

FASD News and Views



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









Established in 2003

Questions We Are Asked

Question: *The holidays are coming up and I'm dreading family parties. My kids are 8 and 5 and both on the fetal alcohol spectrum. The parties are long, loud and crowded. The excitement and activity makes the kids anxious and overstimulated. The new and different food choices also create problems. HELP!!*

Answer: Exposure to the sights, sounds, smells and the busy-ness of the holidays, which are a joy to many, can simply overwhelm some of our kids. This is a time of the year when your planning, assessment and teaching skills are going to be put to the great use.

First, planning: Get all your invitations together and mark them on your calendar. Attend the events that allow for the most success and enjoyment for your family. Sometimes, it is helpful to keep calendar information and schedule information from your child until just prior to leaving for the event because waiting for anticipated events can cause great anxiety for some children. Consider the time of day, stimulating factors and menu. If the event will run for a long time, consider attending for a short period when your children might be most likely to

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enjoy themselves. If you know the environment and the hosts are agreeable, plan for a quiet area that you and your children can go for some down-time. Bring items that you use at home for comfort such as stuffed animals, games, music and perhaps noise-cancelling headphones. Ask the host about the menu and consider whether your children should eat at home before the event or make one of your child's favorite foods and bring it to the event to share. Many families feed their children

before attending an event so that children do not arrive at a party hungry or cranky. Practice appropriate conversation skills, such as introductions, with your children prior to the party. You can also “introduce” your children to guests via pictures before you arrive at the party so they may be more familiar with faces when you arrive.

Second, assessment: Consider the activities that will likely occur at the gathering and how your kids might respond to these activities. If family gift-giving creates challenges for your children, perhaps you can arrive after gifts have been opened and their gifts can be discreetly placed in your vehicle and opened when you decide the time is appropriate. Will there be guests at the event who as yet do not understand the challenges your children experience? If possible, speak to them before the event or privately during the event to explain how pre-natal exposure to alcohol has affected your children. Engage their assistance in creating a safe, accepting environment. Assess the environment. Are there potential hazards such as pets that could scare your children or that they could potentially hurt, electronics that they might have unrestricted access to, medications or other potentially harmful items? If such concerns are present, consider asking the hosts to remove the danger or, if that’s not possible, be prepared to provide close supervision of your children.

Third, teaching: This is where you get to educate your friends and family about how pre-natal exposure to alcohol has affected your children. Explain the cause of fetal alcohol spectrum disorders and the range of challenges that an individual might

experience. Share as much as you’re comfortable sharing about your children’s sensory, learning and behavioral challenges and the interventions you’ve put in place to help them be successful and safe. For those who want to learn more, suggest some of your favorite websites and resources.

Best wishes for a safe and happy holiday season.



National Christmas Tree – Washington DC 1983

Things Our Kids Say

Jamie, 11 years old, upon receiving his sandwich at lunch: “There’s nothing in this BLT besides bacon, lettuce, and tomato!”

40 Years and Beyond: Fetal Alcohol Spectrum Disorders Conference Held in Michigan

The Michigan Fetal Alcohol Spectrum Disorders Task Force presented a day-long conference on September 12, 2013 entitled “Our Journey of 40 Years and Beyond: Living and Learning with FASD”. The conference was attended by over 220 people including parents, individuals with FASD, teachers, nurses, doctors, social workers, and community program staff. Sponsors of the conference included local parent support groups from Ann Arbor and Grand Rapids, CARE of Southeastern Michigan, the Developmental Disabilities Institute, MCFARES/NOFAS Michigan Chapter, the Great Lakes FASD Regional Training Center, Merrill Palmer Skillman Institute, and the Michigan Departments of Community Health, Human Services and Education.

The conference marked the 40th anniversary since the term Fetal Alcohol Disorder was used by Dr. Kenneth Lyons Jones and Dr. David Smith in the first U.S. article describing the impact of prenatal alcohol exposure on several children born to mothers who were severely alcoholic. Dr. Jones, who currently serves as the chief of the University of California San Diego’s Division of Dysmorphology/Teratology and has written over 400 scientific publications, gave the key note address highlighting what we have learned about the impact of prenatal alcohol exposure on individuals throughout their lives and prevention and intervention best practices. Other speakers included Dr. Mark Sloane from the Children’s Trauma Assessment Center who spoke about the intersection of genetics, toxic traumatic stress and prenatal drug and alcohol exposure and Dr. Sally Burton-Hoyle from Eastern Michigan University and a member of the national Interagency Autism Coordinating Committee who presented on understanding behavior as communication and positive ways to support people. Dan Dubovsky, FASD specialist from the SAMHSA FASD Center for Excellence, closed out the conference with a session on building on the strengths of individuals with FASD and their families to increase abilities and inclusion in their communities.

