



# 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 will soon be bringing home our 4 year old son who has been diagnosed with fetal alcohol syndrome. Do you have any suggestions that might ease his transition to our home?*

### Answer:

Congratulations to you and your son. First, you might want to consider how you will prepare your home for the arrival of your son. At least initially, keep things very simple. His room should have minimal decorations and accessories (i.e., his bed, a dresser and maybe a sitting area for quiet play). In your living areas, limit the toys available for play. You can switch out toys as his interests change but provide a limited number of choices.

Though family and friends will want to meet your son, consider holding off visits for a week or two so that you can spend time alone as a family. You'll want to spend time learning each others' habits, likes and dislikes. Develop some rituals such as snuggling in bed on Saturday mornings or walks around the block after dinner. Spend time holding him and reading

or telling stories.

Slowly introduce your son to your worship setting. Perhaps you can visit during non-service hours and talk about what happens during an actual service. During the service, plan for distractions and challenges such as sensitivity to noise levels, lack of attention for the length of the service, and hunger.

Though you may not need the resources, keep a file with information about support groups for adoptive families and for fetal alcohol spectrum disorders. If you ever have questions or need direction, group members may

be able to provide first-hand accounts of their experiences.

Try to obtain as much information from your agency about your son's pre-natal, birth and early years. Consider

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seeking educational testing from your local school district to gain some information about possible educational needs. Also, see your pediatrician for an initial visit that doesn't involve any invasive testing.

*If you have already welcomed a child into your family and have additional suggestions, please send them to Charisse at [charisse@mcfares.org](mailto:charisse@mcfares.org). We will include them in the spring newsletter.*

*If you'd like your question to be answered in this newsletter, please send it to Charisse at [charisse@mcfares.org](mailto:charisse@mcfares.org).*

## One Step at a Time! And then Repeat.

By Ann Kagarise

I guess I'm really having a pity party at the moment. For the most part, I just keep going and I don't let the disabilities ever ruin my day. Today, I am feeling sad. That's the best emotion I can come up with. I have a phone now, like everyone else. I mean a Droid razor HD. I do have trouble with the basic stuff, but I found a ton of apps. All kinds of games, etc. I wanted to play them and enjoy. With me having the mind I do, I like the peg game and

games that are simple one slow task for me to do and figure out as I go. I can't think fast and I found out tonight that I really don't understand even the easiest of games. I have to ask my daughter how to do them and even the simplest of just move this mom or that reminds me of just how much I don't understand. I was left to try on my own and I had no idea. So I went from game to game to game. I must have tried 10 or more, same result. Plus with all that's on there, my attention is about 10 seconds so I go from thing to thing to thing and actually instead of getting stuck on any one game, I got stuck on trying to figure out a game and moving on to the next. All day, I have moved from topic to topic or thing to thing and just felt lost. I can kind of do the kid games as long as they are very easy. I guess, right now, I just want to be like everybody else. even teens can do the games I can't. When you see a 10 year old connect and process and execute in the



amount of time it took me to just begin to see it and process...not even close to moving to execute...it takes me about 20 seconds to think through something to start to begin to move to figure out what to do and then it takes me several moves of doing something wrong before I figure out the right way. So, what takes a 10 year old to do in 10 seconds it takes me maybe a good minute or so. And many times, I have to just stop the game because I

simply am not able to grasp it so I have to move on. My brain is SLOW! I think that is partly why we have to have very little to process around us to do things. when there is a lot going on in the room, I can't do anything I have to process. I need space, quiet, and a lot of time to do things. Each thing that is added to the room, takes away from my ability to do something.

So for teachers teaching kids like us, the best way for them to learn, is repeat repeat repeat, help them execute it with them. Have them try to repeat back. If they don't can't do it ONE STEP AT A TIME! Let them do that step. THEN move on to the next. Just know directions are not our friend. Following simple directions is very very hard. I always looked around at others before I could figure out what to do next. We are great observers. What am I

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supposed to do? Look to your neighbor and then you will know. Cheating? no not really. we just don't know what we are supposed to be doing. Don't understand teh concepts on the page. Need a lot of instruction and time to figure it out. We could be removed from the room with a one on one instructor making sure we are understanding. Do this enough times on one step, we will be ready to move on to the next. Explain first step—have us say it back—have us do the one step— Repeat Explain second step—etc. Then speed up that process SLOWLY.

Do you know what its like to see everybody else in the room get it, but you? Everybody else is on step 5 and you are just getting started on one.

I tried to line dance before. Embarassing!!! Everyone was on step 10 and I was still trying to figure out step two.

Teachers, parents and caregivers...your fasd kid that looks like they don't know what to do, you kid that is trying to do what everyone else is doing in the room and

continually looks around...they really dont get it. They are not making it up. FASD is significant brain damage. The areas of the brain that are affected...don't work that great, if at all. Unfortunately. Just do it with us until we are able to do it slowly by ourselves. It reminds me of the Bible story...Moses. He told God he could not even speak eloquently. God gave him Aaron to follow. Aaron did it all at first. Moses watched. Then they did it together. Then Moses was left to do it on his own. It was a process. A long one. If you rush it, we will be left too soon and then nothing was accomplished. If you do it our pace, then we will get it and be able to do it on our own. It might take hours, weeks, or years. But do it as long as we need then we will be ready to move to the next step.

