

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 12-year-old son, Daniel, will start middle school in the fall. Several of his friends have access to electronics, including smartphones, which are able to access the internet. During the next school year, Daniel will have access to an iPad that he's able to bring home from school to use for his schoolwork. We're concerned that if we get a smartphone for Daniel or if he has access to the internet from his iPad, he may access inappropriate sites on the web. Do you have any suggestions for how we might monitor his usage?*

Answer: You are wise to plan for Daniel's introduction to the increased use of technology. We are all exposed to technology in almost every area of our lives. Most adults and even young teens use cell phones. Many students have access to the internet at school, in other public places and most homes have access to the internet. Since many of our children look more mature and responsible than they are capable of acting, we may be seen as over-protective when we implement strict rules for electronic usage. Expect behavior at his maturity level rather than his chronological age and help other adults who interact with your son to set the same rules and expectations.

Model appropriate behavior as you use your cell phone. Use appropriate language and manners during phone calls and use your phone in appropriate locations and at appropriate times. You are sending the message that phone use is a

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privilege that comes with responsibilities. A cell phone can, if used properly, be a great safety tool. It will allow your son to contact you if he is away from home and has an emergency. On the other hand, if used inappropriately, a cell phone can create serious problems that will be very difficult to undo. A basic service phone, with a texting plan if you're comfortable with that, will allow him to contact you while also preventing him from accessing the internet. Controls can be placed on the phone that limit usage during certain hours and if you allow texting, you may be able to monitor who he is texting and the content of those

texts. While at home, the cell phone can be kept in a public place, especially at night.

Meet with school staff prior to the start of the school year to discuss your concerns about the use of the iPad. Check with the school IT staff to see what safeguards are put on the tablet. If you're concerned about him having the tablet at home, inquire how much work must be completed on the tablet and if there are alternate methods available to complete the work. Express your concerns in terms of how inappropriate use of the tablet might affect your son and share the restrictions you would like to see implemented.

To introduce him to proper use of the computer, you can offer him some screen time at home that is both supervised and tracked via parental supervision software. Ensure that the computer is placed in a visible area of your home

and require that it stay in public view. Develop a schedule and time limits for use. Consider establishing time limits for television, also. Establish which programs are acceptable to view and monitor that only those programs are viewed. As often as possible, view television as a family. Establish the rules, post the rules and review the rules frequently.

Recommended websites to help you learn more about cell phone and internet safety:

- <http://www.netsmart.org/Parents>
- <http://www.safekids.com/kids-rules-for-online-safety/>
- <http://www.nationalcac.org/prevention/internet-safety-kids.html>

If you have any FASD-related questions, please send them to Charisse at charisse@mcfares.org

Michigan FASD Task Force 2016-2018 Goals

The Michigan Fetal Alcohol Spectrum Disorders Task Force met on November 19, 2015 at the Downtown Lansing Capital Area District Library for a strategic planning session to cover the years 2016 through 2018. Leigh Tenkku Lepper, who is a professor of social work and public health and a NOFAS Affiliates Committee member, led us in a day to think through our goals and hopes for the next few years. Leigh stressed that the focus of our strategic plan should be doable and helped us build on the past strategic plans. After much discussion and sorting of our priorities 3 main goal areas were identified:

Goal 1

Make MCFARES, as the NOFAS affiliate, the clearinghouse for FASD information in Michigan and accumulate information regarding services and resources available for parents and professionals.

Goal 2

Educate all individuals involved including but not limited to foster care workers, parents, court personnel, physicians, and teachers for the benefit of the child so that everyone has all the information possible and access to resources, referrals, screening tools, and intervention strategies.

Goal 3

Empower adults with FASD through screening, diagnosis, treatment, interventions, and support.

Groups have formed around each of the goal areas to create an action plan with 2 or 3 activities. If you are interested in working on a group goal or joining the task force, please contact Ann Carrellas at ann.carrellas@wayne.edu or 313-577-8562. We are all very excited to be moving forward with our new strategic plan!

NOFAS Summit Summary

The National Organization on Fetal Alcohol Syndrome (NOFAS) held the 2016 Affiliate Network Summit in Washington, D.C. from June 20th through June 22nd. The Affiliate Summit gives representatives from NOFAS and from Affiliates throughout the United States as well as from Canada and the Ukraine the opportunity to discuss key topics in our field.

