

## Mark Your Calendar

### Support Meetings

First Saturday of the Month

#### When:

May 4, 2024  
June 8, 2024\*

\*Second Saturday in June  
No meetings: Jul, Aug, Sept

#### May Business Meeting

10:15 - 11 am

#### Where:

#### May Support Meeting

11 am - 1 pm  
Berkley Public Library  
3155 Coolidge Hwy  
Berkley, Michigan

Zoom option and June details will be on FXAM FB page and [FXAM.org](http://FXAM.org)

### Special Events:

#### May 24, 2024

Fragile X Awareness at Comerica Park  
See page 3.

#### July 25-28, 2024

19th International Fragile X Conference  
Orlando, Florida  
See page 4.

#### August 2024

FXAM Family Picnic  
Watch for details!

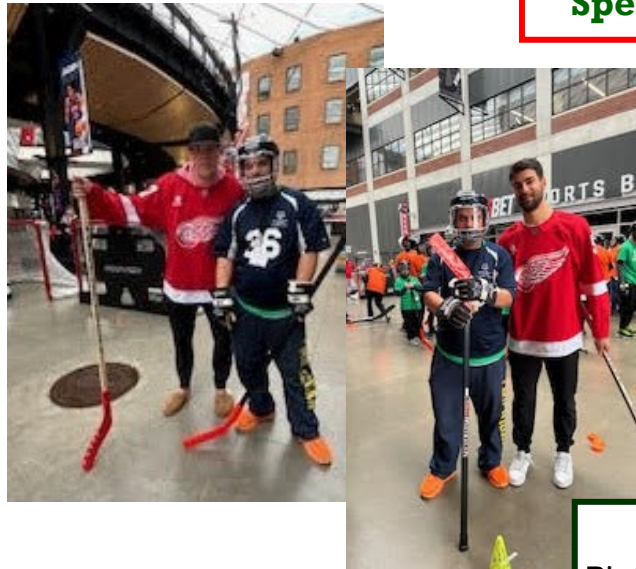
Fragile X Association of Michigan  
[FXAM.org](http://FXAM.org)

Contact Information:  
313-689-3340

PO Box 1414  
Troy, MI 48099-1414

## Three Cheers for...

### Detroit Red Wings Special Olympics Day



The Detroit Red Wings hosted 100 local athletes for a Special Olympics Michigan Poly Hockey Celebration. The invited athletes watched the Red Wings practice at Little Caesars Arena's BELFOR Training Center. After the Special Olympics athletes participated in a hockey skills clinic on the Via concourse led by several Detroit players.

**Nicholas -**  
Pictured with Daniel Sprong (L) and Joe Veleno (R)

## GO WINGS!

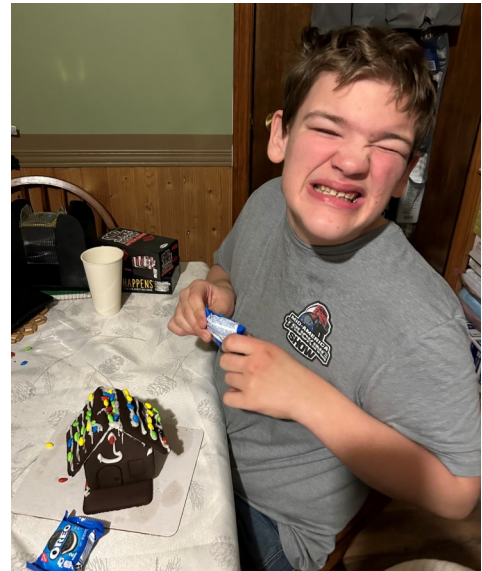


**Jacob -**  
Pictured with Jeff Petry (L) and Dylan Larkin (R)



More "Three Cheers for" continued on page 7.

**From the President's Desk** by Tiah Solway



***We interrupt this quarterly column to let you know that these two adorable children are keeping Tiah too busy to write for this issue. She hopes to see you in May, July and/or August at one of the upcoming events detailed in this newsletter!***

**University of Michigan Fragile X Clinic**

Big news to share! Genetic Counselor Jessica O'Shea is joining the UM Fragile X Clinic to serve as the Fragile X Clinic Coordinator. Appointments for evaluation for Fragile X Syndrome in the UM Fragile X Clinic will be available starting Summer of 2024.

