

Mark Your Calendar

Support Meetings

**FXAM Zoom
Support Meeting
Tues, Jan 19, 2021**

7 - 8 pm

Email Mary Beth at
mblangan@hotmail.com
if you still need the link
or visit FXAM.org.

*Due to the Covid-19
quarantine, 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!*

**Fragile X Association
of Michigan
FXAM.org**

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

**PO Box 1414
Troy, MI 48099-1414**

Three Cheers for being in this together 2020/2021

Hoping the photos and details our members shared make you smile!



**The Branch Family -
Looking good in their
Christmas family photo.**

**See page 7 for the start of
many more photos from
our FXAM family!**

Michigan Covid-19 Vaccine Rollout

The purpose of this information is not to make a vaccine decision for you but to assist you in identifying when and how vaccines are being rolled out in your area.

Basic information for the State of Michigan can be found here:

Michigan.gov/COVIDVaccine

On this page you will find helpful resources, such as: Frequently Asked Questions, Covid-19 Vaccine Prioritization Guidance, Covid-19 Vaccine Plan – Draft, and much more.

More detailed information can be found at your county's public health website. Easily find your county's website by visiting michigan.gov/mdhhs/0,5885,7-339--96747--,00.html

The county website will provide instructions on how to proceed. In Wayne County, it appears that they are having hospitals drive the vaccinations and appointments. In Oakland County, on the county website they want you to register your email or TEXT Oakgov, they provide a text number, for registration for an appointment. Some counties share a website, for example Dickinson and Iron County in the UP. Continue to check on details as info may be updated.

Each county's scheduling may look quite different from another county.

The one common thread is that there are no "Walk-Ins", appointments must be made and how appointments are made are very county specific.

Please think of neighbors/friends who may not have access to the information, who are not electronically connected and assist them if you can.

Between the Lines

Book Review

Autism Discussion Books

Details on Autism Discussion Books are reprinted with permission from the Facebook Autism Discussion Page.

Approximately six years ago, from the encouragement of our page members, we expanded the information from the Facebook Page into the “Autism Discussion Page” book series. At the time, the initial two volume series was a collection of the narrative articles posted on the page, organized into an easy to read toolbox of strategies for supporting those with autism. To this date, we have sold over 30,000 copies of the books, with excellent reviews by parents, teachers, professionals and individuals with autism. Many parents and professionals report that the two-book series is their major go-to resource for helping those they support. Instead of labeling the books, volume I and II respectfully, the books are usually referred to by their color, blue and green. Recently, we added the third (Brown Book) to our series to provide additional information on the processing differences and daily challenges associated with them. A short review of each book follows.

1. **(Blue Book)** The Autism Discussion Page on the core challenges of autism: A toolbox for helping children with autism feel safe, accepted, and competent

This book provides an in-depth view of the four-basic sensory, cognitive, social, and emotional areas of vulnerabilities for individuals on the spectrum. There is a comprehensive view of each area of vulnerability with detailed guidelines on how to support the child through these challenges. When readers are finished, they will have a good understanding of how their children perceive the world, process information, and act the way they do. The book takes you through all the sensory challenges that are common for those on the spectrum, how they process information differently, why they struggle so much socially, and how overwhelming their emotional world can be. From this awareness, it becomes easier to understand and accept those with autism, as well as help them regulate our world. Whether you are a parent, teacher, professional, or someone on the spectrum yourself, this book will be of value to you.

2. **(Green Book)** The Autism Discussion Page on anxiety, behavior, school, and parenting strategies: A toolbox for helping children with autism feel safe, accepted, and competent

This book covers some of the major challenges that children and families experience during their daily routine and how to address each challenge. We cover stress and anxiety, addressing behavior issues, co-occurring conditions, stretching comfort zones, harnessing strengths and preferences, parenting and discipline strategies, teaching empowerment skills, and a host of mentoring strategies for coaching your child in basic life skills.

