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From the Editor

**2014 FOD/OAA Conference in DC!**

One YEAR from now the FOD/OAA National Metabolic Conference will be in Washington, DC ~ July 24-25, 2014!

Our main local Sponsors are still being worked out , so hopefully we will be able to post on our site soon. Kathy Stagni [OAA Director] and I are exploring Hotel options right now with the great help of Eileen Shank [MCAD mom and event planner] and Jana Monaco [OAA mom], so once we decide on the location we will let everyone know. We haven’t made a decision yet on a $50 registration fee per person. Due to a large donation for the 2012 Conference, we didn’t charge that fee. As for DONATIONS ~ *We truly appreciate every penny that our members donate via cash, buying FOD Awareness items, and doing your own fundraisers. We also have some NEW Awareness Items for sale ~ the FOD Ribbon Car Magnet and the FOD Car Sticker!*

So please keep us in mind when you choose to donate in 2013!

In the meantime start thinking of TOPICS you’d like to hear ~ we will have FRIDAY dedicated to FOD specific speakers/topics [and OAA has their own speakers] and SATURDAY will be our JOINT day with topics similar to both FODs and OAs. Keep in mind we can’t speak on EVERY SINGLE FOD on Friday . However, most of our speakers will mention some specific ones throughout their talk, but because we want to get as much info out as possible and reach as many as Families as possible we try to broaden the main talks. BUT we ALWAYS have breakout sessions for specific FODs and ALL of the SPEAKERS are available on Friday and Saturday for individual questions etc at the FRIDAY NIGHT RECEPTION for Speakers, Families and Professionals and through lunch on both days. We may also have a child activity room, but that depends on our funding and availability of local volunteers. Each Family would still be responsible for having a designated person for their child/ren in the room, however. *The talks and open times with our FOD experts are INVALUABLE to our Families ~ along with the fantastic opportunity to network and get to really know other FOD FAMILIES from around the world IN PERSON!*

Refer to our [Conference](#) page on the site to see the format and past agendas and topics. START SAVING and we hope to see some NEW FACES as well as ’old’ ones in DC next July!

In this issue, we have LOTS of Nutrition Updates and suggestions. We also highlight in the Medical Update a new Study that is being conducted at the NIH. And lots of smiling faces in our KidsKorner , New Babies and Reach for the Stars sections!

Please also 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 [Give 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 or on our [facebook Cause page](#). You can also order your very own embroidered or screenprinted FOD polo shirt , cap, or any other item of various colors from the same embroidery company that I purchased our Speaker shirts from the 2010 Conference! They have our logo on file .

**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!’**
We invite all those with an FOD to join, to provide de-identified medical information to the new FOD Connect Registry to help everyone in the global FOD community ~ patients, families, researchers, clinicians, and pharmaceutical companies ~ to learn more about Fatty Oxidation Disorders.

The goal is improved diagnosis and medical care, as well as empowerment of patients and families through knowledge, connections, and support.

FOD Adults 18 yrs+ can join on their own ~ if an FOD child is under 18 yrs old or if he/she is over 18, but does not have the ability to answer the questions for themselves, then parents/legal guardians can join.

If you have any questions about the FOD Connect Registry, or to opt in and Join, please feel free to contact us with any questions. Help our researchers find answers to help you live your life to the fullest ~ join our FOD Patient Registry and participate in future trials and studies!

In the future, we will be developing disorder specific surveys so we can learn more about EACH FOD!

Another way to CONNECT with other FOD Families and some Professionals is to join our Facebook Group and/or our google Email List. We have over 900 members on facebook and 1100 members on the google List.

♥ Please be sure you have completed the ‘JOIN OUR GROUP’ form BEFORE you request to join either group. ♥

To help EDUCATE and CREATE AWARENESS please also share our website and brochure with ALL in your Family and your Professional contacts! I often mail extra brochures when I mail out FOD Awareness items [bracelets, magnets, tshirts etc] that members have purchased.

Professionals ~ I can mail a larger # of brochures if you contact me and send your address with the # of brochures/cards you’d like for your office or clinic.

And for those that would like to create FOD Awareness in your own town by having your own fundraiser, PLEASE DO — your donations to the FOD Group are tax-deductible! Please be sure to complete the Family Fundraiser form so you are aware that it is your own fundraiser and not one endorsed or solicited by the FOD Group. Contact me if you have any questions!

Make a CHOICE to SHARE your experiences with others ~ it MAY SAVE A LIFE!

~ Deb Lee Gould, MEd FOD Director
Our son, Dominic, was born on April 3rd, 2008. He was born a screaming but healthy boy at 7 pounds 3oz and good Apgar scores. I had a fairly normal pregnancy with one scare of preterm labor at 31 weeks. I took it easy and he stayed in until he was full term. The same day he was born the hospital at one point said he had low blood sugar, but it did rise after feeding him and stayed up. After our 2-day hospital stay we were excited to go home and show his 3 older brothers our tiny new addition to our family.