Appointments can be scheduled in the UM Fragile X Clinic by requesting a referral from your child's primary care physician or another specialist who follows them.

More information is available by calling 734-764-0579.

Ask to speak with Jessica for more information about the clinic. FXAM welcomes Jessica to the Clinic!

You can welcome her in person if you're going to the conference in July!

For appointments for those affected by FXTAS, you'll still call the East Ann Arbor Health and Geriatrics Center at 734-647-5670. Ask for an appointment with Dr. Peter Todd in the Ataxia Clinic. For exciting news regarding Dr. Todd, please see page 8!

## Fragile X Awareness Day at Comerica Park!



**May 24, 2024**

**6:40 pm game**

**Detroit Tigers vs. Toronto Blue Jays**



The Fragile X Association of Michigan has paid to be the nonprofit charity of the game so come help us raise awareness and cheer on the Tigers! We'll have a FXAM table in the stadium to share info about Fragile X. **100 tickets** are a part of our sponsorship.

Tiah Solway will be taking requests for tickets via:  
our FXAM Facebook page  
or email [jtsolway@rocketmail.com](mailto:jtsolway@rocketmail.com)  
Contact Tiah by **Friday, April 26**  
to tell her the **# of tickets** you'd like  
and corresponding **t-shirt sizes**

You are not guaranteed tickets. You will be contacted to confirm if you have tickets plus additional details regarding getting tickets and shirts.

**Let's have a fun FXAM event cheering for the Tigers and our families and spreading some awareness of Fragile X!!**

**"Never let the fear of striking out keep you from playing the game."**

*~Babe Ruth*

## Through the Maze

Looking for other things to do in conjunction with your conference trip to Orlando, check out these venues:

**The East Coast (about an hour from Orlando):**

Kennedy Space Center - [kennedyspacecenter-tickets.com/](http://kennedyspacecenter-tickets.com/)

Cocoa Beach - [visitflorida.com/places-to-go/central-east/cocoa-beach/](http://visitflorida.com/places-to-go/central-east/cocoa-beach/)

**Central Florida:**

Silver Springs State Park - [silversprings.com/](http://silversprings.com/)

**The West Coast:**

Weeki Wachee - [weekiwachee.com/](http://weekiwachee.com/)

Ellie Schiller Homosassa Springs Wildlife State Park  
[floridastateparks.org/parks-and-trails/ellie-schiller-homosassa-springs-wildlife-state-park](http://floridastateparks.org/parks-and-trails/ellie-schiller-homosassa-springs-wildlife-state-park)

St. Pete/Clearwater - [visitstpeteclearwater.com](http://visitstpeteclearwater.com)

And much more to explore at Visit Florida - [visitflorida.com/](http://visitflorida.com/)

## 19th International Fragile X Conference

The 19th International Fragile X Conference is in Orlando, Florida from July 25-28th!

If you've never attended a conference, please consider attending to connect with families, gather info from eXperts and come away with the supportive knowledge that you are not alone on this Fragile X journey.

If this isn't your first conference, you already know why you want to attend this Fragile X family reunion!

Go to [fragilex.org/get-involved/international-fragilex-conference/](https://fragilex.org/get-involved/international-fragilex-conference/) for more information and to register for the National Fragile X Foundation's biennial conference! **Please note that early bird pricing ends on April 30.** Don't miss the discounted registration fees! Hotel information is also at [fragilex.org/get-involved/international-fragilex-conference/](https://fragilex.org/get-involved/international-fragilex-conference/); reserve your room early to make sure you're at the Renaissance SeaWorld in Orlando.

Once again, the Fragile X Association of Michigan is happy to be granting conference scholarships to help our members afford to attend this important conference. The final amount of each scholarship will be decided after we have the final number of scholarship applicants. **To apply for the FXAM conference scholarship**, email Tiah Solway at [jtsolway@rocketmail.com](mailto:jtsolway@rocketmail.com) to let her know you are interested in being considered. Mention in the email if you applying for a scholarship for one or two family members including names and if you'll be attending in person *or* virtually. **Apply via email by Friday, June 14, 2024.**

**By July 31**, you'll need to verify that you attended the conference by submitting receipts (hotel, etc) and after verification, in mid August you will be paid the scholarship money.



