

FASD News and Views



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



Established in 2003

Questions We Are Asked

Question: *I attended the MCFARES 2019 Living and Learning with an FASD conference in Lansing. We were given so much information. I'm excited to learn more and assist MCFARES in some way. How can I do that?*

Answer: For many who attended, the conference was just the beginning. The presentations helped several of our participants understand that there is so much more to learn. Thank you for recognizing the need to learn more and taking steps to make that happen.

There will be many opportunities available that can help you increase your knowledge. For instance, MCFARES will be hosting FASD 101 and FASD 201 courses throughout the state. When those trainings are scheduled, they will be announced on our website (<https://www.mcfares.org>) and on the MCFARES Facebook page (<https://www.facebook.com/groups/MCFARESFASD/>).

Dan Dubovsky will be returning to the state for several training opportunities. Check with your local community mental health center to see if he'll be in your area soon. Adrienne Bashista, the co-founder of

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FAFASD (Families Affected by Fetal Alcohol Spectrum Disorders), hosts webinars that are scheduled regularly throughout the year. You can visit her website to learn about upcoming webinars (<https://fafasd.org/workshops-and-training/>). The MCFARES website has links to articles and videos on many different subjects relating to fetal alcohol spectrum disorders (<https://www.mcfares.org>).

If you're interested in joining the Coalition to help us further our goals, let us know and we'll add you to our list. You can also help MCFARES in very simple ways by making a tax-deductible financial contribution. Also, see pages 12 and 15 of this newsletter to learn other ways to contribute to MCFARES.

Now that you're becoming FASD-informed, you can begin to help those around you understand FASDs. You can share this newsletter and other MCFARES resources with others in your workplace and with family and friends. Anyone who has questions regarding fetal alcohol spectrum disorders can contact us at info@mcfares.org. We'd be happy to connect others with the information they're seeking.

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

Documentary Screening Follow-up

On Thursday, May 16th, about 25 people attended a screening of the documentary film, "Moment to Moment: Teens Growing Up with FASDs" by NTI Upstream. After the screening, the group, most of whom were parents of children on the spectrum, spent some time talking about the film and discussing ways in which they can most effectively help their children navigate the teen years.



If you would be interested in attending or hosting a film screening, please contact Charisse at charisse@mcfares.org.

Barbara Wybrecht Receives Award

Barbara Wybrecht has spent decades working to raise awareness of fetal alcohol spectrum disorders, has been a featured speaker at conferences around the world and has supported countless numbers of parents in their journey to find services and supports for their children. In one way or another, every person who attended the 2019 Living and Learning with an FASD conference has benefitted from Barbara's tireless commitment to increasing awareness of and services for FASDs.

It was only fitting, then, to recognize Barbara by presenting her with the 2019 FASD Lifetime Achievement Award for Exceptional Innovation, Vision, and Leadership. Emily Rusnak, MCFARES Vice-President, offered a brief presentation that



highlighted some of Barbara's accomplishments. Included in the presentation was a letter written by Tom Donaldson from the National Organization on Fetal Alcohol Syndrome (NOFAS) thanking Barbara for her many years of hard work. After the presentation, one of the conference attendees was overheard saying, "I never knew we were amongst such greatness."



Congratulations, Barb, and thank you for your tireless dedication and service to others.



Living and Learning with an FASD Conference

May 17, 2019

On Friday, May 17, 2019 close to 300 people gathered in Lansing to learn about fetal alcohol spectrum disorders from many of this country's top experts. Keynote speakers included Christina Chambers,

Ph.D. from the University of California, San Diego who spoke about the prevalence of FASDs; Julie Kable, Ph.D. from Emory University spoke about ways to improve

the lives of individuals who have FASDs and Heather Carmichael Olson, Ph.D. from the University of Washington spoke about the Families Moving Forward program that has been implemented in several CMHs in Michigan.



Breakout sessions included talks by Nate Sheets who spoke about cognitive supports for people with FASDs; Adrienne Bashista who spoke about the brain-based approach to FASD interventions; Julie Kable and a panel of parents who spoke about education interventions; Barbara Wybrecht and a panel of self-advocates who spoke about living, learning and succeeding with FASDs and she did a second talk about gaining equal justice for those with FASDs; a panel of professionals from agencies that provide supports and services to children and adults who are on the fetal alcohol spectrum; Anna Hon and a parent who spoke about lessons learned from living on the reservation; Charlyss Ray and Mary Jo Kurily spoke about sensory strategies for FASDs.

The conference took over a year to plan. Seeing the conference hall filled with standing-room-only participants was worth the many long hours of preparation. We look forward to seeing everyone again at the next conference.

If you'd like to be informed of future conference and training opportunities, please send an email to info@mcfares.org with "Add me to the email list" in the subject line.



