

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 14-year-old daughter has a very difficult time maintaining proper hygiene during her monthly cycle. She experiences extreme mood swings which may increase her seizure activity. We've tried many interventions including Depo-Provera shots, birth control pills alone and we recently learned that her uterus is too small for an IUD. As a temporary strategy, her doctor has put her on estrogen and a birth control pill. She is developmentally about 6 years old. The doctor suggested we consider a permanent procedure that would leave her unable to get pregnant. However, I'm concerned about doing anything that would permanently prevent her from having children as she talks about wanting to have a baby. At this time it seems impossible that she'll ever be mature enough to parent a child, but how can I make that decision not knowing what the future will bring? Are there any temporary fixes that might help to eliminate her cycles for the next several years?*

Answer: We have no way of knowing what the future holds for any of our kids whether or not they have special needs. We do know, though, at a developmental age of 6 years old, your daughter is not equipped developmentally or emotionally to handle pregnancy, childbirth or parenting. As the current methods your doctor has prescribed haven't been successful for your daughter, it might be time to consider seeking advice from another doctor or a different medical specialty who might have more experience with women who have developmental delays. It is possible that a doctor

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specializing in gynecological issues might know of methods to prevent/decrease monthly cycles and to help you with strategies to help your daughter learn to care for herself during her cycle. If your daughter receives services from a behaviorist, that person might have familiarity with ways to assist your daughter. Also, seek advice from other families who have faced similar challenges to see what strategies they've employed.

Your daughter will likely be physically capable of bearing children for many years. In order to

protect her from an unplanned pregnancy, one which will create a set of challenges beyond what your daughter may be capable of handling, permanent measures to prevent a pregnancy may be considered. It is a decision that your daughter and/or her legal guardian will have to discuss about how to accomplish permanent protection from pregnancy.

Another thought to consider is protecting your daughter from unwanted sexual advances. She may be unable to defend herself in situations where she is unsupervised and is faced with an aggressor who is intent on taking from her something she is unable to willingly offer. It will be important to provide supervision and an “external brain” to help her navigate situations that may leave her unsafe or vulnerable. At some time point,

your daughter may leave your home to live on her own or in a supervised setting. It might be especially important then to ensure that your daughter is protected from pregnancy.

If your daughter enjoys being with babies and young children, perhaps she will find enjoyment volunteering in a nursery or young children’s program. This way, under supervision, she can experience the joy of caring for children and experience a range of childcare duties. A childcare worker could work with her and help her to learn what it takes to care for a baby or young child on an on-going basis.

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

Michigan FASD Task Force 2016-2018 Goals

The Michigan Fetal Alcohol Spectrum Disorders Task Force met on November 19, 2015 at the Downtown Lansing Capital Area District Library for a strategic planning session to cover the years 2016 through 2018. Leigh Tenkku Lepper, who is a professor of social work and public health and a NOFAS Affiliates Committee member, led us in a day to think through our goals and hopes for the next few years. Leigh stressed that the focus of our strategic plan should be doable and helped us build on the past strategic plans. After much discussion and sorting of our priorities 3 main goal areas were identified:

Goal 1

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.

Goal 2

Educate all individuals involved including but not limited to foster care workers, parents, court personnel, physicians, and teachers for the benefit of the child so that everyone has all the information possible and access to resources, referrals, screening tools, and intervention strategies.

Goal 3

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

Groups have formed around each of the goal areas to create an action plan with 2 or 3 activities. If you are interested in working on a group goal or joining the task force, please contact Ann Carrellas at ann.carrellas@wayne.edu or 313-577-8562. We are all very excited to be moving forward with our new strategic plan!



Our Caring and Compassionate Advocate

Betsy Soden

Betsy Soden and I have been friends for 32 years. We met when she became a volunteer for the Parent Mentoring program that I coordinated at Catholic Social Services. As we grew to know each other better, we discovered that we were both adoptive parents and as I told her of my son, she soon began to wonder if her son might also have FAS or FAE as they called it at that time. This was the beginning of our travels down similar paths. Thus began the friendship of Ted and Vern as well.