3. **(Brown Book)** The Autism Discussion Page on stress, anxiety, shutdowns and meltdowns: Proactive strategies for minimizing sensory, social and emotional overload.

This book analyzes the daily stressors that people with autism experience, the draining effects that tax their nervous systems and the resultant stress, anxiety, shutdowns and meltdowns. Trying to navigate a world that presents them many challenges results in ongoing physical, mental and emotional drain. Continually taxing their processing skills and leaving them vulnerable to sensory, social and emotional overload. Understanding these processing differences allow us to make modifications and accommodations to better match the expectations and demands of their daily routine to their processing abilities. Making the world more autism friendly. This book will provide proactive strategies for minimizing stress, anxiety, meltdowns and burnout.

Continued on Page 3

Between the Lines

Autism Discussion Books *(continued)*

Which Book Should I read?

If you haven't read any of the books, are purchasing only one book, or are purchasing two or three at the same time, I highly recommend that you read the blue book first. Although the books stand alone and each can be understood without prior reading of the others, the blue book provides the most comprehensive information on the core challenges for many with autism (sensory, cognitive, social and emotional challenges). This book provides the foundation for all the material in the other two books. The new (brown book) assumes that the reader has either read the blue book or has good working knowledge of the four core challenges covered in the blue book. This third book expands on the information from the previous two books, focusing on topics that were of most interest to our members on the Facebook.

Amazon link to the books. These books can also be purchased in Kindle editions.

[Autism Discussion Page on the Core Challenges of Autism: A Toolbox for Helping Children with Autism Feel Safe, Accepted, and Competent: Nason, Bill: 9781849059947: Amazon.com: Books](#)

Between the Lines

Just Imagine!

“The Autism Discussion Page on stress, anxiety, shutdowns and meltdowns” **(Brown Book)**

Just imagine if what you are seeing, hearing, touching, and smelling all come in fragmented and cannot be integrated. Where each sense is competing for attention and not working together. A world where you must block out all other senses to concentrate on one, or that you use your peripheral vision only because looking directly at something is too overwhelming. Just imagine if you must hum to yourself to filter out stimulation so you can attend and think. Just imagine!

Just imagine if you cannot sort out the relevant from the irrelevant details to focus attention on what matters, and then when one detail is changed, the whole picture falls apart. Where nothing is familiar because it is continually changing. Where there is never predictability to build stability. When a person changes her glasses, hairstyle, or perfume, you no longer recognize her. Imagine if you cannot distinguish faces and must recognize others by how they smell or move. Where one day you know who you are talking to, and the next day you don't. When you walk into a room and do not recognize it because one piece of furniture has been moved or replaced. How can you begin to feel safe and secure? Just imagine!

Just imagine sitting in a classroom where the flicking and humming of the fluorescent lights are giving you a headache, the smell of the markers and paste are making you nauseous, the scratching and screeching of the pencils around you assault your ears, and the hardness of the chair you are sitting in hurts your body. Just imagine sitting in each class anxiously waiting for the bell to ring and send your brain into panic. When the sounds of congested breathing from the person behind you are overpowering what the teacher is saying. You continually tap on the desk, fidget and hum to yourself to stay organized. Just imagine!

Just imagine if you cannot concentrate on the person you are talking to because her perfume is overwhelming, or the reflections bouncing off her necklace is calling your attention. Just imagine when you can hear the words but cannot see the faces you are talking to. Or when you try to join a group of friends, but the multiple voices drown out each other into a mix of jumbled sounds. When you finally grasped and understood what was said, the conversation has moved on before you can respond. Or when you know what you want to say, but cannot find the right words, or get your mouth to say them.

Continued on Page 4

Between the Lines

Just Imagine! *(continued)*

Just imagine if you cannot understand the thoughts, feelings, and perspectives of those around you. You cannot read the expressions, gestures, and actions simultaneously to understand meaning. That you cannot read the invisible cues and unwritten social rules that help provide the backdrop for understanding what is expected. That you are always out-of-sync with others because you cannot listen, think, and act simultaneously. The words are coming too fast, too loud, and too much for you to process. When the facial expressions do not seem to match the words you are hearing. When you guess wrong at what is expected and are confused by the negative reactions, they elicit. When you continually try to fit in but always fail. Just imagine!