Macomb Project SAFE FASDay, 2019

On Saturday, September 14 Macomb Project SAFE will host an open Project SAFE meeting to recognize International Fetal Alcohol Spectrum Disorders Awareness Day. Families, friends, professionals and anyone else interested in learning more about fetal alcohol spectrum disorders and supporting the efforts of MCFARES is invited to join us. We'll enjoy a meal together, give the kids some time to play in the gym, have a time for the adults to talk and maybe even enjoy a game of MCFARES FASD Trivia. We'll have some nice prizes for those who join us.

If you'll be joining us, please send an email to info@mcfares.org with "Macomb Project SAFE FASDay" in the subject line and the number of people in your group in the body of the email. We look forward to seeing you there.



Help Wanted in Muskegon



Kinship Care Family seeking 3-5 on-call and/or part-time support persons to help transport children to activities, appointments, extra-curricular activities, and, at times, help with dinner, homework, etc. Days and times include Monday – Friday, 2 p.m. – 7 p.m., depending on the day's schedule. Rare, but on occasion, schedule may require some first shift hours. Will compensate. If interested, please contact Amy at amy.circleoffriends@gmail.com.



Friends of FASD is now organizing its second annual Friends of FASD 5K!

WHEN: Saturday, September 21st, 2019, 8:30 a.m.

WHERE: Shiawassee Park in Farmington MI

Registration is now OPEN! And kiddos who register with an adult are only \$15.

Please visit www.friends-of-fasd.com for more information.

The proceeds go to fund small grants for children with FASD and last year we were able to award FOUR small grants!



Please help spread the word! It's a virtual run too! Register anywhere in the continental US and I'll mail you a T-shirt and swag bag.

Friends of FASD is a registered non-profit 501(c)3. We are looking for sponsors. I'll do the soliciting if you email me at FriendsFASD@gmail.com with contact information for businesses who might be interested in helping us out.

Kent County Project SAFE

If you're in the Kent County area, mark your calendar for Saturday, September 7 at 4:00 p.m. Families will be gathering at Cascade Township Park for an afternoon of fun, and encouragement. Further information will be given on the MCFARES Facebook page (<https://www.facebook.com/groups/MCFARESFASD/>) and the MIFASD Facebook page (<https://www.facebook.com/groups/mifasd/>). Contact Juline Lloyd for more information (juline@mcfares.org).



Lansing Area Project SAFE

In May three families from the Lansing Area Project SAFE group visited Dow Gardens. The group enjoyed a visit to the gardens and then had lunch together on the grounds.

The Lansing Area Project SAFE group is in the process of planning future events. Contact Brian Hagler (bhagler3@icloud.com) or Cathy Mielke (cathymielke1@gmail.com) for information about future Lansing: Project SAFE events.



Dow Gardens, Midland, MI

Meet Erin, Owner of Beadweaveitornot

My name is Erin and I'm not perfect.

I am an adult with Fetal Alcohol Syndrome. I am adopted. I was put into foster care when I was 2 months old and the same family adopted me when I was almost 2 years old.

For most of my school years I was verbally bullied, because I was shorter than my other classmates. Also because I learned at a different level than them.

Middleschool was the hardest, I became depressed, confused and angry. Though I never let anyone see it.

The older I got and the more I learned about my birthmoms drinking. I became less depressed, confused and angry. Instead I consider my life a miracle. God protected me. I am excepting the fact that I am not going to grow out of my disability and I can't change it.

I have always liked doing crafts especially with little seed beads. I have made paper beads and putting them into the jewelry. (earrings, bracelets)

I started making jewelry about 8 years ago. I did use to sell to family and friends, and people at church. Now I have decided to make it a business. In my jewelry I have one different colored bead. And that shows that I am not perfect, and that i am ok with my disability.

When I am selling at craftshows, or at the farmers market and FASD conferences. I tell the costumers about the different colored bead. I tell them its to show that I am not perfect and then I tell them that I have FAS and how it has effected me.

I have many family and friends buy and wear my jewelry. both seed bead and paper bead. They have told me that people have been admiring and asking about the jewelry they wear. (bracelets, rings, earrings.) They have been helping me spread the word about FASD. I have also had costumers tell me that they either know someone who has FASD or has a child with FASD.

Its good to know I am not the only one.

Contacts and social media.

Email:

erindekorte@gmail.com Or beadweaveitornot@gmail.com

Facebook:

[Beadweaveitornot@facebook.com](https://www.facebook.com/Beadweaveitornot/)

Blog:

<http://madaboutbeading.blogspot.com>



This is Me

Faith, age 5

Faith started soccer this spring and is doing a great job! She loves running and kicking the ball, she is a great team player! We are so proud of her, go Faith!



