



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 sons are 3 and 6 years old. They both have been diagnosed with FAS. Caring for them takes much of our time and energy and we're left with little desire or ability to join in any activities outside our home. Do you have any suggestions about how we can better handle our situation?*

Answer: Caring for the needs of our children can be exhausting. It is sometimes all we can do to get meals on the table, children dressed and ready for school and laundry washed and dried. We may be able to implement some strategies to lighten the load and provide time and energy for fun family activities.

Try to assess your boys' abilities. Are you doing jobs that they might have the ability to do on their own? Consider things like collecting garbage, setting and clearing the table, loading and emptying the dishwasher, dusting, making beds, folding and putting away laundry, etc.

Make a chore chart assigning specific tasks to each child and then teach the expectations of the task, maybe taking picture of how the task is completed correctly. Mount those pictures on a task board. At first, it may seem more work to teach and monitor the task; but, in time, your children will become more independent (of course, review may be necessary) and responsible. Implement a routine to your day and mount the schedule in a visible place.

Review the schedule throughout the day. Sometimes our children are less anxious if they know the events of the day. Seek out caregivers who will offer support to your family. Decide what "support" means to you and find someone who meets that definition. Does support mean watching the children while you have an evening out? Perhaps it is doing your shopping or some other chore you do not enjoy. Find someone who understands and accepts your parenting style and will meet the needs of your children in the ways that you suggest.

Find an activity that your family can enjoy together. If your children misbehave when they know a special event is scheduled, tell them about the event just before leaving for it.

The goal is to enjoy the activity together.

Find an online or in-person support group. Families in Michigan can find a list of support groups at the end of this newsletter. Also check out <http://www.nofas.org/resource->

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directory/ to find resources in your state. Through a support group, you can learn new strategies from other families and learn about local resources.

As your children grow and change, the challenges you're experiencing will also change. You'll develop new strategies that will work for your family.

NOFAS Summit Recap

A hot day in June via...plane...train... automobile...and the walk to the hotel, I finally arrived in Washington, DC for the NOFAS Summit.

I went to the summit as both a representative of MCFARES and a representative of Early Head Start Macomb. As such, on Wednesday, when many others went to "the Hill" to share their talks and experiences with senators, I stayed "home." This said, I was able to attend the orientation that preceded. Those who went to "the Hill" did not go as a NOFAS representative. However, we were provided with an informative orientation to the opportunities in advocacy. We were also updated on what was important to the senators. The good news is that there was support from both parties.

We also met as affiliates. I was overwhelmed by all the representation from around the nation. Too often I feel as if the voice for FASD is very small and weak. There can be a loneliness often felt in this work. Yet at the summit it became abundantly clear that we are NOT alone. There is so much wonderful work going on around the nation. There are many FASD "soldiers" speaking out and educating folks...so much community. Most impressive was the number of parents that represented affiliates. Having the privilege to work with many families, I have heard too often how there does not seem to be a great deal of parent representation. As I have traveled outside of Michigan, I am pleased to say that this just is not the case. I have learned along side both adoptive and bio parents. Some parents are in the work inspired by the relationship with their child. Some parents are in the work because of an equal commitment to their professional callings.

The summit included updates on research and opportunities to learn from what each of us are doing. There were many ideas shared and I found myself impressed with all that the larger affiliates were doing. We look different depending on where you go. Many small like us, others have grown their resources so as to offer more services such as screening, evaluation and family support. All grew from different seeds: a parent's home, a university, a human service organization... all committed to the

same things. I think many who attended would agree that the best and most important part was the opportunity to connect to others with the same goals and vision. This provided hope, inspiration, support and validation.