About 4 days after arriving home I realized Dominic was not eating very well and was very sleepy. I knew having previous children that they do sleep a lot those first few weeks, but he was barely waking to eat or latching on, then falling right back asleep before he had a good feed. My husband and I decided we'd let our Pediatrician know at our next visit coming up. A few hours later that same day we received the call...a call we would never forget.

The hospital said that our newborn screening came back positive for VLCADD and that as high as his fat levels were it was a definite. We were told not to google this disorder, but to come straight to Children's Hospital where he would be admitted and we'd meet our Geneticist and Dietitian for a treatment plan. It was a nightmare not knowing yet what VLCADD was, knowing our child had it and that it was very serious. We did not know if he'd have a normal life, if he'd even live long. As we arrived we were put right through a very busy ER and he was immediately cathetered and hooked up to an IV through his tiny head since his veins were so little. He was also put on a heart monitor. We were put into a room where we tried to sleep but could not, watching our baby and not knowing what our future would bring.

The next morning we were met by our new Doctor, a Geneticist, that would be treating our child, and a dietitian. We learned about what he had. I was to immediately decrease breastfeeding to only 3 times in a 24-hour period and supplement with a special medium chain formula. We learned that he'd have to be fed frequently and never fast. So for the next few months he'd have to eat every 2 hours around the clock. And he would have to be on a very strict low fat diet for life. Any time he would ever get sick where he could not keep food down or could not eat he would have to be hospitalized and on a special D10 IV to prevent any serious complications. And his heart would have to be closely checked a few times a year to be sure that no damage had occurred. This was so much to take in.

We were discharged with a plan on how to care for him, but we came home heart-broken and scared for him. We barely slept for the next few months with the constant feedings and uncertainty if he was eating enough. We also looked up as much information on this to become knowledgeable on how to care for our special child. We also joined a very helpful FOD Family Support Group. It was a very stressful first year.

We’ve had some hospitalizations over the next few years and continue to in times of illnesses. Hospitalizations are very hard on our entire family. One year he was sick on Christmas Eve so we ended up in the hospital over Christmas. Something we hope will not happen again!

Today Dominic is a healthy, happy 5-year-old boy. He is amazing and knows his diet well. We've had some concerning times though ~ one time we found him in a corner eating chocolate and then we worry until his next echocardiogram.

Yet, we cannot imagine our life without him. He is our light. We thank God every day for the newborn screening that saved our child's life!

De-De Doering,
Mom to Dominic
dededoering@yahoo.com
My name is Tasia Rechisky, a Senior at Boston University pursuing a dual degree in Business Administration and History. I am the President of the Undergraduate History Association. I am a member of two honor societies – Beta Gamma Sigma and the National Society of Collegiate Scholars. I work at the Hubert Humphrey Fellowship Program and will be a Contracts intern this summer at Raytheon in Woburn, MA.

I have had VLCAD, Very long-chain acyl-CoA dehydrogenase Deficiancy, since birth. I am currently in the triheptanoin (C7) medical study out of Pittsburgh Children’s Hospital originally developed by Dr Charles Roe, formerly of the Baylor Health Care System [Note: Dr Jerry Vockley in Pittsburgh now runs that Study since Dr Roe is retired – click New patients. needed for Triheptanoin (c7) oil Study and scroll down to FOD Research. Studies for more info].

I am feeling great and have found that living with VLCAD, in fact anything, is possible!

Tasia Rechisky
trechisky@yahoo.com or trechisk@bu.edu

♥ ♥ ♥

"If you enjoyed this book please consider sharing it with your metabolic team, as many metabolic facilities are still unaware that this book exists! And we would like all families who have children with LCHAD, VLCAD and TFP to have access to this resource!"

I checked on the process of delivery and turn around with a variety of people and it seems that the book typically takes about 1-2 weeks for delivery. So although there was an earlier concern apparently that was a glitch that has not been repeated (good to know!)

"My Special Body" is a children’s book that was written for children with LCHAD, TFP and VLCAD deficiency and was published over a year ago [Written by LCHAD mom, Stephanie Harry]. If your child has been diagnosed with one of these conditions and you have not yet received a copy please visit http://www.fodsupport.org/book.htm on our FOD website to fill out an order form. Currently, Stephanie [the author] is trying to reach out to the metabolic clinics and make them aware that the book exists! Her desire is that all families with these metabolic conditions can utilize the book and she can sure use your help! If your child visits a metabolic clinic throughout the year, if you would consider sharing with them information about the book or Stephanie’s contact information this would be very helpful!

You and/or your clinicians are welcome to contact Stephanie at srharry374@hotmail.com
Stephanie Harry blog www.harryfamilyblog.blogspot.com
Using cord blood to humanize mice to study immune function in inborn errors of metabolism (IEM)

Humanized mice?
In the last decade, several mouse models have been constructed that allow researchers to transfer or engraft foreign tissues and cells. The NSG mouse, developed by The Jackson Laboratory in Bar Harbor, Maine, lacks an immune system and is able to accept human immune cells and tissues better than any other mouse strain. By transferring human immune cells or tissues, the mouse immune system becomes humanized.