(If you would like to be featured in our next “This is Me” column, please send your story and a picture to info@mcfares.org.)

Now that’s Silly

Q: What do cows play at parties?

A: Moosical chairs

Shared by Thanos S.

NB This . . .

Sometimes we struggle to figure out how to most appropriately address our child's behavior in a neurobehavioral manner. Here's a scenario and a response to addressing the behavior using a neurobehavioral approach.

Scenario: Must complete morning routine and leave for a doctor's appointment by 1:00 p.m.

- 1. Neurobehavioral Challenges:** Unaware of concept of time, distracted by other activities, unable to shift gears independently, unable to independently sequence events so that he can be ready on time.
- 2. Scenario Without Accommodations:** Left to his own devices, he'll play video games or talk on the phone rather than get ready to leave for the doctor.
- 3. Accommodations:** Understand that he cannot, on his own, get himself ready to leave so don't place expectations that he cannot successfully accomplish. Walk him through morning activities to get him ready in a way that's meaningful to him (sometimes verbal direction is too much so texting gives him the information he needs without the stress on his ears). Be observant that he completes the tasks. Keep the morning activities as non-stressful as possible. Prepare for unexpected delays by having snacks on hand and distractions that will keep him busy during the appointment. Distractions, such as having a saved movie on the Kindle or a video game work really well when there are delays (i.e., long waits). Bring bottled water and snacks for the drive.
- 4. Neurobehavioral Approach to Success:** Offer him 2 or 3 of his favorite breakfast choices so that he's more likely to eat a good breakfast. Do the same for lunch. Remind him that he has a doctor's appointment and what activities will be happening before the appointment. Help him through each transition by reminding him what's next (verbal or text, depending on his level of stimulation). Leave plenty of time to get the appointment. Bring a portable video game, music player or video player for distraction.
- 5. Explanation:** Due to his complicated needs, he sees several different doctors and has at least one appointment per month which he finds boring and annoying. To help him get through the day, accommodations need to be made to prevent him from melting down and refusing to go to the doctor. He now understands the process of each appointment and knows that after the appointment, we do something fun and he can make his own choices for the rest of the day.



Michigan FASD Champion Spotlight

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

1. I love to go barefoot in the summer.
2. I love to drive anywhere and everywhere.
3. I love cilantro and arugula.

What is your favorite season and why? I love summer because I can go swimming, keep the windows open and wear shorts.

It's a warm, beautiful summer day. You are free all day to do whatever you wish. How will you spend your day? I would spend all day swimming in a warm, calm lake with family and/or friends...or by myself if no one wanted to join me. I would end the day with my family eating dinner (one that I didn't have to cook) and playing games outdoors.

Favorite Color – Royal blue

Favorite Sport – swimming

Favorite Store – Trader Joe's



What is your favorite movie? Why? The Blues Brothers for many reasons but mainly the music, especially Aretha singing "Think." I often think of this song in my head. After hearing Nate Sheets' presentation at the FASD conference, it now seems very fitting.

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

Tell us about your job: I am a stay at home mother of 22-year-old twins who I treasure. They have FASD and developmental trauma along with some other diagnoses. Also, my husband is self-employed. My training as a physical therapist has been very helpful in raising our children but I was only able to work a few years outside the home as running our household and advocating for our children is more than a full-time position.

What attracted you to your current job? Our kids! As for my physical therapy career, I always knew I wanted to help others and stay active. As a child, I remember my best friend's father and family friend telling me (when he was terminally ill), "if you have your health, you have everything" and it made a quite an impact on me.

What, in your opinion, is the biggest need related to FASD in Michigan? I believe the greatest need is for training and understanding of FASD throughout all aspects of our community - especially in the educational, law enforcement and judicial systems.

At the conference, I was very excited to hear that the FMF (Families Moving Forward) program has come to 4 Michigan counties. I have hopes of it continually expanding, not only geographically but also in personnel training. In addition to training the CMH (community mental health) workers who are the program providers, I envision educating other professionals so they understand FASD and the FMF program. In turn, they could offer adjunct support when they come into contact with anyone in the FMF

program. I think the school system would be an excellent starting point with counselors, social workers, psychologists and police liaison officers all being trained to understand and assist students (and families) if needed. I believe programs like these are most effective when all the spokes of the community wheel are knowledgeable and supportive.

#2 is the lie! I don't mind driving but I dream of being chauffeured around so I could get more things done, totally relax or even nap.

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. If you have time to help us out with any of these activities, please send an email to Charisse at charisse@mcfares.org.

