

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 son, age 16, has FAS. He is doing fairly well at school with some supports, has a few good friends and has volunteered at church for the last few years. He likes a girl at church and would like to date her. The girl is also 16-years-old and she and her parents have knowledge of our son's challenges. The teens have known each other for many years and have worked in several ministries together. Her parents are agreeable to allowing the teens to spend supervised time together. We're reluctant to allow our son to begin dating. What should we do?*

Answer: It is understandable that you would have some anxiety about opening this door because once opened it will be very difficult to close. As you work with your son to help him understand the differences between friendships and romantic relationships, you will want to emphasize the importance of responsible behavior and help him to define and verbalize what it means to act responsibly in dating relationships. Rather than denying him the opportunity to date, develop a plan for behaviors that he must achieve prior to beginning a dating relationship. Walk him through scenarios that include possible break-ups and how he might deal with those feelings. Have on-going discussions with him about this subject and use real-life examples to explain your expectations (you'll find plenty of examples in

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popular media and from the stories he hears from friends).

Consider reading some resources such as:
<http://www.fddc.org/sites/default/files/file/publications/Sexuality%20Guide-Parents-English.pdf>
<http://www.mass.gov/eohhs/docs/dph/health/prevention/hrhs-sexuality-and-disability-resource-guide.pdf>

<http://www.arc-spokane.org/PDFs/Sexuality%20and%20Developmental%20Disability%20parent%20guide.pdf>

Set up opportunities to help him successfully achieve the goals you've set. For instance, plan group events where your son, his intended girlfriend and other friends have an opportunity to socialize. Closely monitor his behavior (and that of the other teens) and ensure that he doesn't have the opportunity to be alone

with the girl (hold the other teens to the same standard). When the time is right, arrange for the young lady to join your family for a meal or other activity where the teens will have some time alone (though, still supervised). After each activity, review with him how the event went.

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

Michigan FASD Task Force 2016-2018 Goals Update

Goal 1 - Update

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.

- Enhance the MCFARES website by adding information so that it becomes the hub of information and resources related to FASD in the state and nationally.
 - Thanks to Emily Rusnak's extensive work, the MCFARES website has been updated and revised. Please visit <http://www.mcfares.org/> and look around. If you have ideas or suggestions for additions, please send an email to info@mcfares.org.
- Contact a local university to function as the lending library of print and other materials for MCFARES. The materials would be available to any person who is a library card holder in Michigan who belongs to a library with MEL transfer abilities.
 - Items that were held in the MCFARES library have been donated to Oakland University with the expectation that most will be available through MeL (Michigan eLibrary). Once the books are entered into the MeL system, any Michigan resident with access to a library can request shipment of the resource to their home library.
 - Our next goal is to develop a list of materials that are accessible through the MeL system.
- Develop a way to respond to common issues that arise in the news to educate the public about the real costs of prenatal alcohol exposure and FASDs.
 - This "Talking Points" flyer can be used as an information resource when responding to news stories, when speaking with legislators or when making presentations about FASD http://media.wix.com/ugd/834b84_6b5e44a523934d95b8a417d408986515.pdf
 - Please send suggestions for updating or adding to the flyer to info@mcfares.org

continued

- Outline and put into place how-to procedures concerning contacting legislators on matters of concern
 - The “Talking Points” flyer listed above can be used when talking with legislators. Also, feel free to share with legislators any of the flyers found on this page: <http://www.mcfares.org/fasday>
 - If you have occasion to speak with your legislator about FASD, please let us know. Send an email to info@mcfares.org.

Being the External Brain; Tips and Tricks

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

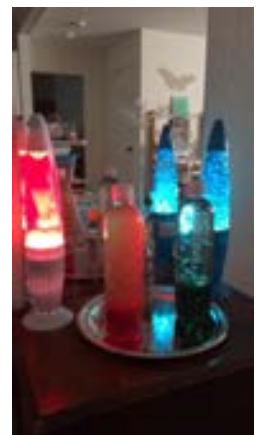
By Courtney Duke



It's that time of year again; back to school season, which for my family almost always results in routine changes and the dysregulation that follows. I have found that full-time dedication to sensory input during times like this can really help level my child out, or at least decrease the length of an episode. Stifling symptoms of organic brain damage for 6-7 hours a day, 5 days a week can exhaust and frustrate our children; so it's important to be ready with acceptable outlets when they get home! Doing so will cut down on undesirable behaviors, making the evenings more enjoyable for the whole family. In this issue we will discuss the benefits of sensory exploration and examine the process to expanding your comfort level in regards to sensory activities.

The majority of this summer has been spent recreating spaces in our home, in order to give QT an environment most conducive to her needs. After some reflection I came to realize the following: we don't need a typical living room-because of her rigidity in routine, we rarely (if ever) have company; we don't need a dining room table and chairs-we never use them because we are most comfortable eating while we snuggle and watch TV (laptop trays are the best!); there is no need whatsoever for her to have a typical “bedroom” of her own-she is unable to sleep alone, so I put her bed in my room and now we share and both sleep better!

