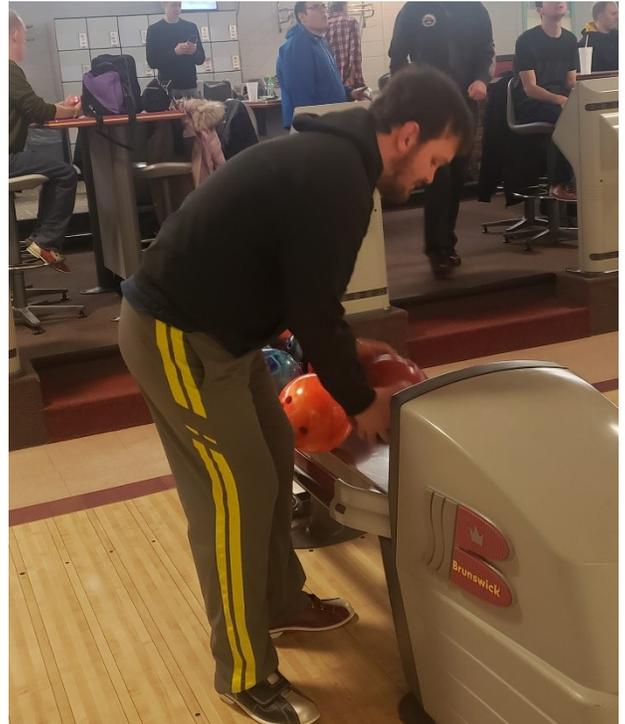
**Andrew** - was (somewhat) agreeable to helping his speech therapist with the new microgreen project at school. He even (gasp!) touched soil and lived through it. Way to participate Andrew!



**Ted, Andrew and Mary Beth** enjoy their fireplace keeping them toasty during Michigan winters.

## Three Cheers for...

**Andrew** - receives services from Community Living Services (CLS). His support coordinator, Justin, connected him with a group in the Waterford/White Lake area. Each month they meet for crafts, bowling, and movie night. So far he likes the bowling the best!



## Three Cheers for...

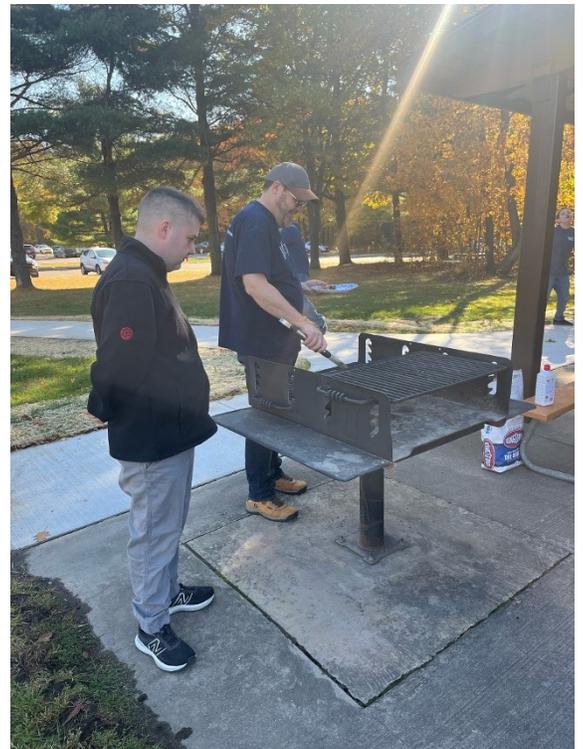
**Kevin** - keeps busy every day with game shows (note his cool The Price is Right t-shirt!), walks, chores, Minecraft builds, Paw Patrol and SpongeBob. He also likes to bowl while Dad or Mom cheer him on! Kevin loves his sisters (in person) and his brothers (via FaceTime to NC). His family is always working on getting him out more and lately with finding a new CLS respite worker (unfortunately, his moved on to a new career in October after 8 years). Decorating for the next holiday is fun and 28-year-old Kevin likes to keep his bedroom door updated! Kevin, you have a great smile!