This year much of the focus was on promotion and fundraising. Ideas shared were inspiring. I left inspired and impressed by the commitments of many. Until my attendance, I used to think "*Caregivers already have their hands so full. How can they possibly do more?!*" I witnessed from the many parents represented just how possible it could be. I was left hopeful that the voices of the parents going to "The Hill" were the loudest of all. Even in a whisper, they yelled their own personal stories. I left with a sense of just how much louder MCFARES' voice can be. A wise person once said "*Many hands make light work.*" MCFARES needs more hands. With more working together we could implement some of the activities shared by others: educating OBGYNs & Pediatricians, fundraising with the help of local merchants, increasing resources of support for those affected and their families.

The work is exhausting as is the care of our loved ones who are affected. Working together is a must! -For sanity and for change. What would happen if we each committed to 20mins a week: a phone call made, an article written, a doctor informed, a sponsor for the newsletter obtained, a volunteer recruited, a parent supported, a provider directed, a small mailing sent, little FASD labels stabled to candy ready for Halloween trick-or-treaters, ... FASD IS preventable. We can make a difference in the lives of others and creating community can make our own lives feel a little more supported. Our work doesn't have to feel lonely and we don't have to wait for others to make the changes we need.

Submitted by Amy Park-Goeddeke, MSW, LMSW, IMH-E® (III), CTS, Mental Health Specialist and FASD Field Trainer, Macomb County Head Start

Building an Advocacy Strategy

Effective advocacy, of any kind, requires a solid strategy or plan. Practicing skills will help to feel more comfortable and confident in accomplishing your goals that you have set out. In order to make advocacy effective you should always:

- 1) Identify the problem
- 2) Educate yourself through in-services, trainings, or attending support groups related to your child's disability
- 3) Identify your rights, know what rules and regulations to refer to so that you can use correct information
- 4) Develop a solution and strategies to address problem/ goal

***The planning process will be the most consuming part of the process. Sometimes even the best laid plan will fail. Learning how to negotiate a compromise can be an important component to affective advocacy.**

Step 1: Problem Analysis

We have all been overwhelmed by challenges in our lives at one point another. All advocacy starts with a good understanding of the problem. **You have to understand what you want before you can do anything about it.** It's key to remember that sometimes problems can be hard to break down.

- 1) Not all problems can be solved, or easily resolved
- 2) Some problems are easier to resolve than others
- 3) Pick the battles that you want to fight
- 4) You don't have to resolve all problems at one time

***The key is to pick out the problem that is most important to you and address that one first. Once you outline the problem, identify your goal, and identified the facts of your problem, you are ready to move onto information gathering.**

Step 2: Information gathering

In order to be able to effectively advocate, you must have a clear understanding of the facts you know, and a good grasp of what information you may need to gather for resolution of your goals.

- 1) Educate yourself with rules and regulations specific to your situation
- 2) Who can I go to, or who can I contact to help me gather what is needed
- 3) Who are the decision makers that I need to involve in order to solve problem

***Preferences and wants are not typically not illegal, and therefore are not the same as a right that someone has under a law or policy. It is critical to understand the difference between enforceable rights and things that we refer to as being a "right that is not is not covered under any law or policy".**

Step 3: Solution Analysis

After you have figured out what your rights are and have broken down the problem, then your ready to work towards a solution that fits your problem. Always consider what you want to happen. Ask yourself, "What do I need?" Do

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you need an apology, emotional needs, or do you need something concrete? In researching your rights, you might have learned some of the possible solutions available to your situation. When you determine what you want to happen it's always good to contact an advocacy organization or a friend to find out what others have faced the same problem, and how they may have resolved their problems, and what happened in their case.

*** Often, you'll be able to score a partial victory even if you don't obtain your ideal solution. Ask yourself in advance what alternatives you would be willing to accept.**

Always stick to the supervisory ladder when attempting resolving your problem: if you take your problem "straight to the top", then you run the risk that the person will say "no" and you'll be left with no recourse. Also always consider potential allies who might help you with your problem "you get more bees with honey than you do with vinegar".

Step 4: Building your case

Once you have decided what you want and whom to contact, you can begin building your case. Ask yourself the strength of your position; what do you have to strengthen your position? Has an established rule or regulation been violated? Do you have current evaluations and diagnoses in writing?