**Reminder: this was printed in the 7/2023 and 1/2024 newsletters**

### FXAM Conference Scholarships for the NFXF International Conferences

Conference scholarships will only be open to FXAM members. How do you know if you're a FXAM member? Contact Mary Beth Langan, FXAM Corresponding Secretary, if you are unsure ([mblangan@hotmail.com](mailto:mblangan@hotmail.com)). While membership is FREE, we need a membership form completed so we have some details on who is a part of FXAM. You have to live in Michigan or be an Ontario family who lives close enough to be active. We need your info to help us know who we are serving. We need to know more about your family in case new families in your area need a close connection. Near or far in Michigan, we try to make sure FXAM families know they are not alone on their Fragile X journey via our support meetings, events, quarterly newsletters and FXAM Facebook page.

To apply for the 2024 FXAM Conference Scholarship, in addition to being a FXAM member, we will be requiring that scholarship recipients be active members in our group. What does that mean exactly? Being active could look completely different for each family, so we are providing a list of ways that you can remain active in our FXAM community. Moving forward, in order to qualify for a conference scholarship, you will need to fulfill at least one of the following:

- 1) Volunteered at a FXAM fundraiser or event in the two years since the previous conference.
- 2) Held a fundraiser in the two years since the previous conference where the proceeds were donated to FXAM (virtual, Facebook, lemonade stand, garage sale, etc).
- 3) Attended a minimum of 4 support group meetings, which are available virtually or in-person, in the two years since the previous conference. Since we only have one year before the next conference, we will be lowering that requirement to 2 meetings for the 2024 scholarship applicants.

In addition to these requirements, we will also ask for scholarship recipients to share with the group something about your conference experience in the newsletter following the conference (the October edition). This could be an article written about your experience, notes on something you learned, or photos from the conference. This is so that all FXAM members can share in your experience!

We hope you'll take this next year to become an active member of our FXAM community if you're not already, and most of all, we hope to see you at the 2024 NFXF International Conference from July 25-28 in Orlando, FL!

## Orlando Parks Disability 101 *by Sally Nantais*

### Walt Disney World (WDW) Disney Disability Access Service (DAS)

<https://disneyworld.disney.go.com/guest-services/disability-access-service/>

Effective May 20, 2024, the DAS pass is changing. You must have a virtual chat with a cast member before your visit. You will no longer be able to register at Guest Services on the day of your visit. You can pre-register if you are booking online by using the live video chat with a cast member. The Pre-registration (covers all park visits) must be within 30 to 2 days of your live chat (Disney counts down to your visit). Passes are good for sixty-days, may be changing to 120-days in the future, as long as the number in your party doesn't change you do not need to reregister for every visit.

Download the "My Disney Experience" App; the App easily allows you to check in for rides. DAS gives you a time to arrive at the ride. You can only check in to one ride at a time, once you enter the line queue (through the lightning lane), you can check in for your next ride. The return time you receive doesn't have to be exact, you can check in at that time, or any time after the return time. The App will eat up your battery life, especially if you are using the map and checking wait times (some ride wait times aren't incredibly long and you may not want to use the App, you may want to ride them while you are waiting for your next check-in). Consider bringing along a portable charger.

Do review the Walt Disney World - Guide for Guests with Cognitive Disability

[https://cdn1.parksmedia.wdprapps.disney.com/dam/disney-world/guest-services/cognitive-disabilities-services/WDW\\_Cognitive\\_Guide\\_2021.pdf](https://cdn1.parksmedia.wdprapps.disney.com/dam/disney-world/guest-services/cognitive-disabilities-services/WDW_Cognitive_Guide_2021.pdf)

Do not hesitate to reach out to a cast member if your family needs a break, or a quiet spot.

Do try to plan what you will do. I try to alternate between shows and rides.

Do bring ear protection if your child is sound sensitive. Austin no longer requires ear protection but when he was younger it was a must and at one point he decided when to use them. After one trip when he didn't use them, we no longer brought them along.

If you are driving in, opt for preferred parking. Yes, it costs a little more but when it's time to leave the park, a shorter exit is worth it (with no waits for trams, etc.).

Character Meet and Greets: lines can grow very long, very fast. It would not be uncommon to wait two hours to see Woody and Jesse. If there is a specific character your child wants to meet, do that first. I've found that sometimes it's even easier to do a meal with character dining. It may cost a little more, but you'll have numerous interactions during your meal with your favorite characters. Much less stressful than a long line!



