



FASD NEWS AND VIEWS

A Michigan Coalition for Fetal Alcohol Resources,
Education and Support (MCFARES) Newsletter



Established in 2003

Questions We Are Asked:

We have two kids who are on the fetal alcohol spectrum. They are 8 and 11 years old. Do you have any suggestions for extracurricular activities for them?

Extracurricular activities are a great way for kids to practice socialization skills, make new friends, learn new skills and have lots of fun.

First, consider their interests and abilities then seek out activities that fit their interests. If your children enjoy sports, try city or school leagues. Some of our kids aren't able to compete at that level and do very well in "challenger" or "VIP" leagues. Through their recreation departments, many cities have programs geared for individuals who have special needs.

You might also want to look at scouting programs. Scouting programs offer many

opportunities for our children to experience success, try new things and build confidence. Some scouting programs do very well in taking into consideration the special needs of our children.

Look into programs at the library in your community or in surrounding communities. Most have summer reading programs and activities throughout the year that may be of interest to your children. Typically there is no cost to these programs.

You can find information about different activities through local support groups, through your school system or through

SPRING, 2011



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your city's recreational department.

See page 2 for a listing of some activities in Michigan.

If you'd like your question to be answered in this newsletter, please send it to Charisse at charisse@mcfares.org.

Recreational Activities in Michigan

Statewide:

American Heritage Girls

http://www.ahgonline.org/pages/page.asp?page_id=146921

Boy Scouts

<https://beascout.scouting.org/BeAScoutMap.aspx>

Camp Fire USA

http://ww2.campfireusa.org/campfire_cf/localdesc_council.asp?StateID=MI

Civil Air Patrol

<http://www.gocivilairpatrol.com/>

4-H

<http://www.4-h.org/get-involved/find-4-h-clubs-camps-programs/>

Girl Scouts

<http://www.girlscouts.org/councilfinder/results.asp?STATE=MI>

Young Marines

<http://youngmarines.com/StateUnits.asp?Action=State&StateCode=MI>

Special Olympics

<http://www.somi.org/About-SOMI/RegionArea-Information.html>

YMCA

<http://www.ymca.net/>

Boys and Girls Clubs of America

<http://bgca.org/Pages/index.aspx>

Macomb/Oakland County:

FAR Conservatory of Therapeutic and Performing Arts (provides creative arts therapy and recreation services)

<http://www.farconservatory.org/>

Elite Cheer

<http://www.elitecheermichigan.com/teams.php?ex40=Y>

Pride of Trilogy Cheer

<http://www.ctcofmi.com/index.php?componentName=Teams&scid=30385>

Please help add to this list. If you have information about recreational activities in your area, please email Charisse at charisse@mcfares.org.

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

Scenario: Father and daughter just returned from a shopping trip. Father has the "deer in the headlights" look.

Father (to mother): "WORDS, WORDS, WORDS!! Girls are NOT made of sugar and spice and everything nice. Girls are made of WORDS! And girls who have an FASD don't even breathe between them!!!!"

Save the Date:

Special Education Fair, March 24, 2012

The Macomb Intermediate School District (MISD) Special Education Fair which will be held on Saturday, March 24, 2012 at the MISD building on Garfield Road in Clinton Township. The event is free and open to parents whose children receive special education services and to professionals who serve students who have special needs.

Janice Fialka, a national trainer, presenter and advocate, will give the opening presentation. Attendees will have the opportunity to choose from several break-out sessions which will address topics of importance to parents of children who receive special education services.

A continental breakfast and boxed lunch will be provided.

Registration information is not yet available but if you wish to attend the event, email Charisse at charisse@mcfares.org.

Registration information will be sent to you when it is available.



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.

January 23, 2012

February 27, 2012

March 26, 2012

April 23, 2012

May 21, 2012

Visit MCFARES on the web at

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

and on Facebook at

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

Saved by Faith

"When will they call us?" I anxiously asked my husband, Mark. "It's not God's time yet," he answered, "You have to have Faith!" Eleven years ago, I was so excited to receive our first call from the foster care agency. We were set and ready to go! The crib was up, and we awaited the call. We had discussed what we thought we could handle and had crossed FAS off the list, primarily because we were told that there would be lifetime implications and that these children would never bond with their parents. Ironically, we got the call the very next day. "We have a two month old baby girl; she has FAS," the worker said. "Just think about it," she continued, "Her name is Destinee Faith." And with that, our journey began!

