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From the Editor

We hope all of you had a very healthy and safe holiday season...we are jumping right into 2016 as we plan our upcoming July FOD/OAA International Metabolic Conference ~ please refer to page 4-5 for more in-depth info.

We are thankful that The Metabolic Clinic at Children’s Hospital Colorado and the University of Colorado School of Medicine offered to be our Premier Sponsors!

As we have experienced through our Networking over our Facebook Group and google Email List, it is so very important to KNOW that you are not alone in your challenges of living with an FOD or having a child/children with an FOD. That is the wonderful thing about attending one of our Conferences ~ to be able to talk face-to-face with other adults and Families AND our Professionals. Those that have attended in the past often come back for the camaraderie and to learn more about these ‘invisible disorders.’ Because we only have our Conference every 2 years, I truly hope that many of you will be able to attend this summer!

Always remember ~

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

FOD (Fatty Oxidation Disorders) Family Support Group
PO Box 54
Okemos, MI 48805

517.381.1940 phone
866.290.5206 fax

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www.fodsupport.org

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James Gibson, MD, PhD
Specially for Children, Austin, TX
Dear FOD members: I would like to personally thank all of you that have offered to plan your own ‘Family Fundraiser’ to create awareness of FODs, as well as to raise funds that will help us continue our worldwide efforts free of charge.

We are in the process of expanding our ability to do fundraisers in the US so I will keep you posted when our process changes. We have been offered the pro bono services of an attorney to help us in this challenge of filling out all the correct forms for the various states. We strive to run our nonprofit as best we can, and it’s wonderful that others have stepped up to help us!

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, you can purchase our FOD Awareness items and wear them with Pride! Additionally, when you shop on amazon, be sure to bookmark and shop every time from our FOD amazon smile 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 with our expenses throughout the year and with raising funds for Research and Clinical Training of new metabolic professionals.

So please keep us in mind if you are able to donate anytime throughout 2016 and beyond!

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, TFF, 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.

---

Our premier Sponsor/Host for our 2016 FOD/OAA International Metabolic Conference is The Metabolic Clinic at Children’s Hospital Colorado and University of Colorado School of Medicine.

We will meet ALL Day on Friday (8-5pm) and HALF DAY on Saturday (8am -12pm). Speakers and Topics will be posted as they become available.

Conference Registration: Our eventbrite.com Registration Form (for anyone over age 5) for Families & Professionals is now activated - this form is important for determining meal counts.

There is NO Conference Registration fee for Families, but Professionals will pay $50 per person. Check here for updates after Jan 1, 2016.

Hotel & Conference: $120 per night (plus tax) for a double or king

Westin Westminster
1 0 6 0 0 W e s t m i n s t e r B o u l e v a r d
Westminster, CO, 80020
Phone Reservation: 888.627.8448

Hotel Online Reservations: Guests can access the FOD/OAA link to make their reservation thru June 24, 2016!

If you are interested in becoming a Conference Sponsor or Donor or Vendor for our July 2016 Conference please contact Deb or Kathy Stagni (OAA Director).
Our 2016 FOD/OAA International Metabolic Conference is for parents, family members, affected individuals, professionals and exhibitors that have an interest in Metabolic Disorders.

It is only through generous donations and sponsorships that the FOD Group and OAA are able to offer such an important opportunity every two years to Families and Professionals eager to learn more about our disorders. Our premier Sponsor/Host is The Metabolic Clinic at Children's Hospital Colorado and University of Colorado School of Medicine.

If you are interested in helping our efforts as a donor or a Conference Sponsor please refer to each Group's website linked above or contact Kathy Stagni directly at mkstagni@gmail.com or call 763.559.1797!

Fatty Oxidation Disorders and Organic Acidemias are a group of rare metabolic disorders whereby fatty acids and protein, respectively, cannot be broken down in the body to be used as energy, especially in times of fasting or illness, and are treated through dietary changes and medications. When undiagnosed, severe medical complications and/or death can occur:

The importance of our Family Conference is to allow our members to meet other parents and professionals and learn more about their own or their child's rare metabolic disorder. The focus for this conference is for Families to learn more about the medical management, nutrition and the social needs of caring for yourself or a child with a chronic disorder; specifically those with rare metabolic disorders. On Friday, we will have two separate sessions with our own Speakers - one for the FOD Group and one for the OAA Group and there will be a Friday Night Reception from 6-8pm for Families and Speakers. Saturday we will meet in our separate rooms for networking, breakout sessions, and then finish up jointly with our Professional Panel Question & Answer time.

The conference is a wonderful opportunity for Families to meet each other and have the opportunity to speak with professionals on an informal level. Children are encouraged to attend the Friday night Reception and we offer a variety of snacks and drinks during the Reception. Breakfast and Lunch and snacks are provided to all Registrants on Friday and there will be ONLY Breakfast and snacks on Saturday - the Conference ends at 12 noon. There will be NO LUNCH served on Saturday.

There is NO registration fee for FOD/OAA Family participants for the 2016 Conference - but you will still need to complete an Online Conference Registration Form for each member (age 5 and older) of your family/party attending! If you decide to register using the paper form, please mail the form to Deb Lee Gould, PO Box 54, Okemos, MI 48805. You can register up to 6 persons at one time. Printed Conference Registration Form.