Just imagine if you do not feel connected to your body, cannot walk without looking at your feet, or lose the feeling of your body unless you are moving or tapping parts of your body against objects. When you do not feel pain or are hypersensitive to any soft touch. When the clothes you are wearing feel scratchy and hurt. When you feel off balance when walking and have difficulty coordinating your movements. Just imagine if you cannot sense your internal body cues to tell you that you are hungry, stressed, or need to use the bathroom. You feel like your body is not part of you, but as an object, you must manipulate. A body that can be a friend or enemy based on continuous, confusing feedback. Just imagine!

Just imagine if your emotions are too strong and overwhelming for you to identify, label, and control. That emotions come on like a tidal wave with little warning and ability to control. Your thoughts and feelings are not connected enough for you to make sense of them or anticipate when they will happen. Just imagine when you are so sensitive to the emotional auras of those around you that you cannot identify if the emotions belong to you or others. When you cannot identify, label, or control, not just the emotions but also your reactions to them. When you interpret all emotions as fear and panic at first notice. When you are scared to feel. Just imagine!

Just imagine if the world is so unpredictable, confusing, and overwhelming that you are constantly on high alert and anxious all the time. You are on guard for the next unpredictable sensory assault or unexpected social demands. When your immediate environment's physical, social, and task demands are coming too much and too fast. Your brain starts to shut down, you lose the ability to speak and act purposely, and your body begins to hurt with pain. The panic overwhelms you with the need to escape. When you scream, run, or lash out in uncontrolled fear and rage. Just imagine!

When you try to intervene, discipline, or support what you see from me, please take a moment to “just imagine” what it is like for to be me at that moment. Once you can imagine, you can begin to understand and learn how to support me. It is so important for my safety and security and to my emotional survival. Just imagine!

This article will be published in the upcoming book, “The Autism Discussion Page on stress, anxiety, shutdowns and meltdowns” Reprinted with the permission of the Autism Discussion Page.

“See the light in others, and treat them as if that is all you see.”

~ Wayne Dyer

Through the Maze What's on the Web

Training is still going on in a virtual format

The Arc of Western Wayne County

It is never too early to start planning for the future. The Arc of Western Wayne County has taken their *After I'm Gone* program to Zoom.

The *After I'm Gone* Program assists families who have a child or an adult with a disability in planning for their future when they are no longer able to provide care.

This program is offered free of charge by The Arc of Western Wayne and The Arc Northwest Wayne County.

View the schedule here: [2020 to 2021 AIG Flyer final.indd \(thearcnw.org\)](#)

You must RSVP via email for these webinars in order to get a participation login. tequila@thearcww.org

Each *After I'm Gone* session will include a virtual happy hour starting at 5:30 pm.

Michigan Alliance for Families

Upcoming Events:

January 20

Epilepsy and Comorbid Mental Health and Emotional Issues with Epilepsy Foundation of Michigan, 7-8 pm.

January 21

Assistive Technology Experiences From Parents Like You with Carolyn O'Hearn 12-1 pm.

February 3

IEP Course: Explore Your Child's IEP with this four week course (2/3, 2/10, 2/17, 2/24) 7-8:30 pm.

February 4

Rethinking Guardianship: Facilitating Lifelong Self Determination with Dohn Hoyle, 6-8 pm.

February 9

Log On and Log In to Virtual Meetings with Special Education Mediation Services, 11am-12 pm.

February 12

Behavior is Communication with Sally Burton-Hoyle, 1-2 pm.

