

# FASD News and Views



A Michigan Coalition for Fetal Alcohol Resources, Education and Support (MCFARES) Newsletter



Established in 2003

## Questions We Are Asked

**Question:** *My wife and I recently adopted two boys, ages 6 and 9, who have fetal alcohol syndrome. We also have older kids who are 17, 19 and 21. With our older kids, sports were a very big part of our lives. I helped coach their hockey, soccer and softball teams and each of the children excelled in at least one sport. How can I get our younger children involved in sports if they are so distracted that they are barely able to sit still at the table to eat a meal?*

**Answer:** Though the challenges your younger sons experience due to prenatal exposure to alcohol may make involvement in sports more of a complicated, some children on the spectrum can be very successful at sports. Many children have both the desire and the ability to play sports and there can be many benefits for them. Benefits may include increased focus (both on and off the field) and improved motor skills. Andrew Peterson is a runner who has fetal alcohol syndrome and has qualified to run the Boston Marathon (<https://www.runnersworld.com/general-interest/how-this-special-olympian-reached-his-dream-of-qualifying-for-boston>).

Expose your sons to a variety of sports and find out what they might be interested in playing. Try a season or two in the sport of their choice to see if they can handle the pace of game with their same-aged peers. While team sports seemed to work for your older children, you may want to consider trying out some individual sports with your younger children. Consider sports such as

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swimming, skating, track and field, karate or bowling.

As you coached teams for your older children, consider coaching your younger children who may need extra support, encouragement and closer direction. As their parent, you will have insight

into the most appropriate ways to guide and direct them. In addition to learning to perfect the physical actions of the sport (i.e., kicking the soccer ball, swinging at the baseball, throwing the bowling ball, etc.), you have the opportunity to help guide them to learn appropriate social skills (i.e., how to appropriately accept losing a game, how to congratulate the other team, how to support team members, etc.). If you will not be coaching your sons, speak with their coaches before the season begins to help them understand the needs of your boys and continue to be available to support coaches should challenging behaviors arise.

To find teams that might work for your sons, consider looking at your local recreation department. Some departments have Challenger leagues for young people who need a little extra support when playing sports. Special Olympics might be available through your local school or county. Schools often know of other programs that might be appropriate for children who have special needs. Your local support group may also be a source of information about sporting programs that may fit your children.

*If you have any FASD-related questions, please send them to Charisse at [charisse@mcfares.org](mailto:charisse@mcfares.org)*

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## Pure Michigan



## Belle Isle, Detroit

## Macomb County Project S.A.F.E. Monthly Potluck Dinner



Project S.A.F.E. (Supportive Activities for Everyone) has been meeting in Macomb County since February, 2008. Project S.A.F.E. began as an opportunity for families who are affected by fetal alcohol spectrum disorders to come together to enjoy a meal, enjoy friendship and socialize in a safe, supportive atmosphere. Over the years we have met at the homes of some of our families and at various churches in Macomb County. We have had families join us from as far away as St. Clair, Grand Blanc and Saline. Through Project S.A.F.E. we've enjoyed some great meals, learned more about FASD and have developed great friendships.

If you are interested in joining other families for a meal, friendship and a chance for children to play together, please contact Charisse at [charisse@mcfares.org](mailto:charisse@mcfares.org). We're looking to expand Project S.A.F.E. into other areas of Michigan. If you'd like to learn more, please contact Charisse at [charisse@mcfares.org](mailto:charisse@mcfares.org).

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### GoodSearch

Please consider helping MCFARES raise funds to support individuals and families who are affected by pre-natal exposure to alcohol. Each time you conduct a search at <http://www.goodsearch.com/>, a donation is made to MCFARES. Please designate MCFARES as your charity of choice. You can also use GoodShop for your on-line shopping needs. A percentage of your on-line purchases will be donated to MCFARES.

