



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 4 year old daughter is not yet fully potty trained. She'll have accidents during the day while playing and sometimes at night. The other day I found that she had wet in her bedroom within an hour of going to bed but rather than wet in her bed and pajamas, she had taken off her pajamas and wet on the carpet near her bed. I have found wet clothes in her closet and wet floors in other parts of our house.*

Answer: Due to many factors (lag in maturity, sensory issues, muscle tone) some children affected by pre-natal exposure to alcohol do not experience full control of their bladder or bowels until age 10 or so. In the meantime, it would be helpful to seek input to rule out genetic, neurological or medical causes. It would also be helpful to seek a psychological evaluation to see if there might be other behavioral considerations.

Try to notice if there are triggers that might cause a wetting incident (does she wet when she's overly tired, does she wet after she's had a hard day at school, does she wet after she has been in trouble). Should you discover a wetting incident, remain calm, show no emotion and be matter-of-fact about the clean-up process. Simply remind your daughter of the proper bathroom procedure and practice it. Help all others who care for your daughter to follow the same procedures.

Develop a bathroom routine using the same words and actions each day and consider developing a picture schedule (<http://www.do2learn.com/picturecards/printcards/index.htm>). Try limiting liquids a few hours before bed. Try waking her and taking her to use the restroom just before you retire for the night. Some interventions may work for a time and then cease to work necessitating attempts at other options. It may be appropriate to use padded underwear (i.e., Pull-Ups), at least in the evening. Here are some other suggestions:

<http://www.come-over.to/FAS/ToiletTrain.htm>,

SPRING, 2013



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<http://www.toolboxparent.com/PowerTools/Joyce/Wetting.aspx>

If you have experience, ideas or suggestions for this family, please send them to charisse@mcfares.org.

If you have questions for News and Views, please send them charisse@mcfares.org.

Stuck in the Middle

By Linda Quirk

As I start to write this article, I am actually living the middle of the story. I do not yet know how it will end. My son was admitted to Residential Treatment February 2013. R is 9 ½ with a history of trauma. He came to us at 3 months of age and had already been through so much. He was born at 34-36 weeks (no prenatal care, so actually gestation time is unknown), was exposed to meth, cocaine and alcohol in utero. He suffered a brain bleed (IVF) at birth, cardiac arrest in which it took them 20 minutes to stabilize him, intubation for 10 days, NICU for 28 days. Oh, and his family of origin, for various reasons depending on whom you ask, did not visit him in the hospital. He spent 28 days in a NICU with a different caregiver every 8 hours. This is not what a newborn needs, as we well know. He was placed in a first foster home when he was 28 days old and social services finally figured out his family of origin wasn't around to claim him, and was placed with us as a foster to adopt family at 3 months after a short hospitalization for seizures.



Whew.

I give you R's background because it is so traumatic. For our son, who carries the diagnoses of Bipolar (or Mood Disorder, depending on the diagnosing authority), Fetal Alcohol Syndrome and Pervasive Developmental Disorder (NOS), life is a struggle. He cannot read facial cues, he is not adept at social situations, he assumes people do things "on purpose," and generally has had a lifetime of failures in his short 9 years on this planet.

We do not home school. I wouldn't know what to do and I need the respite from this very complex child. I am fairly good at getting my child's needs met at school. I am also married to an attorney licensed to practice in Michigan and California.

He comes in handy when I need him to wear a suit and look menacing. He doesn't need to say a thing which is good because he doesn't know squat about special education law. No one has actually caught onto that yet. Don't tell.

So how did we get here? To Residential Treatment? Because R is no longer safe to himself or to others. He attacks his parents, his siblings, the animals in the house, and occasionally, peers. We have called the police, they have transported him to the hospital by ambulance. They are starting to get to know us in our small Village.

R has had 5 short term hospitalizations for stabilization, 1 longer term hospitalization in a facility that purported to treat the child and family and did not, and now we are involved in family therapy at Wedgwood Christian Services and R is in a minimum security setting for residential

treatment.

