

Mark Your Calendar

Three Cheers for...

Support Meetings

Due to Covid-19, most FXAM meetings and events are cancelled until further notice. We will post on our FXAM Facebook page and website if there will be any virtual meetings/events. Stay tuned. We will gather in thanks after this has passed. Wishing you continued health!

Special Events:

March 1, 2022

Advocacy Day

Virtual

See page 11.

Fragile X Association
of Michigan
FXAM.org

Contact Information:

313-689-3340

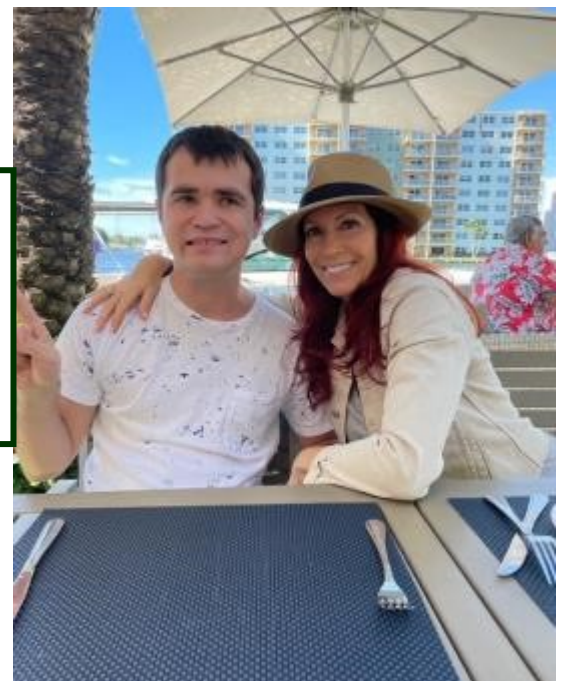
PO Box 1414

Troy, MI 48099-1414



Jacob - had a successful first date! He asked his girlfriend Emma to go see Disney's animated movie Encanto. They had a great time and give the movie a thumbs up!

Jennifer Silverton - Has been very busy as a co-founder of Xceptional Heroes. See page 7 for the write-up on mLive on the group.



Three Cheers for...



Andrew - CLS approved Andrew to attend the Living and Learning Center in Northville. They provide transportation to and from. It has been an amazing experience so far. He has been exposed to so many diverse job opportunities. They are great about texting pics of him on the job. More details on the center is on their [website](#).



Three Cheers for...



Adam - For the church group Christmas party, Adam and Brian were challenged to wrap Malinda (aka Adam's mom) as a Christmas present. Isn't she a pretty present!!



Adam - walked in a 5K Breast Cancer Awareness walk in Detroit on the Riverwalk with his breast cancer survivor caregiver, Theresa, and his roommate, Brian, in October.

Three Cheers for...



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☆☆ **Michael** - May the force be with you, every day!! Christmas was special with a light saber and a Michigan shirt. You'll notice the light saber isn't the only thing glowing in these pictures.
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Three Cheers for...



Detroit - Andrew, Mary Beth and Ted had a fun time hanging out on Christmas Eve in and around Campus Martius!



Andrew - With family and friends walked around the Ford House (Grosse Pointe) for a cool experience called Starry Lights. Andrew's not a fan of going out after dark, but he did a great job on our December 26 holiday stroll.

Three Cheers for...



Austin - for being an eXceptional traveler with his mom on their numerous trips to and from Florida, with stops in Georgia to visit Gramps, Aunt Pam and Uncle Jimbo. Aunt Pam added a new family member, Snoopy, aka Snoop Dog. As you can see, Snoopy and Austin got along very well.



'Xceptional Heroes' in Genesee County use superpowers to fight against the odds of adversity in special needs community

By Isis Simpson-Mersha | isimpson@mlive.com [mlive news article](#)

GENESEE COUNTY, MI — “Bingo!”

Someone shouted excitedly as they realized they had matched their board with G47 - the number and letter combination was the winning piece for one of the Xceptional Heroes.

Xceptional Heroes, a group of people that share a common bond of having a relationship with someone who has an intellectual disability and those with intellectual disabilities, was formed nearly five years ago to help create an environment to foster social and enriching living skills and engagement.