## Three Cheers for...



**The FXAM  
Father and Son  
Picnic and Playday  
10-22-2022**



## What About Tomorrow? *by Sally Nantais*

Although we share so much in the world of fragile X, some of us are a little further on the journey than others.

One thing is sure, things will change and we need to prepare for change. Although the change may vary, there are some constants.

There are things you can do early on to prepare for adult life transitions. What happens when your child turns 18 becoming eligible for SSI and Michigan's Home Help Program, and what happens when they turn 26. Learning what happens when you start collecting social security and that dirty little "M" word, Medicare. It can feel a little daunting.

With me at 65 and Austin now 30, we've been through a lot of changes.

Thankfully, when Austin was 12, I actually started preparing for the future. The best thing I did was attend a few "After I'm Gone" programs offered through The Arc of Western Wayne County. I'm pleased to see that they still offer many programs through virtual sessions, check them out at [thearcww.org/aig/](http://thearcww.org/aig/). Don't just limit your search for information and assistance to this Arc, check out your local Arc, you can find them at [arcmi.org/find-your-local-arc/](http://arcmi.org/find-your-local-arc/).

Our local Arc assisted us in putting a durable Power of Attorney (POA), medical and financial, in place for Austin, and it's worked well over the last twelve years. If you are **undecided** if you should use a POA or Guardianship, do put a POA in place immediately just prior to or on the date your child turns 18, it is easy to change a POA to Guardianship, but very difficult to do the opposite. When your child turns 18, if you have nothing in place you have no voice in making decisions for him/her, they are considered an adult. You would not have a voice at their IEP, without a voice with legal rights you cannot effectively advocate for your child.

Other Michigan resources, The Michigan Alliance for Families, [michiganallianceforfamilies.org/](http://michiganallianceforfamilies.org/). Check out their Special Education Resources, they have a section on "Transition to Adulthood Topics".

Enroll in a Community Mental Health Services Programs (CMHSPs):

[michigan.gov/mdhhs/keep-mi-healthy/mentalhealth/mentalhealth/cmhsp/local-mental-health-services](http://michigan.gov/mdhhs/keep-mi-healthy/mentalhealth/mentalhealth/cmhsp/local-mental-health-services)

In Wayne County, we were able to have services provided through Community Living Services (CLS); providers may vary depending on the county you reside in. Our CLS representative made it very easy to enroll in the Michigan Home Help Program: [michigan.gov/mdhhs/doing-business/providers/providers/other/homehelp](http://michigan.gov/mdhhs/doing-business/providers/providers/other/homehelp). I am Austin's Home Help Provider, I am paid for providing care.

It seems like I have to forever prove that my child is permanently disabled, to be honest, what a pain in the arse. First it was for SSI, quickly followed by jury duty selection, him turning 26 to keep him on my husband's insurance, me collecting Social Security at 62 (he had to reapply for benefits under RSDI) and changing his social security to pull off of his father's when he started collecting benefits because of his MS. I am still in the process of changing Austin's RSDI to pull from my husband's (yes, I am a cougar) but this is a change that needs to be done. When looking forward to Austin's future, because mom quit working early on, we want Austin to pull from the larger social security account. This will be his main source of income. We did run into a small hiccup in the system when whoever was doing the initial query did not identify Austin as an adult disabled child. I have been working on this since May, hoping it will be resolved soon.

So word to the wise do keep up with yearly physicals and routine visits to the doctors or specialists you never know when you might need a document, from a professional, stating your child is permanently disabled.

On the next page, I have included the latest version of a handout related to a child turning **18** and the application process for SSI that I created for a newsletter a very long time ago.

"If you change the way you look at things, the things you look at change."