Here are some opportunities that require only a few hours a month or less:

- **Non-profit Accountant:** *Frequency:* probably 2-3 times/year. *Location:* from your office. *Time commitment:* probably no more than a couple hours/year.
- **Non-profit Lawyer:** *Frequency:* probably 1-2 times/year. *Location:* from your office. *Time commitment:* probably no more than a couple hours/year.
- **Project S.A.F.E.:** *Frequency:* about once a month. *Location:* varies. *Time commitment:* about 3 hours for each activity.
- **MCFARES FASD News and Views newsletter:** *Frequency:* four times/year. *Location:* varies. *Time commitment:* your choice.
- **Literature Packets:** *Frequency:* as your schedule permits. *Location:* your community. *Time commitment:* your choice.



Looking for Resources, Education and Support? Help is Just a Click Away

If you are looking for resources, education and support for FASD, consider joining us online on both of the MCFARES Facebook pages.

MCFARES hosts a public Facebook page, where new research and information about FASD is discussed with Michiganders and folks interested in FASD from around the globe. We also make announcements about Project SAFE meetings and other events. Visit our public Facebook page here: <https://www.facebook.com/groups/MCFARESFASD>

If you prefer a space on Facebook that does not post to your own newsfeed, then consider joining the MI FASD group--MCFARES social networking spot for families, practitioners, and self-advocates. We offer new research and information about FASD in this space. It is also a group that allows parents/caregivers, practitioners, and self-advocates to ask questions and receive support from people who "get it". Most of the members are from Michigan, but we do have a number of national members including some national presenters on FASD. Visit our closed support group space here: <https://www.facebook.com/groups/mifasd/>



Consider joining us online to help gain a better understanding of the disorder and find a support network of your peers!

Pure Michigan



**Ft. Holmes
Mackinac Island**

Bragg

Anna, 22 . . .

is going to Team Guts day camp where she will play games, work out and cook. The program knows Anna very well and they understand FASD. She gets to go to Team Guts Wednesdays and Fridays. Anna really enjoys Team Guts because everyone is so nice.



Jay, just turned 7 . . .

has been enjoying private drum lessons. Music helps relax him and work on dexterity skills.



Joy, 16 . . .

competed in Macomb County Special Olympics and won two blue ribbons in the 50-meter dash and standing long jump and a yellow ribbon in the soft ball throw.



Marcin, 22 . . .

continues to work as a cashier at a large home improvement store. He interviewed for a full-time position and was given the job. He receives his first raise this pay period. Also, Marcin has received many customer service pins. He recently spoke at an employer recognition event. He was chosen to speak by his job developer due to his ongoing success. Of course, we continue to be very proud of him and happy for him!



Brag, cont'd

Niko, 8 . . .

went to a fishing derby on June 8th and caught 4 bluegill. He was featured in a local newspaper.



If you would like to feature your brag in the next newsletter, please send the information to info@mcfares.org with “Newsletter Brag” in the subject line.

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

Kroger Community Rewards

Please consider registering MCFARES as the beneficiary of rewards using your Kroger Plus card. The MCFARES organization number is GK535. 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.



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.



This Quarter's Recommendation: Website

Nate Sheets' website, Oregon Behavior Consultation (<http://www.oregonbehavior.com>), provides links to valuable YouTube videos and podcasts. Nate is a behavior consultant in Oregon who specializes in working with individuals and families affected by FASD. You can also follow him on Facebook at <https://www.facebook.com/cognitivesupport/>.



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.

Ingham County

Lansing: Project SAFE, Meets monthly at various location in and around Ingham County. Contact Brian Hagler, bhagler3@icloud.com, or Cathy Mielke, cathymielke1@gmail.com, for more information.

Kalamazoo County

Kalamazoo Area Fetal Alcohol Spectrum Disorder parent/caregiver support network, KAFASD. This is a local (West Michigan) closed Facebook support network, with occasional social events, trainings and meetings. Join KAFASD at <http://www.facebook.com/groups/KAFASD/> or contact Robin at (269) 731-4577 or Kathy at 269-303-1402 for more information.

Kent County

West Michigan FASD Support Group, Meets 3rd Wednesday of each month, 7 – 8:30 p.m. September – May (no December meeting), Westminster Presbyterian Church, 47 Jefferson Avenue, Grand Rapids, MI 49503. Contact Sandy Kezenius, 616-648-9259 or sandnkez@hotmail.com; Cory Tait, 616-550-4273 or taitville@comcast.net; or Barbara Wybrecht, 616-485-8665 or bmwybrecht@gmail.com for more information.

Self-Advocates with and FASD in Action (SAFA), generally meets on the 3rd Wednesday of each month, September – May (no December meeting). The meeting is for adults age 18 and up who have an official FASD diagnosis. Contact Rob Wybrecht, 616-901-5980 (cell) or rob1195@yahoo.com or robw436@gmail.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.

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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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.***
