

FASD News and Views



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



Established in 2003

Questions We Are Asked

Question: *Our 8-year-old daughter is in a self-contained 3rd grade classroom. Her teacher just implemented a plan that uses a daily point sheet. Students lose points for infractions such as being off-task, not following directions, not completing homework and those who fail to earn a set number of points before recess lose part of recess. The system is too complicated for my daughter to follow. I'm concerned that it won't help improve her behavior and may do just the opposite. How do I approach the teacher?*

Answer: This type of behavior program, basically a token economy, can be a challenge for our children to understand and learn from. Though your daughter may be able to correctly state every classroom rule, she may not understand what the rules mean and how to perform each required task. In the end, she may be punished (i.e., lose recess time) for behaviors that are out of her control.

How you advocate on behalf of your daughter may depend on your relationship with her teacher and the school. It may be that the teacher is unaware of the needs of students who are on the fetal alcohol spectrum. If that is the case, it may be helpful to provide education about FASD in the classroom setting. You can refer the teacher to this page

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on the MCFARES website:
<https://www.mcfares.org/schoolresources> and

consider printing out (or, emailing) some pages from the resources that relate specifically to your daughter.

If needed, you can call a team meeting and/or an IEP review/redevelopment meeting and add accommodations and modifications to the plan that will help meet the needs of your daughter. You can also request that your daughter's education team be trained in the neurobehavioral approach to addressing the needs of students who are on the fetal alcohol spectrum.

Your goal as an advocate for your daughter is to help the school move toward creating an environment that will help your daughter succeed in school. They will need to put a plan in place that will support her strengths and adapt the environment to assist her in areas of weakness.

If you have any FASD-related questions, please send them to Charisse at charisse@mcfares.org

Pure Michigan



Tahquamenon Falls

International Fetal Alcohol Spectrum Disorders Awareness Day, Macomb County Project S.A.F.E. Open Meeting

Saturday, September 8, 2018



On Saturday, September 8th, families from Macomb and surrounding counties gathered to recognize International Fetal Alcohol Spectrum Disorders Awareness Day. We enjoyed a potluck meal, learned about fetal alcohol spectrum disorders, and heard from some of our local families.

Project S.A.F.E. meetings are held monthly for individuals and family members who are affected by FASD. If you'd like to join for a future meeting, please email Charisse at charisse@mcfares.org for more information.

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

Member Spotlight

Tell us 3 things about yourself (two things are true, one is false):

1. My favorite quarterback is Aaron Rodgers.
2. I taught special education for 12 years.
3. My dog's name is Sugar.

What is your favorite season and why?

Fall. It's football season, it's not too hot or too cold and my birthday is in September.

It's a cool, crisp fall day. You've got the day off work and no commitments. How will you spend your day?

I would love to drive up to the UP to visit my oldest up at Michigan Tech with my kids and my boyfriend. This way we could see the fall color change all the way throughout the state.

Favorite Color – cobalt blue

Favorite Sport – football

Favorite Store – Kohl's

What is your favorite movie? Why?

My favorite movie is Jerry Maguire. It's about football. Do you notice a theme here? Also, it has life lessons throughout the movie with which I can relate.

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

My colleagues at work at The Arc...they are the best!

Tell us about your job:

I am the Director of Quality at The Arc of Macomb helping to ensure that The Arc is in compliance with federal and state rules, guidelines and regulations. I handle substantiated allegations against staff who have been investigated by the Office of Recipient Rights. I analyze incident reports and Rights Complaints for trends in order to develop proactive strategies for reducing their occurrences. I am also the management representative of Production for the day program at The Arc. I make sure we are in compliance with the standards and regulations of ISO 9001:2015.

What attracted you to your current job?

I love working with people to help them become the best person they can be through focusing on strengths and developing strategies to accommodate challenges. I started off as a Special Education Advocate and have moved into a position where I work with the Office of Recipient Rights through Macomb County Community Mental Health to ensure that all staff that work with our recipients of services are providing quality services to individuals with developmental disabilities.