The primary focus of this year's agenda was Working Together to Improve and Increase Awareness and Resources as presented by NOFAS Vice President, Kathy Mitchell. Highlighted during the opening session was the importance of connecting with other organizations in order to integrate FASD into other substance and drug prevention organizations, agencies, the CDC and treatment centers.

New to the summit was the introduction of the Young Adult Network which was started by MOFAS (Minnesota Organization on Fetal Alcohol Syndrome). This group helps young adults going through post-secondary transition in learning self-advocacy skills. The approaches at MOFAS for working with youth are to increase social and recreational opportunities, developing healthy friendships, increasing peer leadership, volunteering and service learning as well as supporting other organizations and attendance at retreats and personal growth opportunities.

During the summit the 2016 Subcommittees were formed. It was decided that this year's focuses would be on:

- the Juvenile Court Bench Guide,
- FASD Diagnostic,
- IDEA (having FASD become a separate Special Education Eligibility category),
- Messaging (consistently throughout the network),
- Funding,
- CMS/FASD Education/Actuaries Statistics on Possible Cases of FAS/FASD.

NOFAS President, Tom Donaldson, scheduled a meeting for me, one of the NOFAS lobbyists and one of the legislative assistants of Representative Candice Miller. During our meeting with Legislative Aide Evan Sunisloe I urged him to speak to Representative Miller to join the Congressional Caucus for FASD. The bipartisan caucus was founded in 2004 and is being reorganized this summer. The caucus will convene briefings and publicize events that influence national policy on FASD prevention, identification and treatment. It is co-chaired by Don Young (R-AK) and Frank Pallone (D-NJ).

I encourage everyone to contact their Representative and request that they join this caucus that will provide a forum for members of Congress to establish a dialogue with individuals that are working to prevent and treat FASD. Go to www.house.Mi.gov/mhrpublic/ to find the contact information for your Michigan representative.



Walk With One of Our Families



Gabby/Duncan are raising awareness and support for families living with disabilities by participating in the Easter Seals Walk With Me fundraiser at the Detroit Zoo. Individual walkers and teams join hundreds of other passionate people in their communities for a day full of entertainment, fun and, of course, our signature walk! Since 2003, over 230,000 people have participated in 615 Walk With Me events nationwide generating nearly \$41 million to support families at Easter Seals. This year, you can help Easter Seals accomplish even more!

Each participant's motivation to walk is unique; it may be for themselves, a child of a loved one, a neighbor or a colleague. 20% of the US population lives with a disability today- like autism which has become a significant issue for too many families. We walk for them, their future and the families who love them. Walk With Me to help people with disabilities live, learn, work and play. Here is information about one of our local families. We are so excited to be this year's Easter Seals Michigan ambassadors!

For those of you who don't know us, here's a little introduction:

Laurel and Steve Smith adopted two Russian children – Gabby, 13, and Duncan, 12 -- when the children were very young. While the youths have progressed in their decade here, some of the effects of the trauma they endured haven't been erased. Both children spent time in orphanages, hospitals, as well as private residences, where they were both neglected. Exactly what the children experienced is unknown.

Gabby was adopted when she was 25 months old and when she arrived here she was 15 pounds, 27 inches – size of a typical 4-month-old in the United States. Thanks to hormones, she has grown to about 4 feet 11 inches tall and 80 pounds. Her “hyper vigilance” and rigidity is a sign of post-traumatic stress disorder. Duncan was adopted when he was about 8 months old. He was diagnosed with attention deficit disorder that later developed into Asperger's syndrome. Both of the children have problems with food and “will eat anything” because they were not well-fed in Russia. In fact, Duncan prefers his food cold because that is what he is used to. Both have also been affected by a lack of love and affection during infancy, including being held or cuddled.

That's why their parents, Steve and Laurel came to Easter Seals Michigan and took advantage of the new LUNA Model program that helps children with trauma. Our goal is to raise funds for Easter Seals Michigan through our walk team, Team Curving Path. Any level of support is greatly appreciated. You can also walk with us by joining our team and fundraising to help us reach our team's fundraising goal! We look forward to seeing everyone at the walk!

P.S.: If you know anyone who you think would like to help us reach our fundraising goal in this event, please share my page with them!