The members of the organization who have intellectual disabilities are referred to as Xceptional Heroes, Jennifer Silverton, the group’s co-founder, said.

Filling the gap

Teresa White, 53, said her son, Tyler, was the catalyst to start the group because he was the first one to graduate high school.

“I was the first one to learn that it’s like falling off a cliff,” White said of the absence of social interaction once her son graduated. “Everything in school is so structured and the activities and you’re around friends and then there’s nothing. There’s no social engagement for them. We really didn’t know what to do and how to do it.”

Aidan Silverton, Jennifer Silverton’s son, graduated soon after Tyler. Once he was out of school, his mother noticed the skills he was learning and the social interaction that came with the school setting was suddenly gone.

White and Silverton realized it was up to them to fill the void of structure, socialization and continued life skills for their adult children with intellectual disabilities.

The mothers got together and founded Xceptional Heroes nearly five years ago.

White reached out to her friends and other families to give somewhat of a warning for what was on the horizon for their children.

“I think he got really just withdrawn into himself and he wouldn’t actively go out and look for anything to do,” White said. “I was always pushing him.”

Jennifer Silverton noted there are programs that are available to people with intellectual disabilities such as ClemsonLife at Clemson University in Clemson, South Carolina and Mason LIFE at George Mason University in Fairfax, Virginia.

Her son attended both programs but they aren’t cheap.

The basic ClemsonLife program fees start out at \$12,000 per semester, and the program at Mason LIFE is \$20,910 per year for in-state tuition or \$28,600 for out-of-state tuition, according to their respective websites.

“While there are living skill and training options, there’s a whole host of other challenges; getting the individual there,” Jennifer Silverton explained. “Most of these families have parents that are working out of the home, most of these individuals don’t drive, so transportation is a huge issue.”

'Xceptional Heroes' - *continued*

Even when families can afford the training options, Jennifer Silverton added, there's still a social component that's missing.

"Our goal is to create these social opportunities that come with living skills and social learning and engagement options," she said.

Some of the activities the group offers take place weekly such as Bingo at a local park, cornhole, ice cream socials, bowling and a "mystery" event. The group also goes on outings to the Detroit Zoo and Detroit Tigers game.

The group has accumulated 140 members across Genesee County that include caregivers, family members, and Xceptional Heroes over the years.

Aidan Silverton and Tyler Shue are friends and the pair were eager to win a game of Bingo at one of the organization's weekly outings at Physicians Park in Grand Blanc.

It was a sunny day in August as about a dozen Xceptional Heroes chatted with friends, ate snacks and focused on the game of chance.

"It's a family - we're not even friends, we're a family," White said. "This laughter after the COVID shut down, they were so isolated."

A social life

Aidan Silverton, 23, has Fragile X syndrome, a genetic disability that presents similarly to autism.

Because of his disability he sometimes needs help with calming down, reading and math, both he and his mother explained.

However, Aidan Silverton embraces his athleticism. He enjoys running and basketball as well as volunteering.

Tyler Shue, 25, owns his own home that he co-purchased with his father. He graduated in 2015 from Grand Blanc High School and then the Transition Center in Flint in 2019.

"This group helps us get together and we get to hang out," Shue said.

He continued to say if the group didn't exist he doesn't think he would have the opportunities he has to connect to others like he does now.

"For me, it's just about hanging with everyone," Shue said. "We haven't got together in two years because of the pandemic. It's nice to have everyone together and have communication again. Get out and do stuff."

Hayley Bragg, 19, appeared to be enamored with playing several rounds of Bingo with her friends at the park.

When she isn't with the Xceptional Heroes group, she roller skates and competes in competitions.

The roller figure skater recently returned from the 2021 Figure Skating National Championships in Cedar Rapids, Iowa where she won sixth place in the loops category.

Bragg joined Xceptional Heroes a few years ago and keeps coming because she gets the chance to be with her friends.

Bragg is cognitively impaired, which can make it difficult for her to concentrate, and sometimes is the cause of her wandering and getting out of her seat in class, she confessed.

Bragg is headed to a new school this fall at the Transition Center in Flint.