Betsy's numerous FASD activities include serving on the steering committees for five parent and professional FASD conferences, presenting on the Parent Panel, speaking to University of Michigan social work students, each and every semester, coordinating the Parent to Parent Support Group, volunteering at the FASD diagnostic clinic at University of Michigan and sharing her experiences and wisdom on the Yahoo Group. She and Vern also served on the first state wide FASD Task Force. They were a team each with their own unique gifts. Whenever I had a new idea, they were **always** there to encourage me and offer a helping hand.

Betsy was very accomplished in other areas as well. She graduated from Plymouth High School as Valedictorian. At the University level, she was a member of Phi Beta Kappa. She obtained her Master's Degree with a major in English as a Second Language. Later she received a Fulbright Scholarship to Japan.

We are saddened that our dear friend is no longer close by but her words and smiles and hugs will be with us all and others with whom we share her spirit.

Barb Wybrecht

This Worked for Us

Haley and Horses

Haley was 5 years 7 months old when we met her. Soon thereafter her physical therapist suggested we enroll her in dance, gymnastics, or therapeutic riding...these might help her with coordination and the neurological issues. Therapeutic riding centers had 2-3 year waiting list. While she enjoyed 2 years of gymnastics, 1 season of dance, and 6 years of junior cheer, the neurodevelopmental issues effecting her motor skills and coordination keep her from competing.



In March 2013, I met the coach of the junior and high school equestrian teams. He owned a ranch with 20+ horses, gave private riding lessons, and was the volunteer equestrian team coach at our same school. We began with daily lessons for one week. Haley loved being with the horses and riding. The coach felt she was 'made' for riding.

It's been three years now. She is a different person on the horse. She is focused and gives her best. She continues to learn more taking 1-2 lessons each week and rides several other times during the week. She was on the junior high equestrian team for three years (April-June) and 1 year on the high school team (August-October). Her team won reserve champs at Districts, reserve champs at Regionals, and placed 7th at State. Not bad out of over 350 high school teams. She also competes at the local Spur Shows, ShowMe Shows, and other shows. She rides English, Western, and Bareback styles. She loves jumping horses and gaming. Haley has ridden many different breeds of horses. She has taken lessons in Michigan, Arizona, and Florida.



This has done wonders for her self-confidence. She reports: "I improved." She feels and is very successful. She would rather be riding or caring for horses than do anything else. Our kids struggle with so much. Riding gives her the assurance she can do really well in at least one thing—riding! She said she feels free and like she can fly when trotting, jumping, cantering, and galloping horses.



Haley wants to become a horse trainer. Thus this month, she began volunteering at a local riding stable. She helps bring in 16 horses. She puts them in feeding pens. Give them grain. She puts out hay in the pasture. Then she lets them out and they graze on the hay. She brushes the horses and cleans the dirt out of their hooves and makes sure there is water in their troughs. She 'mucks' stalls out, too. She talks with the horses and tells each one how special they are.

The downfall of riding is the cost. Lessons vary between \$35 and \$50 per lesson. To lease a horse is can run \$400 to \$500 per month. Owning a horse cost even more each month. When she began riding, we used the barn's tack (saddle, bridle, bite, pad, etc). Now, we have purchased her own that fits her. She has her own boots and helmets too. When completing at shows, she has special show clothes.

Haley loves riding. She hopes to ride and compete throughout high school and then become a horse trainer learning from her coach.



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.



Simply Loving Them

"Just take them home and love them." That's what we were told when we adopted our children. "Love them and in six months you'll never know they had such a rough start." We hung our hats on those promises. And, for a minute it seemed as though they were accurate. We were a family. We had fun together and learned a lot about each other. Our support systems were in place right from the beginning. Family and friends were very involved in our lives. We were active in our faith community. We were aware of therapeutic and educational services available in our area should we need them. The adoption support groups that we had connected with during our adoption journey were shelved because all was right in our world. And then, overnight it seems, it all came to a crashing halt.