Signed,
Gabby, Duncan, Laurel, and Steve

It is free to register and do the zoo walk. Doing the walk is your admission to the zoo that day. There are festivities before the walk begins but no real 'finish line', so things are most exciting before the event. Being the ambassadors, we will be hanging out most of the day. After the walk, everyone is free to stay at the zoo as long as they want. It is the first Sunday in August.

Join Team Curving Path, please! People MUST REGISTER TO WALK. You can't just show up that morning.

Donations are welcome & encouraged as this IS a fund raiser for Easter Seals. You get a t-shirt for \$100+ in donations. (An Easter Seals shirt...we don't have the money to have team shirts made up. Sorry!)

http://es.easterseals.com/site/TR/WalkWithMe/WWMEastMichigan?team_id=142798&pg=team&fr_id=3735

Donate Time – Work with Us!

Do you have a few hours to spare? We have several different opportunities to help you put your spare time to good use. Do you like kids? Maybe you can enjoy Project S.A.F.E. with us and supervise the children after dinner so that parents have some time to talk. Do you have website-building skills? We'd love your help re-designing and updating the MCFARES website. Do you have newsletter-designing skills? We could use your help putting the quarterly MCFARES FASD News and Views newsletter together (we'll develop the content and you can organize it into the newsletter).

Kroger Community Rewards

Please consider registering MCFARES as the beneficiary of rewards using your Kroger Plus card. The MCFARES organization number is 91150. We thank you for your support. Funds raised will assist MCFARES in providing support to individuals and families affected by pre-natal exposure to alcohol.



JOIN US FOR THE 8TH ANNUAL



WALK WITH ME



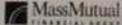
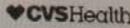
LIVE 8.7.16
LEARN
WORK
PLAY



DUNCAN & GABBY
2016 CHILDREN AMBASSADORS
Easter Seals Michigan

Easter Seals Michigan serves and supports people with disabilities or special needs and their families so they can successfully live, learn, work and play in their communities.

ONE MILE FUN WALK THROUGH THE DETROIT ZOO | CHECK IN AT 7:30 AM REGISTER AT WALKWITHME.ORG/DETROIT

Contact Jennifer Cleary at jcleary@essmichigan.org or 248.475.6412

Team:
Curving Path

Easter Seals
Michigan

*Please join us
or donate!*

[http://es.easterseals.com/site/TR/WalkWithMe/WWMEastMichigan?
team_id=142798&pg=team&fr_id=3735](http://es.easterseals.com/site/TR/WalkWithMe/WWMEastMichigan?team_id=142798&pg=team&fr_id=3735)

GoodSearch

Please consider helping MCFARES to raise funds to support individuals and families who are affected by pre-natal exposure to alcohol. Each time you conduct a search at <http://www.goodsearch.com/>, a donation is made to MCFARES. Please designate MCFARES as your charity of choice. You can also use GoodShop for your on-line shopping needs. A percentage of your on-line purchases will be donated to MCFARES.



What Would You Like to See in Our Website?

MCFARES members are working to update the website. We'd really appreciate your input to help make this site the best it can be. Here are some subject areas. We'd like to know about your favorite books, websites, resources, etc. Please send your suggestions to us at charisse@mcfares.org. Here are the topics:

- Diagnosis
 - Diagnostic models
 - Differential diagnosis
 - Diagnoses under the FASD umbrella
 - Developmental Issues
 - CNS Involvement
 - Brain Morphology Differences
 - Facial Morphology Differences
 - Growth Issues
 - Epigenetics
 - Sleep Issues
 - Behavior Needs
 - Treatment and Services
 - Evidence-based treatments
 - State services
 - Regional/Local services (would be good to have people from each region complete this piece)
 - Secondary Disabilities
 - Education
 - Adult Issues/Needs
 - Criminal Justice
 - Prevention
-

Project S.A.F.E. Special FASDay Activity, September, 2016 (Supportive Activities for Everyone)