You MUST register online, to register and see all events visit:

[Upcoming Events: Learning Opportunities – Michigan Alliance for Families](#)

Opportunity: Parent Coordinator & Program Assistant

[Career Opportunities: Parent Coordinator & Program Assistant \(1836\) \(successfactors.com\)](#)

Purpose: Under the direction of the Center for Health Equity Practice Sr. Project Coordinator, the Parent Coordinator will join CHEP staff working with families, public health, and other community partners on innovative solutions that will improve health outcomes and quality of life for families of children with special health care needs, including those within historically oppressed populations. The Parent Coordinator will utilize personal experience as a parent or caregiver of a child with special health care needs to support multiple projects, with a focus on social justice as it intersects with disability.

Select [Blue](#) link above to learn more or apply.



NATIONAL FRAGILE X FEBRUARY 24, 2021
ADVOCACY DAY

Learn more and register at:

[Advocacy Day 2021 \(fragilex.org\)](http://fragilex.org)

NFXF Advocacy Day 2021

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 live training session on **Friday, Feb 19** from 2-4 pm.

Clear your day for meetings on **Wed, Feb 24** between 9 am - 5 pm.

Register at the link above: \$25 for an individual to participate or \$50 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!

University of Michigan Fragile X Clinic

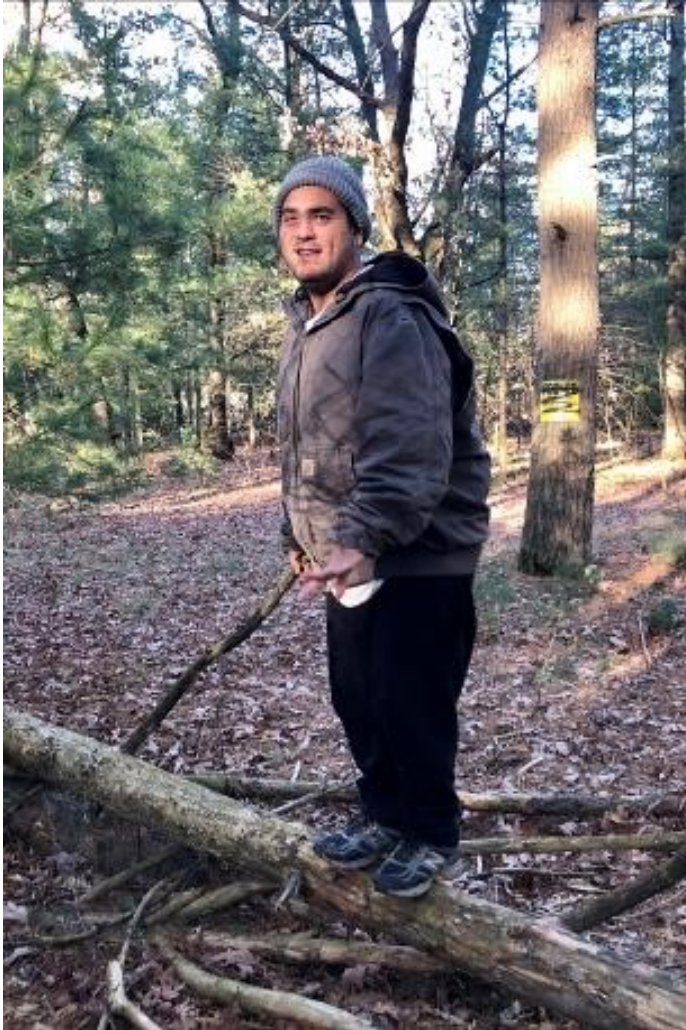
For more information on the Fragile X Clinic or to make an appointment:

