

FASD News and Views



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



Established in 2003

Questions We Are Asked

Question: *We are adopting our 3-year-old nephew since my sister is unable to care for him. It has been suggested we look into FASD because she drank throughout much of her pregnancy. Several acronyms have been thrown our way: FASD, FAS, FAE, etc. What do all of these mean?*

Answer: Let's start with the acronyms. FASD stands for fetal alcohol spectrum disorder and includes the range of disorders caused by prenatal exposure to alcohol. FASD is not a diagnostic term but includes the spectrum of diagnostic terms which are:

- FAS (fetal alcohol syndrome): a diagnosis of FAS requires:
 - Abnormal facial features (smooth philtrum (the line between the nose and the upper lip), small palpebral fissures (the distance between the inner and outer corners of the eyes) and thin upper lip);
 - Growth problems (height and/or weight below the 10th percentile) and,
 - Central nervous system problems
 - Confirmed maternal alcohol use helps to substantiate the diagnosis but is not required.

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- ARND (alcohol-related neurodevelopmental disorder): memory and intellectual problems especially in the areas of math, memory and impulse control. Behavioral problems may also exist.

- ARBD (alcohol-related birth defects): structural problems with heart, kidneys, bones or hearing.
- FAE (fetal alcohol effects): an outdated term that was used to describe intellectual and behavioral problems in an individual when facial features are not present. ARND and ARBD replaced the FAE diagnosis.

Now that we have the basics of the alphabet soup down, it's time to talk about seeking a diagnosis. Gather as much written information you can about pre-natal history, growth and developmental information available for your nephew. Most who are affected by pre-natal exposure to alcohol will experience executive functioning deficits. Though psychological testing cannot be done on a 3-year-old, at some point in the future, testing will be appropriate, at least initially to obtain baseline data. Adaptive functioning testing can be done when your nephew is 4-years-old and might provide more useful information than psychological testing as IQ testing may not provide valid information about the individual's abilities. Here is a link to Recommended Assessment Tools for Children and Adults with Confirmed or Suspected FASD: <http://come-over.to/FAS/AssessmentsFASD.htm>

Seek a diagnostic center in your area by going to <http://www.nofas.org/resource-directory/> and clicking on your state. The diagnostic center may have a lengthy waiting list and may require you to complete a packet of information about your nephew's pre-natal and developmental history. Depending on the set-up of the diagnostic

center you choose, your nephew may be seen by a team including professionals from various specialties and the assessment could take from as little as a couple hours to a couple days. After the appointment, the team will review the information gathered and discuss their results with you. They'll likely make some recommendations offering suggestions for follow-up services to consider.

If you have an FASD-related question that you'd like answered, please submit it to: charisse@mcfares.org. You may find your question answered in our next newsletter.

Things Our Kids Say

We were driving by a carpet store, they had a sign saying they make area rugs. Meg suggested we get one for Area 15 (our Special Olympic local designation.)

ANNA, age 7: Are the brownies ready?
ME: They are cooling, they won't be ready for about 20 minutes.
ANNA: (hollering out the door) Reuben, the brownies are ready!

Website Remodeling

We're remodeling our Michigan FASD website. What would you like to see and do there? Please share your comments and links at charisse@mcfares.org.

On Being a Parent

Coming to Terms with His Disability

It's not like we're new at this. We've been together 15 years and he's not a baby anymore. I'm still sometimes baffled, surprised and annoyed, though, by his behaviors. Will he ever stop asking me how much longer until we leave for the party? When will he learn to independently brush his teeth and comb his hair? Will he ever stay in a room by himself or will he forever follow me through the house, even when I'm in the bathroom, pacing until I finally emerge?

He woke this morning totally unfocused in actions and completely rigid in thought processes. I knew this would be a day where medications would barely decrease the confusion and fears. It's going to be a day where expectations must be kept to a minimum. It's a full moon and the end of the school year is near. Add to that some changes at home and we've just produced the perfect storm of anxiety that he can't process or put into words. I can choose to lash out when he is unable to do the most basic of tasks like take his meds or get dressed but he needs me to be his external brain. Right now he can't do these things on his own. We know that this too shall pass. We'll weather this storm just as we've done so many times before.

