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From the Editor

Welcome to FOD Awareness Month! Even though USA Today is no longer printing banners for the Charity Spotlight section, we are still promoting and sharing all that we know about Fatty Oxidation Disorders around the world! You can help in this effort by sharing your Family Stories with your family and friends, as well as co-workers, professionals and everyone else that is willing to listen. Please also share our banner on your social media sites. Another way to create awareness is to purchase some of our Awareness items and wear them with Pride! Also when you shop Amazon be sure to bookmark and shop every time from our FOD AmazonSmile link — we benefit from all of your purchases ALL year round by earning a certain percentage of your total purchase! Donations made to the FOD Group are tax-deductible and will help us as we begin planning for our July 2016 Conference. So please keep us in mind if you are able to donate anytime throughout 2015 and beyond!

THANK YOU Keith Widmann for once again creating this year’s banner honoring his daughter, McKenna (9, MCAD) and in memory of Kyle Symes (adult VLCAD).

Speaking of Family Stories — you will notice we have only one to share in this issue. In order for this to be YOUR Newsletter, everyone has the opportunity to submit a Family Story or other items, such as pictures, New Babies, accomplishments, resource suggestions, special articles (families and professionals), or anything else you feel our members would enjoy reading. The submission deadline for the Jan 2016 issue will be DEC 15. 2015.

As for our next National Metabolic Conference in late July 2016 we are still searching for a Major Sponsor and Host (although Denver has shown some interest) — if a University, Hospital or Clinic is interested in hosting us (if not Denver, possibly in the Midwest) please contact me or Kathy Stagni of the OAA. You can read more about our past Conferences and view our Speaker Presentation slides on our site.

Again, please continue to create awareness of FODs with your family, friends, and medical professionals, as well as create your own ways to raise funds, via ‘Family Fundraisers,’ so we can continue to spread the word about FODs via our website, Conferences, speaking at hospitals, and other various ways that allow us to offer all of our services free of charge. Also, when buying online please remember when you use the iGive link on our site, the FOD Group gets a percentage of your sale. We also earn funds by using GoodSearch as a search engine, or using the Donate button on our site.

Families ~ We welcome ALL new or updated Family Stories and pictures and we encourage Families dealing with the less common FODs [i.e. HMG, GA2, Carnitine Uptake Defect, TFP, CPT 1&2 etc.] to share their experiences. We’re also always looking for more low fat recipes, poems, ‘Silver Linings,’ pictures, and ‘Reach for the Stars’ accomplishments of our kids/adults/families.

Professionals ~ we need to hear from you too! New Medical, Research, Nutritional, Counseling/Coping, etc articles are always appreciated.

Whether you’re a Family or a Professional, we are all striving to create awareness, education, screening and diagnosis, long-term clinical treatment, and research ~ by sharing your story or your expertise...

‘We Are All in This Together!’

♥ ♥ ♥

Take care...
Deb Lee Gould, MEd, Director
Dr Mark Korson introduces a new Center for Educational & Metabolic Consultative Services

Note from Deb: We are honored to support such a wonderful endeavor! Please share this article by Dr Korson so MANY will learn how these much needed services can benefit physicians, specialists, and dietitians learning more about inborn errors of metabolism.

It gives me great pleasure to introduce you to the Genetic Metabolic Center for Education (GMCE). With a multi-faceted educational focus, we aim to advance a mission we both share -- to see that patients with metabolic disease are diagnosed in a timely way as to be educated about their disorder, and thus be able to take advantage of a growing number of effective therapies to improve their lives.

GMCE will provide educational solutions and consultative services directly to clinician caregivers and providers to improve the clinical diagnosis and management of their patients with metabolic disease. These services will be made available through technologically-advanced communications and distance learning.

To learn about our plans to service the medical community through our Consultative & Clinical Support Service (CCSS), a first-of-its-kind, technology-based advising program refer to our website at http://www.geneticmetabolic.com.

GMCE will also soon provide a depth of educational resources to expand availability of physician training in topics related to the care of metabolic patients. These services will be made available through a suite of innovative technology solutions that aim to bring distance learning to medical students, clinicians, and trainees around the globe, including: Live, inclusive, and interactive video-conferences, webinars, and training modules for both specialists and trainees.