Be prepared! All rides end in a gift shop. In all of our theme park adventures, we've only had one problem. It was when we bought a gift and had it sent directly to our hotel so we wouldn't have to carry it around. Austin didn't understand. This was on our first visit years ago.

Some of Austin's favorite things are the shows and the meet and greets. We do have an autograph book, his current one is almost filled, we will get another one. After a visit I print the photos of him with the character and place it next to their autograph. We also buy the Disney Photo Pass to capture our adventures.



## Orlando Parks Disability 101 by Sally Nantais (continued)

### Universal Orlando - Attraction Assistance Pass (AAP)

We just got our IBCCES pass, you will need to provide information and a letter from your child's doctor. The IBCCES pass can be used at Universal Orlando and Hollywood, and many Six Flags Parks. At this time it is not mandatory to have an IBCCES pass. What does it eliminate? No questions asked at guest services. You must start your visit at guest services, the pass is good for two weeks as long as the number in your party doesn't change. If your child struggles with stairs make sure they check the "Alternate Stairs" box.

You can obtain the IBCCES Individual Accessibility Card (IAC) by registering at [www.accessibilitycard.org](http://www.accessibilitycard.org) within 30 days of your visit to the park.

Universal does not have an online ability to check in for rides. You must go to the ride, check-in in-person and the attendant will give you a return time. You can only check in for one ride at a time. Do download the Universal Orlando App, The App will provide wait time at rides (this will help, you can check in at a ride with a longer wait time and identify rides you can do while waiting with a much shorter wait time), maps, character locations, etc.

### Sensory Guide for Individuals with Cognitive Disabilities

[universalorlando.com/webdata/k2/en/us/files/Documents/UOR\\_Cognitive\\_Disability\\_Guide.pdf](http://universalorlando.com/webdata/k2/en/us/files/Documents/UOR_Cognitive_Disability_Guide.pdf)

### Guide for Rider Safety and Accessibility

[universalorlando.com/webdata/k2/en/us/files/Documents/universal-orlando-riders-guide.pdf](http://universalorlando.com/webdata/k2/en/us/files/Documents/universal-orlando-riders-guide.pdf)

Do take the time to review, one of our most challenging rides is "Harry Potter and The Forbidden Journey". For Austin just trying to get on the seat is challenging, it's a moving platform, and creates anxiety. Mom just typically holds his arm very tight and drags him into position. Through the guide I discovered there is a non-moving platform available, you need to request it.

Like Disney: think about using the preferred parking if you drive to the park. Do bring ear protection if an individual is sound sensitive. Do Download the Universal App, you can easily find where character meet and greets are. Do pre-planning. All rides end in a Gift shop.

Do consider the two-park pass, this enables you to ride Hogwarts Express. Unlike Disney, the Parks are right next to each other, with a two-park pass (Universal and Isle of Adventures) you can walk or ride the Hogwarts Express to both parks. Please note the videos/animations on Hogwarts Express differ, depending

if you are entering or leaving Hogsmeade. Hogsmeade (Isle of Adventure) is very busy, the Gringotts area next to King's Crossing is too much of a sensory overload for Austin.

We do the water rides last so we don't have to walk around the park wet all day, but during July one may not mind getting wet. You will get soaked on Popeye & Bluto's Bilge-Rat Barges, Dudley Do-Right's Ripsaw Falls®, and the Jurassic Park River Adventure (depends on seat location, if you are in the front row, you are getting a good soaking). Rain ponchos help you to stay dry.

Have lots of fun! Please connect with me if you have any questions.



## Three Cheers for...



**Michael** - put Mom's phone together and it works beautifully. He was very proud of this as you can see. Joyce never needs to call the "Geek Squad" with Michael in the house.



**Keir** - needed his worksite to be changed to inside his school building for safety purposes. His creative teachers and job coaches ordered him a cleaning cart and now he's a "Keir-stodian"!