Immune function in patients with IEM using humanized mice
Our laboratory focuses on studying immune system function in patients with IEM. Specifically, how good are immune cells from patients with IEM at fighting off infections? One of the tools that we use is humanized NSG mice. White blood cells from blood samples from patients with IEM may be transferred to NSG mice where immune function may be studied. There is a limitation, however, eventually the white blood cells see the mouse organs as not human, and attack the mouse causing graft-versus-host-disease. The mice eventually die. With white blood cells from a blood sample from an IEM patient, we have a window of 5 weeks to study immune function before graft-versus-host-disease ensues.

Why cord blood?
While this way of studying immune function is useful, a more long-term solution involves using cord blood samples. Cord blood samples, collected at the time of a baby’s birth from the umbilical cord, contain hematopoietic stem cells. Hematopoietic stem cells have the ability to become all the different cells of immune system: T-cells, B-cells, dendritic cells, macrophages, etc. Hematopoietic stem cells from human cord blood can be transferred into NSG mice where they “grow up” and learn how to be human immune cells that can function normally inside the mouse. The major benefit is that since the cells have “grown up” inside the mouse, there is no graft-versus-host-disease, allowing the mice to be studied for longer periods of time. In addition, as mouse gets too old, we can then transfer the bone marrow containing human immune cells to a new mouse, thus keeping the IEM patient sample going for future studies.

How to participate
We are looking for cord blood samples from patients with IEM to help us better understand the function of their immune cells and their ability to fight infection. Cord blood samples may be donated for our studies via our clinical protocol, the NIH MINI Study: Metabolism Infection and Immunity in IEM. As part of our protocol, we have “samples only participation” where families may donate cord blood samples and other tissues. Cord blood samples may be obtained from already frozen stores or arrangements may be made at the time of a child’s birth. Cord blood samples donated to the study will be used to create humanized NSG mice. If you have any questions regarding cord blood donation, or participating in our clinical protocol at NIH, please contact us below.

Ms Janet Shiffer, C-RNP
Family Nurse Practitioner
Study Coordinator
Phone 301.451.9145

Dr Peter McGuire
Principal Investigator
Phone 301.451.7716

Website: http://www.genome.gov/mini/ Email: ministudy@mail.nih.gov
Medical ‘Bits of Info’

We often get questions over the facebook Group or the google Email List about ‘which fats are good or bad’ for those with FODs. Dr Charles Roe gives us an explanation of the various oils that many Families have in their homes.

● ● ●

Palmitate (C16), stearate (C18), and oleate (C18:1) are all non-essential fatty acids (“bad fats”) and enter readily into beta oxidation where their metabolism will stop at the enzyme deficiency in FODs. They should be reduced in diets for FOD patients. From the attached table you can see that Canola oil is very high in "bad fat" content.

Table 1: Comparison of Fatty Acid Composition of Commercial Oils (gm/100 gm oil)

<table>
<thead>
<tr>
<th>OILS</th>
<th>C16 + C18</th>
<th>C18:1</th>
<th>C18:2</th>
<th>C18:3</th>
<th>Non-Essential</th>
<th>Essential</th>
</tr>
</thead>
<tbody>
<tr>
<td>Canola</td>
<td>5.8</td>
<td>56.1</td>
<td>20.3</td>
<td>9.3</td>
<td>61.9</td>
<td>29.6</td>
</tr>
<tr>
<td>Soy</td>
<td>14.1</td>
<td>22.8</td>
<td>51.0</td>
<td>6.8</td>
<td>36.9</td>
<td>57.8</td>
</tr>
<tr>
<td>Corn</td>
<td>12.4</td>
<td>27.3</td>
<td>53.5</td>
<td>1.2</td>
<td>39.7</td>
<td>40.9</td>
</tr>
<tr>
<td>Flaxseed</td>
<td>9.4</td>
<td>20.2</td>
<td>12.7</td>
<td>53.3</td>
<td>29.6</td>
<td>66.0</td>
</tr>
<tr>
<td>Walnut</td>
<td>9.0</td>
<td>22.2</td>
<td>52.9</td>
<td>10.4</td>
<td>31.2</td>
<td>63.3</td>
</tr>
</tbody>
</table>

Also refer to the Published manuscript: Charles R. Roe, Diane S Roe; Mary Wallace, R.D.; Brenda Garritson: Choice of Oils for Essential Fat Supplements can Enhance Production of Abnormal Metabolites in Fat Oxidation Disorders. Molecular Genetics and Metabolism 92: 346-350, 2007.