As you may remember I began cultivating this concept back in 2011 when I began soliciting help for a prior iteration. I’m proud to say as the newly formed GMCE we are now in a position to increase awareness about metabolic disease among those in the medical community, including: clinicians, health professionals, medical students, and post-graduates trainees.

I’d like to also acknowledge that the FOD Support Group has been very generous in the past in supporting these types of educational efforts. You will be pleased to know that we will be working very closely with Jerry Vockley and Children’s Hospital of Pittsburgh to ensure that all pre-existing grant funds for this cause will continue to be used to support the efforts for which they were intended.

Mark Korson, MD
Medical Director
Genetic Metabolic Center for Education
121 Loring Avenue, Suite 520
Salem, MA 01970
mkorson@geneticmetabolic.com
http://www.geneticmetabolic.com
Family Stories

My name is Joshua Allen and I have MCADD. As a young boy I was told that I may face several forms of limitations due to my disorder. Today I can say that having MCADD has proven to be more of a blessing than a limitation.

As a child my father instilled in me a passion for the game of golf. The first tournament I ever played in was preceded by a stomach virus but after begging my parents to let me play they finally gave in. That tournament at the age of four ignited my love for the game and in the coming years I devoted an increasing amount of my time to practice. The competition opened doors for me as I traveled extensively and was able to meet players and families from all over the world. In my earlier years I was able to win multiple U.S. Kids Golf Local Tour events and earn player of the year on the Tour. This enabled me to participate in the U.S. Kids World Golf Championship at ages 7, 9, 10, 11, and 12. I also competed in the European Championship in Scotland which was an experience that I will never forget. Once entering high school I was able to win the IJGT Shootout at Eagle Pointe as a Freshman. I also finished tied for eighth in the Donald Ross Junior the same year. As my high school career continued I participated in several AJGA events, a tour known for producing collegiate golfers, and had several high finishes. Consequently, I will be a member of the Men’s Golf team at Wofford College in the fall where I earned the Old Main academic scholarship.

I also played varsity soccer for my high school during my freshman and sophomore years. The coach for our team was an old timer who had been inducted into the North Carolina Coaches Hall of Fame for his countless State Championship wins. He always spoke of how an individual with the most heart would outwork and beat an individual with talent. He was aware of my disorder but never made excuses for me. At summer camp I was held to the same expectations as any other individual on the team. Morning practice consisted of a four mile run followed by the Indian run, then wind sprints followed by poles which were the worst. I always made certain that I finished in the top 3 in all of these conditioning drills because I am a small guy but I wanted to play more than anyone. I worked harder than any individual and at times Coach Forbes as well as the players forgot I even had a disorder. This earned me the nickname “Pee Wee” as I was small and gritty never letting anyone get the better of me. I played some during the season but not a lot due to my team being composed of eight players who each had four state championships. Finally my number was called to start during the state championship when my good friend suffered a serious knee injury. My teammates and I poured our heart and soul into that that game and when the final whistle blew we were the State champions. Coach Forbes looked at me afterwards and said, “Well Pee Wee you didn’t screw up.” Coach was a tough love type of guy but he made real men who knew who they were and because of him I know who I am; an individual who will put in the hard work it takes to succeed in sports and in life.

So I will say it again, MCADD is not a limitation but a blessing. Anything anyone else can do, a person with MCADD can do and sometimes can do it even better. MCADD has allowed me opportunities that otherwise I would not have had. For example, I served on the North Carolina newborn screening committee and have been able to meet many extraordinary children. I also participated in a junior golf charity event my junior and senior year in which our group of junior golfers raised over $100,000 in just two years to help support the Nicklaus Children’s Healthcare Foundation. I hope that my work with this foundation will help children to overcome whatever medical obstacle that they might face.

My friends tell me all the time that they forget I have a disorder. They all know about it and look out for me but at the end of the day I’m just another one of the guys. I am on the receiving end of countless jokes and still have my friends talk junk to me after they block my shot during a heated game of basketball. I embrace being a person with MCADD because I love winning and MCADD is just another thing to overcome. MCADD serves as a reminder that I can do anything and that it cannot define who I am. I will always manage my MCADD on a day to day basis and I will never let my disorder control my life. No one is perfect and everyone can make the most of their situation.