### Amazon Smile

If you shop on-line with Amazon.com, please consider using this link: A donation to MCFARES will be made each time you shop: [smile.amazon.com/ch/35-2394822](https://www.amazon.com/ch/35-2394822)



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## A Picture Speaks a Million Words

I have been a mother now longer than I have not been. I passed that milestone this past year as my son officially is now more than half as old as I am. I have five children, all with their own needs. We have had many adventures and many joys on this journey, but my heart broke in ways it never has in all my years in this station as mother, when my 6 year old daughter with FAS shared with me how she felt about school and herself.

She began kindergarten this year in a new school with an IEP I believed would offer her the most advantage in getting along successfully in school. As an educator myself, I thought I had made every prediction I could into her needs. I worked to provide her with the support I thought would help her feel as though school was welcoming her with both arms. Even though I was nervous for her to begin this next chapter in her young life, I was hopeful. Over the coming weeks, I realized that no amount of support would compensate for a willful lack of understanding about the diagnosis my daughter carries around in her little body. I naively thought that because I cared about my daughter, others would too dig in and find compassion for the symptoms of her dysregulated brain. I was wrong. No number of professionals, like my daughter's developmental pediatrician, calling to personally answer any questions the staff might have, or links to websites, books, or information on the topic of FASDs made it into the way my daughter is taught and connected with every day at school.

School is a place my daughter wants so badly to fit in, and wants to know that she is worthy of being. It has not been that for her, and, in turn, it has led to the greatest heartache of my adult life. I watch a child who day after day gets dressed in

clothes she feels proud of, buttons her coat, pulls on her shoes, and stands with me waiting for the bus with a smile. As the early days of the school year unlocked this door to unrealistic expectations from teachers, consequences that can't possibly match the offense, and a lack of true empathy for a child whose brain tricks her again and again, it became clear that somewhere, even though she was smiling, she was beginning to understand how the world might reject her. She had already survived foster care, an adoption by another family who ended up horrifically abusing her, and being returned to foster care to land in my arms. She is one of the strongest hearts I know, but school was becoming this place where she slipped into fight or flight too fast. She didn't have an external brain that also had an education about FASDs attached to it. Day after day we stood at the bus stop, repeating the mantra I taught her, "*I am smart. I am kind. I am worthy. I am strong. I am able.*" There were days she repeated it with such sincerity that I could feel a lump in my throat as I led her through each word. Every time I watch her walk away and climb the stairs of the bus, I think, "*You, little girl, are one of the bravest people I know.*"

Last night, I realized how much this experience is affecting her. She came home from school, and we went through the usual nighttime routine. I gave her a bath, and helped her with her pajamas. She asked if she could play in her room with her dolls and her play kitchen. I told her, "Sure", and without thinking much more about it, I went downstairs. I got busy figuring out dinner, and the business of the evening in a family of seven. After a little while, I realized it had been quiet up in her room for some time, so I went to check on her. I found her asleep on the floor of her toy room with

a doll in a stroller and her Magnadoodle right next to her. As I went to pick her up, I looked at the picture she drew, still etched on the Magnadoodle, and I instantly felt tears welling up in my eyes. I picked her up, and rocked her in the rocking chair. She stirred a little, and I asked her what she had drawn. Half asleep, she whispered, “*Sad faces. Bad girl.*”



My 9 year old son came into the room, and asked me what I was looking at. I showed him his sister’s drawing. He said that it made him sad, because he felt that his sister’s teachers didn’t know how to “take care of her.” He said, “*I don’t think they are nice to her. She can’t help it.*” He leaned over and kissed her forehead in a way I’ve never seen before, and told her goodnight. As she lay on my lap, falling back to sleep, she said, “*I’ll keep you safe, Mama.*” I told her it isn’t ever a kid’s job to keep their mama safe. She was quiet a minute, and said, “*No. Mama and Daddy keep me safe.*”

As the parent of a child with an FASD, and more specifically in this case FAS, I have heard everything from school staff and others who are ill informed. They will “change” her. They can “fix” this. My daughter is “willful” and “disobedient.” I am too permissive with her, and too overbearing

with them. They assume everything except that this sweet child has brain damage, and is suffering the effects of child abuse and abandonment.