~ Wayne Dyer

## What Every Parent Should Know About Supplemental Security Income (SSI) and Your Child Turning 18

*The Social Security Administration (SSA) manages Three different programs: Supplemental Security Income (SSI), Retirement Survivors Disability Insurance (RSDI) and Social Security Disability Insurance (SSDI).*

**1. When a child with a disability turns 18, they can file for Supplemental Security Income (SSI).**

- At 18, when they apply, it's based on their income ALONE, not yours. • If your family exceeds the income cap, you cannot apply prior to 18, if you make an appointment prior to their 18<sup>th</sup> birthday YOUR income will be included.
- If you make the appointment after their 18<sup>th</sup> birthday only the applicant's income counts.

**2. What is considered Income?** Savings and checking accounts, mutual funds, savings bonds, certificates of deposits, joint accounts, real estate and other resources in the applicant's name. Any earned or unearned income. Any asset in their name that could be sold and converted to cash will be counted as a resource, part of their income. Be cautious with trusts. Special needs trusts (not in the child's name, but designed to benefit the child) may provide an opportunity for additional funds outside of the income cap. If special needs trusts are not set up correctly, they can end up jeopardizing the person's ability to collect SSI and eligibility for Medicaid. An alternative to a special needs trust could be an Achieving a Better Life Experience Accounts (ABLE), learn more at: [ssa.gov/ssi/spotlights/spot-able.html](https://ssa.gov/ssi/spotlights/spot-able.html)

**3. How far back do they look at income during the application process?** In our case they went back three years; this could change. If you have savings bonds, mutual funds, college funds, and/or stocks in your child's name (even if they only have joint ownership) you may need to dissolve or move the accounts out of your child's name. Plan for this well in advance. It may be nice that relatives provide savings bonds at each birthday or Christmas, but keep in mind **these do add up**. They will be listed as income and when your child applies it could make them ineligible to receive SSI. Another thing to be aware of is any wills or beneficiaries your child is listed in, any large sum of money that goes to them directly (even in the future) will make them ineligible for SSI and more importantly impact their ability to receive Medicaid.

**4. Guardianship/Power of Attorney.** You will need to decide if you will obtain guardianship or have a durable power of attorney. This is a personal choice, you need to do what's right for you and your child. Guardianship from state to state, and in some cases county to county may vary. You may need to obtain legal assistance. Your local Arc or a neighboring Arc, or a parent advocate group may be able to assist you with this matter.

Find your nearest Arc at [arcmi.org/find-your-local-arc](https://arcmi.org/find-your-local-arc).

**5. Will your child/dependent pay rent or will they share in the household expenses?** If your child shall pay you rent/room and board, you need to report the amount they will pay. If you charge rent, you will need to account for this on your taxes. If your child will **share** in the household expenses, you need to be prepared at the Social Security appointment to list everyone who lives in the household, their SS number(s) and monthly household expenses (mortgage, gas, electric, water, cable, groceries, etc.). If you state you will provide for all of your child's needs, he/she will receive a reduced benefit amount.

**6. Online application.** If you want to save time at the appointment, fill out the application online and make your own copies for your records and to submit at your appointment. Bring a printed copy of the application along with you, in our case all of the meds crossed over fine from the online form, but not all of the doctors information did (even when the meds they prescribed were listed, the doctor details were not.)

**7. Identification.** Apply for your child's State ID card long before your appointment. You will find this helpful in creating their financial account and setting up their SSI. Secretary of the State offices have a handicapped line if your child struggles with long waits. What to bring with you: [michigan.gov/sos/0,4670,7-127-1627\\_8669\\_9040\\_9043-312849--00.html](https://michigan.gov/sos/0,4670,7-127-1627_8669_9040_9043-312849--00.html)

**8. Financial account.** If you want to use a direct deposit option, open your child's bank/credit union account prior to your appointment. Make sure you have the institution's routing number and your child's account number with you.

**9. Supports for your application.** Keep in mind, you/your child will grant the SSA access to all of their medical records but there are other pieces of information you may wish to include with your child's application, not available in the medical records, or available but you may wish for them to stand out. Bring copies of documents from throughout their lifespan. If you kept records of medications, doctors, therapies, evaluations, hospital stays, etc., throughout their lifetime it will be much easier to assemble your supports. **SSI is not granted based on a diagnosis**; it is granted based on ability to work.