fragile-x-clinic.med.umich.edu/

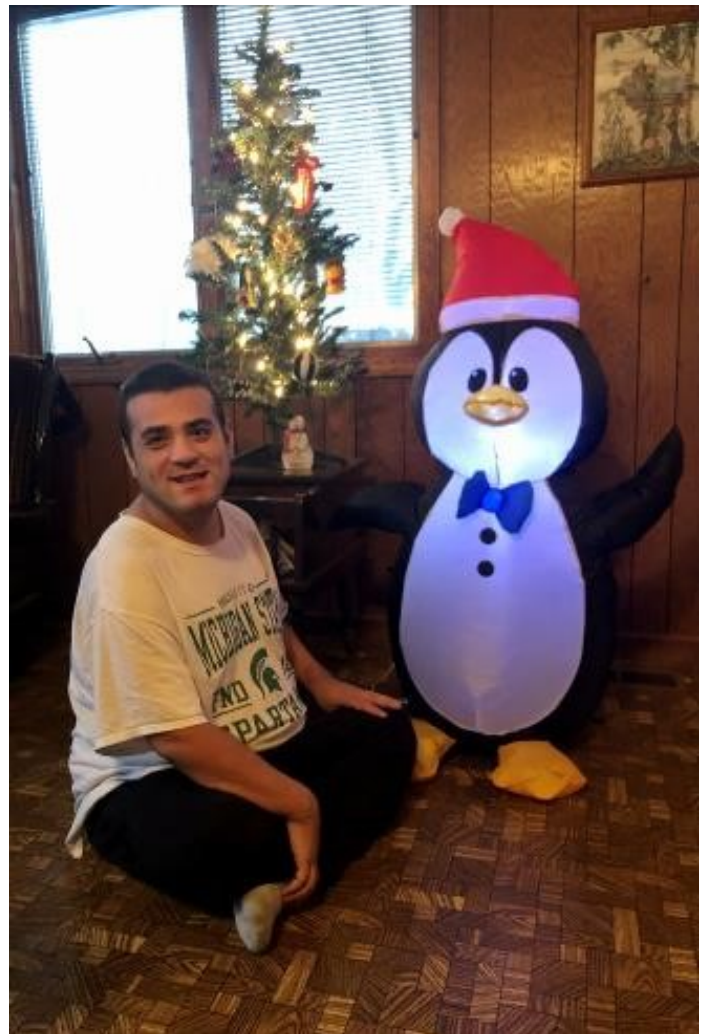
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We Are All In This Together 2020/2021

