

## Mark Your Calendar

### Support Meetings

**First Saturday of the Month**  
(No meeting in December)

*When:*

**November 6, 2021**

Please watch our FXAM Facebook group and FXAM.org for details of a virtual meeting.

### Special Events:

**TBD**

Please watch our FXAM Facebook group and FXAM.org 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...



**Antonio** - Here he demonstrates how to celebrate a holiday weekend at the cottage.

**Andrew** - He had his first visit to the University of Michigan to see his beloved cousin Ian. We checked out Ian's dorm room and ate at Pizza House! A successful first visit!



## Three Cheers for...



**Kyle** - First day of school shared by Grandpa Roger.



**Austin** - Best part of traveling by car to Florida is we were able to stop and see Grandpa in Georgia. Austin keeps his mother on her toes. She had an extra project when he remembered that the Disney+ movie "Muppet's Haunted Mansion" was out in October. His TV wasn't hooked up in his room in Florida with his Roku so he signed up for a one-year contract for Disney+ through Xfinity. Thankfully, mom was able to fix, now to purchase anything through Xfinity a pin is required.



## Three Cheers for...

**Kevin** - If you've followed Kevin in our newsletters you may remember he has struggled with leaving the house. Mom, Marie, reports he is making great progress. He enjoys walking the family's greyhound, Penny. And we do believe, he loves to ham it up in front of the camera!



## Three Cheers for...



**Jacob** - He has had so many amazing experiences this year. (Top L) Jacob and his sister after a rainy, muddy football game. He did not get much playing time but dove straight in when it was time to celebrate the win! (Top R) Jacob doing a homecoming proposal at school. He was very nervous but with the help of his school peer he pulled it off. She said yes!! (Bottom L and R) Jacob with his date before the homecoming dance. He enjoyed a dinner and played at the arcade before a full night of dancing.



## Research

### Bringing Your STX209/Arbaclofen Data Home

The National Fragile X Foundation (NFXF), with the help of several professionals, has secured an agreement to obtain STX209 trial participant data through a reconsent process. Science cannot move forward without your participation, so NFXF has partnered with Dr. Elizabeth Berry-Kravis to create an eConsent option for bringing your STX209 data home to the [NFXF Data Repository](#).

Whether you were in the study for the long haul, or maybe it wasn't successful for your child, **your data, your information is important.**

Please follow this link for the consent process:

[fragilex.org/our-research/projects/stx209-reconsent/](http://fragilex.org/our-research/projects/stx209-reconsent/)

### More on STX209/Arbaclofen

STX209/Arbaclofen is going back in for FDA consideration for a path to approval under **Allos Pharma**. Allos has received the rights to Arbaclofen for fragile X from the Simons Foundation. They are looking for testimonial letters from families about how well the medication worked for them. Families were asked to provide a letter of support explaining on a personal level how Arbaclofen improved function and/or affected the quality of life for their child and family.

### About Us - Allos Pharma

We are a global team dedicated to improve the lives of patients with Fragile X Syndrome and Autism Spectrum Disorder. Our work spans three decades of research in neuroscience and intellectual disabilities. The "mGluR theory of fragile X" proposed by MIT Professor Mark Bear and collaborators in 2004 is widely considered to be a key conceptual breakthrough, and laid the foundation for development of disease-modifying therapies for treatment of Fragile X Syndrome and Autism Spectrum Disorder. Allos Pharma is committed to develop and market the first approved therapy in Fragile X Syndrome.

The name Allos Pharma is derived from allistic, meaning not autistic.

[allospharma.com](http://allospharma.com)

## Research

### The SC Family Experiences Study

Numerous studies recruiting.

**Participate in Adult-Focused Studies:** Select a link below to learn more.

[Women who are carriers of the fragile X premutation](#)

[Mothers with a son or daughter with fragile X syndrome](#)

[Mothers with a son or daughter who is typically developing](#)

[Mothers with a son or daughter with autism spectrum disorder](#)

**Participate in a Study on Adult Transitions in Fragile X Syndrome:** Select the link below to learn more, can be done virtual.

[Young adults with fragile X syndrome](#) who are in their **last two years** of receiving school-based services, including:

- High school juniors and seniors
- Students who are participating in the final years of a school-based transition program

[Participate – USC \(scfamilystudy.com\)](#)

[SCFamilyStudy@gmail.com](mailto:SCFamilyStudy@gmail.com)

(803) 777-5049

### Spark - Simons Powering Autism Research

Does your child have a dual diagnosis of Autism? If so, think about joining Spark.