Joshua Allen

joshuaallen@coastalnet.com

Reminder from Deb about FOD Family Fundraisers ~ please be sure to note that the FOD Group does not sponsor any Family Fundraisers. We also have some of this info on our site as well (https://www.fodsupport.org/.../FamilyFundraiserFormsforFOD.pdf) for those that want to do FOD Awareness projects. Please note Families CANNOT use our EIN tax # (or our logo) when doing your fundraiser - only the FOD Group can use it. If individuals would like a tax deduction, then they HAVE to directly write a check (or paypal online) to the FOD Group or buy Awareness items (http://www.fodsupport.org/awareness.htm) - and then I will send them a tax receipt.

Please be sure to consult with your tax or legal specialist or accountant to determine what % is allowable for the tax deduction if you make a direct donation to the FOD Group. Thank you for reading and understanding our policy on Family Fundraisers.

Family Fundraiser Information

[Please read if you plan on doing your own Family Fundraiser]
Research Opportunity:  
**Adults with MCAD Deficiency**

Dr. Jerry Vockley and his colleagues at the Children’s Hospital of Pittsburgh of UPMC are conducting a 7-week evaluation of safety and biochemical changes of the drug Ravicti™ in MCAD patients. Ravicti™ is currently approved for treatment of urea cycle disorders, but laboratory studies in cells have suggested that Ravicti™ may also increase the amount of MCAD enzyme activity.

To be eligible for this study, you **must be 18 years or older and have MCAD deficiency caused by two copies of the 985A>G mutation.** Patients who have kidney or liver failure, or are pregnant or breastfeeding are not eligible. You must also be able to travel to Pittsburgh on four occasions and will be required to stay overnight in the Clinical Research Center for your first visit.

For more information, contact the research coordinator, Elizabeth McCracken, MS, CGC at (412)692-5662 or Elizabeth.McCracken@chp.edu.

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**Medical ‘Bits of Info’**

- **Heat Intolerance information** ~ from mitoaction.org

- **Understanding Carbs, Proteins, and Fats and How the Body Burns Them**

- **Medical Food ~ Cyto B2**

A tasteless, microencapsulated, powdered form of Riboflavin for individuals over the age of 1 year with Mitochondrial Cytopathies or Glutaric Acidemia Type II.

Cyto B2 powder is a Medical Food specifically formulated using a proprietary microencapsulation process. Tasteless Cyto B2 powder represents a practical solution to the dosing of riboflavin for metabolic and mitochondrial patient, without the offending taste and staining of the compound.

- **‘Anything but plain’**

Great article about Dr Holmes Morton and the Clinic for Special Children in Strasburg, PA.
I have decided to run the Spartan Vermont beast in honor of both my buddy Donna in the IR4 program, as well as my own son since his runner disappeared, my Mikey bug. If you don’t know, Mikey was diagnosed with a rare genetic disorder called SCADD at birth. It’s an FOD or fatty oxidation disorder. It means his body doesn’t make the enzyme that processes fats. Therefore, he has to be fed frequently like a diabetic. But unlike a diabetic, he goes into crisis faster, his blood sugars remain normal most of the time, he gets dehydrated fast, and has been hospitalized often. The website for his genetic disorder is: www.fodsupport.org, if you want more information about these rare disorders.

This is why I’ve been so vocal this year with his support staff at school, and trying to get the rare disease bill passed in the state. It was not. So...I am running the hardest obstacle course in the industry to bring more awareness. I am training every day, running, and I have lost 80lbs to get to this point.

Spartan races has set up a partnership with everyday hero’s, a group that fundraises for events like this, for causes like mine. So, I am asking if everyone can share my request to sponsor me for my race, by going to this page below to donate, and to do everything possible to pass the word! If everyone I know can donate even $5, and re-share to their pages, etc, we can possibly raise money that will benefit the FOD group, and possibly find a cure.

The every day hero’s site for me is: https://spartan-2015.everydayhero.com/us/ctmikki Thank you VERY MUCH for reading this, and helping me in the next 90 days of my journey to my first Spartan trifecta!!!

Michelle Cotton

ATTENTION FOD FAMILIES ~
FUNDRAISING EFFORT AT ITS BEST!