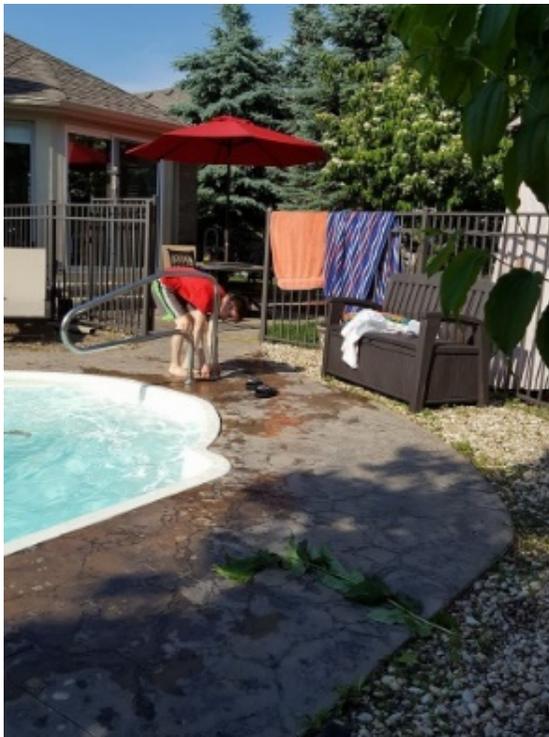
Join us on Saturday, September 10th for our annual International Fetal Alcohol Spectrum Disorders Awareness Day event. We'll meet for an open Project SAFE meeting where friends, extended family members and the general public are encouraged to join us to learn more about FASD, learn how to support our families and how to help MCFARES raise awareness in the community. For more information or to confirm your attendance, please email Charisse at charisse@mcfares.org.



Braggs

<p>Jacob K. . .</p> <p>. . . age 22, has earned his driver's license.</p>	<p>Anna P. . .</p> <p>. . . graduated from high school in June and earned her certificate. She will be continuing in her district's new TRAILS (Transitioning Responsible Adults In Life Skills) program in September. Her goal is to pursue a career working with animals and/or children.</p>
<p>Marcin P. . .</p> <p>. . . graduated from high school in June and earned his diploma. He will be attending Oakland Community College in September to pursue a degree in business. He is currently working with Michigan Rehabilitation Services to assist with employment.</p>	<p>Barb P. . .</p> <p>Was featured in a story in the Detroit Free Press about Special Olympics. See it here: http://www.freep.com/story/news/2016/07/12/detroit-lions-welcome-special-olympics-athletes-camp/87008302/?post_id=259146771136764_259146981136743# =</p>

This is FAS



It is early evening. His daytime meds have run their course; it is too early for his evening meds. It took his sister several attempts to explain to him how to hang his towel over the fence so that it will warm in the sun while he swims. Fortunately, she was patient in her explanations and he did his best to follow along until he achieved success.



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 2nd Thursday of each month; 1:30 – 2:30 p.m., Partners in Prevention office in the First Presbyterian Church at the corner of US23 and Long Rapids Road, Alpena. Contact Mary Schalk at mary@nemcpi.org or 989-359-2880 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. Eaton Intermediate School District, 1790 Packard Highway, Charlotte, MI 48813. Located right next door to Walmart. Contact Michelle for more information at besa_93@yahoo.com.

Kent County

West Michigan FASD Support Group, Meets 3rd Tuesday of each month, 7 – 8:30 p.m., Westminster Presbyterian Church, 47 Jefferson Avenue, Grand Rapids, MI 49503. Contact Sandy Kezenius, 616-874-9522; Corry Tait, 616-550-4273; or Barbara Wybrecht, 616-241-9126 or bmwybrecht@gmail.com 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.

Adoptive Families Support Group, Meets 3rd Tuesday of each month, 6 – 8 p.m., Holy Family Catholic Church, 9669 Kraft Avenue SE, Caledonia, MI 49316-9723. Contact Shelley Garcia, 1855-MICH-P2P, x705 or sgarcia@afsn.com for more information.

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.

Muskegon County

Support group for foster/adoptive/kinship families. Very active group meets weekly for various activities. Contact Janice Hilleary at Bjhilleary@comcast.net or 231-286-7892 (cell phone).

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 Vern Soden for more information, vsoden@umich.edu.

Statewide List

Foster, Adoptive, and Kinship Support Groups by County <http://afsn.org/services/foster-adoptiveand-kinship-support-groups-by-county/> (not all groups are FASD-specific)

On-line Support

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

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Updated 4/16



MCFARES is the Michigan NOFAS Affiliate

MCFARES Member Agencies

Arc Services of Macomb
(fiduciary)

Macomb County Office of
Substance Abuse

Family members of affected
individuals

Oakland University School of
Nursing

Macomb Intermediate School
District, Early On

Macomb County Community
Mental Health

Macomb Family Services

Macomb County Health
Department

Madonna University



***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