**10. Where to learn more:**

- Social Security – Supplemental Security Income - [ssa.gov/ssi/](https://ssa.gov/ssi/)
- Understanding SSI - [ssa.gov/ssi/text-understanding-ssi.htm](https://ssa.gov/ssi/text-understanding-ssi.htm)

Note, not SSI but **important**: At 18, if your child is male, you will need to register them for selective service, this can be done at: [sss.gov/](https://sss.gov/)

*Compiled by Sally Nantais through research and her experience when her son turned 18. Revised 1/6/2023*

## From the President's Desk by Tiah Solway

Hello FXAM Families!

I hope everyone had an enjoyable holiday season. As we enter into another new year, the Fragile X Association of Michigan would like to know how we can better serve those in our community. In order to do that, we need participation from you! We require the involvement of our members so that we can continue to enrich the lives of those affected by Fragile X, but in a way that makes sense for the changing times. While FXAM is a completely volunteer-run group, we've offered some pretty great opportunities over the years. We're still not at the level of pre-Covid participation and need to know what really interests your family the most moving forward. Over the years, your family's needs have changed. We want to make sure we're growing and evolving as well so we can continue to meet your needs. You will see a link below this column. Our newsletter will be shared via email addresses we have, posted on FXAM.org under Support and shared to our FXAM Facebook page. The link will take you to a questionnaire that should only take a few moments of your time. Some are multiple choice questions; some have space for you to share much more with us! The answers to these questions are very important and could very well shape FXAM for years to come. I encourage you to complete the questionnaire and help FXAM be the best Fragile X group it can be for our FXAM families.

May 2023 be full of positive times for you and your family!

<https://form.jotform.com/221608307295052>

### Caregivers Corner

I cope by taking Michael to lots of family gatherings, where he can talk to lots of different people while I do the same. ~ **Joyce**

I wait until the house is quiet and everyone else has gone to bed and I get lost in a story. I sit down with a good book, or I watch a movie. I do something that gets me out of my own head just for a couple hours. ~ **Tiah**

I try to take pleasure in the little things in life. I also enjoy talking (online or in person) with fellow Fragile X moms, playing euchre, escaping into a movie/series or book, cranking up music when I'm alone in my FleX, and letting Celexa lower my anxiety to a level I can manage! ~ **Mary Beth**



It would be very easy to wallow in what we can't do as a family because of Austin and/or Jerry's limitations. I decided I still need my adventures. I knocked zip lining off my bucket list. I have vowed that I'm not going to stop having adventures. They may not be as often, and they might be alone but I need to put myself in time out, take a break, and have an adventure. ~ **Sally**



Editors:

Mary Beth Langan 313-689-3340

[mblangan@hotmail.com](mailto:mblangan@hotmail.com)

Sally Nantais 734-486-5636

This newsletter is published quarterly and sent to all members and supporters of FXAM. Permission is granted to reproduce and distribute this newsletter for noncommercial purposes.

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.

**313-689-3340**

[mblangan@hotmail.com](mailto:mblangan@hotmail.com)

**FXAM.org**



**NATIONAL FRAGILE X  
ADVOCACY DAY**

***FEBRUARY 27-28, 2023***

**Learn more and register at: [Advocacy Day 2023 \(fragilex.org\)](http://advocacyday2023.fragilex.org)**

This year's training and visits to The Hill will be LIVE and in person February 27-28th. February 27th is a training day and February 28th is Advocacy Day. Full details and Registration available at the link above.

\$30 per individual to participate; children up to age 10 are free.

FXAM offers an Advocacy Grant to help ease your budget and encourage more of you to participate!

If interested in the FXAM Advocacy Grant,  
please email Tiah at [jtsolway@rocketmail.com](mailto:jtsolway@rocketmail.com)  
by February 1, 2023 to apply for the grant.

Thank you for considering advocating for Fragile X!

### **Why Advocate?**

"Unless someone like you cares a whole awful lot, Nothing is going to get better. It's not."

*Dr. Seuss, "The Lorax"*