My initial impression of residential was not good. It looked to me (and still does at times) like glorified babysitting. There is structure, much more than we can give at home. There are rules and consequences (sometimes), staff that rotates every 6 to 8 hours, set meal and snack times, outings and behavior expectations. There is not much communication between personnel when shift changes occur. We have lost information between home and RTC and school. The school became frustrated as it appeared there were no consequences for aggression at school. R does not receive homework (it is in his IEP) but if he does not finish school work it can be sent home to be completed. The residential

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treatment center staff ignored this initially. I finally called a meeting between R's therapist at the center, myself and the teacher where we discussed what the expectations would be. It's still not perfect, but at least the center staff does not ignore his aggression at school or his work if he has not completed it at school.

The subject of whether R's placement at school (EI contained classroom) is appropriate is ongoing. At this point, we believe R is better served in a setting that concentrates on daily living skills rather than academics. But that is for another article.

Communication between staff and parents was lacking, as well. R had to be returned to the center early one visit because he was torturing his sister, hair pulling, hitting, etc. When I called that afternoon to see how he was the staff told me he was fine, he was outside playing in the snow and quite a happy camper. You can imagine how upset I was. Where were the consequences for his behavior? Isn't that what he is doing in RTC? Learning how NOT to hit, pull hair, etc? How is he going to learn that if he is allowed to be a happy camper mere hours after the incident? Unfortunately, this was on a Saturday and I was not able to reach his therapist.

When I called her on Monday morning she agreed that it had not been handled well and had a talk with staff. The next time that happened, R was "grounded" for 24 hours. A much better consequence for R. Maybe not for staff, as they had to put up with his moaning and groaning.

We moved rather quickly from visiting him at RTC, to taking him out for the day, to taking him for Friday afternoon and Sunday all day on the weekend. As of mid-March we have not yet had an aggression-free weekend. Once we have a few of those under our belts, we will move to an overnight.

Each time the visit plan changes, we meet as a family with the therapists to come up with a plan. It

is important that the girls know the plan and know that the expectation is that R will be safe. And to know what the plan is if he is not safe.

At the beginning of April we came upon the end of R's first 60 day term at RTC. His time has been extended 30 days. We need much more than 30 days, but have the added stress of renewing each month. Just another worry to add to the others.

With all the recent budget cuts I worry that they will try to send him home before we have adequately addressed his issues. He has an appointment with a neurologist at DeVos Childrens Hospital in May. Until then, no med changes will be made. I continue to be concerned that his mood is not adequately leveled, important in a child with a Bipolar diagnosis. And I continue to try to get each treating entity to "talk" to one another so that R's treatment is for the whole person that he is and can be.

And so the story continues

Linda is a mom to 3 grown children who are on their own and 3 children who are adopted and who have special needs. She lives in western Michigan. You can reach her at nutsinmich@gmail.com

You can read all about Linda's de-cluttering experience at:

http://www.womansday.com/home/organizing/desk-organization?click=main_sr#slide-7

Bragging

Talent Show

Marissa Q, age 10, performed in a talent show at school. Her mom reports that she was "fabulous."



Sweet 16

Megan P., age 16, and her Special Olympic basketball team won 1st place at regionals and took 4th in their division at the state finals. Megan also celebrated her 16th birthday while at Special Olympics. And, to make the event even more special, Megan was asked to go to Prom in May.



Super Kids/Smart Choices

The Super Kids/Smart Choices Summer Socialization Program will be held Monday through Thursday, July 15-25th at Richards Middle School in Fraser. Students age 5 through 17 who were pre-natally exposed to alcohol are invited to attend. Each day will start at 8:30 a.m. and end at 2:30 p.m. Students will need to bring a lunch each day. The cost is \$30 per child.

The program is a collaborative effort between the Macomb Intermediate School District and Wayne State University Occupational Therapy program. Students will spend a half day improving their socialization skills and the other half of the day working on fine motor skills and sensory integration skills.

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.

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 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/>

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

19 year old is told that it'd be \$5 to have his tooth removed.

He agrees to have his tooth removed then asks when he'd receive his \$5.

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

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, 616-241-9126 or bmwybrecht@aol.com; Corry Tait, 616-550-4273; or, Sandy Kezenius, 616-874-9522 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.

On-line Support

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

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.*

MCFARES

44050 N. Gratiot

Clinton Township, MI 48036

[Recipient]

Address Line 1

Address Line 2

Address Line 3

Address Line 4