

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 12 year-old-son will be going to middle school in the fall. Do you have some suggestions about how to prepare him for the transition from elementary to middle school?*

Answer: Your son will be experiencing many changes this new school year. Before the school year starts, help him to express his concerns and be there for him as you both navigate through the concerns. Assess some possible concerns that your son may have. For instance, is he worried that he will be unable to find his way around the new school? If so, schedule a time prior to the beginning of the school year for him to tour the school to find his locker and his classrooms. If possible, learn the combination to his locker and help make sure he can successfully open the lock. If the school will allow it, arrange for your son to introduce himself to his new teachers. He can also work with you to write an introduction that he can share with all of his teachers and others who will work with him at school (here’s an example, modify it to suit your needs:

http://www.fan.org.nz/_data/assets/pdf_file/0004/33475/Parent_Info_booklet_Hey_Teacher.pdf).

In addition to having concerns about getting around the school, your son may be worried about the amount and difficulty of schoolwork. Talk with him to learn about his concerns and work with teachers (possibly through his IEP if he has one) to help relieve his concerns. Help him to put words to his concerns

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and learn to express them in a way his teachers will understand. Also, help teachers to learn how to recognize when he’s stressed and overwhelmed.

Teens, especially those on the fetal alcohol spectrum, may have difficulty with friendships, including dating relationships. Have ongoing discussions with your son about his relationships with his peers and help him to make good choices. Some schools provide peer mentors, social skills

programs or other interventions to help students who need special assistance with peer relationships.

If your son is interested in sports or other after-school activities, review with him all of his options. Talk with coaches or leaders of the activities that he is interested in and learn more about what will be expected of him if he joins the activity. Once he chooses an activity, work with the school to help him be as successful as he can be. He may need increased supervision during activities or other accommodations such as having rules and expectations clearly explained and reviewed on an on-going basis.

Continue to keep the lines of communication open with your son and with his teachers, coaches and others who work with him. Try to head off any challenges by addressing them as soon as they arise. Help your son learn self-advocacy skills by helping him to define his dreams, desires and concerns and learn how to express them appropriately to those who can assist him. You will be his main support and cheerleader through his school years and will have the ability to help him to be as successful as he can be.

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

SAVE THE DATE

Macomb County FASDay, 2017

On Saturday, September 9, 2017 from 5:30 – 8:30 p.m. at Fellowship Chapel in Sterling Heights, MCFARES will host an open Project SAFE meeting to recognize International Fetal Alcohol Spectrum Disorders Awareness Day (FASDay). We will enjoy a meal together, learn about FASD, hear from some of our families and play our annual FASD Trivia Game. Plan to join us for the fun and invite your family members and professionals.

MCFARES has hosted an event to mark FASDay since 2005. Please mark your calendars and plan to join us this year. For more information, please contact Charisse at charisse@mcfares.org.

If you'd like to join us for this event, please email Charisse at charisse@mcfares.org to let her know how many guests you will be bringing.

Q: How do you make an egg roll?

A: Push it
(from our friend Wyatt)

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)



Michigan FASD Task Force

2016-2018 Goals Update

Goal 3 of the FASD Task Force 2016-2018 Strategic Plan is as follows:

Empower adults with FASD through screening, diagnosis, treatment and interventions, and support.

Goal Update: Work on goal 3 continues. While the goal references adults, this goal actually applies to anyone with FASD and those who care about them. A survey focused on those with FASD and those who might have FASD but be unaware was developed and early returns were received. Similarly a second survey that focused on the capabilities of Michigan FASD Screening and Diagnostic Centers was also developed. Evaluation of the survey responses continues. In working on the goal, there was a realization that while a survey was appropriate, empowerment of those with FASD might be aided by a more personal understanding of what it is like to have FASD or be a caregiver for someone on the spectrum. A means of gaining this experience that is more personal, but still sensitive to and respectful of the individual may be appropriate to gain an understanding of how daily life and the world are experienced through an FASD lens. Discussion within the Task Force revealed that a more personal initiative would be expected to require substantial resources of funding, time and staff that are currently unavailable but may offer a beneficial future line of inquiry/research. Plans are also underway within Goal 3 to ask other state FASD organizations how they view Goal 3 and what they do to support, assist and encourage those with FASD and those who care for them. Information gained could then be used to provide initiatives within Goal 3 and other goals within this and future strategic plans.

If you or someone you know has not yet taken the survey, please consider completing it: <https://www.surveymonkey.com/r/FASDexperiences>. We thank you for your time.

Late Summer Middle of Michigan FASD Meet-up

Saturday August 19, 2017, 11 a.m. – 5 p.m.