*Ann Kagarise is an FASD blogger/advocate and freelance photographer from Ohio. She was prenatally exposed to alcohol and is an accomplished "writer who is trying to help change the world one written word at a time." Ms. Kagarise is writing a book about a young girl with FASD. You can contact her at [kagarise.ideahouse@gmail.com](mailto:kagarise.ideahouse@gmail.com)*

## MCFARES is Adding New Members

Please join the MCFARES team to help raise awareness of FASD by sharing prevention and intervention information and helping to develop new programs for FASD intervention. We are accepting new members from throughout the state.

Meetings are generally held on the fourth Monday of each month from 12:30 – 2:00 p.m. at the Arc-Macomb offices. We would love for you to join us if you are in the area, but you can maintain involvement via email and phone if you are not in the area.

Please contact Charisse at [charisse@mcfares.org](mailto:charisse@mcfares.org) to be added to our member list.

Visit MCFARES on the web at <http://www.mcfares.org/index.html> and on Facebook at <https://www.facebook.com/groups/93728110628/>

## Bragging

### Choices

Developing an ability to handle emotionally-laden situations is challenging for any teen but sometimes especially so for a teen affected by pre-natal exposure to alcohol.

Just recently, Cindy C., had to make a split-second decision about how to act when a fellow student grabbed her breast. Previous experiences of abuse have caused Cindy to react in an aggressive manner but on this occasion, Cindy sought out a teacher and explained what happened. After the incident, Cindy testified in to the Board of the Education and the student was suspended.

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### Super Kids/Smart Choices

MCFARES has received preliminary approval to hold the Super Kids/Smart Choices summer socialization program this summer. At this time, we do not know when or where the program will be held but we will begin discussions about that soon.

The program will probably be held in late June or late July in Macomb County. Any family who is able to transport students to Macomb County is eligible to attend the program.

If you are interested in enrolling your child or know of a family who is interested, please send an email to Charisse at [charisse@mcfares.org](mailto:charisse@mcfares.org).

### Good Luck, Laura

After serving many years on the MCFARES board, Laura Gressinger is moving on to other pursuits.

We are thankful for Laura's knowledge and assistance during the process of applying for non-profit status. Laura's kindness and generosity is well known to all who know

her. You will be greatly missed, Laura.

Please  
keep in  
touch.



## Second European Conference on FASD

The Second European Conference on FASD was held in Barcelona, Spain in October,

2012. Barb, Ted and Rob Wybrecht attended



the conference. There were 200 attendees from 24 countries including Russia, the Ukraine, Norway, France

and many others.

Rob was part of a panel that included two birthmothers, one from England and the other from the Netherlands. The fourth panel member was a young woman who has FAS and is the mother of a 9-year-old son who was not prenatally exposed to alcohol.

In this picture, Barb, Ted, and Rob pose with Dr. Ken Lyon Jones who diagnosed Rob with fetal alcohol syndrome. Rob was the first infant in the United States to be diagnosed with FAS. That was 40 years ago.



Thank you, Wybrecht family, for continuing your quest to raise awareness of fetal alcohol spectrum disorders.

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

From Gabby's mom:

Gabby, age 10, fed her dog. After eating, the dog was laying on the floor, resting. Gabby laid her head on the dog's tummy then looked up and said, "Her stomach is going grrrr-glub-glub-grrrrrow."

I said, "She's digesting."

Gabby looked HORRIFIED and asked, "She's DYING?!"

I said, "No, that's what tummies do to food--digest it, break it down. Sometimes it's noisy."

Gabby was relieved, "Wow, I was afraid you said she was about to die."



## Did You Know . . .

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](mailto: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](mailto: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](mailto:Charisse@mcfares.org)).

#### Alpena County

FASD Family Support Group, Meets 3<sup>rd</sup> Thursday of each month; 6:30 – 8 p.m., Thunder Bay Transportation Authority, 3022 US23 S, Alpena. Contact Mary Schalk at [maryschalk@verizon.net](mailto:maryschalk@verizon.net) or 989-734-2877 for more information.

#### Eaton County

Eaton County Foster Adopt Support Group, Meets 1<sup>st</sup> 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](mailto:besa_93@yahoo.com).

#### Jackson County

Jackson County, Parenting Challenging Children. Meets 2<sup>nd</sup> 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 3<sup>rd</sup> 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](mailto:bmwybrecht@aol.com) or Corry Tait, 616-878-1839 for more information.

Self-Advocates with and FASD in Action (SAFA), generally meets on the 3<sup>rd</sup> 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](mailto: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](mailto:Charisse@mcfares.org) or 586-329-6722.

Brunch Bunch, Monthly, 2<sup>nd</sup> Tuesday, 9 a.m. – 11 a.m., In Clinton Township, Contact Charisse at [Charisse@mcfares.org](mailto:Charisse@mcfares.org) or 586-329-6722 for location details.

### **Monroe County**

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

### **Washtenaw County**

Ann Arbor Support Group, Meets 4<sup>th</sup> Wednesday of each month, 7 – 9 p.m. Contact Betsy for meeting dates or cancellations in November, December and January. St. Joseph Mercy Hospital, Education Center, Classroom #5, 5305 East Huron Drive. Contact Betsy for more information, [betsysoden@juno.com](mailto: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>

*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 Member Agencies

- 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.*

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## MCFARES

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[Recipient]

Address Line 1

Address Line 2

Address Line 3

Address Line 4