Disagreements started creeping into our day over the slightest things. Requests such as, "We're leaving in 10 minutes. Please put on your shoes" were met with tantrums and thrown toys. Bedtime, which used to involve stories and prayers, became a battle of wills. Mealtime, which had been so enjoyable, began to be dreaded.

As our life slowly rolled toward what was, for us, uncharted territory, we knew we had to reach out for help. Traditional parenting techniques like time-outs and time-ins did little to improve our relationship. Love and Logic, parenting classes, sensory integration therapy, biofeedback did little to improve behavior. We were financially drained, emotionally drained and our jobs were in jeopardy because we were frequently absent from work. We called in the reinforcements. Friends and family did what they could to help. Prayer groups were started for our family. We sought ideas from our adoption support groups.

As we were standing at the edge of the cliff waiting for the next strong wind, it happened - behavior severe and dangerous enough to warrant inpatient hospitalization. The slow downward descent turned into an avalanche. The first hospitalization was followed by a second and a third. Residential treatment, our last hope, was tried. And, failed. The children met their pre-determined maximum number of days. And, still, the behavioral challenges increased and became more dangerous.

When we thought we were at our lowest, we found how much lower we could go. The first protective services complaint was made. We were investigated on a charge that was, to us, so obviously untrue that we thought it would be dismissed immediately. An investigation was begun. Our other children were interviewed about the incident. We were put on a plan. No sooner was that complaint closed that a second, then third complaint were made. More investigations, more interviews, more plans. No answers. No direction for the future. No hope. More hospitalizations. More returns home in an unstable state. More threats: keep all of your children safe or they'll all be taken away.

We understand that the needs of our children are extreme. Though we haven't met many other families who live with such significant challenges, we know there are other families in Michigan. None of us wants to give up on our children. At the same time, we're hanging on by a thread. The system has failed our children and there are no good options to take.

"Take them home and love them." If only it was that simple.

The author prefers to remain anonymous.

Identification Cards

Sometimes our kids are in a situation where they need to produce information about themselves in an emergency situation such as when stopped by a police officer. Or, sometimes we would like to educate the public about the behaviors exhibited by individuals who are on the fetal alcohol spectrum. This website offers some templates that can be used to develop identification cards to share information about FASD.

<http://www.fasdwaterlooregion.ca/strategies-tools/identity->

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.



Bragg

Gabby and Duncan...

... have been appointed Michigan's first boy-girl co-ambassadors for Easter Seals.

Andy P...

... received SSI after a 14-month wait. He is looking forward to finding a semi-independent living situation and learning how to cook on his own, budget, get along with his roommates. He has begun participating in Special Olympics and attends a clubhouse program daily.

Meg P...

... had the opportunity to skate with Olympic, World and National ice skating champions for a fundraiser for her Special Olympics team. Meg and her team met with the pros at an afterglow reception. It was a once in a lifetime moment for Meg and her team.



Things Our Kids Say

- Gabby, "Mommy! We got a package from the P.U.S. man!" (UPS...)
- G (3rd grade): Someone stole my agenda. (they call their daily schedule notebook an agenda)
 Me: STOLE it? Really?
 G: Well, I put it in my desk this morning and it wasn't there to go home. Somebody stoled it. Yes, they did. It is gone.
 Me: Did you tell your teacher it was missing?
 G: NO! She would be disappointed in me. I cannot disappoint her, she is too nice. Will you send her a note on the computer?
 Me: Won't she still be disappointed?
 G: No, cuz you're telling her, not me. She will be disappointed in you.

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. We usually meet on the 2nd Saturday of each month. If you're able to join us, please contact Charisse at charisse@mcfares.org to RSVP and confirm that the activity will be held as scheduled. Note: Unless other arrangements are made, these meetings are reserved for family members only.



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



Belle Isle, Scott Memorial Fountain



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.

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 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

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

RECIPIENT

Address Line 1

Address Line 2

Address Line 3

Address Line 4
