



FASD NEWS AND



VIEWS Questions We Are Asked:

Things have just settled down after the start of the new school year and soon we'll be gearing up for the excitement of the holidays. How do we maintain some sense of equilibrium during the holiday season?

The excitement and activity of the holidays can cause great stress for our children who are on the fetal alcohol spectrum. The family/friend visits, the gift giving/receiving, the lights and decorations all combined may leave them overtired, over-stimulated and overstressed.

Before the holidays begin, have discussions with your family to decide what activities you will attend, what behaviors will be accepted and how best to handle public situations where conflict may occur. Remind your children of these agreements before arriving at events and review behavioral expectations.

One of the stresses some families experience is pressure to attend events at times and places that may be challenging for our children. In these instances it may be necessary to educate others about the challenges our children experience and the causes of these challenges. Once educated about the reasons we must make the choices we do, hopefully you'll be supported and assisted during gatherings.

If evening activities are difficult for children, arriving early may be advised with a defined exit plan (decide what behaviors/incidents would cause you to leave an event early). For children who get over-stimulated, plan for a way to have some quiet time – perhaps reading a book in a quiet room or going for a walk or drive may be calming for the child.

Our children may have some challenges gracefully accepting gifts that may not meet their expectations. Practicing social graces before a gift-receiving event may be warranted (for example, model and practice saying a polite “thank you” and immediately acknowledge to your child when appropriate behavior is shown).

If possible, schedule gift giving/receiving for a time that will be most appropriate for your child (if your child becomes over-anxious waiting for giving/receiving, schedule it for the beginning of the gathering; if children become too focused on

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gifts that they might not be able to play with immediately, exchange gifts at the end of the event).

Stick to your normal sleeping and eating schedule if at all possible and try to avoid putting the children in circumstances where they are overtired or over-hungry (consider giving children a snack before arriving at an event in case the meal is delayed).

Holidays can be a time to bring families closer together. With planning and forethought the holidays can be a very

Recommended Reading: The Big FASD PICTURE!

In this issue, MCFARES recommends its own publication: The Big FASD Picture! This spiral-bound book was updated by MCFARES in 2009. It has eight sections which include a definition of FASD, prevention information and school intervention information.

This publication provides helpful information for parents who are just learning about FASD. It is

also a useful tool for professionals who are working with affected children.

The book is available online at http://www.mcfares.org/big_picture/big_picture.html or can be purchased for \$10 by contacting Charisse Cossu-Kowalski at Charisse@mcfares.org or by calling 586-329-6722.



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

Scenario: Dad and teenage daughter who was pre-natally exposed to alcohol are driving in their car. Daughter sees a car with several antennas on it.

Daughter: "Dad, why does that car have all those fishing poles on it?"

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

October 25, 2010
November 22, 2010
December 20, 2010
(tentative lunch mtg)
January 24, 2011

Visit MCFARES on the web at

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

and on Facebook at

<http://www.facebook.com/group.php?gid=93728110628&v=wall&ref=ts>

MCFARES Celebrates 7th FASDay Event:

Better Beverage Challenge and Walk-Along at Macomb Mall

Saturday, September 11, 2010



On Saturday, September 11, 2010 shoppers at Macomb Mall in Roseville were treated to a tasty surprise. MCFARES held its annual “Better Beverage Challenge” to help raise awareness of Fetal Alcohol Spectrum Disorders and to recognize International Fetal Alcohol Spectrum Disorders Awareness Day.

Beverages were prepared by MCFARES, Arc Services of Macomb, Macomb ISD Early On, Macomb Family Services,



Project SAFE and American Heritage Girls. Approximately 130 shoppers stopped by to learn about FASD and to participate in our Better Beverage challenge. In the end, it was “Shark Attack” prepared by Arc Services of Macomb that took the prize for the “Better Beverage” for 2010.

Congratulations, Arc of Macomb. Be prepared for some stiff competition at our 8th Annual FASDay event!



Always Sisters

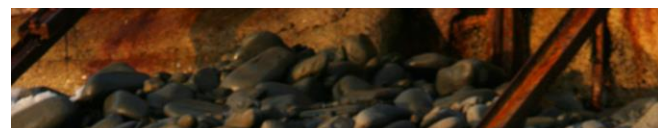
Living with Faith

When I was asked to write about how my little adopted FAS sister fits into my family, many things came to mind. The first thing I thought about was how she often pesters me. I recalled how her syndrome leads her to be loud and hyperactive. Although I know it's not her fault, I found myself wondering what it would be like to have a more controlled younger sibling that doesn't find amusement from constantly clapping. Then I thought about how she reacts around my friends. She always attaches herself to my guy friends and her clinginess makes them uncomfortable. For that reason, I try to avoid her being close to them. That made me realize that even I often don't want to be close to her. She is so crazy and uncontrollable most of the time. Also, she overreacts and is very obnoxious. Ultimately I remembered that those traits were because of her birth defects. Among her physical abnormalities, I thought about how her mind is still not properly developed. It saddened me to remember how hard she has to try to be at the level the other kids her age are at. When she was in school, she would sit down and look at one page of homework for a lengthy amount of time because she was confused or distracted. The other defects I thought about were more troubling to me. I recalled how my sister has to take many medications. Thinking about this upset me because I worry about her problems with her teeth and