Refer to: Choice of oils for essential fat supplements can enhance production of abnormal metabolites in fat oxidation disorders

Sincerely, Charles R Roe, MD

Pharmaceutical Update

Vyvanse® (lisdexamfetamine dimesylate) Capsules, (CII) Now Approved in the US for Maintenance Treatment

In Children and Adolescents with ADHD

Shire plc, the global specialty biopharmaceutical company, announced that the US Food and Drug Administration (FDA) approved the prescription medication Vyvanse® (lisdexamfetamine dimesylate) Capsules, (CII) as a maintenance treatment in children and adolescents with Attention-Deficit/Hyperactivity Disorder (ADHD). Vyvanse is currently approved as a maintenance treatment in adults with ADHD. With this new approval, Vyvanse becomes the only stimulant approved for maintenance treatment in children, adolescents, and adults (patients ages 6 and above) with ADHD.

[from Climb Enewsletter - May 2013]
The Nutrition Guidelines Project is a multi-year project that was developed out of the acknowledged need for the development of evidence and consensus based nutrition guidelines for medical nutrition therapy (MNT) for people living with rare inborn errors of metabolism (IEM) e.g. propionic acidemia (PROP), maple syrup urine disease (MSUD), medium chain acyl Co-A dehydrogenase deficiency (MCADD), and phenylketonuria (PKU). The project is funded by a Maternal and Child Health Bureau Health Resources and Services Administration (HRSA) grant administered by the Southeast newborn screening and Genetics Collaborative (SERC) and staffed by experienced dietitians representing the professional society, Genetic Metabolic Dietitians International (GMDI). The project objectives include:

1. Developing a systematic methodology to critically and objectively gather and review both evidence and consensus based information. IEM specific evidenced based information includes; available IEM disorder specific peer-reviewed published research studies as well as available IEM disorder specific gray literature such as; non-peer reviewed IEM medical nutrition therapy (MNT) book chapters, metabolic clinic IEM protocols, and IEM MNT educational lectures. IEM specific consensus based information, gathered from surveys and meetings of clinicians experienced with managing these disorders, is also vital due to the lack of IEM evidence based information.

2. Developing an internet based portal to direct and document the development and progress of each nutrition guideline. This allows each guideline to be transparent and revisable to all members of the work group.

3. Organizing and recruiting experienced and expert metabolic dietitians and physician volunteers to participate in the development of nutrition management guidelines.

4. Publishing the IEM specific nutrition management guidelines to standardize IEM specific medical nutrition therapy based on current evidence and consensus based information.

Given the complexity and variability of each IEM, along with the paucity of scientific literature regarding treatment and management of these conditions, this project has presented many challenges. But we are working through these challenges due to the importance of developing these guidelines, and we appreciate the patience of our patients and their families who are anticipating the publication of IEM nutrition guidelines.

In April 2013, SERC-GMDI announced that the Maple Syrup Urine Disease (MSUD) Nutrition Guidelines developed with this new evidence and consensus based method was available for viewing via the GMDI website. Currently efforts are ongoing to validate and update the existing GMDI MCADD and VLCADD nutrition management guidelines and to develop nutrition management guidelines for PKU and Propionic acidemia. We will keep you posted on our progress.

US National Library of Medicine, Newborn screening coding and terminology guide website: accessed Feb 2013

Together as Nutricia North America we will provide:
- The highest quality and most complete line of metabolic products
- More patient education materials and online learning sessions
- Events and support for patients and families on a national and local level
- Assistance obtaining coverage for your preferred metabolic products
This Food Diary info and example pages were created by:

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chomer@sfcAustin.com

3-Day Food Diary Record

General Instructions

● Please write down everything that your baby eats or drinks, no matter how big or how small -- everything counts!
● Record what your baby ate as soon as a meal or snack is over. Don’t depend on your memory at the end of the day.
● Be specific. Write down exactly how much is taken in. Record foods in measurable amounts such as ounces, cups, teaspoons or inches; avoid using “sips” or “bites”. Use brand names if possible. Remember to write down the “extras” such as margarine on a cracker, water added to juice, or formula mixed into baby cereal.
● Please do not use words such as “a bottle of milk” or a “bowl of cereal”. We need to know how big the bottle or bowl was and the type of milk or cereal: “4 ounces of Similac Advance” or “1/2 cup of Cheerios”
● Please write down only one food item per line. Listing two items together on one line makes it difficult to tell how much of each food your baby ate.
● NOTE: the word “cup” refers to a standard 8 ounce measuring cup. If a food comes in a portion cup (such as applesauce) please list the ounces in the portion cup (4 ounces, 6 ounces, 8 ounces, etc.) and how much of the portion cup your baby ate.
● If your baby is nursing, write down the number of minutes he fed at the breast.
● Finally, if your baby takes any nutritional supplements such as a medical food, formula, vitamins, herbs or medications, please list them

Example of the wrong way to keep a food diary

Date: Saturday
This day was: ____ typical ____ less than typical ____ more than usual

<table>
<thead>
<tr>
<th>Time</th>
<th>Food or Drink</th>
<th>Brand name</th>
<th>How much?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Morning</td>
<td>Cereal with milk</td>
<td></td>
<td>1/2 bowl</td>
</tr>
<tr>
<td></td>
<td>Juice</td>
<td></td>
<td>1 bottle</td>
</tr>
<tr>
<td></td>
<td>Gerber</td>
<td></td>
<td>1/2</td>
</tr>
<tr>
<td>Lunch</td>
<td>Gerber</td>
<td></td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>Milk</td>
<td></td>
<td>1 bottle</td>
</tr>
<tr>
<td>3:00</td>
<td></td>
<td></td>
<td>1</td>
</tr>
<tr>
<td>Dinner</td>
<td>Cereal</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Applesauce</td>
<td></td>
<td>3 bites</td>
</tr>
</tbody>
</table>
Example of the **CORRECT WAY** to keep a food diary!