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

There are many needs, but if I had to pick three I would say the following:

- 1) Educating the educators.
- 2) Developing support systems for individuals affected by FASD and their families that help them to navigate throughout their lifetimes.
- 3) Housing for individuals living with FASD and advocating for the support they need to live independently.

#1 is a lie. I am a diehard Lions fan and I loathe Aaron Rodgers from Green Bay.



Friends of FASD 5k Fundraiser Saturday, September 15, 2018

On the morning of Saturday, September 15th, 2018 almost 50 people gathered for the first Friends of FASD 5K. The run / walk started and ended in Shiawassee Park in Farmington, MI and the course went around the downtown Farmington area and around the high school.

The participants included sponsors, exhibitors, high school volunteers, and runners and walkers from the greater Detroit area and beyond - one family even traveled from northern Michigan to participate in the event.



It was a great morning and an amazing feeling to be surrounded by compassionate people who all cared about Fetal Alcohol Spectrum Disorder.

Aside from the actual event at Shiawassee Park, another 24 people from across the country participated in the Friends of FASD 5K as virtual participants - they registered online to run or walk on their own schedules and locations, and received a T-shirt after the 5K and can proudly wear their Friends of FASD 5K T-shirts to spread awareness for FASD across the country.

The Farmington Police were also kind enough to place squad cars at the corners of the race route for safety and their flashing lights also added some excitement to the race course.

Each participant received a T-shirt and several red rubber Friends of FASD bracelets at the finish line so that they could share the bracelets with others and, in turn, spread awareness for FASD.



During the after race party, sponsors set up exhibits for



participants to browse and passed out samples and coupons. There was also a raffle with items generously donated by local businesses. One lucky winner won a camping grill, and another coupons for 25 free Slurpees from 7-11.

The 5K was sponsored by Anna's House Restaurants, who generously covered all of the race costs. Med-Trans, FlightCare, Kids in Motion Pediatric Therapy Services, State Farm and 7-11 were also gracious sponsors of the event.

Friends of FASD is a non-profit 501(c)(3) and all of the proceeds from the 5K will be used for therapy scholarships for children with FASD who live in Michigan. The 2018 Friends of FASD 5K raised almost \$2,000! We're still waiting from some donations from sponsors and once all of the donations are in, we'll open up scholarship applications! Please stay tuned for information on that - hopefully here in the next newsletter.



We're also planning another Friends of FASD 5K for September 2019! Email kjbwagner@gmail.com if you want to be added to the email list of participants, volunteers or sponsors.

Metro Parent Article about the event: <https://www.metroparent.com/daily/parenting/special-needs-resources/michigan-family-adopts-child-with-fetal-alcohol-spectrum-disorder/>

SAVE THE DATE

Friday, May 17, 2019

The Michigan FASD Task Force and MCFARES will be hosting a conference in downtown Lansing on Friday, May 17, 2019. Planned topics include: Education for Children who have an FASD, Supports and Services for Adults, Living with FASD, FASD and the Brain-Based Approach among many others. The conference will benefit those who are affected by prenatal exposure to alcohol, their family members, nurses, teachers, speech therapists, social workers.

If you are interested in being put on the mailing list to be notified when registration opens, please email Charisse at charisse@mcfares.org. Please feel free to share this information with others who might be interested in attending.

About the DiG FASD Research Study



<https://digfasd.org>

844-378-0002

fasd@iu.edu

www.facebook.com/FASDresearch

The purpose of the “Dissecting the Genetic Contributions to Fetal Alcohol Spectrum Disorders” (DiG FASD) study is to understand how genetics affects the various features of FASD.

To do this, researchers at Indiana University are recruiting individuals who were prenatally exposed to alcohol or have an FASD. Participation in DiG FASD will take place from home. There are no in-person visits. There is no cost to participate in the study.

Who Can Participate?

The DiG FASD study is recruiting anyone over the age of 7 who speaks English and was prenatally exposed to alcohol or has an FASD diagnosis.

How Do I Start?

To start, go to <https://digfasd.org>. You will see the study consent forms that describe the study and ask you to provide an electronic signature. There is a **video** for younger participants to help them understand the study. You can stop and ask questions at any time.