We wore our best clothes and had a brand new car seat the day we went to pick up our little one. From the moment, I laid eyes on her and held her in my arms, she was mine! My prayers began that very day - that we would be able to keep this very special bundle of joy that they told me weighed 8 pounds. We brought her home, bathed her, and dressed her all up, complete with bows in her hair. The fun had begun! Kristi and Nick had a new baby sister to love and fuss over, and everyone couldn't wait to see her. We even had church pictures that evening. That picture still hangs in the hall today, cementing the memory of the day she became part of our family.

She was such a good baby. She ate and slept and had the biggest smile you ever saw. We were naïve to this FASD. My husband and I had decided, through prayer and petition, to just treat her as we did the other two. She did,

however, seem stiff and jittery at first and would jolt from time to time while Mark would rock her. She slept with her eyes partially open. I distinctly remember the first time she fell asleep in Mark's arms. He had won! She had given in, and the bonding had begun. Little did we realize that she was still suffering the secondary withdrawals that would go on for months. She had almost died in the hospital. She was septic, blue, and her skin was molting. She spent her first two weeks in the hospital - poor little baby...such a rough start.

She met her milestones that first year. She was such a joy, and everyone thoroughly enjoyed her. She was passed around so much at church, you would have thought her a hot potato! We immersed her into an over stimulated home with tons of neighborhood kids, constant piano lessons as I taught over 25 kids at the time, and more activities than I could keep up with. That's how we do it here. She was determined to keep up with the bunch, and she did.

From the very beginning, I began adding supplements to her bottle. I added a dietary supplement to every bottle. I was told that it was a polysaccharide that promoted brain development and great results had been seen in Down Syndrome children. I tried it and began my desperate search to "cure" her. Despite my best efforts, she did not gain weight and was put on Pediasure which unknown to us had 75 mg or so of choline in every bottle. She was exclusively on Pediasure as her only drink for the next 8-9 years. Since then, choline has shown some potential to restore brain function in some studies. We

Faith at age 3



Saved by Faith, Continued

continued to pray for God's healing, and that we would be "...in the right place, at the right time, with the right kid, with the right stuff." This is our family mantra.

At three, she was formally adopted and potty trained, at least enough to get her to preschool and begin activities such as dance, gymnastics, and even basketball camps offered at our church. We immersed her into everything we could. She was 'playing' the piano with me, often sitting in my lap for hours of lessons, and she loved all the educational videos that we played for her. Everything was carefully considered for her. She started preschool at 3; a head shorter than anyone in the class, and arms so thin, I thought they might snap. She did well at St. John. She had extremely loving teachers who knew her and our family well. She thrived.

At four, she continued at St. John, and I also sent her to Montessori. I knew she need more, more, more. We continued running from one activity to the next as we now had three busy young children in the house, each activity challenging her in a new way. I distinctly remember how the basketball buzzer would make her jump to the ceiling. At first, she would cry. However, over time, she adapted to this pace and became desensitized to the sounds and scenes. She even traveled well, meeting Mickey at three and visiting Florida at least twice per year. We were going, going, going!!!



Faith at age 10

I prayed that she would be able to attend Kindergarten at St. John Lutheran School like my other two. She had to take a test to pass into Kindergarten; it was not automatic. She passed! I was amazed at how she was learning. Could her brain be untouched when her body was so scarred from her birth mother's alcohol abuse? She had been formally diagnosed when she was 18 months. The developmental pediatrician started at her head and went to her toes. She displayed every physical deformity that went along with FAS. We were told that her IQ would be in the 70s. Perhaps, with my Masters Degree in School Social Work, I could fix her. I just listened and left. She would overcome this. I would not believe this grim diagnosis. Where was the hope? She was my hope, my Faith! We would persevere. Back to work!!!

She continued at St. John for Kindergarten where the teacher changed the environment for her at first until she learned the rules and routines. In first grade, her teacher said she asked every day when lunch would be, but they loved her and taught her. She learned more sign language that year. They signed all their Jesus songs. Faith was excited because we taught her sign language as a baby because we were told she would have speech delays due to her hearing loss. We knew she was bright when she put two signs together at 11 months.