her seriously damaged esophagus. I often wish she was as healthy as the other kids her age. Ultimately, in the end of all my thinking I realized something. I realized that although she is crazy, obnoxious, and somewhat slower than the kids her age, I will never think less of her because she is my sister. My heart will always go out to her and I will love her just as I would any blood related sister. It doesn't matter to me where she came from or what she has, as long as she is mine and she never leaves me I am happy. She is so special to me and her heart is so huge for her small size. For example, she doesn't want me to leave for college someday. She would prefer I take "online college". Also, she colors me pictures all the time. So, after all my deep thinking about how she fits in, I found that she is perfect here and that I would never trade her for the world. I love my little sister, Faith.

Written by Kristina Sienkiewicz, age 16. Kristina is a junior at Lutheran High School Northwest.





Living Gluten Free

Reasons for going on the gluten free diet vary. Some adults go on it to see if they can lose weight, some people have gluten intolerance or Celiac Disease (an autoimmune disorder where the body cannot process gluten), while some parents of autistic children or children with FASD put their children on a gluten free diet to change behaviors. Whatever the reason, taking gluten out of the diet suddenly limits which foods a person can eat and where a person can eat.

Gluten is a protein found in wheat, rye, barley and oats. For people with an intolerance or celiac disease, the gluten causes the villi in the intestines to flatten, meaning they do not absorb nutrients, causing slowed growth, headaches, muscle and bone aches, intestinal troubles, etc. For some autistic people and others with FASD, the gluten can cause an almost opiate effect. They crave the gluten like a junky craves a drug. These people will go through withdrawals when gluten is taken from their diet. I've heard behaviors get worse before they get better and, if there is a slip-up, the parents can tell right away just from the behavior the gluten causes.

The gluten free diet is hard, especially in the first few months. The biggest hurdles are cross-contamination from odd sources: the toaster, double-dipping the knife in the jar of mayonnaise, the butter, the cooking pans, towels or napkins shared by family members. There is also the problem of hidden gluten, gluten in strange places and undeclared gluten. Some ketchup has gluten, soy sauce has gluten, lipstick, shampoo, lotions, medicines and sunscreens can all have gluten. Gluten is also in things like malt flavoring, "natural flavors" and fillers. Investigation is a must. At the very least, the parent or person on the gf diet should read all food labels every time they buy the product. It makes for some long grocery trips. Eventually, skimming food labels gets quicker but it is necessary EVERY time you buy

food because ingredients change, usually without warning.

In our house, we have a separate butter container for gluten and non-gluten times. We have learned to use one spoon to take the mayonnaise/jelly/peanut butter out of the jar and a different knife to spread it on the bread so we don't contaminate the whole jar. We have a toaster oven so we can take the rack out and wash it before toasting gluten free bread. We have a completely separate cabinet for gluten free snacks our daughter can freely eat. We buy lots and lots of fresh fruit and vegetables. We cook nearly all our meals from scratch. I bake bread, cakes and cookies from scratch because gluten free mixes are expensive. We actively search the internet for novel ways of making "classic" recipes; we make brownies with black beans instead of flour, birthday cake is made with garbanzo beans. We try to give as much fiber-filled food as we can because the gluten free diet removes 'healthy' things such as whole wheat! We use different flours such as amaranth, quinoa, flax and sorghum. I read labels on everything: shampoo, toothpaste, soap, ice cream, cheese, pickles, salad dressing, lotion, laundry detergent, etc. I've found gluten in every one of those items, that's why we make our own.

Places I've found help for sticking to the gf diet are mostly on-line: The yahoo group Silly Yaks

(<http://health.groups.yahoo.com/group/SillyYaks/>) and the many blogs have been wonderful sources of information. A few of my favorite blogs are:

<http://www.glutenfreegirl.blogspot.com/>

Gluten Free cont'd

<http://www.bookofyum.com/blog/>

<http://www.glutenfreegoddess.blogspot.com/>

Local stores that carry gluten free food (aside from the obvious of fresh fruit, vegetables, plain meat and dairy items) are: Celiac Specialties (Rochester Hills and Novi), Whole Foods, Trader Joes, Kroger and Meijer. Many health food stores also carry gluten free items too, as well as on-line stores such as [Amazon](#), [AuthenticFoods.com](#), [kinnikinnick.com](#), [glutenSolutions.com](#), [Enjoylifefoods.com](#) and more.