Provide Information

After you finish the consenting process, you will be asked to complete some online forms and to provide information about any FASD-related diagnosis. We will call you to confirm your willingness to participate.

Provide Facial Photographs

Besides answering the questions online, you will be asked to take photographs of your face using a cell phone, tablet, or digital camera and upload the photographs to the study site. We will analyze the photographs to better understand how the combination of your DNA and prenatal alcohol exposure might affect facial features.

Provide a Saliva Sample

You will be asked to provide a saliva (spit) sample for genetic research. We will use your saliva to obtain and analyze DNA to better understand how the combination of your DNA and prenatal alcohol exposure might affect facial features.

All the information and the photographs you provide will be kept confidential and secure, and will be used for research purposes only. No photographs or personally identifying information (such as name, address, or telephone number) from this study will be published.

Get Started

Thank you for reading about our study – we hope you'll want to help us with our research. Please go to <https://digfasd.org>.

Get Connected

Contact us at 844-378-0002 (toll free) or fasd@iu.edu. Like our page or share our posts on Facebook at [FASDresearch](#) or Twitter at [@FASDresearch](#).

About Our Team



Tatiana Foroud, Ph.D., is a Distinguished Professor and Chair of the Department of Medical and Molecular Genetics at Indiana University School of Medicine (IUSM) in Indianapolis, IN. She has over 20 years of experience conducting genetic research. Dr. Foroud is a founding member of CIFASD, and has been a leader in the field of FASD research for more than 15 years.



Leah Wetherill, Ph.D., is an applied statistician at IUSM with 20 years of experience researching the genetics of alcohol dependence. She also studies how prenatal alcohol exposure affects the risk of ADHD and similar disorders. She has been part of CIFASD since its inception, and has travelled to South Africa and across the USA to help CIFASD study FASD.



Elizabeth Rowe, Ph.D., is the newest member of the team and is Project Manager of DiG FASD. Her experience in researching gene-environment interactions and running a genetic research study is vital to the DiG FASD team. After you sign up for the DiG FASD study, Dr. Rowe will contact you and answer any questions you have.

Q: Why don't you iron your four leaf clovers?

A: You don't want to press your luck.

From our friends Paige and Emily S.

Braggs

Joy, age 16 . . .

went to homecoming and had a great time. She’s had a great start to the school year and has auditioned for the band. She’ll start concert band in November.

Jay, age 6 . . .

is coloring inside the lines perfectly all the time! He mastered this new skill and no stopping him now!

Another skill is he is remembering to look at his visuals in class and locker on what to bring home every night from school. Repetition is key and he is getting it!

Jay is also remembering the days of the week and what happens on those days in school for gym, music, art, computers etc. He is also reading books his class is learning and grasping the concept of site words and can write them too!

Anna, age 21 . . .

shared the story she wrote, “Never Give Up on School,” at the FASDay open Project SAFE meeting in Macomb County. Anna wrote the book to tell others about the types of things she and other students like her need in an educational setting.



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).

How to Frustrate a Person with FAS

This has been the summer of home improvements, some planned and some unplanned. The work on our house upset routines, made for some very sullen teens and also, surprisingly, annoyed the fish in our large reef tank!

How do I know the fish were annoyed? Well, it was only one of the fish. He's a surgeon fish, also known as a tang. This guy's name is Moe. As new windows were being put in, he tormented 2 other fish by smacking them with his tail. This is where the surgeon part comes in. These fish have a small, very sharp blade sticking out at right angles to their body just before the tail. Yes, Moe was trying to slice his tank buddies!



For the human part of the family, the worst part of the unplanned updates was having a new combination washer-dryer delivered and the old ones taken away. Gabby, almost 16 at the time, had been doing her own laundry for many years. She was quite proud to be able to do it and put it all away herself. When she came here from Russia at 25 months, she knew how to fold her blanket neatly and put it at the end of her bed. So, she just built on that skill over time. She watched and learned how to carefully do the wash using our front loader, transfer things to the dryer, clean out the lint and nicely fold everything to put away in her room.



