

Mark Your Calendar

Support Meetings

First Saturday of the Month

When:

May 4, 2019

June 1, 2019

(No meetings in July, August & September)

Free Child/Adult care in May.

Must RSVP!

See page 2.

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:

May or June 2019

FXAM Moms:

Let's Do Breakfast!

See page 2.

May or June 2019

FXAM Parents:

Let's Get Together

See page 2.

August 2019

FXAM Family Picnic

Watch for details!

Fragile X Association of Michigan

FXAM.org

313-881-3340

contact@fxam.org

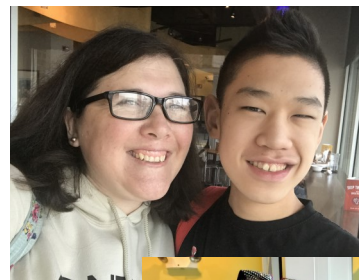
Three Cheers for...



Keir Buikema - did a great job as a Mr. Avondale contestant. He was the first student with special needs to compete in a popularity competition that raises money for charity.



Nicholas Weber - has mastered tractor driving. Some moms are much braver than others.



Joyce Kregler - for a successful fundraiser at Noodles & Co.

Top: Joanne and Michael

Bottom: Darienne and Joyce



Dads' Night Out - A small but mighty turnout of FXAM Dads last November: Aaron, Derek & Karl.

Don't miss the May meeting!

Four parents will be sharing experiences with adult transitions.

Come listen and for Q&A.

7:00 pm panel begins

6:40 pm for pizza and salad

What's going on ...

Free Child/Adult care at the meeting on May 4!

6-9 pm Free child/adult care available but space is limited!

You must **RSVP!**

6 pm Business Meeting / **6:40** Pizza & Salad for all / **7 pm** Panel Discussion begins

If you are bringing children/adults requiring care,

RSVP by May 1 either on the FXAM Facebook post or to

mblangan@hotmail.com with names and ages.

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

FXAM Moms: Let's Do Breakfast!

Saturday at 9:30 am

Watch Facebook for a survey as to

which Saturday morning in May or June

We'll choose the venue depending on who is attending!

Come join us for some Mom-only time!

Email mblangan@hotmail.com so we
can keep you up to date with our breakfast plans.

FXAM Parents: Let's Get Together!

Saturday evening for refreshments & fun

at Sherwood Brewing Company

sherwoodbrewing.com

Watch Facebook for a survey as to
which Saturday evening in May or June.

Please note: This is not a free FXAM outing.

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

The Social Security Administration (SSA) manages TWO different programs:

Supplemental Security Income (SSI) 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 18th birthday YOUR income will be included.
 - If you make the appointment after their 18th 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
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.
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
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.

(continued on page 4)

SSI (continued from page 3)

10. Where to learn more:

- Social Security – Supplemental Security Income - ssa.gov/ssi/
- Understanding SSI - ssa.gov/ssi/text-understanding-ssi.htm
- Transitioning to Adulthood, Michigan Alliance for families - michiganallianceforfamilies.org/webinar
- Alternatives to Guardianship - michiganallianceforfamilies.org/resources/guardianship/

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/

Compiled by Sally Nantais through research and her experience when her son turned 18. Revised 4/7/2019.

Transition Checklist by Sally Nantais**What to do before your child turns 18:**

- State ID Card
michigan.gov/sos/0,4670,7-127-1627_8668_53359_53361-213197--,00.html
- Any assets/resources over \$2,000 in their name, dissolve or move to a trust or ABLE account.
- Contact your local Arc to determine what transition services they may assist you with:
arcmi.org/find-your-local-arc/
- Power of Attorney (you may change later to guardianship, but when your child is 18 you need to have something in place that allows you to advocate for your child).

What to do after your child turns 18:

- Apply for Social Security ssa.gov/benefits/disability/.
- Register to Vote michigan.gov/sos/0,4670,7-127-1633_8716_8726_47669---,00.html
- Register for Selective Service, males only sss.gov/
- Contact your **county's** Mental Health Agency, find contact information here:
michigan.gov/mdhhs/0,5885,7-339-71550_2941_4868_4899-178824--,00.html

Request an intake, new client interview.

The agency will schedule the first intake appointment with the consumer/family/guardian. Nonemergent intake appointments shall be scheduled within fourteen (14) days; and persons discharged from hospitals shall receive an appointment within seven (7) days.