She has been sent to the principal’s office several times already this week, and most of it could have been avoided with understanding and a different approach. When I pick her up every afternoon, she runs to me, with open arms, and joyfully tells me she has had a great day. If I ask her if she hit or was sent to time out, sometimes she knows, but often she says no. This isn’t a way to avoid the responsibility, and it isn’t a lie. She just didn’t remember, and she didn’t process the events like the person who reprimanded her. This week she imitated a non-verbal child with ASD who she shares special education minutes with. He became upset at one point during a lesson, and began to scream repeatedly, hitting the teacher. My daughter is an observer. It is like her superpower. She watches her peers to know what to do, and then she imitates it. When this little boy began to scream, my daughter did too. When he hit, my daughter did too. She sat in the office after that with the principal standing over her, demanding apologies she is, by now, trained to give to avoid further trouble. I am positive most of the time she doesn’t know why she’s apologizing. In the long and winding email the teacher sent me to explain the situation, she wrote that she was sure that my daughter engaged in this behavior to “see what the teacher would do.” How she could possibly understand my daughter’s intentions without understanding her diagnosis is a trick I have yet to learn. To me, this appeared to be a frustrated teacher coloring the event with her own emotional response. This is part of the problem. My kid and all our kids can’t change their brains and all of the confusion that comes with it. If they could, they would. I see it in my daughter’s face. If she knew

how to give me what I asked sometimes, I know she would in an instant. She can't though, and she won't be able to. The part that allows me any hope at all is that *I can*. Teachers, doctors, and other professionals that work with our children can too.

**FASDs are more common than the rest of the world knows.** It is at least as common as autism. A study released in the Journal of the American Medical Association (JAMA) reported that as many as 2-10% of all children are living with the effects of prenatal exposure to alcohol. The most recent study on autism reports that roughly 2% of children are affected by this diagnosis. This all means that potentially there are more children living with a disability that is unspoken about, and seemingly unknown to teachers and the education world. As a classroom teacher, I was ignorant to the diagnosis before my kids. Now that I see this diagnosis clearly as a parent, I recognize how many children that have passed through my classroom, who were likely living with an FASD. It is heart-breaking to me that the stigma society has placed on biological mothers who drank alcohol, knowingly or unknowingly, is what keeps it silent. I never see billboards or hear public service announcements

about FASDs, and telling parents the benefits of early intervention, or even proper diagnosis. Parents who don't know the law fall between the cracks of the IEP process, and are cowed into thinking their child's inability to attend, remember, sit still, be quiet, keep their hands in their laps, follow directions – is their fault. The truth is, it's all of our faults if we don't become the loudest voices in an incredibly quiet room. FASD is not invisible to the people who love and care for someone affected by it, and we have to start writing the story we want our kids to inherit. I am trying very diligently to not live an echo chamber of the challenges this diagnosis presents. I can't buy into the idea that my daughter will end up in jail or addicted to drugs or alcohol. I won't. She will be the best of herself. She will be *kind, and worthy, and strong, and able*. It is all I can do. It is everything I can do.

-Mom of 5 ([faster.with.friends@gmail.com](mailto:faster.with.friends@gmail.com))

<https://pdfs.semanticscholar.org/9574/f10d44c51adde7a1abfc01dbf03a09f11c78.pdf>

<https://jamanetwork.com/journals/jama/article-abstract/2671448?redirect=true>

Q: What happens to a frog's car when it breaks down?

A: It gets toad away.

From our friend Emily P.

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## Member Spotlight

### Juline Lloyd

I am excited to fill the role of secretary on the MCFARES board. I'm passionate about raising awareness of FASD, and supporting families and individuals affected by it.

Tell us 3 things about yourself (two are true, one is false – see end of the story to find out which is false)

1. I have 4 kids, 2 dogs and a cat.
2. I love snow skiing.
3. My hobbies include, traveling, and eating good food!

What is your favorite season and why?