The new machine is also a front loading machine but it has a big dial, many buttons and no dryer to transfer things to. On the first day I read how to run a load from the manual. We trooped down together with our laundry.

I went through all the steps. Gabby was nervous. I started the machine and it got going. She asked how long. I told her we had to wait a minute

while the machine weighed the load and calculated the time. Gabby turned and

marched out of the laundry room, telling me she would not be waiting to see that. I

would be doing her laundry because the machine was stupid.

Over the period of three weeks, Gabby slowly progressed from only bringing her laundry down to watching what I did. I discovered in those weeks, there was a button to save a program, so I did. I brought Gabby down to show her. She said that was good but I could still plan to do her wash.

One Saturday morning, she asked me to show her the button I had told her about. We went through everything together. We waited and the numbers came up, 3:15. I said, "Ok, in 3 hours and 15 minutes, her clothes would be dry." I asked her how would we remember to get them.

Three hours is a long time. She suggested a timer. I said that was a good idea. Our usual timer only went to 90 minutes so we needed to find a timer that could do a longer time. Gabby

suggested my iPad. We found the timer and set it for 3 hours, 15 minutes. When the timer went off, Gabby ran downstairs to get the laundry. It was just finished. It was very hot! She brought it up and folded it. I thanked her for helping so nicely. The next Saturday she started everything herself. She came running to me and said, “Mom, come downstairs and see what I did!” I went down and the machine was running. She could do her own laundry again! Gabby was so happy!

We are still working on the new dishwasher. It is still stupid. I think things will change in another month or so! For now, I just remember to ask her to come hand me the plates and silverware so she can see where things fit. Patience will help Gabby learn how to use this stupid machine too. Time, patience, modeling for her. It works.



Submitted by Laurel who, in addition to being mom to Gabby and Duncan, is also a creator of fine knit and crocheted items and keeper of the Smith Family Zoo and Aquarium.

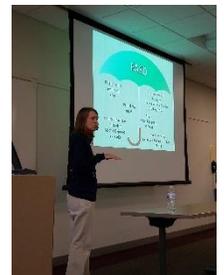
Fetal Alcohol Spectrum Disorders: The Basics



On October 2, 2018 Emily Rusnak, Ph.D., CCC-SLP spoke to almost 40 educators and support staff at the Macomb Intermediate School District.

The topic of the presentation was Fetal Alcohol Spectrum Disorders: The Basics. Participants learned about what FASD is, how it affects individuals across the lifespan, prevalence information, diagnostic information, diagnostic

challenges, and intervention strategies. Plans are being made to provide another training session in the spring, 2019 to cover interventions. If you are interested in learning more about intervention strategies, you can be placed on a “Save the Date” list by contacting Charisse at charisse@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.

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. Thanks for your help.

Barb P., recommends viewing this ESPN video about Andrew Peterson, a 25-year-old runner who has FAS. You can view the video and read the story here:

http://www.espn.com/specialolympics/story/_/id/23906336/special-olympics-usa-games-marathoner-andrew-peterson-was-born-run

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).

Alpena County

FASD Family Support Group, Meets 2nd 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 or 989-359-2880 for more information.

Eaton County

Eaton County Foster Adopt Support Group, Meets 1st 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.

Kalamazoo County

Kalamazoo Area Fetal Alcohol Spectrum Disorder Support Group (KAFASD), Meets 2nd 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.

Kent County

West Michigan FASD Support Group, Meets 3rd 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 for more information.

Self-Advocates with and FASD in Action (SAFA), generally meets on the 3rd 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.

Adoptive Families Support Group, Meets 3rd 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 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 or 586-329-6722.

Brunch Bunch, Monthly, 2nd Tuesday, 9 a.m. – 11 a.m., In Clinton Township, Contact Charisse at 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 or 231-286-7892 (cell phone).

Washtenaw County

Ann Arbor Support Group, Meets 4th Wednesday of each month except November (meets 3rd 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.

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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Updated 11/17



MCFARES is the Michigan NOFAS Affiliate

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.*