“The Next Best Thing to Fruits and Vegetables”

Any orders from our FOD members and their families will benefit the FOD Group
Whole Food Nutrition is extremely beneficial to those affected with FODs and those that are not!
Please take a look at my website and click on “watch the video” beneath the Juice Plus bottles.
Then give me a call or an email to place your order.
Please be sure to tell me you are an FOD family!

CALL OR EMAIL ME WITH QUESTIONS!

Mom to
Kayla, 14y, SCADD, Unidentified Mito, Pulmonary Valve Stenosis (repaired), Epilepsy, SLD, PDD-NOS, SID...who knows what else!!!
Naomi, 17y, unaffected, untested, GIFTED-HIGH HONORS STUDENT!
Pepper Pike, OH, USA
Family Fundraisers...cont’d

One of our CPT 2 grandmas, Rosemary Forrest, suggested we fundraise through bravelets.com ~ Thank you Rosemary for such a great suggestion.

Our FOD bravelets page is LIVE! You can choose blue, yellow or silver for colors on most of the items.

$10 will be donated from each item to support our Group!
Please SHARE with others!

Rosemary’s granddaughter also had a fundraiser ~

“As part of her homeschool project my non-FOD granddaughter, Clara, (sister to Matt, CPT2) is donating half the profits from a craft booth she planned, stocked, manned!”

♥ ♥ ♥

MaryAnn Raccosta Book Sale: For every book (The Survivor, The Hero, The Angel) sold during the month of May she donated $3.00 per book to fodsupport.org. You can still purchase her book ~ Be sure to use the AmazonSmile FOD link so the FOD Group can get the extra donations from AmazonSmile. For more information about MaryAnn.

NBS Update

EVERY city should have a billboard like this ~ it would SAVE LIVES!

[MN Dept of Health Billboard]
Reach for the Stars!

Congratulations to Adam Fulton (adult LCHAD) upon graduating from the University of California at Santa Cruz on June 13, 2015!

He received his Bachelor of Science degree in Bioengineering.

Adam hopes to find a laboratory/research job in the Silicon Valley, “to learn more skills and to apply those values I have learned during my education.”

We DID IT!!! PERFECT ATTENDANCE for Logan (age 9 CPT2)

We are so excited about this. He hands down had the best teacher he has ever had and the parents/classmates were understanding and cautious.

Melissa Gilbert Melgil10@hotmail.com

Two accomplishments for Jared (almost 16 yrs old, MCAD) from California all in the same week!

** Receiving his certified food certificate so he could now work

** Receiving his Driver’s Permit

The ‘Silver Linings’ of FODs ~
What is your ‘Silver Lining?’

Meadville Tribune:

**Meadville girl surprised with trip at Make-A-Wish event**

Story and pic: Isabella Linz, 8 (VLCAD), of Meadville gets a kiss from her mom Carrie at center court in McComb Fieldhouse at Edinboro University of Pennsylvania on Wednesday night during halftime of the men’s basketball game against Gannon. Linz was surprised with a bunch of gifts including a trip to Hawaii from the Make-A-Wish Foundation.
**Parent to Parent Q & A and Suggestions**

**Q:** We need help getting enough calories and fluids into our 5 year old. He is tube fed, which makes it a little easier (I honestly don't know how parents do it with children who eat and drink!) but we are still struggling.

**A:** My heart goes out to you. We feed our guy all by mouth...and at times it does feel like all we do is eat all day...which is hard! But I will preface my suggestions that our son is not a picky eater and does not struggle with nausea most of the time...so you have some really great challenges at hand! I feel like anything I suggest you probably have already tried...but I will share a couple things that we do...and perhaps it will spark a new idea?

1. **When Christopher has been sick and we worry about calorie intake I had a nurse suggest to us to try smoothies. We have to up his intake of fluid to about the same amount...which is a lot! But with smoothies we can get the calories and liquid in. We try to pack as much in it as we can. You can use coconut water (it’s use may depend on specific FOD) to make ice-cubes (so you are not adding non-caloric water and providing electrolytes) There is the obvious, packing tons of fruit in a smoothie but you can also do greek yogurt...or if he likes the taste of peanut butter you can add PB2 a low-fat powdered peanut butter that adds extra calories. His nurse at NIH also says she can hide lots of veggies in smoothies without her son being the wiser (spinach especially)

2. **Sometimes reading distracts Christopher while he is eating...sometimes it helps...and then it makes me feel like we are having quality time on those long days where it seems that all we are doing is eating.**

3. **I feel like I have tried to get creative hiding things in things...I put bean flour in pancakes....cooked lentils in spaghetti sauce (you can’t tell at all)...perhaps if you can talk more about what his food challenges are we can help you figure out how to hide them?**

Keep your head up! And know that you are doing a great job! Wish I could be of more help!!!