The University of Michigan is part of the Spark project.

To learn more about Spark:

[sparkforautism.org/](http://sparkforautism.org/)

To learn more about the program at U of M:

[Study Seeks to Better Understand Causes of Autism \(uofmhealth.org\)](http://uofmhealth.org)

Do more than belong: participate. Do more than care: help.  
Do more than believe: practice. Do more than be fair: be kind.  
Do more than forgive: forget. Do more than dream: work.

*~William Arthur Ward*

## Adventures with Super Cal



### We'd like to introduce you to Super Cal!

Inspired by the character Flat Stanley, from a story by Jeff Brown, Super Cal is a new Fragile X Superhero!

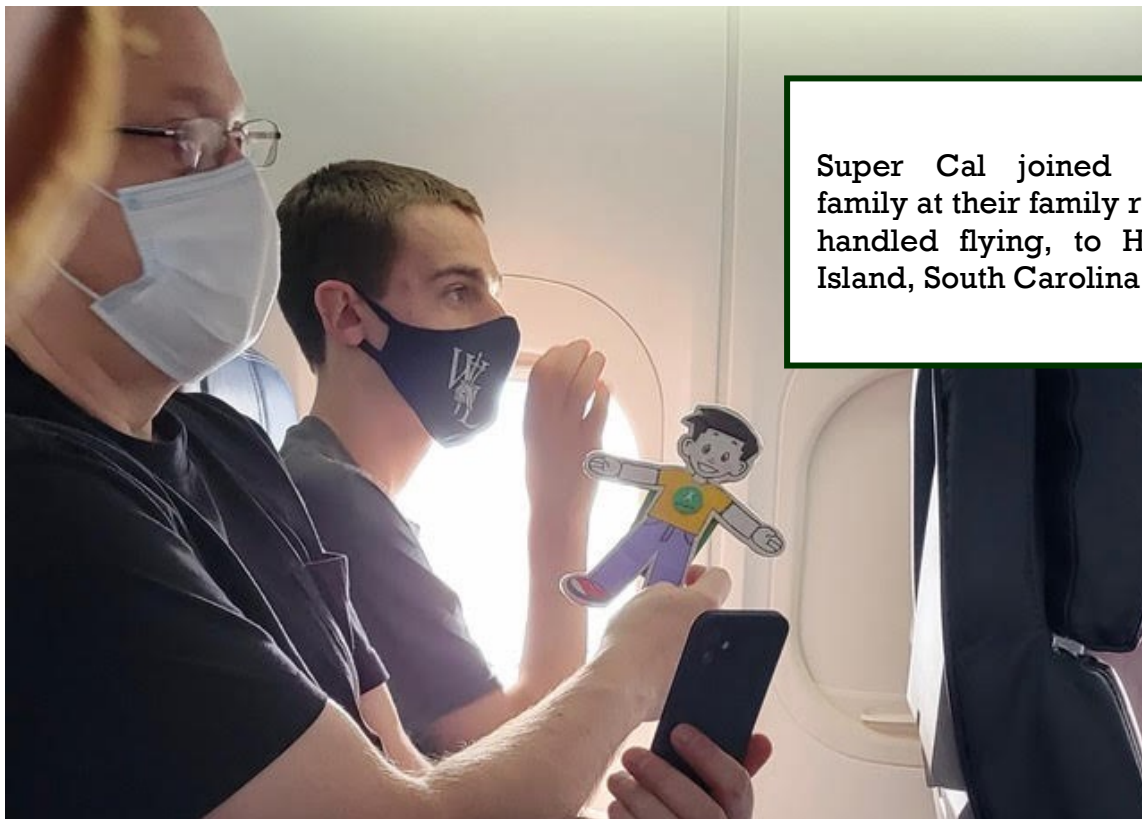
Super Cal is visiting some FXAM families and enjoying creating memories of your daily routine, a favorite activity and/or an extraordinary excursion.

He can stay with you for a week or two and your parents can share the photos of him visiting your home on our FXAM Facebook page so we can all keep track of his adventures!

If you have questions about his travel plans, please email Sheryl at: [romanjsr@aol.com](mailto:romanjsr@aol.com)

We look forward to seeing where he visits, who he sees and what they do together!

Go Super Cal!



Super Cal joined the Fodor family at their family reunion. He handled flying, to Hilton Head Island, South Carolina, like a pro.

## Adventures with Super Cal



While finding statues around Savannah was fun, it was the beach with Paul Fodor that was Super Cal's favorite activity.

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**FXAM.org**