

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 daughters are 8 and 10. We have had a really hard time getting them to settle for the night and go to sleep. Do you have any suggestions?*

Answer: There is no single cause that creates sleep challenges for all kids who are on the spectrum. There are, however, some categories of challenges that you may want to assess. First, you'll want to do an evaluation. This evaluation can be formal (i.e., a sleep study to identify possible medical causes for sleep issues) or informal (i.e., keeping a log to identify factors that contribute to challenges or factors that assist in creating a good night's sleep).

If you pursue a formal assessment, seek a referral to a trusted professional who will perform tests appropriate to your child's symptoms. Seek referrals from your trusted health care providers or fellow parents whose children have experienced similar challenges.

There are many methods of doing an informal assessment at home. For example, keep a log of activities, behaviors, needs and anything else that effects the girls' sleep patterns. Try to assess events, behaviors, instances when the girls are able to go to bed and fall asleep quickly. Also, assess the same for nights when the girls are unable to settle quickly. Consider such things as whether or

	Questions We Are Asked	1
	This is FASD	3
	Being the External Brain	4
	Grand Rapids Conference	7
	Support Groups	9

not pre-bedtime activities excite or calm your girls. Keep track of the reasons why they leave their rooms. Are they asking for food, are they too cold or too hot, is there too much noise in their room or even too little, are they asking for more light or less light? During your assessment, you may find that each of the girls has different needs. For instance, one might prefer sleeping in a very dark room and the other may need a nightlight. One may find it calming to have a bath or shower before

bedtime while the other finds that stimulating. Once you have some ideas of what keeps them from sleeping and what helps them to sleep, you can develop a plan.

For many of our kids, a consistent bedtime routine is key to helping them to learn to stay in their room at bedtime and fall asleep on their own. Developing a routine may go a long way to helping the girls stay in bed and fall asleep. Begin evenings using a visual schedule and help the girls reference the schedule so that they know what to expect throughout the evening. Working with the girls to help them develop the schedule may encourage them to follow it.

Some families consider using prescription medications such as Clonidine or natural products such as Melatonin to aid with sleep. Essential oils (such as Cedarwood or lavender), either in a diffuser or rubbed on feet, may be another option to consider. If bath time is a calming activity for your child, consider an Epsom salt bath before bedtime.

Some children need a snack before bed because hunger may keep them from falling asleep or may contribute to them waking during the night. Experiment with protein-based snacks and carbohydrate-based snacks. Children have different metabolisms and some may do better with proteins and others do better with carbs. Seek input from your trusted medical professional for a referral to a dietician who might be able to provide information specific to the needs of your child.

When looking at the bedroom environment, provide blackout shades for those who prefer to sleep in a very dark room or a soft light that does not shine in their eyes for those who need some light in their room. For those who need a cool room, an overhead

fan might provide needed cooling without creating a distraction to be played with. Heavy blankets can be useful for children who prefer to be warm when they sleep.

For those with sensory issues, a weighted blanket may provide the deep pressure that will calm them and allow them to fall asleep. Soft pajamas and soft bedding may also help decrease sensory issues. For those who are bothered by sounds outside their room (appliances, television, telephone, etc.), a sound machine may be helpful.

For children who experience high levels of anxiety, separation may be difficult. These children may require reassurance that they are safe before they can fall asleep. For these children, it may be helpful to have a bedtime routine that includes reading together and/or reading of social stories. After the children are in bed, it may be helpful to keep rest of house quiet so kids don't feel they're missing out from activities.

For further information:

Time Timer (gives children a visual display of the amount of time left for a task):
[https://smile.amazon.com/TIMER-INCH-MODEL-AUDIBLE-
 OPTION/dp/B001UAMZCU/ref=sr_1_3?ie=UTF8&qid=1483818171&sr=8-3&keywords=time+timer](https://smile.amazon.com/TIMER-INCH-MODEL-AUDIBLE-OPTION/dp/B001UAMZCU/ref=sr_1_3?ie=UTF8&qid=1483818171&sr=8-3&keywords=time+timer) (Affiliate link)

Sleep Problems in Children with Fetal Alcohol Spectrum Disorders:

<https://depts.washington.edu/fasdnp/pdfs/CHEEN-SLEEP2012.pdf>

Sensory Processing and Sleep Challenges in Children with Fetal Alcohol Spectrum Disorder:

<http://www.caot.ca/otnow/sept09/sleep.pdf>

NOFAS Recommendations:

<http://www.nofas.org/health/>

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

This is FASD

For the last several years our 22-year-old son had been mostly independent in doing his laundry. He could run the washer and dryer with very little help. The washer recently broke down beyond repair. In comes the new-and-improved washer with buttons, lights, sounds and so many choices. He had the “deer in the headlights” look when he saw the control panel. The washer that he had used comfortably for years turned into a machine that he figured would take years to master.