Much love, Stephanie Harry Christopher LCHADD 5.5 Georgia srharry374@hotmail.com

**Q:** Hello, fellow FOD moms, I’m reaching out to get some advice/reassurance/suggestions.

We have a 9 month old (so far asymptomatic) MCAD baby girl. She’s not a very good sleeper. It’s not terrible, but she still wakes up twice or three times a night (or more now that she’s teething). And when she cries, she’ll go right back down if I nurse her or my husband gives her a bottle. It’s not too bad, compared to other problem sleepers I’ve heard of, but it’s getting to be exhausting. Our Metabolic doctor told us that she can go 8 hours a night without eating, unless she’s sick/feverish.

Quite frankly, I’m feeling frustrated with how she won’t sleep longer than 4 hours (she’s done 5-6 a few times, but it’s not common). But whenever I talk to anyone about this, their advice is always to let them CIO (Cry It Out). No matter what, don’t pick her up at night, and DON’T feed her. Of course, all these people don’t have a kid with MCAD, so I feel uneasy about not feeding her at night. The way I see it, if she’s crying and she’s eating, then she was probably legitimately hungry, and since feeding is the only real instructions for dealing with MCAD, I just don’t feel comfortable letting her cry. I’m very chill about everything else, this is the one issue where the FOD scares me.

I just want some words of encouragement. Have any of you successfully done CIO, or is this just a bad idea with MCAD? She’s only 9 months, but is there anything I can give her before going to bed that will sit longer in her stomach? Natalia

**A1:** I know it can be very disconcerting to be out of step with the other moms. However, you are the best at knowing what your baby needs. If you are not comfortable letting her cry, surely there is a good reason why.

A bit of our story that might be encouraging. My first child, Sarah (now 13), did not sleep through the night until she was 2. She was nursing at night until she started sleeping through. We did not have a diagnosis for her, but we could tell that she needed to eat. We had many people-relatives, friends, her pediatrician- tell us to let her cry, she would adjust, etc. She would not have. She is extremely fasting intolerant, and I think how long each person can go without eating will vary widely. It was shortly after our daughter started sleeping through the night that she became very ill and had a series of metabolic crises. We went another 9 years without night feeding and she was in very seriously poor health. After we found the FOD site and started right away with no fasting, her health turned around and has been pretty good for the last two years. She is currently still going through diagnostic testing, and it is looking like a primary mitochondrial disorder. I know this is different than MCAD, so, as always, only consider our story as informative, not necessarily advice for you.

I don’t really see how your doctor can be at all sure how long your daughter can/should go. It will depend on her own body, her growth rate, stressors like illness, heat, etc. Absolutely trust your instinct and the information your daughter is giving you. Some people tried to tell us that our daughter was just lonely or bored and that we were reinforcing the behavior by responding. But how could that have been, when she only

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(cont’d on page 9)
nursed quickly and dropped right back to sleep? No play, chatting, etc. She was needing food. Now that we know how to care for her, we are so glad in retrospect that we kept doing what clearly worked for her. I will certainly admit that all this nighttime feeding is tiring, but as your child grows there may be ways to get her the foods she needs without too much fatigue.

Keep up the good work!   Rosie   Near St. Louis MO   mom to Sarah, 13, carnitine def + ???mito and four other similar kids

Jimrosiesarah@gmail.com

A2: I am a mother of 5 children. My oldest is 29 and youngest is 10 (Note from Deb: this response was written a few years ago). 3 biological and 2 adopted. Sleep training has been something that is heart breaking to me. Before I had a child with an FOD, I felt this way. You are a mom who seems to be so tuned into your baby, and I know your gut and intuition are telling you what your daughter needs. I know how exhausted you must be. It is hard to go months without a decent night’s sleep. These are our children we are talking about, not a pet or something you need to train to fit into your schedule. Two out of my 5 have been "bad" sleepers. Today they happen to be my most social and outgoing children. Maybe they just have more of a need to be with people. Or our special kids need to eat!