**Date:** March 7
This day was (check one): ____ typical ____ less than usual _X_ more than usual

<table>
<thead>
<tr>
<th>Time</th>
<th>Food or Drink</th>
<th>Brand name</th>
<th>How much?</th>
</tr>
</thead>
<tbody>
<tr>
<td>5:30 am</td>
<td>Breast milk</td>
<td></td>
<td>20 minutes</td>
</tr>
<tr>
<td>6 am</td>
<td>Vitamin</td>
<td>Poly-Vi-Sol</td>
<td>1 ml</td>
</tr>
<tr>
<td>7:30 am</td>
<td>Baby rice cereal</td>
<td>Beechnut</td>
<td>3 Tablespoons</td>
</tr>
<tr>
<td>7:30 am</td>
<td>Formula</td>
<td>Good Start Soy</td>
<td>4 ounces</td>
</tr>
<tr>
<td>9 am</td>
<td>Banana rice rusks</td>
<td>Baby Mum-Mum</td>
<td>1 1/2 pieces</td>
</tr>
<tr>
<td>9 am</td>
<td>Breast milk</td>
<td></td>
<td>4 oz bottle</td>
</tr>
<tr>
<td>11 am</td>
<td>Stage 1 green beans</td>
<td>Gerber</td>
<td>3.5 ounces</td>
</tr>
<tr>
<td>1 pm</td>
<td>Apple juice</td>
<td>HEB</td>
<td>2 ounces</td>
</tr>
<tr>
<td>1 pm</td>
<td>Water</td>
<td>tap</td>
<td>2 ounces</td>
</tr>
<tr>
<td>2:30 pm</td>
<td>Stage 2 apple/apricot</td>
<td>Earth’s Best</td>
<td>1/2 of 4 oz jar</td>
</tr>
<tr>
<td>4 pm</td>
<td>Formula</td>
<td>Enfamil Premium</td>
<td>3 ounces</td>
</tr>
<tr>
<td>6 pm</td>
<td>Mashed potato, plain</td>
<td>Fresh/boiled</td>
<td>3 Tablespoons</td>
</tr>
<tr>
<td>6 pm</td>
<td>Dry cereal</td>
<td>Cheerios</td>
<td>1/4 cup</td>
</tr>
<tr>
<td>7 pm</td>
<td>Carnitine liquid</td>
<td>generic</td>
<td>2 ml</td>
</tr>
</tbody>
</table>

**Sample blank sheet** (make as 8.5 x 11 page)

<table>
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<tr>
<th>Time</th>
<th>Food or Drink</th>
<th>Brand Name</th>
<th>How much?</th>
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</tbody>
</table>

**Note from Deb ~ I saw this wonderful article about a terrific metabolic dietitian in the UK that saved ‘a little life’ and is working tirelessly with one of our VLCAD Families and many others!**

*In professional terms Anita is a world leader. She has written 300 papers on metabolic conditions and travels internationally, lecturing and teaching doctors, families and other dietitians*
One of our Families, Melissa Bell, has put together a wonderful brochure about ‘Lyme Disease and Tick borne Co-Infections.’ She also has included some info below about mitochondrial dysfunction.

Mitochondrial dysfunction is a very common secondary problem caused by Lyme Disease [this was the case with my son]. As set forth in the Cleveland Clinic site, patients are often diagnosed with mitochondrial disorders, when there is actually an underlying cause, such as Lyme Disease.

http://my.clevelandclinic.org/multimedia/transcripts/parikh_understanding_mitochondrial_disorders.aspx

**Diagnosis of Mitochondrial Disorders**

**Question from individual:** How common are misdiagnosis of mitochondrial diseases because they are fairly rare? How would this affect the patient in terms of their treatment?