## Three Cheers for...



**Collaborators**

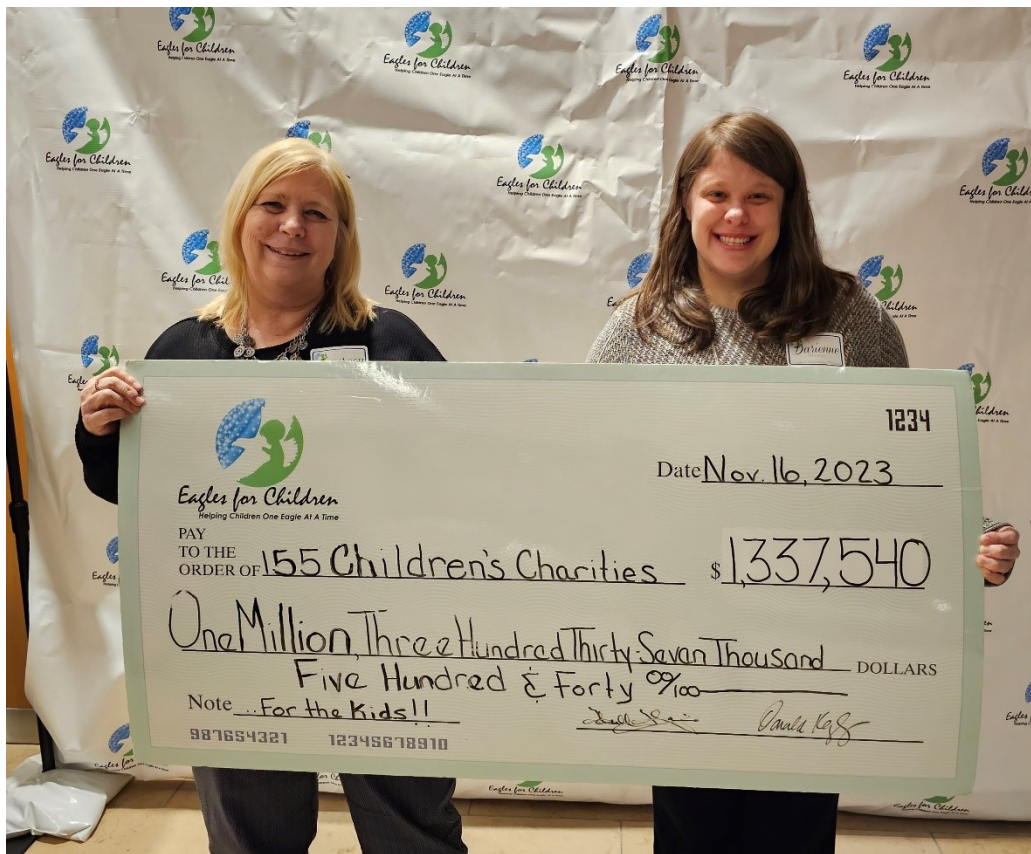
- Sami Barmada
- Ryan Mills
- Alan Boyle
- Gary Smith
- Jack Parent
- Hank Paulson
- Magda Ivanova
- Hayley McLaughlin
- Kristin Koutmou
- Venkatesha Barsur
- Mike Sutton
- Eva Feldman
- Jay Brito Querido
- Rachel Nlederer
- Michelle Hastings
- Frank Rigo (Ionis)
- Gary Bassell (Emory)
- Aaron Goldstroom (UMN)
- Sylvie Rouskin (MIT)
- Chris Pearson (UT)
- Nicolas Charlet (IBGMC)
- Katsura Asano (KSU)
- Phil Smaldino (BSU)
- Christine Klein (Leuven)
- Aaron Frank (Arrakis)
- Peng Jin (Emory)
- David Nelson (Baylor)
- Len Petrucci (Mayo)
- Adrian Isaacs (UCL)
- Anke Dijkstra (Amsterdam)

**Dr. Peter Todd** - On March 4, there was a celebration at the University of Michigan in honor of his installation as the inaugural Chester and Anne Alecks Sackett Endowed Professor. Various chairs and collaborators spoke about his accomplishments in the field of FXTAS/Fragile X and Dr. Todd gave a speech telling great stories about how he started in this field of research, what's going on now and where it's headed. If you'd like to read about his research, visit [fraxa.org](http://fraxa.org) and search Peter Todd. A new article should be on their site very soon! You can also google Peter K. Todd Lab for more details.

FXAM is grateful for Dr. Todd's research and his clinic hours with adults with Fragile X and FXTAS at UM.



**Three Cheers for...**



**Eagles For Children at the Dearborn Country Club** - Lauren and Darienne got to pose with a huge \$1.3 million check that represented money raised by multiple golf clubs and split among 155 charities. On our behalf, they accepted a \$2,500 check from Eagles for Children to be used toward our Detroit Tigers Awareness Night at Comerica Park (see page 3).

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