Breakout session included panels led by parents and adults who have FASD on community programs, representatives from the Michigan Partners for Freedom speaking about self-determination, transition planning, diagnosing teens and adults, understanding the complexities of interventions, estate planning, and an update on Michigan FASD programs by the FASD State Coordinator. A panel of adults with FASD featured the experiences of three of the founding members of SAFA, Self-Advocates with FASD in Action living and learning with FASD.

The day was very successful with many positive comments about the quality of speakers and presentations and the valuable information that was shared.

Written by Ann Carrellas, LMSW, Research Assistant, Developmental Disabilities Institute, Wayne State University, Detroit, MI. If you wish to contact Ann, her email address is: do9921@wayne.edu

MCFARES Celebrates FASDay in Macomb County at an Open Project S.A.F.E. Evening

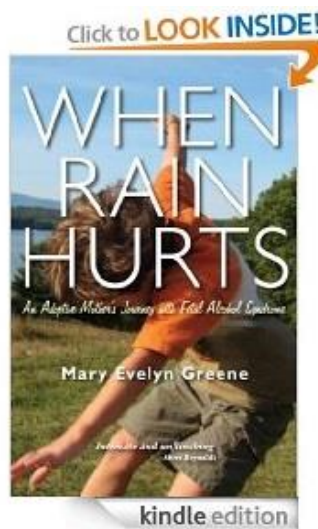
On Saturday, September 14th, our families and guests enjoyed a wonderful pot-luck meal together, our kids had time to play in the gym and we all enjoyed a fun game of “What do You Know about MCFARES and FASD?” Everyone enjoyed trying to answer the questions for a chance to win prizes.

Project S.A.F.E. meets monthly, typically on the 2nd Saturday of the month. Contact Charisse at charisse@mcfares.org for times and location.



Book Review: When Rain Hurts by Mary Evelyn Greene

Mary Evelyn Greene’s book, *When Rain Hurts: An Adoptive Mother’s Journey with Fetal Alcohol Syndrome* is a story that is very similar to ours. Greene captured the frustrations, challenges and delays of the adoption process while giving a very personal feeling to the experience. As with many adoptive families, the Greene’s were assured that they were adopting two healthy children only to discover fairly quickly that one of their children had some very serious developmental and behavioral challenges. Greene details their search for an answer to their son’s challenges and her experience attempting to find treatments for his needs. The family seeks help from some of



the most well-known professionals in international adoption and in diagnosing fetal alcohol spectrum disorders. They are relentless in their search for educational and therapeutic strategies that will help their son. Greene is brutally open about her feelings as she journeys through the adoption process, through the behavioral challenges and into the diagnostic process.

The book is a great read for any adoptive parent especially those who are struggling with behavioral challenges. Family members, therapists and educational professionals should also read this book to gain an understanding of challenges that many adoptive families face.

Braggs

Gabby

Gabby S., 10 years old, was recently appointed captain of the service squad at her elementary school.

Congratulations, Gabby!



Joshua

Joshua K., 19 years old, recently earned his yellow belt in karate. He's been taking lessons for about 4 months.

Congratulations, Joshua!



Young Adult FASD Conference

What a great time I had at the Young Adult FASD conference this past August in Ohio. Over 25 individuals and their supports spent a great weekend at the Widewater Retreat Center. Some of us were shy at first, but that



changed after the first meal, from then on, we were there to be with our peers and get some information.

A lot of it I hadn't thought much about, but I learned how to: advocate

for myself, what to do if stopped by authorities, interviewing skills, checking and other money skills, how our brains are different and more. For fun we could swim, paddle boat, fish, do archery, craft, sing at the campfire, make s'mores and more...and make sure your room's clean so you can win the golden broom (see picture) award!!!

It was great to meet other people and their supports who know what my life's like without going into detail, I rarely get that. I realized that there are other people like me and I felt kinda normal!

I hope they have it again and everyone should try to get to some event like this sooner rather than later.

Written by Andy P.



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>

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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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