Look for the signs near entrance 1 and by the meet-up area

Hawk Island Park

1601 E. Cavanaugh Road,

Lansing, MI 48910

\$3 Ingham County resident entrance fee, \$5 non-resident entrance fee

Portable shelters will be available. BYO drinks, plates, utensils and a dish to pass. Also, bring chairs, bathing suits and towels. Hawk Island has a fun splash pad and accessible play structure as well as a lake for swimming and boat rentals. We will have an informal 5k walk/run at 1 p.m. Come rain or shine from the east, west, north or south to put faces with the names we see in our support groups. We figured out a day, time and location, you bring your family and the fun! For more information, contact Laurel Smith at mama2russians@gmail.com



Being the External Brain; Tips and Tricks

What's worked, what hasn't, and keeping your cool in the storm

By Courtney Duke

Last night I came across the first article I wrote for this newsletter. It was about setting up your home environment to meet the needs of your child. I remember feeling so proud-like I'd finally gotten it all figured out and couldn't wait to share the news with everyone! I must tell you I feel a little silly now-less than a year later, because when I look around our home I see nothing resembling that article. There are locks on the cabinets and toy closet. Our beloved animal shelter playroom has been 100% emptied (sans pillows and a loft bed blocking the window). The door to that room has been cut to provide line-of-sight supervision and there's a lock on the outside now. Every toy that has the potential of being used as a weapon has been eliminated or is behind a locked door. All the effort I had put in to creating a "sensory enriching environment" turned out to have the opposite effect. I was headed in the right direction, I just hadn't learned the benefits of "novelty" yet.

I suppose I could go a little easier on myself-we all know how one working strategy can lose its efficacy at any time. What remains in the environment are a few things that are used multiple times a day; safely and productively:

- Indoor swing
- Small trampoline
- Loft bed with slide
- Large empty dollhouse (dolls and furniture are in a locked, mobile cabinet brought out for play)
- Significantly pared down animal shelter props (food bowls, leashes, collars, etc are locked and can be brought out for play)
- Art desk/Sensory table (sensory tub, sensory media, art materials are locked and brought out in small quantities as appropriate).

We need locks to keep her safe from the inability to regulate emotions and responses. To keep her safe from the life-long regret of seriously hurting someone or something she forgets she loves. To keep me safe from the trauma of "targeted" violence. To keep me safe from overreacting out of fear and desperation. To assure both of us that "our home is a safe place" and to keep it from looking and feeling like a war-zone.

Somewhere in my mind I knew feeling "safe" would help her settle, but I didn't understand fully until I actually saw and heard it in action. Moral of the story: do what works in the moment, but prepare yourself that it may not work forever. You might have to reevaluate things a million times, but that doesn't mean you've failed. It means we are awesome super-parents who are observational and responsive.

Brag

Armando

13-year-old Armando ran his first 5k race. He ran the whole race without stopping even though he has asthma.

Joy

Joy, age 15, was named most cheerful student at Neil Reid!

Christopher

Christopher, age 11, received 3 medals at Special Olympics summer games: a silver medal in mini javelin, a silver in 100m dash, and a gold in standing long jump. This is his 4th year competing and he had an amazing time.



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).



NOFAS Summit Summary

National Organization on Fetal Alcohol Syndrome (NOFAS)

2017 Affiliate Summit

By Sue Lind

The National Organization on Fetal Alcohol Syndrome (NOFAS) held the 2017 Affiliate Network Summit in Washington, D.C. from Monday, June 12 through Wednesday, June 14. The Affiliate Summit gives representatives from NOFAS and from Affiliates from throughout the United States, Canada, the United Kingdom and the Ukraine the opportunity to meet, participate in valuable workshops, and advocate on Capitol Hill.

The Summit was focused on the Stamping Out Stigma Campaign, FASD Awareness Month, an update from the Center for Disease Control and Prevention, Prenatal Exposure to Opioids and Other Substances of Abuse, Strengthening the Affiliate Network, A Collaborative Approach to Policy Action, Social Media, Fundraising Strategies and Networking and Briefings with Policymakers. NOFAS and the Affiliate Summit attendees also created an action plan for next steps for the Affiliate Network.

During the Summit, I had the opportunity to meet with two Legislative Aides. The first was Dan Riffle, the Health LA for Representative Conyers in the 13th District. The second person that I met with was Maureen May, the Health Legislative Fellow for Representative Kildee in the 5th District. During both meetings we

discussed the prevalence of individuals born with a FAS every year and the cost of individual with FASD over their lifetime.

With both Legislative Aides, the need for the congressmen to vote in support of level funding for the CDC National Center on Birth Defects and Developmental Disabilities was expressed. Also requested was to vote in support of level or increased funding for the entirety of the National Institute on Alcohol Abuse and Alcoholism. There was much to talk about in regards to the President's FY2018 Budget for the CDC, which reduced funding for the National Center on Birth Defects and Developmental Disabilities by \$35.4 million. The fiscal year (FY) 2018 President's Budget request for CDC and the Agency for Toxic Substances and Disease Registry (ATSDR) includes a total funding level of \$6,037,243,000 in discretionary budget authority and the Prevention and Public Health Fund (PPHF). This is an overall decrease of \$1,222,431,000 below the FY 2017 Annualized Continuing Resolution (CR) level, which is a 17% reduction.

I encourage everyone to contact their Representative and request that they join this caucus that will provide a forum for members of Congress to establish a dialogue with individuals that are working to prevent and treat FASD. Go to www.house.Mi.gov/mhrpublic/ to find the contact information for your Michigan representative.

Kid Funny

Me: Do you want pizza tonight?

Her: Yeah. Extra pepperoni, no sauce. I'm layin' off da diet.

Me: Hahaha. Do you know what that means?

Her: Hahaha. No idea, momma; no idea.

Pure Michigan



Silver Lake Sand Dunes



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.

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 Support

Families and Supports Affected by FASD: <http://groups.yahoo.com/group/FaSAFASD>

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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.*