**Speaker: Dr Sumit Parikh:** This is a difficult question to answer. It seems that mitochondrial disorders are not that rare - but we have had difficulty in diagnosing them. Also, the path to diagnosis is complex in that it requires many tests and there is no ‘one’ test that makes the diagnosis, but rather a person reviewing and interpreting the entire medical picture, or ‘clinical story’ and lab test results. What we find too often is that when a patient has symptoms that a diagnosis has not been made for, mitochondrial disorders often get invoked as a diagnosis. We frequently see patients labeled with a mitochondrial disease diagnosis who in fact have something else, whether it be a genetic syndrome, or another medical issue like celiac or Lyme disease. See also:  [http://www.immed.org/newsletters%20uploads/Aug2011%20PDF%20newsletter%20uploads/Nicolson%20Lyme%20Disease-1.pdf](http://www.immed.org/newsletters%20uploads/Aug2011%20PDF%20newsletter%20uploads/Nicolson%20Lyme%20Disease-1.pdf)

Dr. Horowitz, a prominent Lyme doctor, recently listed mitochondrial dysfunction as one of 15 issues to be addressed to recover from Lyme:  [http://www.lymeneteurope.org/forum/viewtopic.php?f=7&t=3820](http://www.lymeneteurope.org/forum/viewtopic.php?f=7&t=3820)

For children suffering from mitochondrial dysfunction, I believe that Lyme Disease bears careful consideration. LD, or another chronic underlying infection, may be the root cause of the dysfunction.

Please do not hesitate to contact me with any questions.

Warmly,
Melissa Bell  jaxbells@comcast.net
Mom of 3 in Florida
13 year old son with mito dysfunction [unspecified FOD] secondary to Lyme Disease and co-infections
11 year old daughter with Lyme Disease
5 year old daughter with Lyme Disease

**NBS Update**

I wanted to share my daughter’s interview link on the CDC website about having MCADD!

‘**Newborn Screening: Lives Saved and Dances Danced**’

Tara  Karina -MCADD  Michigan  tkgj4@yahoo.com
Reach for the Stars!

I thought you might enjoy seeing an article the OC Register posted on our daughter Mackenzie, and her fundraising for "Cure Mito"  [Note from Deb: shows that children are a powerful force too!]

❤️ Photo in the article is Mackenzie and her 2 cousins.


Patty Bird  pattybird@cox.net

❤️ ❤️ ❤️

Joshua is one rare little guy  ... Joshua a ‘forgotten’ victim

Happy International Rare Disease Day [was Feb 28, 2013 ] - Joshua has Glutaric Aciduria Type 2 which is incredibly rare. We have 3 of us in Australia that I know. Port Macquarie News ran an article on Rare Disease Day, and Josh was part of it. I’m so proud right now of my child I could burst. It’s been a struggle, but 10 years of being alone until recently and I now we have some Aussie battlers to "share."

Lynda Gamack, Mom to Josh (GA2)  https://www.facebook.com/lgamack

❤️ ❤️ ❤️

When we were faced with a HUGE crisis of Ryan’s, my now adult daughter stepped up and became very involved with the boys. As a result, this is her post graduate work/project  www.verdeviewec.org  and I now have the boys involved and becoming more self- directed and self-advocating. They have been very healthy, knock on wood and I am so blessed to have your site and support in those early struggling years. This is my family’s way of paying it forward. Thanks for being a wonderful model and inspiration!

Lori Piccirilli  lori.piccirilli@gmail.com

❤️ ❤️ ❤️

I am proud to announce that Doug [18-LCHAD] will be serving his Mormon mission for 2 years in the Alabama-Birmingham Mission. I want to thank you all, my FOD friends, who have supported our family. We love you all.

Scott Schulte  http://www.scottschulteonline.com/

[Note from Deb: Scott has a terrific accomplishment of his own ~ he is writing a book on the great wrestler/coach Dan Gable ~ please check out his website and book info on facebook!]

❤️ ❤️ ❤️

URGENT NEED for Medical Professionals

With more Families being identified with an inborn error of metabolism (through expanded newborn screening), our Families will need ongoing Clinical Care from knowledgeable and caring professionals. In addition to our Newborn Screening Advocacy by many of our Families, our Group is hoping to also bring awareness to medical schools and other medical organizations and facilities the need for educating and training new Professionals (physicians, metabolic nutritionists etc) in the field of Medical Genetics and Metabolism to treat our children, as well as our FOD adults. We are also raising funds for Clinical Training.

[see our website for the donation box]

Once we raise enough Funds we will be able to offer grants to US Clinical Training institutions.

We NEED your help NOW and in the FUTURE so our children will thrive and grow into adulthood with the best of ongoing care!
Q: My five-year-old is at a point where he's ready to learn some things about his condition (MCAD). Does anyone have any advice for this conversation? I'm not sure how to begin.

A1 from Terrie ~

Keep it simple, straight forward, and stick to the basic, relevant facts. At 5, he'll understand if you tell him his body works differently from yours. Give a simple description of the way bodies break food apart for use to grow, have energy, etc., then let him know his doesn't quite work in the same way so he has to live a little differently to make sure he helps his body make the best use of what he eats. I've had to teach my youngest about MADD/GA2 so she understands why our oldest daughter has to do things differently. I kept it very basic at the beginning and, as she gets older & asks more questions, we give more detail. She LOVES learning about energy, digestion, mitochondria, and all this. It's turned her into a HUGE support for us and she is quick to protect and defend her older sister, if she thinks Mallory is upset and/or slipping into a crisis. She now recognizes the beginning signs of Mallory's onset and will kindly offer to get her something to eat or drink, knowing quick action can often resolve the onset of a crash.