Summer is definitely my favorite season. I love being warm, I love sunshine and I love long summer evenings sitting on our deck.

Favorite Color – Green

Favorite Sport – hmmm, I'm not much of a sport person.

Favorite Store – Bed Bath and Beyond and Nordstrom's Rack

What is your favorite movie and why?

This is a hard question to answer. Right now, I would have to say it is "A Man Called Ove." I loved the book and the movie. I like how Ove is forced to live a bit outside of his comfort zone and finds friendship in unexpected places.

What is one thing you could not go without during your day?

I am on my laptop a lot! Mostly for school or projects I am working on. I think I would be lost without it.

Tell us about your current job:

Right now, I am a mom and a student. I am working on my Master of Science in Nursing Degree. After this semester I only have 3 more classes!

What, in your opinion, is the biggest need related to FASD in Michigan?

Awareness! I do not think people understand what FASD is or the impact it has every day on so many people. If we can raise awareness, I think we could start improving services and decreasing the rate of FASD in Michigan.

The Lie....I love snow skiing. I do not like snow skiing! Am I allowed to say that in Michigan? I grew up in a warm climate and skied for the first time as an adult.



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## Michigan FASD Task Force 2016-2018

**Goal #1:** Make MCFARES as the NOFAS affiliate the clearinghouse for FASD information in Michigan and accumulate information regarding services and resources available for parents and professionals.

**Goal #2:** Educate all who come into contact with individuals who have an FASD for the purpose of improving lifelong outcomes by increasing access to information, to resources, referrals, screening tools, and intervention strategies.

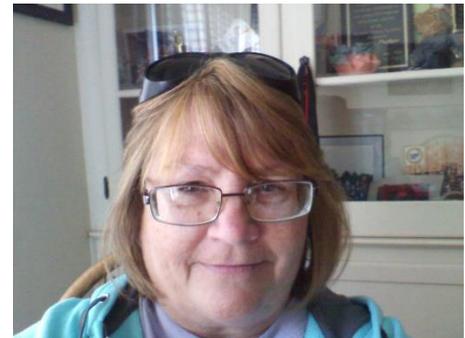
**Goal #3:** Empower adults with FASD through screening, diagnosis, treatment and interventions, and support.

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## Thank you, Barb Parker, for your service

Barb Parker has served on the board of MCFARES since 2008 and has decided to step down. Barb and her husband, Steve, are the parents of three children who are on the fetal alcohol spectrum. Their youngest child is 21-years-old and now their attention can be turned to frequent camping trips and activities with Special Olympics.

During her tenure on the Board, Barb assisted the Coalition in completing the paperwork necessary to become a non-profit organization, assisted annually in the preparations for the International Fetal Alcohol Spectrum Disorders Awareness Day activities, and helped to develop and coordinate Project S.A.F.E. monthly meetings. Barb's focus while a Board member with MCFARES was to identify and develop services and supports for families.



Thank you, Barb, for your service and dedication to raising awareness of fetal alcohol spectrum disorders. We appreciate your commitment and hope you find lots of time to camp.

## Braggs

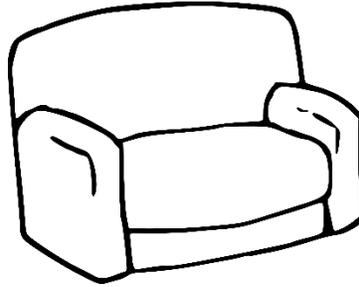
<p style="text-align: center;">Gabby, age 15 . . .</p> <p>. . . usually helps as a junior leader in the church's special needs class each week. Recently, she was asked to be a buddy for a kindergarten boy who has extreme ADHD. Gabby spent the entire class with the boy, redirecting, helping and gently helping him return to his group. She played "smashing dinosaurs" with him during free play. During this time, Gabby was able to listen to and understand the bible story and was able to re-tell the story later.</p>	<p style="text-align: center;">Armando . . .</p> <p>. . . made the honor roll.</p>
<p style="text-align: center;">Gabby, age 15 . . .</p> <p>. . . loves her new high school and is getting mostly As and Bs in her classes. She just finished reading MacBeth with her English class and loved it!</p>	<p style="text-align: center;">Megan, age 21 . . .</p> <p>. . . was featured on WXYZ-TV to talk about the Special Olympics of Oakland County Winterfest. Catch her here:  <a href="https://www.youtube.com/watch?v=4KVNj4qt nN4&amp;sns=em">https://www.youtube.com/watch?v=4KVNj4qt nN4&amp;sns=em</a></p>
	<p style="text-align: center;">Toby Alan, parent . . .</p> <p>. . . successfully advocated for his son with the Michigan Department of Special Education. Toby filed a complaint because the district was violating his son's IEP. The district was given steps to correct the violation, which may also affect hundreds of other special education students. The district was mandated to make up the special education service hours that were outlined in the IEP but not provided.</p>