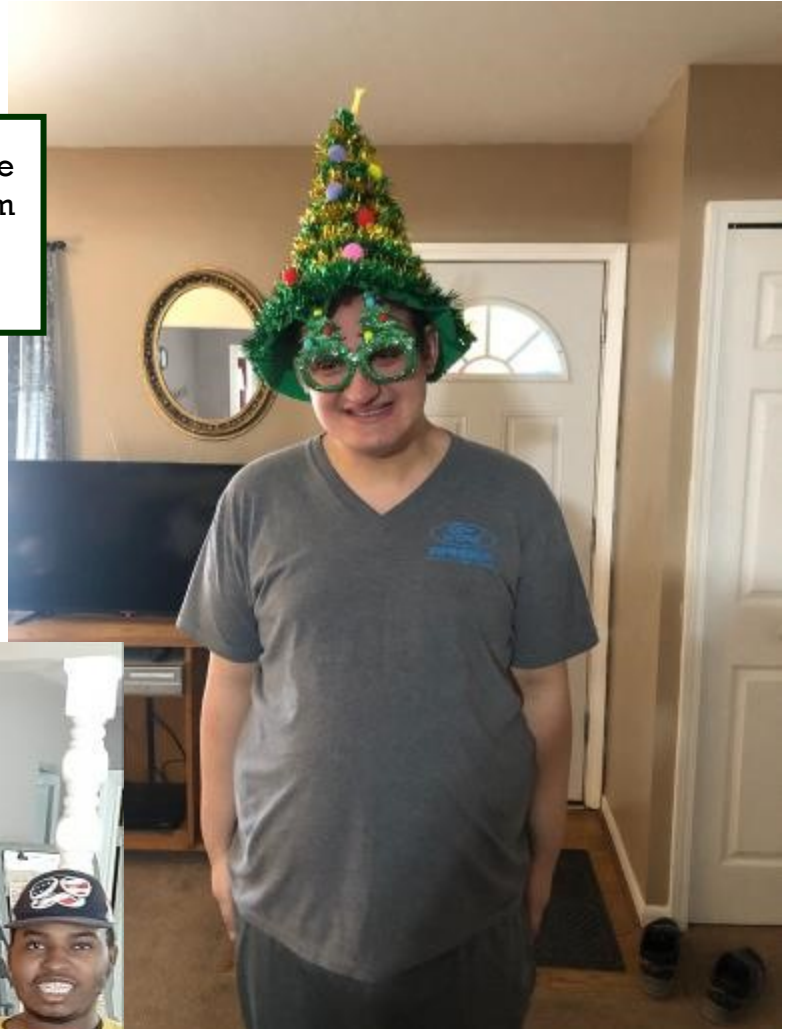


Angelo - Thanksgiving and Christmas at the cottage.



We Are All In This Together 2020/2021

Adam - Getting festive for his Christmas Zoom gathering with his church group.



Adam - With his roommate Brian; he can't wait to get back to in-person learning!

We Are All In This Together 2020/2021



Kyle and Roger (Grandpa) -
Pictured during gift giving.

Roger - Picture to the right, an
awesome selfie that Sally
encouraged him to send to check in
with all of us.