- Ask yourself what does the other side have to gain from resolving the problem in your favor?

- What benefit is it to your child, is it educationally relevant?
- Sometimes persistency pays off; the other side might decide to give you what you want rather than hearing from you on a daily basis.
- You must also look at the other side of the argument, why is the other side taking their position? Is there a rule or policy involved?

***The most important part of building your case is gathering documentation.**

Acknowledging the other side's point of view as you advocate for yourself shows that you appreciate the other side's needs and this will help you maintain relationships along the way.

- Current evaluations with findings and recommendations
- Current diagnosis's on script
- Report cards, MEAP scores, samples of school work

Step 5: Planning your strategy

There are a variety of ways to approach any given problem. You do not have to plan your strategy alone; you can contact an advocacy agency to get input. You should spend some time reflecting on what you plan to do before you do it. Try to take out the parts of the story that may be emotional for you, but might not be relevant to the resolution to the problem.

- Use the advocacy planning sheet for guidance
- Hold an informal meeting to touch on concerns
- Mediation can be a useful tool if you feel that you may not be able to effectively voice your concerns, or you have

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concerns that other may not listen or hear you.

- Draft an agenda so that you can stick to your talking points
- Get all information and documentation in order of talking points.
- Be prepared to offer up suggestions and strategies for resolution to problems.
- Take someone with you to help you build your position, counselor, advocate, family friend, therapist ect.

***Remember that it takes time to develop highly skilled advocacy approaches. Even the best advocates don't always win; losing may be as much a reflection on the system as on the advocate. Always give yourself credit for good, effective approaches. Evaluate your activities and build on skills through ongoing trainings to heighten your skills.**

This article was provided by the Arc Macomb. For further information and support, contact <http://www.arcmi.org/>

MCFARES Meeting Dates

Meetings are generally held on the fourth Monday of each month from 12:30 – 2:00 p.m. at the Arc-Macomb offices. Contact Charisse at Charisse@mcfares.org for more information.

November 26, 2012

December (probably lunch meeting off-site)

January 28, 2013

February 25, 2013

March 25, 2013

Visit MCFARES on the web at

<http://www.mcfares.org/index.html>

and on Facebook at

<https://www.facebook.com/groups/93728110628/>

Bragging

Kids Getting Jobs



Two of Debbie's daughters have gotten jobs recently. One will be working at a day care center. She'll be working as a sub and will hopefully work full-time after she finishes school next spring.



Debbie's other daughter started a dog-walking business and is doing great at it.

Birthday Blessings

10-year-old Gabby and nine of her friends celebrated her birthday at a bounce house. Everyone had lots of fun. Gabby has also had a successful play date with one of her friends.



Bragging

MCFARES participated in two FASDay activities this year.

First, some of our families shared a prevention message in the community using snack-sized Snickers candy bars attached to a card giving information about the dangers of alcohol use during pregnancy. Information was shared at local doctor's offices, churches, businesses and schools. If you are interested in sharing this great prevention message, please contact Barb at bobbiesue56@gmail.com and she'll send you the documents via email.



Our second FASDay event was held on September 15th. Over 30 people gathered for our monthly Project SAFE potluck dinner, recreation and support gathering. Families enjoyed spending time together, watching the kids play (or joining in), supporting each other and sharing information. We played a game of "How much do you know about MCFARES and FASD?" and several of our attendees won prizes for answering our questions.

Painless Fundraising

As an unfunded Coalition, MCFARES relies on grants, donations and other forms of fundraising to continue operations. None of our members is an expert on fundraising and few of us have the time and expertise to do large scale fundraising efforts.

We have found, though, some very simple methods of raising funds for our Coalition. All it requires is for you to tweak something

that many of you already do. Here are two ideas:

Use GoodSearch as your search engine and designate MCFARES as your charity. Do your online shopping through GoodShop and a portion of your spending will be donated to MCFARES. Sign up for GoodDining and a portion of your restaurant bill.