## Donate Time – Work with Us!

Do you have a few hours to spare? We have several different opportunities to help you put your spare time to good use. Do you like kids? Maybe you can enjoy Project S.A.F.E. with us and supervise the children after dinner so that parents have some time to talk. Do you have website-building skills? We'd love your help re-designing and updating the MCFARES website. Do you have newsletter-designing skills? We could use your help putting the quarterly MCFARES FASD News and Views newsletter together (we'll develop the content and you can organize it into the newsletter).

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## On-line Support Group Starting Soon



### Michigan Project SOFAS Parent Support Group (Strength through Online Fetal Alcohol Support)

Are you interesting in meeting up with other parents but just can't seem to get out of the house? We may have just the answer for you. Join us for Michigan Project SOFAS: A synchronous online meeting designed to provide Michigan families of individuals with an FASD with a caring and supportive space. Please consider taking this online survey so that we might find a time that works for most families. <https://www.surveymonkey.com/r/5JPCN6C>. Please address any questions to [info@mcfares.org](mailto:info@mcfares.org).



**Vision:** The Coalition strengthens served communities' ability to eliminate prenatal alcohol exposure and provide support to persons and families impacted by fetal alcohol spectrum disorders (FASD) by delivering exemplary professional education, public awareness, and support.

**Mission:** Bridging the gap between individual needs and community services

To find out how you can help us work toward our vision and mission, contact us at [info@mcfares.org](mailto:info@mcfares.org).

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## What Do You Read, Watch, Listen To?

In our attempts to learn more about fetal alcohol spectrum disorders, we scour libraries, explore the internet, and question anyone who might know about FASD. We'd like to know about your favorite websites, books, articles, videos, support groups, etc. We'll compile the information and include it on resource sheets or on our website. If you've got suggestions to share, please email your favorites to Charisse at [charisse@mcfares.org](mailto:charisse@mcfares.org). Thanks for your help.

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### Kroger Community Rewards

Please consider registering MCFARES as the beneficiary of rewards using your Kroger Plus card. The MCFARES organization number is 91150. We thank you for your support. Funds raised will assist MCFARES in providing support to individuals and families affected by pre-natal exposure to alcohol.





## Support Groups for FASD in Michigan

### (not all groups are specifically for FASD support)

(Please phone or email contact person prior to attending to ensure that group is still meeting. If information has changed, please email Charisse at [Charisse@mcfares.org](mailto:Charisse@mcfares.org)).

#### Alpena County

FASD Family Support Group, Meets 2<sup>nd</sup> Thursday of each month; 1:30 – 2:30 p.m., Partners in Prevention office in the First Presbyterian Church at the corner of US23 and Long Rapids Road, Alpena. Contact Mary Schalk at [mary@nemcpi.org](mailto:mary@nemcpi.org) or 989-359-2880 for more information.

#### Eaton County

Eaton County Foster Adopt Support Group, Meets 1<sup>st</sup> Thursday monthly, 6 – 8:30 p.m. Pot-luck dinner at 6:00 p.m. Group/training at 6:30 p.m. Childcare available. Eaton Intermediate School District, 1790 Packard Highway, Charlotte, MI 48813. Located right next door to Walmart. Contact Michelle for more information at [besa\\_93@yahoo.com](mailto:besa_93@yahoo.com).