To help him regain his confidence, we’re working on simplifying the process. We’ve turned off the sound that he finds so irritating. We marked the cycle he’ll use for darks and the one he’ll use for whites and practiced how to push the buttons to light-up the correct cycle. He’s pretty close to being able to finish the job on his own. At least until the dryer decides to die.

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.

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)



Being the External Brain; Tips and Tricks

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

By Courtney Duke

Hello again, friends! How did everyone fair during the holidays? I, for one, was thrilled when they were over. For us, the inconsistency of holiday schedules, school breaks, presents, sugar-overload, and late nights was disruptive to say the least. This season's column was intended to give you suggestions on low-cost, high-sensory options...however, we have experienced a turn of events at our house so surprise! This will be a super-special article on "what wasn't working, and how we turned it around (for now!)"

Sometimes no matter how you try to change the environment, it just doesn't work. I found that to be very true over the holiday season for my little one. What finally seemed to help was intensifying the amount of external brain power. It is certainly exhausting, I'm not gonna lie-but it is the only thing that has worked this time to level her out. Below I have listed some of the strategies for being her external brain that have been successful. We have now been meltdown free at home since mid-December.

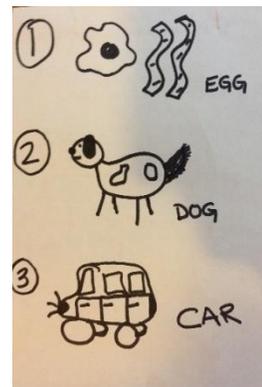
- **Bulk up on the protein.** I've added about 10 times more protein to her daily diet; this girl metabolizes like a boss!!
- **Drastically reduce the sugar intake.** I am not the kind of person who can alumininate sugar or gluten or all the food dyes from our diets. But I have started making some more healthy food choices and it seems to be paying off (almond milk, 100% organic juice popsicles, probiotics, high-protein yogurt, etc)
- **Morning, afternoon, and evening picture plans.** On a dry erase board, she and I sit together and draw up a visual schedule. I found that sending her with a paper version of the plan also reduced anxiety to get on the bus and go to school a couple times. Doesn't work every day but sometimes it helps.
- **Tracking sleep.** I used a free app on my phone called BabyConnect. It tracks sleep, giving you the total hours in a 24 hour period. What I realized is that she absolutely needs 12 hours of sleep in a 24-hour period – without it we had meltdowns. Because of this I've added a nonnegotiable rest time into our day.
- **Timers.** Every activity is timed. When I tell her I am setting the timer for 10 minutes, I write it next to the visual on our picture plan and set the timer on my phone. We get a two minute warning to finish up what we're doing. I have found it necessary to remind her every time that we can come back to what we're doing but we're going to move on now to the next activity.
- **One outing per day.** I'm a single mom so running errands can't be avoided. What I have had to do is prioritize them. When she is with me, we go out only one time in the day. Might be groceries or pet store or both-and I only go to the places I know she can participate. Even at the bank last week she was the "door holder" and a really sweet man gave her a \$1 tip!
- **Mommy minutes.** I have had to build in short blocks of time for myself throughout the day, usually about 15 minutes or so. This allows me small chunks of time to load in some dishes or switch

around the laundry or just sit and rest. This has helped me so much! I think it is also a great modeling tool for her about listening to our body when it needs a break.

- **Compromises and reassurance.** She needs to feel like she has some control. I am understanding this better every day as I've looked into the trauma of her past. She needs reassurance all day long that I love her, I am not leaving her, I am not taking anything away from her. This seems to really have decreased the anxiety that was leading to aggression. When I'm able to make a compromise on something we disagree about, I do. I am looking past behavior to investigate what need is not being met in that moment. If it is safe and within my boundaries of acceptable, we work out a compromise. This way when I ask flexibility of her she's more willing because it feels like a team approach.
- **Shorten school days.** She is having a very hard time maintaining a whole day at school in a class of five students and four teachers. I can see the anxiety every single morning and disappointment and exhaustion when she gets sent home. Because I'm not working and I'm able to come and get her, I do. We usually do a couple Life skill activities in the afternoon Sometimes this works and sometimes it doesn't but either way it is strengthening our attachment and reaffirming to her that I care. I'm listening to her body when she can't. I am her momma and I will help.



Protein!



Picture Plan!

Rob Wybrecht and Erin DeKorte are Engaged!!!

Rob and Erin met many years ago and have worked together to raise awareness of fetal alcohol spectrum disorders. They help run the Grand Rapids area Self-Advocates with and FASD in Action (SAFA) group. They will be married on June 24, 2017.

Congratulations Rob and Erin.

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).

Pure Michigan



St. Joseph lighthouse

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.