She never had the speech delays, but the sign language stimulated her brain, and she learned! She breezed through 1st and 2nd grade with excellent grades and marks in behavior. However, she was still not toilet trained fully. She wore a pull up daily to first grade, never having bowel accidents.

Saved by Faith, Continued

However, she had a few urine spills, and we wanted to preserve her dignity. It was never discussed or made into an issue. We never sweat the small stuff.

By third grade, the toilet issues were resolved, but the work was intense. She was spending hours just preparing for the day ahead. She was keeping up, but we had to drop the dance and extra activities. There was just no time for anything but the school work. She was required to be more independent as well, and this was difficult for her. By the end of the year, we were praying for guidance. St. John had dropped the resource room for lack of funding, and that was our answer. We would homeschool!

Homeschooling began fourth grade and now into fifth. She is excelling and doing grade equivalent work. She does long division, decimals, adding and subtracting of fractions. She even finds the common denominator all without a calculator or any aids. Her writing has improved dramatically, and she knows the parts of speech. She now has the time to participate in art classes, choir, piano lessons, American Heritage Girls, dance, and gymnastics. She even placed 2nd in her last mini-meet with girls her own age. We make no accommodations for her. She understands now that her bio-mother drank, but this is not an excuse for anything. We “don’t try harder, just differently” as they say. She has been able to do anything I have put on the table. We did begin the lowest level of Concerta this year to help her focus longer as her work load as become more challenging, and the results have been wonderful. She continues to be seen by several doctors for her ears and gastrointestinal issues, but she is thriving. Her pediatrician from the start keeps telling us she is making remarkable progress by the grace of God.

Faith is a model of early intervention. She was blessed with a bright and happy disposition that was fostered by all who crossed her path. We challenged her without frustrating her, and have never had any outbursts or bad behavior. Her body is now strong and healthy, and I believe that God is continuing to heal her from the inside out. Our pastor recently told us that when she was a baby, he felt that we had perhaps taken on more than we could handle. He called her poor, frail figure “pathetic.” – not in any mean context, just the fact that the alcohol damage was so severe. To see her today, she is not the same child. Her body is strong and healthy looking, her mind is able, her spirit is strong, and her smile still lights up a room. To all that know us, she is our “faith-baby,” and our journey continues.

Written by Melissa Sienkiewicz. You can contact Melissa at pianolady123@gmail.com.

Melissa shared her story about Faith’s journey at the 2011 NOFAS Summit. You can view it here: <http://www.youtube.com/watch?v=C3V2G2TAQP>

Rob Wybrecht's Latest Venture

Rob Wybrecht has taken his talents in a new direction. In an effort to support others affected by an FASD, Rob has spear-headed the "Self Advocates with an FASD in Action" (SAFA) group. Its mission is to show young adults that there are other people with the same disabilities who struggle in life as well.

Michigan members, who must be at least 18 years old and must have an official FASD diagnosis, meet monthly in the Grand Rapids area. The schedule is flexible but they try to meet on the third Tuesday of each month. They discuss topics related to FASD and provide a social outlet where everyone feels comfortable and isn't worried about being judged or "doing it right."

The group had a retreat in August at Camp Henry.



Dr. Ed Riley and Pat Carver were among the speakers who presented workshops. Feedback from the retreat was positive. One attendee stated: "I felt safe and comfortable around the other people" and another stated, "I can finally be myself and nobody will make fun of me."

Rob is also developing a National Self-Advocate group whose members would attend FASD conferences to support each other and to learn about available programs in other states. His

ultimate goal is to have an appointed Self-Advocate representative from each state.

Thanks, Rob, for all your hard work.

If you'd like to contact Rob, his email address is rob1195@yahoo.com.

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 camp, and host annual International Fetal Alcohol Spectrum Disorder Awareness Day events.

MCFARES incurs many expenses and is currently an unfunded Coalition. You can

help us by providing a tax-deductible donation or assist in donating supplies that 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'd 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, 616-550-4273 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>

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

44050 N. Gratiot

Clinton Township, MI 48036

[Recipient]

Address Line 1

Address Line 2

Address Line 3

Address Line 4