'Xceptional Heroes' - *continued*

"I like it, but I haven't been because I have been doing online classes, but I'm excited about it." Bragg said. Jessica Dail, a member of Xceptional Heroes for several years, is legally blind. To play Bingo she used braille to read her board.

"I just enjoy hanging out with these guys," Dail said. "It's a great group. I think there should definitely be more stuff like this in the community for other people who have special needs."

The group does more than just help those with disabilities. The parents now have a space to connect too.

Shannon Mitchell, 54, attended an Xceptional Heroes outing for the first time with her twin sons during the Bingo game.

"I was nervous about bringing them," Mitchell shared. "What if they don't fit in? What if they annoy somebody with their behavior? Or their noise or something, but everybody has embraced them."

The former worried mother of 24-year-old twins felt right at home during her first visit and plans to keep going.

Mitchell sat with Cindi Dail. The two interacted as if they had been friends for years. The conversation naturally began after a compliment on a pair of eye-catching sandals.

Dail, 53, and her legally blind daughter Jessica have also found the group beneficial.

Jessica Dail had trouble making friends in high school, the mother said.

"She just never had friends to hang out with so this has been amazing," Cindi Dail said.

"It's nice for them to have friendships because we can't fill that," Mitchell said. "We are not their friend, we're their parent. They need their peers and clearly the moms need each other too."

Cindi Dail and Mitchell said Xceptional Heroes is also a support group for moms or other parents as many of them share in the same needs, wants and even struggles for their children.

"We don't have friends either," Mitchell said. "People quit asking you to do things because you're always taking care of your children."

"It's lonely," Cindi Dail added.

They both agree they lead a different life from what others might lead.

For example, the two mothers might not ever experience what it means to be an empty nester, they pointed out.

"It just feels like you are truly on your own, so much at the time and just navigating everything and not understanding the road map," Mitchell said. "What are the rules? How did we get here? How do we get started?"

Much like the rest of the world, many things stopped when pandemic began and that included Xceptional Heroes. COVID-19 stole social opportunities among other things.

When Jessica Dail was asked how she coped during the pandemic, she frankly said, "It was crazy. I think everybody would say that and it still is."

"While everybody has suffered in a variety of ways from the pandemic, I do think the challenges have been very unique for this population, making these social opportunities even more necessary and rewarding," Jennifer Silverton said. "All the more we encourage people to reach out and get involved if you have a disability or you have time to volunteer with the group."

A community effort

Strong leadership made up of volunteers, parents, family friends and community living support workers all have goals they wish to see executed to grow the group and expand the opportunities for the Xceptional Heroes.

'Xceptional Heroes' - *continued*

Gregory Greer, affectionately called “Bubby” by the Xceptional Heroes, is a volunteer for the organization, but also works as a community living support (CLS) for Tyler Shue.

One of the long term goals for the organization he would like to see carried out is a restaurant that would be operated by those with disabilities.

He pointed to the Junction Of Hope Restaurant in Chesaning as an example.

“It’s a restaurant in Chesaning where all of the employees, except for the people waiting, are all special needs,” Greer said.

Christopher Cassidy, 26, has been involved in the special needs community for several years and the interest began when he started volunteering within the community as Boy Scout.

“I love exposure to different worldly things,” he said.

Cassidy is attending college for a bachelor’s degree in education and plans to get a master’s degree in special education.

He volunteers with the group, but also works with Aidan Silverton as CLS and respite worker.

“This group allows for connections to be built. We have many avenues for different experiences,” Cassidy said. “I’ve been able to work with some individuals to help them get jobs or just life experiences through different activities, through sports and other commitments like that. It’s definitely a place to help guide people into interests.”

While the organization doesn’t teach the traditional subjects in school, Cassidy said it does teach social skills such as organization, communication, independent living skills and how to exist as part of the community.

The group is eager to continue growing to serve more individuals with intellectual disabilities in Genesee County.

Xceptional Heroes wants to expand its reach beyond Genesee County, build an intentional community for people with intellectual disabilities with care on site, acquire vans and support staff.

The organization, currently in the process of re-establishing itself as a nonprofit, hopes to secure funding for the long term goals through grant money and fundraising, Jennifer Silverton said.

“My whole purpose is to get them thinking and acting for themselves and just stand by to be a support and just oversight,” White said. “It’s the laughing, the engaging, the interacting with each other. When they’re laughing, you just can’t help but smile and be around that.