I cannot stress enough how much support the Yahoo group, Silly Yaks was to me in the first few years of keeping a gluten free diet. They have hundreds of recipes, links and very supportive people there. They even publish a gluten free candy list every year around this time for Halloween candy!

More and more restaurants have gluten free menus. People still need to be careful ordering from them; more than once we have ordered something gluten free and found a gluten item on the plate. Outback Steakhouse, PF Chang's and Carrabba's are 3 that come to mind. Most Burger King restaurants have a separate fryer for their French fries. Many places will let you order items without the bun/croutons/noodles. People just need to be vigilant to make sure the burger wasn't just plucked from a bun or the croutons weren't just taken from the salad but that both were actually prepared without the gluten and put on a clean plate.

Being on a gluten free diet is hard for anyone. It is very difficult for children, especially if they want to 'fit in' with friends. If you, as a parent, stress how important it is to stay gluten free (be it for behavior modification or for health

reasons), a young child will learn to choose the gluten free foods easily. Our daughter knows if she eats something that has gluten, she will get quite sick. She doesn't want to get sick, so she learned quickly to stick to the gluten free diet. No wavering is allowed, cross-contamination is avoided and it makes for a happier child.

Happiness is A Healthy Pregnancy

That was the theme that MCFARES used for



its entry into the Fraser Parade held on July 25, 2010.

Parade goers learned the prevention message of

Nine Zero: Nine Months Zero Alcohol, Alcohol + Pregnancy Can Harm Baby's Brain. This marked the fifth year in a row that MCFARES marched in the Fraser Parade.



A recent study from Australia is more disturbing than interesting. The purpose of the study was to "examine the association of fetal alcohol exposure during pregnancy with child and adolescent behavioural development". Study results indicated that children born to women who had 2-6 drinks per week (considered in this study as "light drinking") or 7-10 drinks (considered "moderate drinking") had children who were healthy, better adjusted, more evenly tempered than women who had less than 2 drinks per week or who totally abstained from alcohol during pregnancy.

Support Groups for FASD in Michigan (not all groups are specifically for FASD support)

Alpena County

What's wrong with this study? Besides the obvious gaping hole we will title 'Unknown Variables', that FASD Family Support Group Meets 1st Wednesday of each month, 6-8 p.m. How many women have now not only been given permission to drink but are encouraged to drink at what was previously considered one way to feel guilty especially if they didn't have bad intentions (and, from this study -- women may choose to drink and justify their actions by convincing themselves that their child will be better behaved). Guilt is a tough thing to live with and comes when we realize our actions have an effect.

Eaton County

We've already seen the fall-out from releasing such a study -- we've seen it in blogs. The ones that say "I told you it was safe to drink during pregnancy... I did and see how good my kid turned out." (Though, these parents may be fooling themselves). Another study was released recently that seems to indicate that boys who were pre-natally exposed to alcohol may have lower sperm counts as adults).

Do negative outcomes happen in every alcohol-exposed pregnancy? No. Do we know when or to what extent they will happen? No. Is drinking during pregnancy a form of Russian roulette? Yes.

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 517-786-8034.

Here's a brief synopsis of our story:

My husband and I are the adoptive parents of a boy who was pre-natally exposed to alcohol. For years, I was angry with his birthmother. I got over that when I realized it did no good to harbor those feelings. And then, I realized she is most likely also affected by FASD.

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, 616-391-2319 or bmwybrecht@aol.com or Corry Tait, 616-878-1839 for more information.

Currently, our son is a teenager. We have done for him the typical kinds of things many parents do - enrolling him in cub scouts, boy scouts, sports; attending church services regularly; monitoring schoolwork; going camping, fishing, hiking, etc. And then "normal parenting" goes extreme . . . we also employ speech therapists, special ed tutors, behavior therapists; keep him on an all natural diet in addition to various medications; make sure his schooling included OT, special ed services, social skills classes, drive him to school so as to avoid the negative influences of the bus, the first goes on and on. We are currently looking for a Psychologist who understands our son's challenges information, fasdliving@comcast.net or CAP at 517-548-2200.

Though he's a teen, he has the mentality of an 8 year old, can barely do basic math, doesn't understand why he has no friends, and is starting to make choice, which if continued, will bring him to the attention of the legal authorities. My fear is that he will go to 'Juvie' because of hurting someone or taking something. My hope is that IF he goes there, it will be for theft. He has already

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.

Macomb County

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

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/>

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



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

MCFARES

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