I'll add this: one day Maisey had a sudden epiphany regarding her sister's health. It scared her. She came to me and asked, "Mom, is GA2 going to kill Mallory?" I replied, "Not if WE have anything to do about it! As long as Mallory is alive, we have the opportunity to work toward a way to help her. And, Maisey, we are FIGHTERS in this family!"

She loved the response and, now, two years after her epiphany, she sees so much hope for her sister's future. **We try to focus on what we CAN do rather than what we cannot.**

Terrie, St. Louis

Mallory, 24, GA2/MADD

Maisey, 9, unaffected  

[evanandterrie@hotmail.com](mailto:evanandterrie@hotmail.com)

♥

A2 from Fie ~

We have a 3½ yr-old girl with VLCADD. We talk to her over dinner, lunch and during the day about energy and eating regularly - using phrases such as her “batteries will go low” and her “engine runs dry” if she does not eat. She knows that she can’t eat fat, and we take her grocery shopping often so she knows what is allowed and what is not - and what is available! We find it very important to show her all kinds of food, so she does not feel so restricted in her diet - for example, we have sushi for take away, since pizzas are way off limits. We teach her to ask about her food and be interested in her food. So far, we have chosen not to talk about illness or death or hospitals - just keep the conversation about energy, bloodsugar, feeling good and eating well - but she knows that it is a serious matter and that she has a special doctor we go to if she feels unwell. It helps us that in her kindergarten they are very sweet and including in their way of handling her special diet needs.

Our best from Copenhagen, Denmark

Fie Lundsgaard Olsen

mom to Viola, VLCADD, 3½ yo

[fielundsgaardolsen@gmail.com](mailto:fielundsgaardolsen@gmail.com)

Q: I just want to vent and see if this has ever happened to any of the other LCHAD kiddos. One week ago my daughter woke up normally and was her same happy, active self. By 6pm that evening she was having severe weakness and muscle pain to the point that she wouldn't walk for us. It was that sudden and she had no complaints during the day and no previous illness. Of course we took her to the ER and her CK was 40,000 which was the highest it has ever been. She was admitted to the PICU and the next day her CK jumped to 85,000. I just don't understand how this happened and it concerns us that a crisis can happen that suddenly for no apparent reason. Just wondering if this has happened to anyone else?

A from Dawn ~

Jordan has VLCAD and not LCHAD, but she also suffers from bouts of muscle pain caused by high CKs. She is definitely affected by the cold. Often it can be the cold in and of itself, but it's usually a combination of factors.

What was frustrating for me to learn and to comprehend was that it often had no relation to calorie intake. That went against what I had believed to be the main trigger, fasting. Jordan has had an episode of leg pain from being overly excited and standing for a long period of time, even though she was well-fed. Her Dr explained that excitement (positive or negative) raises adrenalin levels which can raise fatty acid levels. Also, shivering releases fatty acids as well.

I know that VLCAD and LCHAD are different, but for Jordan, a combination of cold and excitement (meaning increased adrenalin) has caused a crisis, as has excitement combined with another trigger (not necessarily the cold). It is a very good idea to keep some kind of log to note what it is for your child. Sometimes you can prevent an attack. We were just in Paris for a week, unfortunately the coldest week of the year. Jordan had 2 bouts of leg pain despite my best efforts to control her triggers. If it’s any consolation though, she still had a marvelous time...our kids are resilient!

Dawn, Maryland

Jordan, 20, VLCAD

[dawnd39@comcast.net](mailto:dawnd39@comcast.net)

Q: How do people acquire a service dog?

A from Debbie ~

There is an FOD Mom that has a service dog for her son here in Louisiana.. I tried to connect you guys. I hope you don’t mind but I added you to the facebook Parents with VLCADD children group. Kristin is on this group. Her son, Trevor, has the service dog and they love it. Here is some of the information that she posted on that site regarding the dog.

We worked with an organization called 1Boy4Change. They help provide service dogs for kids at prices average parents can afford. They have many trainers that volunteer their time to help and breeders who donate puppies or provide them at reduced prices. Many other places charge as much as $30,000.00 for a trained service dog. Janet and her son, Chris, who has his own service dog don't believe it should be out of reach for any child or family. Contact them. They have a website and a waiting list, but they are worth the wait. They have a great turn-around time for waiting as well! I hope this helps,

Debbie, Louisiana

Grandmother to Kelli ~ 4 Years old VLCAD

[debbie@dgwarehouse.brcxmail.com](mailto:debbie@dgwarehouse.brcxmail.com)
Love Messages

Condolences...

It is with great sadness that we learned of a death within our ‘FOD Family’ in the last several months...please send your prayers and thoughts for Emma’s Family.

‘With my heart broken in a thousand pieces, I have to inform you guys that my Beautiful Esmeralda Joyce Rendón Oliveras "Emma" born July 16, 2012, died on Thursday, May 16, 2013...her heart couldn't make it. I have a huge pain that no words will fill. She turned 10 months the same day. Please pray for her and my family. Another mito angel reaches heaven.’ ~ Miriam Enid Oliveras

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

Coping & Healing

One-on-one phone/email/skype and in-person Grief Support is available for our FOD Families and the Public that have experienced the Death of a Child or other loved ones and feel the need for extra support or are having a difficult time living with this reality.