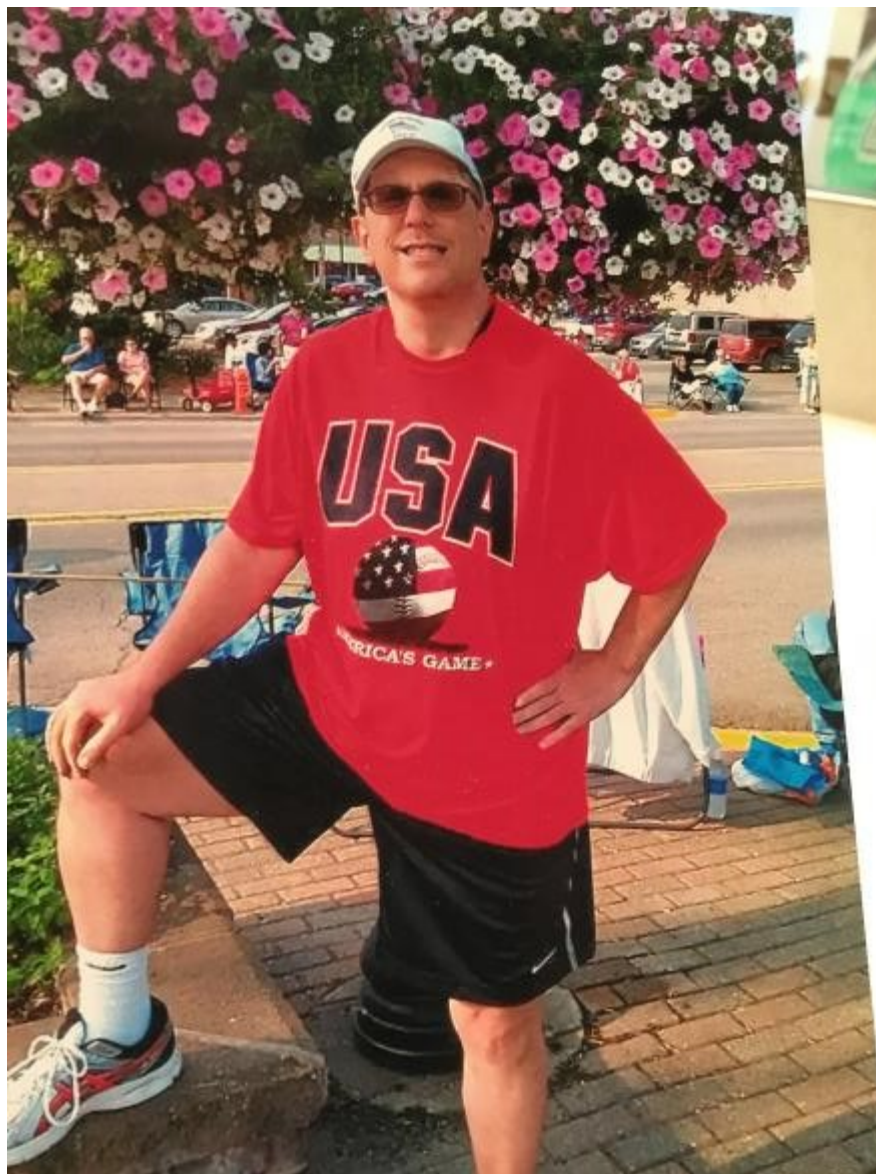
We Are All In This Together 2020/2021



Paul - His favorite Christmas gifts were his go-pro for making YouTube videos and his dragon pjs pictured here!

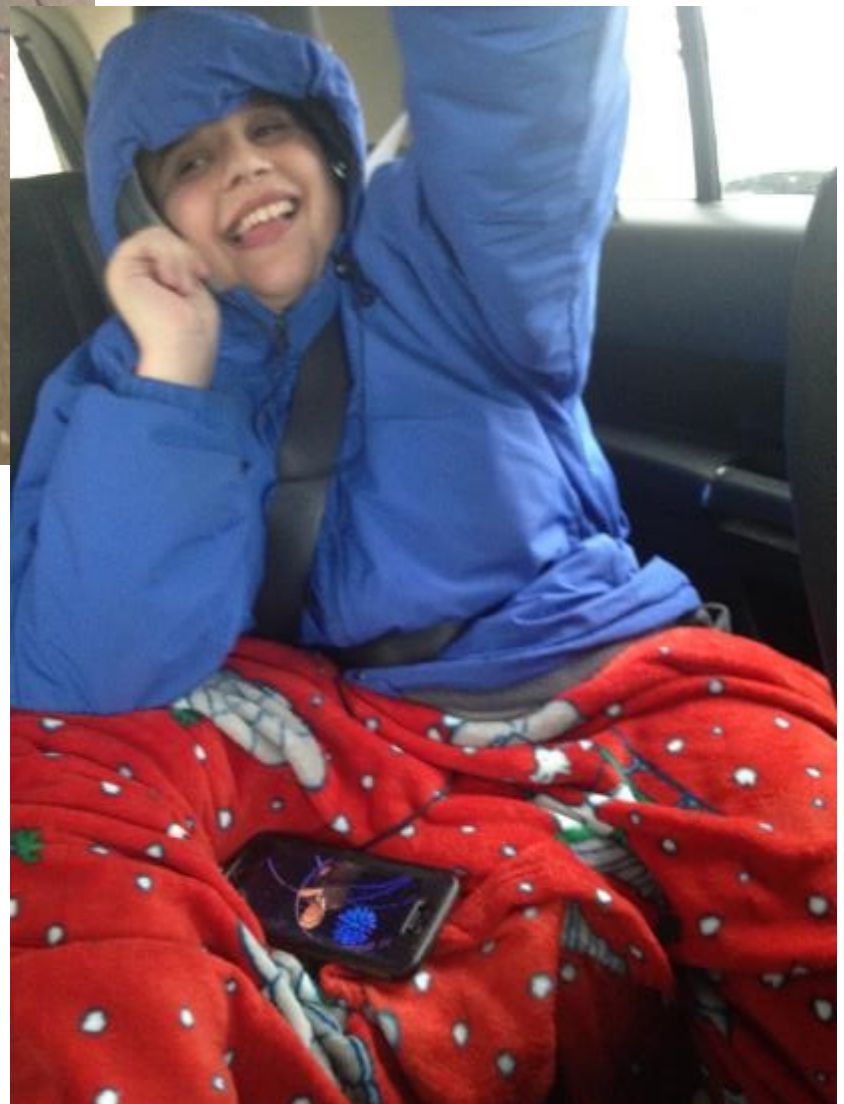


Cassandra and Logan - Having fun with filters.