QT has quickly come to know that our home is her safe place, the place to get her needs met, the place where she is embraced and valued for her uniqueness, and maybe most importantly-the place where she is encouraged to try new ideas and emotions on for size. Our home is not a place of finality, consequencing, punishments, and hierarchy; it is OUR home-a place to be who we are, where we are allowed to make mistakes and try again, where it is safe to “need” and “seek” and even sometimes “avoid”, a place of mutual respect and compassion. We have 2 rules: Be Safe and Be Kind.





When I made the intentional decision to endure the discomfort that accompanies disarray, mess, disorder, etc., I was left with only time to reflect on my own values, the origins of those values, and how/if they fit into my current life circumstance. The answer led to the realization that, because I want my daughter to fully know I love, value, and respect her, my priorities needed to change. Once I was able to shift my thinking from “what our home SHOULD be” to “what our home NEEDS to be”, I became infinitely aware of the need for sensory input in our space, and able to let go of societal expectations. After making the environmental adaptations, I immediately observed dramatic improvements in behavior, listening, emotional recognition and expression, agitation, cooperation, etc. The relationship between QT and I has

improved tenfold. It is my hope that once your own brain has made that shift (and it is not easy!), you will discover your openness to endless opportunity and activities—some you never thought you’d be able to do! Are you ready for a few activity ideas to start your own space-transformation journey? Listed below are a few easy-to-make, low-mess options to try with your child as you broaden your tolerance horizons:

- Sensory bottles: repurpose a uniquely shaped beverage bottle and fill with any interesting item; seal the lid with hot glue (bells, dry noodles, beads, straw pieces, corn syrup, water, mineral oil, cooking oil, etc.)
- DIY music instruments: repurpose any used container (mini laundry soap, paper plates stapled together, ketchup bottle, etc.) and fill it with a pleasant sounding medium (rice, dry beans, sand, etc.)
- Applesauce dough: Mix equal parts of applesauce and cornstarch together, adding more of each until the consistency reaches that of a moldable dough.



In the next issue we will go deeper into specific cost-effective activities and environmental enhancements you can make to further improve the relationship with your little one. In the meantime, I’d love to answer any questions and hear your thoughts. You can contact me at sensoryfairy@gmail.com anytime, I’m happy to help!

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.



MCFARES Recognizes FASDay, 2016 with an open Project S.A.F.E. Meeting



On Saturday, September 10th, families and professionals gathered to recognize International Fetal Alcohol Spectrum Disorders Awareness Day. After enjoying a wonderful pot-luck meal and desserts, we heard from the Smith family who talked about their experience as Easter Seals of Michigan ambassadors. Doug Holman talked with us about his experience pursuing services for his son. Courtney Duke shared information about

sensory activities that she has designed for her home to help her daughter regulate and express herself. Kayla Penner from CARE gave an explanation of the services that they provide. We ended the evening with a quick trivia game and prizes.



Project SAFE meets on the 2nd Saturday of each month. Except for our annual FASday event, meetings are limited to affected individuals and their families. If you'd like more information about attending a meeting, please send an email to info@mcfares.org.



GoodSearch

Please consider helping MCFARES to 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.



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).

Braggs

Leroy, 20 . . .



. . . has just started technical school to become an HVAC technician.

Shi, 6 . . .



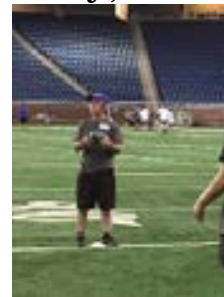
. . . is doing great in a five-student classroom with 3 teachers. She also had 2 new kittens and is loving taking care of them.

Megan, 18 . . .



. . . and her Special Olympics team took the Bronze medal at the State softball competition.

Andy, 22 . . .



. . . attended a Detroit Lions Football Camp where he did stations with coaches and toured the media center, locker room and met Roary, the team mascot.

FASD Conference in Grand Rapids, Michigan

Fetal Alcohol Spectrum Disorders in the year 2016

WHEN:

October 28, 2016, 9:00 am – 3:00 pm

WHERE:

Bethany Christian Services

901 Eastern Ave NE

Grand Rapids, MI 49503

Keynote Speaker – Deb Evensen

FASD – What We Have Learned and How We Have Changed by Helga V. Toriello PhD,

FASD Solutions – Behavioral and Educational Strategies Across the Life Span by Debra Evensen MA

Due to the generosity and creativity of our sponsors, the conference is fully funded, including lunch, and a training DVD.

- Spectrum Health Genetics
- Bethany Christian Services, Post Adoption Resources
- Developmental Disabilities Institute, Wayne State University

Social Work CEUs are pending.

For more information, contact: Barb Wybrecht for further details, bmwybrecht@gmail.com

Registration: Send e-mail to Sherri Irwin sirwin@bethany.org by October 14th.

Audience capacity is 200.



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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Updated 8/16



MCFARES is the Michigan NOFAS Affiliate

MCFARES Member Agencies

Arc Services of Macomb
(fiduciary)

Family members of
affected individuals

Macomb Intermediate
School District, Early On

Macomb Family Services

Macomb County Health
Department

Madonna University

Macomb County Office of
Substance Abuse

Oakland University School
of Nursing

Macomb County
Community Mental
Health



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