#### Kalamazoo County

Kalamazoo Area Fetal Alcohol Spectrum Disorder Support Group (KAFASD), Meets 2<sup>nd</sup> Tuesday monthly, 6:30 p.m. Augusta McKay Library, 105 S. Webster Street, Augusta, MI 49012. For more information, contact Robin or Kathy at [KAFASDgroup@yahoo.com](mailto:KAFASDgroup@yahoo.com).

#### Kent County

West Michigan FASD Support Group, Meets 3<sup>rd</sup> Tuesday of each month, 7 – 8:30 p.m., Westminster Presbyterian Church, 47 Jefferson Avenue, Grand Rapids, MI 49503. Contact Sandy Kezenius, 616-874-9522; Corry Tait, 616-550-4273; or Barbara Wybrecht, 616-241-9126 or [bmwybrecht@gmail.com](mailto:bmwybrecht@gmail.com) for more information.

Self-Advocates with and FASD in Action (SAFA), generally meets on the 3<sup>rd</sup> Tuesday of each month. The meeting is for adults age 18 and up who have an official FASD diagnosis. Contact Rob Wybrecht for more information, [rob1195@yahoo.com](mailto:rob1195@yahoo.com).

Adoptive Families Support Group, Meets 3<sup>rd</sup> Tuesday of each month, 6 – 8 p.m., Holy Family Catholic Church, 9669 Kraft Avenue SE, Caledonia, MI 49316-9723. Contact Shelley Garcia, 1-855-MICH-P2P, x705 or [sgarcia@afsn.com](mailto:sgarcia@afsn.com) for more information.

### Macomb County

Project SAFE (Supportive Activities for Everyone), generally on a Friday or Saturday evening from 5:30 – 8:30 p.m. at various locations in Macomb County. Families meet for pot-luck dinner followed by supervised play for the children and support group time for adults. Contact Charisse at [Charisse@mcfares.org](mailto:Charisse@mcfares.org) or 586-329-6722.

Brunch Bunch, Monthly, 2<sup>nd</sup> Tuesday, 9 a.m. – 11 a.m., In Clinton Township, Contact Charisse at [Charisse@mcfares.org](mailto:Charisse@mcfares.org) or 586-329-6722 for location details.

### Muskegon County

Support group for foster/adoptive/kinship families. Very active group meets weekly for various activities. Contact Janice Hilleary at [Bjhilleary@comcast.net](mailto:Bjhilleary@comcast.net) or 231-286-7892 (cell phone).

### Washtenaw County

Ann Arbor Support Group, Meets 4<sup>th</sup> Wednesday of each month except November (meets 3<sup>rd</sup> Wednesday) and December (no meeting), 7 -9 p.m. St. Joseph Mercy Hospital, Education Center, Classroom #5, 5305 East Huron Drive. Contact Vern Soden for more information, [vsoden@umich.edu](mailto:vsoden@umich.edu).

### Statewide List

Foster, Adoptive, and Kinship Support Groups by County <http://afsn.org/services/foster-adoptive-and-kinship-support-groups-by-county/> (not all groups are FASD-specific)

### On-line Information/Support

MCFARES: <https://www.facebook.com/groups/MCFARESFASD/>

Michigan's FASD Advocacy and Social Network: <https://www.facebook.com/groups/mifasd/>

KAFASD (Kalamazoo area): <https://www.facebook.com/groups/KAFASD/>

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MCFARES is the Michigan NOFAS Affiliate

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## MCFARES Member Agencies

Arc Services of Macomb  
(fiduciary)

Family members of affected  
individuals

Michigan FASD Task Force

Kids Belong/ACMH Board  
Member

Oakland University School  
of Nursing

Parent and Child Services,  
Inc.



*MCFARES needs you. Call us at  
586-329-6722 to find out how you  
can help.*

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