We Are All In This Together 2020/2021

Jason - Has lived in his own apartment independently for 20 plus years. With parental support and part time self determination helpers, he does very well. He misses his Special Olympic activities and hopes they will resume soon. He likes to attend church, eat out with family and friends, and enjoys following University of Michigan sports. He also follows his niece who plays college basketball.

We Are All In This Together 2020/2021



Andrew - His Covid-era daily routine still includes a 1.2 mile walk and a car ride.

We Are All In This Together 2020/2021



The Price Family - Sam graduated and is now attending Western, Jake mastered driving a pontoon and the family enjoyed hiking in the UP.



We Are All In This Together 2020/2021



**Christmas 2020 with the
Lerchenfeld Boys.**



We Are All In This Together 2020/2021



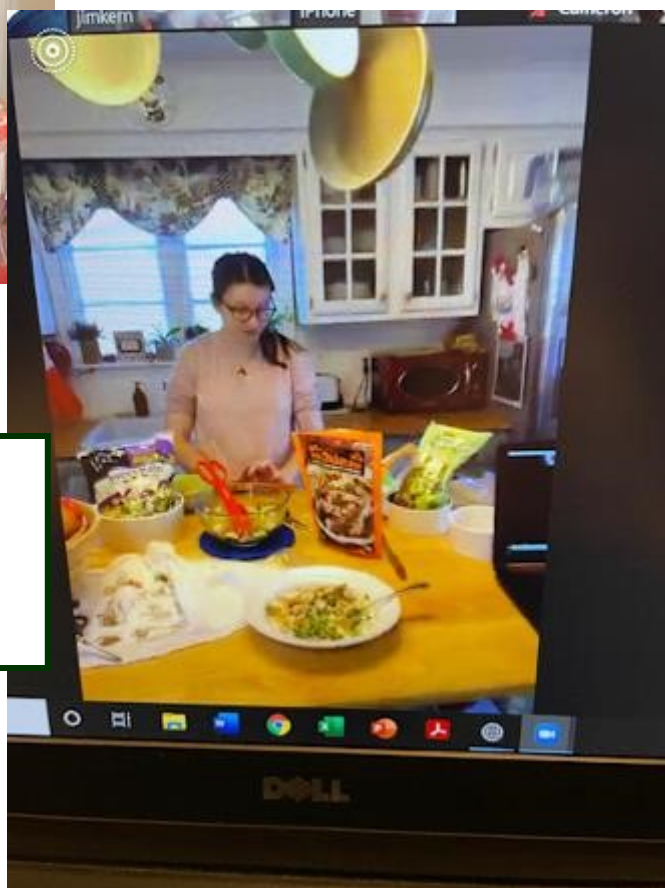
Majeske Family - Just a few photos to share from our family to yours.

We Are All In This Together 2020/2021



Keir - Making a bagged salad. He learned how to make one on Zoom school and now he makes all of our bagged salads!

Indigo - This is a picture of Keir's Zoom school lesson on bagged salads. The demonstrator is his sister!



We Are All In This Together 2020/2021



Kevin - Showing off his Cheetos socks his brother Jon sent him for Christmas.



Stefanie and Kevin - Kevin with his new Halo blanket from his sister Stefanie

We Are All In This Together 2020/2021



Michael - One thing that is a given for Michael is that awesome smile!



The Friendship Circle

Michael participates in the virtual activities offered through the Friendship Circle.

Virtual Programming: [FC Goes Virtual | Facebook](#)

We Are All In This Together 2020/2021



Nicholas - Taking notes in school -just like mom (Lexi) does in her classes. Guess I was a good role model. (Mind you he doesn't read/write LOL). The pups are always there for support and food.



We Are All In This Together 2020/2021



Nantais Family - Mid-November with the entire family working or schooling virtual we decided to visit our Florida home for a few weeks. Social distancing was accomplished very well at Disney Hollywood Studios, SeaWorld and the pool. It was a much needed break for all.



eXtra, eXtra

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Masked up with the Nantais Family - Buzz Lightyear opted to just use his plastic shield.



Keir - Rockin' his mask!