Our youngest who has MADD/GA2, came into our family at 8 months from Korea. Not knowing she had this disorder we fed her whenever she woke up, sometimes 2-3 times a night. In Korea she was in a foster home. In their culture they have their babies sleep on heated mats on the floor next to the parents. They feed them through the night and would often wake her to feed her. This likely saved our daughter’s life. We got some paper work saying she ate 2 times during the night. I can remember thinking Wow!, she is 8 months old and still wakes to eat. I am so grateful to God for bringing this little girl into our home, because we had the understanding and intuition to feed her when she woke up. I am grateful she was not placed in a “baby training” family that would not have had the understanding, and she would possibly not be here today. Today she eats a snack before bed, we place 2-3 snacks and a cup of water or Gatorade on her night stand. They are always gone in the morning. She now wakes up herself to eat and drinks and goes back to sleep. I believe we can call that eat/sleep training! Ha!

I am so sad to think of a child with an undiagnosed or diagnosed FOD crying themselves to sleep at night. A baby only has their cry to tell you they have a need. I don’t believe babies know how to manipulate. I also was never able to force feed any of our babies. If they were not hungry they would push the food away. If they were hungry they ate. God gave them this, and gave parents an inborn intuition. It sounds like you are doing a wonderful job!

God Bless, Patty Bird  Colorado  Mackenzie GA2/Madd   pattybird555@gmail.com

Response from Natalia: I want to thank everyone for your thoughtful and encouraging responses, both through the group server and to my private email. It is very reassuring to have people going through similar issues, even if sleep is really minor in the grand scheme of things. Thank you for taking the time to respond.

I think one of my main issues is that waking at night is exhausting, and sometimes we just need to vent, you know? But I find that many people tell me that her waking up is my fault because I feed her at night. And blegh, I’m happy with choice to feed around the clock, but that doesn’t mean it’s not overwhelming at times. I’m sure you know what I’m talking about. I got to vent here, and it’s good for the soul to let some of that frustration out in a welcoming environment.

I’m going to follow my gut. And my gut tells me that Lucia is hungry at night, and as much as I dread waking up to feed her, well, those are her needs and they won’t last forever. We’ll work on her eating more during the day, but I guess at this point, with the current heat wave, I should just accept that she has metabolic needs at night as well as during the day. And I feel lucky that through NBS, we know that her needs are different.

I feel recharged and encouraged by all your words. And I’m incredibly grateful to have this community. Parenting is hard enough on its own, adding the extra metabolic element is tough. (Or I think it’s hard on its own, we’ve only known what it’s like to have an MCAD baby, lol)

Natalia
mama to Lucia, 9 months, MCAD
Recipe Resource for low fat and vegan recipes:
This is one of my favorite cookbooks. It is low fat and vegan, so it also has substitutions for cheese flavors. I can't eat gluten or dairy so I substitute gluten free flours and such. She uses all the tricks I know of to be low fat.

**Everyday Happy Herbivore: Over 175 Quick-and-Easy Fat-Free and Low-Fat Vegan Recipes**
Christyne B – acbliton@gmail.com

PS use the [FOD Group's amazon smile link](http://amazon.smile.com) to purchase the book so we can get a % of the sale!

**Celeste Fernandez** is very active in FOD things, but in Spanish – she has a [blog](http://www.instagram.com/celestefernandez) which has a lot of recipes of traditional food (Hamburgers, Hot Dogs, etc) but adapted to LCHADers. All the recipes have less than 1% Fat. Hope someone finds it useful!

Recently I (Deb) did a [Canadian radio talk show](http://www.canadiangrandparentsshow.com) about creating FOD Awareness - you can listen to the interview by downloading the above link. The 1st interview is very good too, about canines with a cause - but if you just want to listen about our Group go to the time @ 12:40 and Cam Wells will start my interview. Please share with your Families and others so more become aware of FODs and the support we offer for Families/family members and professionals around the world!

