

History of the Fragile X Association of Michigan

(look at all we've accomplished!)

The Fragile X Association of Michigan (FXAM) was formed in 1987 by parents Mary Ann and Roland Fischer. FXAM was started by volunteers and remains a volunteer-led group. We were granted our 501(c)3 nonprofit status in 2004.

Support Meetings:

- ◆ The first support meeting was held in 1987 at the Fischer Home with Mary Ann, Roland and one other parent in attendance; meetings have been held at Beaumont Hospital-Royal Oak since 1991
- ◆ Meetings began having a virtual option in January 2018
- ◆ Free child/adult care provided at two support meetings per year since 2014; we have seven meetings per year
- ◆ Guest Speakers are brought in from metro Detroit as well as Chapel Hill, NC and Chicago, IL
- ◆ Business meetings are held by the board of directors prior to support meetings and also additional times.

Local Conferences: For many families, traveling to the International Fragile X conference is not an easy or affordable option. Occasionally we bring the experts, and sometimes researchers, to Michigan. FXAM Conferences have been held for families and professionals in 1990, 1994, 1999, 2003, 2005, 2007 and 2015.

Play Dates and Family Fun Activities: We've hosted over ten formal Play Dates and numerous Family Fun Activities including Creative Arts Studio, Teen/Young Adult event, FXAM Basketball Party at Eastern Michigan University and a Family Fun Night at the Gym to name just a few. We have held annual FXAM Holiday Parties and Family Picnics since 1988.

Moms' Lunches (*organized by FXAM, not paid by FXAM*): FXAM Moms have been very busy. There have been over 11 formal lunches; in 2018, we took the lunch venue to Lansing to include some of our mid-state families.

Dads' Nights Out (*organized by FXAM, not paid by FXAM*): The Dads have not been as busy. November 2018 will be the second one but it's an exciting night of Axe Throwing! Word on the street is a few Moms are jealous and a few Moms are a little anxious questioning if a venue with axes mixed with alcohol is safe.

Newsletters: The Fischers printed and mailed many newsletters from 1988-2002. The current format began in January 2005. Mary Beth Langan and Sally Nantais co-edit the newsletter which is mailed quarterly to all FXAM members with copies provided for the Fragile X Clinic at the University of Michigan. 56 newsletters have gone to press since 2005; all available on our website with some great resources for our families.

Website: Our website, FXAM.org, was created by Mike Makris and went live in July 2009. The website has been maintained by volunteers from our group: Mike Makris, The Price Family and, for many years, Sally Nantais.

Fundraisers:

- ◆ 19 Annual FXAM Golf Outings, raising thousands of dollars. The golf outing is organized yearly by Nina and Frank Liberati, and Laureen Majeske. The golf outing is successful thanks to our numerous volunteers and supporters. In October 2005, we first recognized our Golf Sponsors: we had two \$250 sponsors and thirty-three \$150 sponsors. Many of those sponsors are still active today.
- ◆ Other fundraisers: 7 Hansen Family Golf Outings in West Michigan, 5K Fun Run and Walk held multiple times, Dine Out for Fragile X, Poker Runs, Bowling Fundraisers, Comedy for a Cause and so many more! Our most interesting fundraisers may have been the years the Price Family sold pumpkins for Fragile X.

Scholarships:

- ◆ \$62,705 in scholarships awarded since 2004 to FXAM families to help them attend the International Fragile X Conference (held throughout the U.S. every two years).
- ◆ \$2,750 in scholarships awarded since 2011 to families attending Advocacy Day (annual event advocating in Washington, D.C.).
- ◆ \$7,065 in scholarships awarded to local teachers/professionals to attend the 2010 International Fragile X Conference in Dearborn (FXAM was the local host of the conference).

Fragile X Clinic at the University of Michigan:

- ◆ \$17,150 donated by FXAM to help support the clinic since it's grand opening in June 2012.
- ◆ \$35,000 research grant from the Toni Wisne Sabina Foundation in 2018 with FXAM's assistance.

Support of the National Fragile X Foundation:

- ◆ \$56,000+ donated by FXAM to NFXF to support Fragile X awareness, research, advocacy and family support.

October 15, 2018