To help me better understand your situation, please refer to the Grief Intake Form. It can be submitted online or mailed/faxed.

There is no charge for this grief support ~ however donations are always appreciated, and will benefit the FOD Group!

Deb offers free of charge face-to-face Grief Consulting to the local Lansing, MI community ~ specifically for Bereaved Parents, but other losses are supported as well.

Deb Lee Gould, MEd
Bereaved Parent & Grief Consultant
www.bereavedparent.com
deb@bereavedparent.com
517.381.1940
Evelyn Kahlan Johnson was born April 22, 2013, at 35 weeks. What a surprise when mommy developed HELLP syndrome overnight and Evie had to join us early! She was kicking and screaming as soon as she was delivered even though she was a pint-sized 3 lbs. 10 oz! A few days later, we got the call that she also has MCADD, like her older brother.

Duncan, 8, Miranda, 6, Drake, 2 1/2 MCADD, and Evelyn, 1 month, MCADD
Rachel and Seth Johnson
Riverton, UT
sethandrachel21@msn.com

Myles Francis Aitken Born Feb 3, 2013 6lbs 5oz. 18 3/4 inches. His acylcarnitine profile and testing came back normal!

Kristopher Dec 1997 [death from undiagnosed LCHAD or VLCHAD]
Tiegan Feb 1999 unaffected
Brayden Oct 2002 unaffected
Myles Feb 2013 unaffected
Howard & Sandy Laviana-Aitkin
Hartford, CT
redsoxmamma@yahoo.com

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, 11y, SCADD, Unidentified Mito, Pulmonary Valve Stenosis (repaired), Epilepsy, SLD, PDD-NOS, SID...who knows what else!!!
Naomi, 15y, unaffected, untested, GIFTED-HIGH HONORS STUDENT!
Pepper Pike, OH, USA
The Campbell Burns Metabolic Trust is a charity that gives practical and financial help to children aged ten and under, living in the UK, who have been diagnosed with a metabolic disorder. We operate a simple grant system, and welcome applications from families in need. Please encourage families in your care to apply!

Kind regards
Bekki Burns
Chairman, The Campbell Burns Metabolic Trust
Campbell's Mummy
www.campbellstrust.co.uk

Resource for Appealing an Insurance Denial

IDA Cards are custom-made Invisible Disease Awareness Cards created to help educate others. Share these cards with someone who wants to learn more or who is being inconsiderate of your invisible disability. It is an easy way to provide education and awareness without sounding defensive or rude.

Originally created for our own son to help educate others about MCAD, we now offer a variety of other FOD Awareness Cards as well.

Our mission is to provide an affordable, quality product to families to assist with education and awareness of invisible diseases such as the FODs because we believe that “Education is the first step in finding a cure!”

Find us on Facebook at www.facebook.com/orderIDACards

~ NEEDED FOR THE JANUARY 2014 ISSUE ~

Medical Update ~ Please Submit to Deb

Professional Abstracts/Articles of all kinds
(Drs, Nutritionists, Genetic Counselors, Social Workers, etc.)

FAMILY STORIES & Pictures for KidsKorner

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

Duncan, 8, Miranda, 6, Drake, 2½
MCADD, and Evelyn, 1 month, MCADD
Utah

Stella
19-mos-old
MCAD
Ohio

Karina
5 yrs old
MCAD
Michigan

Nalani
4 yrs old
VLCAD
Illinois

Reece
7 mos old
VLCAD
Texas

Hannah
1 yr old
SCAD
New York

Stella
19-mos-old
MCAD
Ohio

Duncan, 8, Miranda, 6, Drake, 2½
MCADD, and Evelyn, 1 month, MCADD
Utah

Please note that we also have an FOD KidsKorner/Adults Gallery and other Pictures on our homepage. To submit a pic please email Deb.


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 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, and raising funds for FOD Clinical Training and FOD Research and long-term investments. ALL donations go toward FOD efforts and programs.

**US Checks can be made payable to ‘FOD GROUP’ and mailed to:**
FOD Group PO Box 54 Okemos, MI 48805

We also have a Secure PayPal link on our Donate page

**ALL US donations are tax-deductible.**

**Our 501c3 Tax ID # is 83-0471342.**

**Reminders**

**Families** - Please send TYPED (preferably in word document) stories etc. by Dec 15, 2013 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, 2013 to Deb.

‘Anyone who does anything to help a child in his life is a hero to me’

~ Fred Rogers

**Communicate With Us**

Please **ADD** me to your mailing list [Conference years]
Family Professional (please circle one)
Name/Address or Address Correction (circle one)

________________________________________________________________________

Please **REMOVE** me from your mailing list:
Name/Address:

________________________________________________________________________

Please include ideas for future issues or your questions

________________________________________________________________________