“FASD Solutions, Behavioral and Educational Strategies Across the Life Span” Conference Summary

By Robin Burgamy



Deb Evensen

Sisters Roxanne and Crystal

A diverse audience of about 175 adoptive parents, professionals, and even some young adults with FASD (cheer!) attended the FASD conference at Bethany Christian Services in Grand Rapids on October 28, 2016, which was the first one of its kind in West Michigan. FASD educator Deb Evensen inspired on the topic of "FASD Solutions, Behavioral and Educational Strategies Across the Life Span". Deb was joined by Spectrum Health FASD Clinic Director and geneticist, Dr. Helga Toriello, whose informative presentation was entitled "FASD: What we have learned and how we have changed".

Spending a day learning and reflecting upon FASD interventions was an exciting prospect for me. I have too little time to strategize about my FASD daughter's future. I need days like this to help me see the big picture. For those unable to attend, here are some of my favorite take-aways:

Diagnostic criteria: Dr. Toriello explained there are actually SIX different sets of diagnostic guidelines that are used across the country and world today. So it is possible that a diagnosis could vary from place to place, depending on where you have your child evaluated. For me, this means it's also possible if you disagree with your child's diagnosis or feel it needs to be stronger (for example FASD instead of just ARND) you could ask for your child to be diagnosed using different guidelines, or seek out a different diagnostic center.

Most inspiring quote: "Think of the injustice of being afflicted with a condition of appearing to understand far more than you do" (Stuart Whitley, Deputy Minister for Yukon Health and Social Services, speaking about FASD). What a great quote to help people start to "get it". I like to add an FASD quote to the bottom of every email I send out as part of my own personal awareness/education campaign. This is going to be a quote I will use.

Key point: *Support them longer, "turn them loose" later:* Keeping in mind that an FASD child's emotional/developmental age may be about half of their chronological age, Deb believes that the traditional age of "18" as the magic number for transition into many aspects of adulthood should be changed to the mid-

20s for individuals with FASD. In other words, plan to keep them in the nest longer. For those of us who have seen scary statistics about how so many of our FASD young adults are prey to addictions, crime and homelessness, this seems like a no-brainer, helpful path to follow. Deb has seen improved outcomes in her work with longer support, and states, "when given a few more years (i.e.. mid-twenties) to grow up, people with FASD do much, much better... the long, winding road to adult life, instead of a straight shot".

Best Awareness video: Public Service Announcement from Alaska. Get some tissue, and watch this 3-minute video here: <https://m.youtube.com/watch?v=D4I5yAs4I5Q> or Google "PSA Alaska FASD". Then share it with your circle.

FASD kids' best years are the early childhood years: This reminded me of what I've thought many times: Childhood truly IS the golden age for the ones we love with FASD because so many fall into traps of addiction, crime, joblessness and homelessness as adults. We need to take time to share joyful and magical moments with our children, we don't know how many they will be able to have.

Celebrate our kids' uniqueness: Deb talked about the tenacity of our FASD kids, how their brains have to work twice as hard to produce half the result, about how too often they show up at school day after day where they make the same mistakes over and over again, only to get made fun of again or be corrected by peers, to get scolded by people who too often don't understand. I thought about how our kids are charming and loving and funny when everything is going okay for them and they are happy - that is our kids at their best.

FASD individuals and law enforcement: Deb shared a story in which she acted as "interpreter" for a woman suspect with FASD, and reminded us that there is much advocacy work to be done to make law enforcement officials aware of the particular vulnerabilities of individuals with FASD: they are more naive, more likely to confess to something they didn't do either for people-pleasing/bonding purposes, or because they don't truly understand what is going on.

Best inspiration for me: I had the good fortune to be seated next to two young women with FASD, both of whom have been at their jobs for a few years! Wow!! Crystal is a dog-groomer, and Roxanne is a preschool teacher! Mom Jane attributes their success to prayer, patience, repetition, repetition, repetition and consistency, and attributes Community Mental Health and Michigan Rehab Services, as well as her church, with helping find stable employment for her daughters.

Helpful materials

Video: *Fetal Alcohol Spectrum Disorders: 8 Magic Keys* is a short animated video which shows some effective strategies for working with FASD kids at school. This would be good for sharing with your child's teachers. You can call your local Michigan library and request to borrow this video through the state's interlibrary loan program, MeLCat.

Book: "Trying Differently Instead of Harder" by Diana Malbin. This is also available on MeLCat.

Handouts: *Build a Circle of Success for Individuals with FASD* by Deb Evensen (c. 2010) and *Real Life Case Scenarios of Individuals with a FASD* by Deb Evensen. Contact me at KAFASDgroup@yahoo.com to obtain a PDF file of these handouts.

Website: All the new advances in genetics and brain science may yield advances in FASD in the future. For learning about epigenetics in a super-easy way: <http://www.whatisepigenetics.com/what-is-epigenetics/>

Q: What did the big, furry hat say to the warm, wooly scarf?

A: You hang around while I go on ahead!



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>

Note: no liability is assumed with respect to use of or inability to use the information contained in this newsletter. Although every precaution has been taken, the authors assume no liability for errors or omissions. No liability is assumed for damages resulting from the use of the information contained therein

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.*