**Moving On With Mito, A Guide for Teens and Young Adults Living with Mitochondrial Disorders** is designed to assist young people with Mito transition from pediatric to adult healthcare. The guide, which helps emerging adults with Mito prepare and stay healthy for the next stage of life, was created by Rob Auffrey, MA, Susan Waisbren, PhD, and Freedom Baird, MS

The online version of this guide that you can actually fill out online is on the [New England Consortium of Metabolic Programs website](http://new-england-consortium.com)

5 Tax Tips for Parents of Children with Complex Medical Issues

We just joined a group here in Utah supporting kids and families with special needs. For their monthly spotlight, they asked if we could write something about MCADD. I hope I got most of it right! I'm just excited about getting awareness out there!

Rachel Johnson

My name is Angie Phillips. I have 2 TFPers. Nathan, now 7 and Abby, now almost 5. I, like all of you out there, has feared and dreaded our kids getting sick for obvious reasons. I used to be at the peds office on a somewhat regular basis with coughs, colds, and infections of one kind or another. This past year when I took Nathan and Abby both in for their yearly checks my ped said “You haven't been here in a while.” My thought “Nope, I have not!” I have finally discovered something that has brought our illness to a much more tolerable level. I stop them dead in their tracks using doTERRA essential oils. I now use oils to help my anxiety and give me the energy I need to function and be at my best. For my kids, when I see a bug coming on, I immediately apply oils and kill the problem before it starts getting bad. With Abby, who ended up using inhalers due to severe coughing for weeks and months after a cold, I no longer use her inhalers! I use oils. I am able to start the healing process right when I notice it happening. This has brought such a piece of mind to me knowing that I have the power in my own home to help them when they are sick. No more waiting on doctors, no more taking unwanted/dangerous RX's, no more paying enormous co-pays, and no more taking my kids to waiting rooms full of sick kids. I want to share this will all of my FOD family! There truly is an oil for everything. If you are wanting more information on this, please give send me an email.

Angie Phillips

**Angie’s Disclaimer:** I don’t recommend running out and buying essential oils from the health food store and using them without being properly educated. That is part of my job as a Wellness Advocate - to educate people on proper use. Essential oils are extremely potent and need to be used with care and understanding. I would love to educate you and your family on this topic as it has become a passion of mine.

**FOD Group Disclaimer:** We just joined a group here in Utah supporting kids and families with special needs. For their monthly spotlight, they asked if we could write something about MCADD. I hope I got most of it right! I’m just excited about getting awareness out there!

Rachel Johnson

My name is Angie Phillips. I have 2 TFPers. Nathan, now 7 and Abby, now almost 5. I, like all of you out there, has feared and dreaded our kids getting sick for obvious reasons. I used to be at the peds office on a somewhat regular basis with coughs, colds, and infections of one kind or another. This past year when I took Nathan and Abby both in for their yearly checks my ped said “You haven't been here in a while.” My thought “Nope, I have not!” I have finally discovered something that has brought our illness to a much more tolerable level. I stop them dead in their tracks using doTERRA essential oils. I now use oils to help my anxiety and give me the energy I need to function and be at my best. For my kids, when I see a bug coming on, I immediately apply oils and kill the problem before it starts getting bad. With Abby, who ended up using inhalers due to severe coughing for weeks and months after a cold, I no longer use her inhalers! I use oils. I am able to start the healing process right when I notice it happening. This has brought such a piece of mind to me knowing that I have the power in my own home to help them when they are sick. No more waiting on doctors, no more taking unwanted/dangerous RX’s, no more paying enormous co-pays, and no more taking my kids to waiting rooms full of sick kids. I want to share this will all of my FOD family! There truly is an oil for everything. If you are wanting more information on this, please give send me an email.

Angie Phillips

**Angie’s Disclaimer:** I don’t recommend running out and buying essential oils from the health food store and using them without being properly educated. That is part of my job as a Wellness Advocate - to educate people on proper use. Essential oils are extremely potent and need to be used with care and understanding. I would love to educate you and your family on this topic as it has become a passion of mine.
Love Messages

Condolences...

‘The wound is the place where the light enters you’
~ Rumi

It is with great sadness that we learned of two recent deaths within our ‘FOD Family’ in the last few months...please send your prayers and thoughts to one of our LCHAD Families and to Kyle Symes’ Families (adult VLCAD)

In Memory of Kyle Quinn Symes

Kyle was born with a rare life-threatening metabolic disease that prevents the body from converting certain fats to energy. Research for these metabolic diseases is critical to someday finding a cure.