It's constant. It's always been constant. And, there no end in sight. Sometimes it seems we're still in toddler-hood, except that now he's 5'6" tall and 140 pounds. Though all parents are told not to compare their child's

development with that of other children, it's been especially reinforced with us. We've been told that he's on his own curve. He'll learn skills in his own time and may require more repetition. He may never be able to learn some skills. His challenges are all directly related to fetal alcohol syndrome. In my more objective moments, I can remember this. It's up to me to help guide him to more appropriate behaviors and choices. He is not purposely making my life challenging; he needs me to help him organize his thoughts and plan his behaviors.

But, still. The kids he met in elementary school are now driving, some have jobs, most are beginning college visits. We had this dream: he'd attend my alma mater for undergrad and his dad's for grad school, following in the path of his siblings. We'd help him furnish his first apartment and plan for his wedding. We'd be available to watch his children and we'd take vacations together. We fervently prayed and planned for his future all the while believing our dreams were his dreams. And then, in prayer, came the realization that those are our dreams, not his. He's on his own path and he's completely fine with who he is. His goal is to volunteer with the senior program at church and help in the gardens. He wants to be of service to others. Who am I to judge that future as less worthy than any held by a college graduate?

What does the future hold for him? That's the question that haunts me during dark,

sleepless nights. We won't be around forever. We've heard the stories about abuses and mistreatment in group homes but his siblings have lives of their own. Is it fair to them to ask them to take him in when we can no longer care for him? Is it fair to him not to ask his siblings to care for him in their homes?

Always at the back of my mind is the gnawing idea that he didn't ask for any of this. And, even with all of the challenges that he must live with on a daily basis (significant sensory challenges, anxiety, memory issues, poor sleep and allergies), he is a very kind-hearted, thoughtful young man. He helps anyone at any time and is known in the neighborhood as the kid who is always willing to lend a hand. He loves going to church which is another place where he is known as the kid who is always willing to help out. FAS is what he has but it is not who he is. He's a young man; a wonderful, genuine young man who has a big, kind, loving heart.

In those quiet moments, as I watch him enjoy his favorite tv shows or watch him make breakfast for everyone, I wonder how I was so blessed to be his mom. I realize deep in my heart that he's fine just the way he is. We'll enjoy today and keep an eye on tomorrow. And, pray. Always pray for wisdom and guidance.

The author wishes to remain anonymous.

GoodSearch

Please consider using [GoodSearch](#) for your internet searching needs and designate MCFARES as your charity of choice. Also check out other ways to earn funds for MCFARES by using [GoodShop](#) when you shop on the internet and [GoodGames](#) when you want to play on-line games. Funds raised will help MCFARES to continue providing resources, support, education and prevention information to the community.

Super Kids / Smart Choices

2014 Wrap-UP

The Super Kids/Smart Choices Summer Socialization program was held in Fraser in July. Nineteen students ranging in age from 5-17 years old registered for this year's program. Several new students enjoyed getting to know our returning our students and everyone made new friends. An added bonus this year was the opportunity for parents to meet once each week and learn from and support each other.

Here's what a couple of our students had to say about the program:

Returning student, age 11: *"It was awesome."*

New student, age 10: *"I can't wait til camp next year. I made friends with so many kids!"*



**Join us for pizza,
desserts and
beverages**

**Information about
FASD prevention
and local services,
supports**

**Test your
knowledge about
MCFARES and
FASD for a chance
to win prizes**

**Donations
appreciated**

**RSVP to Charisse at
charisse@mcfares.org**

**SATURDAY, SEPTEMBER 13, 2014,
5:30 – 8:30 P.M.**

**Fellowship Chapel, 12875 14 Mile Road, Sterling Heights, MI
48312**

MCFARES FASDAY, OPEN PROJECT S.A.F.E. MEETING

(Project S.A.F.E. stands for Supportive Activities for Everyone. We bring families together monthly for a meal, supervised play for children and support time for parents)

International FASDay is held each year on or around 9/9 to raise awareness of the dangers of alcohol use during the nine months of pregnancy.

MCFARES

(Michigan Coalition for Fetal Alcohol Resources Education and Support)

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Braggs

Joy

Joy C. is participating in Challenger League baseball and loving it.