It's a Matter of Perspective: Understanding How Our Kids' Brains Work

Scenario: Dinner time

Dad to 11 year old daughter: You may have 2 hot dogs

Daughter eats two chili dogs, then 3 hot dog buns with chili

Dad to daughter: What happened to the rest of the buns? I thought I told you to have only two hot dogs.

Daughter: Yeah, you said two hot dogs. You didn't say anything about buns or chili.

Did you know...

Members from the MCFARES Coalition are available for in-service training at your agency?

Topics include FASD 101, Signs and



Symptoms, Behaviors and Interventions, and Services and Supports. We can also develop an in-service specific to the needs of your agency.

Fees are typically \$100 per hour per presenter.

Did you know...



Many members of the MCFARES Coalition are parents of kids who were prenatally exposed to alcohol. These members are available to talk with parents to offer information and support.

If you know a family who might be interested in talking with another parent, ask them to email Charisse at charisse@mcfares.org or call 586-329-6722.



Help Us Help Families

You can help MCFARES to continue providing support, information and resources to the community. Members from MCFARES host vendor tables at area events to share prevention and resource information, provide information via phone and email, develop a quarterly newsletter, help fund scholarships to the Super Kids/Smart Choices summer socialization program, and host annual International Fetal Alcohol Spectrum Disorder Awareness Day events.

MCFARES incurs many expenses and is currently an unfunded Coalition. Your tax-deductible donation or donation of supplies will help us to continue serving our community. We could always use printer cartridges (HP 564), printer paper, gas cards

(to help families attend gatherings and medical appointments), grocery store gift cards (to provide food for family gatherings and other MCFARES events), and cash donations (to help pay phone bills, web-hosting, scholarships, etc.).

If you would like to help MCFARES, email Charisse at charisse@mcfares.org.

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@verizon.net or 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. Charlotte Assembly of God Church, Charlotte, across from Meijer on M-50. Contact Michelle for more information at besa_93@yahoo.com.

Jackson County

Jackson County, Parenting Challenging Children. Meets 2nd Sunday of each month, 1 – 2 p.m. Cascades Fellowship CRC, 2390 W. High Street, Jackson, MI 49203. Monthly meeting includes family lunch, child care, crafts and videos for children and youth. Speaker occasionally scheduled. Contact Rev. Bob Devries or his wife Alice at 517-784-8034.

Kent County

West Michigan Support Group, Meets 3rd Tuesday of each month, 7 – 8:30 p.m., Westminster Presbyterian Church, 47 Jefferson Avenue, Grand Rapids, MI 49503. Contact Barbara Wybrecht, 616-241-9128 or bmwybrecht@aol.com or Corry Tait, 616-878-1839 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.

Monroe County

Adoptive Moms Group, Meets 2nd Wednesday of each month, 7 – 9 p.m. Original Gravity, 440 County Street, Milan, MI 48160. Contact Theresa Light at Theresa.light@yahoo.com for more information as dates and locations sometimes change.

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.

Wayne County

Fetal Alcohol Syndrome Caregivers and Families Engaged, Merrill Palmer Skillman Institute, Wayne State University, Skillman Building, 100 East Palmer, Detroit, MI 48202. Contact Maureen Rashwan at 248 470-5469 for more information.

On-line Support

Families and Supports Affected by FASD: <http://groups.yahoo.com/group/FaSAFASD>

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Support Groups for FASD in Michigan

- Arc Services of Macomb (fiduciary)
- Family members of affected individuals
- Macomb Intermediate School District, Early On
- Fraser Public Schools
- Devon Behavioral Consulting
- Macomb Family Services
- Macomb County Health Department
- Madonna University
- Macomb County Office of Substance Abuse
- Oakland University School of Nursing
- Macomb County Head Start



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

MCFARES

44050 N. Gratiot

Clinton Township, MI 48036

[Recipient]

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