The FOD (Fatty Oxidation Disorders) Family Support Group mission is to fund research, connect and network with FOD families and professionals around the world, and to provide emotional and grief support. It is an all-volunteer non-profit 501c3 tax-exempt corporation with donations tax deductible.

Donations to honor Kyle can be made on the FOD website.

Donations may be made by selecting the FOD Research Fund Donation. Please type Kyle’s name in the Special Message box so we may thank you.

[The FOD Group received many donations in memory of Kyle ♥]

~ All of our FOD children/adults will ALWAYS be with us in our hearts ~

~ NEEDED FOR THE JAN 2016 ISSUE ~

Medical Update ~ Please Submit to Deb

PROFESSIONAL ABSTRACTS/ARTICLES OF ALL KINDS  
(Drs, Nutritionists, Genetic Counselors, Social Workers, etc.)

The ‘Silver Linings’ of FODs ~
What is your ‘Silver Lining?’

FAMILY STORIES & Pictures for KidsKorner
**DONATIONS**

*since our January 2015 Newsletter*


**T-shirts, Bracelets, Ribbons, CafePress, GoodSearch browsing, MissionFish/eBay selling, or iGive shopping:** Jessie Rocca, Deanne Garlock. Anonymous iGive donations.

Thank you to all that have bought products from companies on the internet that support the iGive and CafePress.com program of donating a certain percentage to Groups like ours. All of those links are on http://www.fodsupport.org/donate.htm


We greatly appreciate donations to help with daily costs, website fees, supplies, Conference costs, phone calls around the world, rent for the Grief Consult office (rent, advertising, etc) to offer pro bono grief support to local Bereaved Parents & Families (and also via Skype/phone to FOD Families around the world). We also donate FOD funds from undesignated donations to various FOD related entities (ie., for NBS issues, outreach) to support their efforts.

All Undesignated and Grief Consult donations are deposited into the General Fund or Gen Trust Fund, as are Bracelet and Ribbon Sales, CafePress.com, iGive, Goodsearch, and any donation that isn’t specifically designated for the other Funds. Once the Research and Clinical Funds reach a substantial amount (@$50,000) we will be able to offer grants to clinicians and researchers in the US. Additionally, we have 1yr & 3yr certificates and long-term stocks/bonds earning interest and dividends for future FOD endeavors and programs.

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**Reminders**

Families - Please send TYPED (preferably in word document) stories etc. by Dec 15, 2015 to Deb. Continue to spread the word about FODs and the need for screening ~ it will SAVE LIVES!

Professionals - Please let us know about your research and/or clinical work with FOD Families. Send articles, summaries, etc by Dec 15, 2015 to Deb.

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Try to be a rainbow in someone’s cloud

~ Maya Angelou

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The views expressed in the FOD Communication Network Newsletter do not necessarily represent the views of our Advisors or all of our members. Before trying anything new with your child or yourself in regard to treatment, please discuss matters with your doctor or specialist. Please read our Disclaimer on our website ~ it also applies for all communications.

**Communicate With Us**

Please **ADD** me to your mailing list [Conference years]

Family Professional (please circle one)

Name/Address or Address Correction (circle one)

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Please **REMOVE** me from your mailing list:

Name/Address:

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Please include ideas for future issues or your questions

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The 2014 FOD Group 990 tax return is on our Financial page

The bulk of Expenses are for monthly phone, website fees, supplies, Conferences, and for our Grief Consultation office (rent, advertising, etc) to offer pro bono grief support to local Bereaved Parents & Families (and also via Skype/phone to FOD Families around the world). We also donate FOD funds from undesignated donations to various FOD related entities (ie., for NBS issues, outreach) to support their efforts.

Thank you to Erika Wallace - erikawallacepa@yahoo.com (Mailing Lists), Mary Lingle - Mcartwrite@aol.com (Website Designer) and Brian Gould - (newsletter consulting) for all your hard work, and to Mark Heinz mark@markheinz.com & Matt Pfeiffer pfeiffer@danhos.com for their pro bono consulting expertise on email/website information. Keith Widmann 4wdesign@gmail.com for our website slideshow pictures, the FOD Banner for booth displays, and the USA TODAY Charity Spotlight banner ad. Eileen Shank eshank@helmsbriscoe.com for helping us event plan FOD/OAA Conferences. And all of our Conference volunteers.