Meg

Meg, age 17, entered 6 items in the Oakland County Fair through her 4-H club, MI Peeps. She won several ribbons, including the prized Scranlin Memorial Award (pictured) for her "Fairy House."



Rob

In May Rob, 41 years old, drove to Dearborn and back on the next day. He felt so good and he did very well. GPS has given him a whole new world as well as increased confidence. I was with him but he did it all.

Here comes the FAS part. Rob is 41 years old, same age as FAS in this country. He passed his drivers's ed in high school and he would not have needed to take a road test but he did not feel comfortable driving without family. He said that he was afraid that another driver might do something quickly and he could not respond quickly enough himself. This was all his decision. He was about 20 when he felt more comfortable. Then he did have to take a road test since it had been several years since he took the class in high school. He also took a driving class for those with disabilities. He learned some good tips, many the same as they suggest for elderly drivers. He has an excellent driving record, no accidents in twenty years.

If you have other questions why don't you write to Rob. (rob1195@yahoo.com)

Gabby

In St. John-Providence Hospital Newsletter with "Hope"

Her Highness Hope Helps Celebrate Young Girls with Disabilities

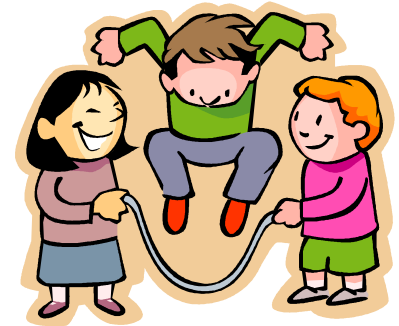
Resplendent in her black tutu, Hope, St. John Hospital's facility/therapy dog, was a royal hit as the official greeter at the Princess Party, an event that celebrated girls with disabilities. The party, held at the Grosse Pointe War Memorial recently, was sponsored by the Motor City chapter of AMBUCS, a non-profit service organization dedicated to working with occupational therapists and other healthcare professionals to fostering mobility and independence for people with disabilities. About 200 girls were treated to a day of fun and pampering, including mini makeovers, manicures, dancing, crafts and lunch. Thanks to Hope's handler Joanne Jeromin for bringing Hope and introducing her to all the princesses at this special event.



Project S.A.F.E.

(Supportive Activities for Everyone)

Project S.A.F.E. is a monthly pot-luck activity for families who are living with FASD. Our families come together for a meal, play time for the children and time for support for adults. Project S.A.F.E. is held at Fellowship Chapel at 12875 14 Mile Road, Sterling Heights, MI 48312. Our scheduled dates are: February 8, March 8, April 12, May 10. We meet from 5:30 – 8:30 p.m. If you're able to join us, please contact Charisse at charisse@mcfares.org (unless other arrangements are made, these meetings are reserved for family members only).



* * Donate * *

Stamps & Things

MCFARES could use your help. Please consider donating stamps so that we might be able to mail information to those interested in learning more about FASDs. We could always use more printer paper so that we might be able to print brochures that provide information about our services. HP 564 printer cartridges are also needed.

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).

Free Book

Addressing Fetal Alcohol Spectrum Disorders is available for free from SAMHSA, and may be downloaded. See <http://store.samhsa.gov/product/TIP-58-Addressing-Fetal-Alcohol-Spectrum-Disorders-FASD-SMA13-4803>



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 3rd Wednesday of each month; 6:30 – 8 p.m., Thunder Bay Transportation Authority, 3022 US23 S, Alpena. Contact Mary Schalk at maryschalk@frontier.com 989-734-2877 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.

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.

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.

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 Betsy for more information, betsysoden@juno.com.

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.



MCFARES is the Michigan NOFAS Affiliate

MCFARES Member Agencies

Arc Services of Macomb
(fiduciary)

Macomb County Office of
Substance Abuse

Family members of affected
individuals

Oakland University School of
Nursing

Macomb Intermediate School
District, Early On

Macomb County Community
Mental Health

Fraser Public Schools

Macomb Family Services

Macomb County Health
Department

Madonna University



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

MCFARES

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Clinton Township, MI 48036

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Address Line 1
Address Line 2
Address Line 3
Address Line 4