“I love seeing that. It’s a cognitive process that they don’t even realize.”

If you or someone you know would like to join Xceptional Heroes or volunteer, visit the [Xceptional Heroes](#) Facebook page for more information.

“Believe in yourself. You are braver than you think, more talented than you know, and capable of more than you imagine.”

~ Roy T. Bennett



NATIONAL FRAGILE X
ADVOCACY DAY

MARCH 1, 2022

Learn more and register at: [Advocacy Day 2022 \(fragilex.org\)](https://www.fragilex.org)

This year's training and visits to The Hill will all be virtual. A virtual event may make it easier for more families to participate!

You must be able to participate in a virtual two-hour training session on Friday, February 25, and clear your day for meetings on Tuesday, March 1, between 9 am - 5 pm.

Register at the link above: \$30 for an individual to participate or \$75 for a household.

This year's FXAM Advocacy Grant fund can assist more of you to participate! FXAM will reimburse the first 20 Advocacy Grant applicants (individual or household). Simply forward your registration confirmation email received to FXAM Corresponding Secretary Mary Beth at mblangan@hotmail.com.

If you want to see if we've reached the 20 maximum prior to registration or for other questions, please email Mary Beth. Thank you for considering advocating for Fragile X!

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

Hello from the President! Although we may be out of touch in person, I miss my Fragile X family dearly. I hope you are all well and your family is healthy. Fortunately, my family and I have not had Covid. Even though we have been healthy, many of us are feeling our own version of Covid long hauler syndrome. The constant pivoting to try to do what is "best" while the rules seem to change often is exhausting. Will school be called off? Are we going back to virtual? Will someone get Covid? It can leave everyone feeling on edge.

We are isolated enough in our lives and the continued separation from friends and family has left me feeling deflated. I'm a very social person and need time outside of my home to recharge from what can be very long days. Going for such a prolonged period without being able to socially recharge has taken a toll. I know many members of our Fragile X family are struggling with the constant challenges and the toll it takes on our kids and loved ones. I hope you are all finding new ways to cope and maintain what little sanity you may have left! LOL! I know my sanity is on its last leg. Often when I am faced with challenging times in my life, I turn to home remodeling projects. We recently renovated the spare room in the basement for Alison (FM 21 in March) and that means I will be getting my own office. Just need to paint, clean the carpet and add a new ceiling fan before I can decorate and move in. Here's to hoping you find a way to rest, restore, and reenergize! Even if that means doing more work to get to where you want to be.

We have also been using our time to refocus and take better care of ourselves. Getting our checkups at the doctor and dentist. Alison has struggled with knee and joint pain for many years and even dislocated her knee a few years ago. I recently learned a friend of mine has Ehlers-Danlos Syndrome and she described many of the same symptoms that Alison has. We called Dr. Felt at U of M and she recommended Alison be evaluated by Dr. Lee in Genetics. Our appointment with Dr. Lee was very comprehensive and she was truly knowledgeable about hyper mobility. She spent over an hour with us going thru all of Alison's joints and checking the amount of hyper mobility they have. Dr. Lee had done research before our arrival on the link between hyper mobility and Fragile X. It seems there is research and studies that show this is a common Fragile X trait. Alison will be starting physical therapy to help her strengthen her muscles and learn techniques and exercises to reduce future dislocations or injuries. I was not aware of the link and wanted to share this so that others can seek early intervention, if needed.

As we look to the future, I hope that we will soon be able to gather once again and share stories of our Fragile X adventures. Hearing funny stories and brainstorming about our kids is truly one of my favorite parts of our FXAM community! If you're motivated to share, we can still do so on our FXAM FB page. Maybe I'll see you there!

eXtra, eXtra

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Kevin - has continued to visit with his behavioral therapist via tele-health every two weeks. He is also trying to get out in the community with his respite/CLS worker Pam, pictured above, but it's been a challenge with the weather. They work on LEGOs and make signs for his bedroom door. That helps to calm his anxieties. He loves working in the kitchen with his sister Helen. We try to stick to a normal routine here at home but with Covid coming back around, and Dad working from home again, it's proving to be a bit difficult.