County will recommend a provider agency and set you up with a support's coordinator.

Through your Provider agency and supports coordinator you will develop a Person Centered Plan, and they can assist you with enrolling in other programs such as:

- Food Assistance (food stamps)
- Home Help (parents can be Home Help Providers)
michigan.gov/documents/dhs/DHS-PUB-0815_198252_7.pdf
- Direct Care Staff
- Respite Care

"I can't change the direction of the wind, but I can adjust my sails to always reach my destination."

~ Jimmy Dean

University of Michigan Fragile X Clinic *by Joe Jacher*

Hello from the University of Michigan Fragile X Clinic!

Happy Spring! As many of you are probably aware, there are numerous clinical trials happening across the country. One of the most frequent questions I hear from families I meet in clinic is, “where can I find out what clinical trials are happening?” The two most up-to-date websites that I use are:

- fragilex.org/our-research/opportunities/clinical-trials/ which is updated by the National Fragile X Foundation
- clinicaltrials.gov which is a database of clinical trials happening across the globe.

As always, if you would like to make an appointment or have any questions about clinical trials, Fragile X syndrome, or our clinic, please contact our office at 734-764-0579. More information on the Fragile X 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

May 2

June 13

August 1

October 3

November 2

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

Thank you to all those who stepped forward and volunteered to be on the FXAM Board of Directors. New to our board are Karl Lerchenfeld as Treasurer and Jodi Lerchenfeld as Board Member. Two of our current Board Members joined our Executive Board: Sulie Tyler as Vice President and Tiah Solway as Recording Secretary. And thank you to Mary Beth Langan for staying on as Corresponding Secretary. I feel so lucky to have the support and input from them and all the other members of our FXAM team.

In keeping with my goal to try new things and say yes to adventure and life, our family drove 15 hours for a spring break trip to South Carolina. The thought of this trip was daunting to say the least. Last summer, Mason started having a really hard time in the car. Lots of yelling and fighting with Alison and this was anytime we rode in the car. Whether it was 10 minutes or 4 hours. We secretly prepared for the trip like CIA agents getting ready for a mission. Plotting, planning and reserving a stunning house right on the Atlantic Ocean. Packing when Mason wasn't looking, slowly gathering beach toys and towels, pretending to clean out the closet and put things away, and NEVER

using the triggers words like trip, vacation, beach or going. During this time, I was also getting ready to go to California for work. This meant that I would be back in town late Tuesday night and leaving for SC at 5 am Wednesday. So everything had to be ready to go before I left for California. To top it all off Alison asked if she could invite a friend to which I said yes. I hope this story isn't giving you anxiety! Everything went as planned and we were on our way before dawn on Wednesday. Mason had his movies, his DVD player, lots of snacks, an iPad, several cell phones, his favorite blanket, his weighted blanket, a backpack of his favorite toys, and a spacious window seat! Several hours into the trip somewhere in Ohio, Mason began to DEMAND pizza! As luck would have it, Derek had packed some leftover cold pizza for just such a crisis. After a short stop to use the bathroom and retrieve the pizza, we were back on the road. Crisis averted! For the most part, it was an extremely successful trip and we made it to the rental house sometime after dark. The week was full of grand adventure and first experiences. It only took us 3 days to get Mason to leave the house and walk

to the beach. The house was on the beach so it was a very short walk. It was his first time in the Atlantic Ocean. He was thrilled at the waves washing over his tootsies. We all went putt-putt golfing and had a great time. Mason played every hole like a cross between a golfer and a pool player. Alison turned 18 during the trip and I took her and her friend horseback riding on the beach. It was magical. I highly recommend it. We walked out on the pier and looked for sharks, talked to the many birds flying around, scoured the beach for shells, encountered several dead jellyfish and Mason insisted their moms were coming to help them, watched the sunset, enjoyed the ocean breezes, played games, ate too much ice cream, slept with the windows open enveloped in the soothing sounds of the ocean. It was by all accounts a successful trip full of lasting memories and renewed family bonds. As we left for home, I was filled with a great sense of accomplishment at having completed our first REAL vacation in over 5 years. About 45 minutes into the 15-hour drive home, Mason demanded a haircut! LOL! Such is life with our kids. I hope that you and your family are planning a summer adventure!

eXtra, eXtra

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Advocacy Day 2019

Washington, D. C.



**The Price Family with
Senator Debbie Stabenow**

 **Fragile X**
Association of Michigan

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