Professionals $50 per registrant (ie, Drs, Genetic counselors, Dietitians etc) - pay via a credit card. One main contact can register up to 4 colleagues. If you decide to register using the printed Registration Form, please mail the form and a check (made out to OAA) to Deb Lee Gould, PO Box 54, Okemos, MI 48805 by June 15, 2016.

Booth Exhibitors do NOT register on this site. Please contact OAA Director Kathy Stagni [mkstagni@gmail.com] for booth fee amounts. All checks will be sent to Kathy Stagni (checks made out to OAA) - Kathy Stagni 9040 Duluth Street Golden Valley, MN 55427.

***ANYONE age 5 and older MUST be registered. All sitters MUST be registered.

This is to provide advance accurate numbers for meal preparations. ***

www.fodsupport.org

'We are All in This Together'
Hotel info & Conference:

**Westin Westminster**
10600 Westminster Boulevard
Westminster, CO, 80020
Hotel Phone: 303.410.5000
Reservations by Phone: 888.627.8448

**Online HOTEL Reservations:** Attendees are responsible for making their own hotel reservations by June 24 to get the lower rate. The Conference rate will also be in effect 2 days before the conference dates of July 8 and 9, 2016. **If you have special requirements (e.g., refrigerator, microwave, crib, etc.) please let them know** when you call to make a reservation. No extra cost for refrigerators. Rooms start at $120 per night (plus tax) - this is the group discounted rate.

Guests can access the **FOD/OAA Conf link** to book, modify, or cancel a HOTEL reservation until **June 24, 2016**.

**Reservations by Phone:** 888.627.8448 and state your reservation is for the FOD/OAA International Metabolic Conference to ensure you are billed at the reduced conference rate.

**Airport:** [Denver airport](http://www.fodsupport.org)
8500 Peña Blvd Denver, Colorado U.S.A. 80249

Here are some links for Transportation options from the airport to the hotel.
- [Shuttle service from DIA to Westin](http://www.fodsupport.org)
- [Metro Taxi](http://www.fodsupport.org)
- [Yellow Taxi](http://www.fodsupport.org)
- [DIA Accessibility information](http://www.fodsupport.org)

**Travel:** Attendees are responsible for their own travel accommodations to and from the conference. Speakers will coordinate through Deb and Kathy for both hotel and travel arrangements.

**Meals:** The hotel chef will be coordinating with us to provide a wide variety of food options for conference meals [Friday Breakfast and Lunch, the Friday night Reception, and Saturday Breakfast (NO Lunch is served) are for all Registered attendees ONLY] to include low-fat and low protein foods to accommodate our families’ needs. All other meals are your responsibility. The online registration form will allow you to make a list of any special dietary requirements needed. The hotel chef will make accommodations whenever possible, but be sure to bring along some of your own favorite snacks etc.

**Child Activity Room:** We will have an activity room for children - however, each family will be responsible for providing someone to supervise their child(ren) (e.g., grandparent/sitters) and those persons must also be registered. We are also looking for local volunteers to help in the room by providing drawing activities, games, videos, etc. Children are allowed in the conference sessions only IF they can do so quietly. Disruptive, noisy children must be removed from the session as a courtesy to all other participants. Older children and teens are encouraged to attend sessions - **every child intending to dine at the conference meals (Friday and Saturday breakfast and Friday lunch and Friday night reception) must be registered. ANYONE age 5 and older MUST register. All sitters MUST be registered.** This is to provide advance accurate numbers for meal preparations.

**Registration Form:** [Online](http://www.fodsupport.org) or by [mail](http://www.fodsupport.org) (the regis form will also be on www.fodsupport.org and [www.oaanews.org](http://www.oaanews.org))

**REGISTRATION DEADLINE - JUNE 15, 2016**

**Printed forms** [and Professional checks made out to OAA] can be mailed to:

**Deb Lee Gould/FOD Group**
P0 Box 54
Okemos, MI 48805 517.381.1940

**www.fodsupport.org** 'We are All in This Together'
I have three stunningly smart and beautiful children, and two of them have CPT 2 deficiency. They were not diagnosed as many children are now, with Newborn Screening tests because testing was not available for FODs in the State of Vermont when my daughter Ariella was born in 2003. When Michael was born in 2005, testing was available, but we later found out that he tested negative.

I recently asked the children to write me a little story about what it is like for them to live with CPT 2 deficiency. Michael said that he doesn't like to get sick because that means he ends up in the hospital and that means getting an IV and having blood draws. He is not a fan of needles. Ariella said it wasn't really that bad. She has to follow a low fat diet and that is okay with her. She wishes her parents wouldn't worry so much when she is sick unless she starts having symptoms. I know she's right, but it's much easier said than done!

Michael was diagnosed at the age of 6 after being admitted to the hospital with a CPK over 83,000. He had been sick for a few days with a fever and a cold. He had a lot of muscle pain, to the point where he couldn't walk well and picking him up to carry him made him cry out. After a while, he was so lethargic he stopped crying out. I brought him to the ER for evaluation. It was by chance that they ran a CPK among the tests I requested. There was a panel of tests I requested to have run because of his pain, as his pediatrician had suggested a few months prior. Michael had had episodes of transient muscle pain when he was playing, ever since he had pneumonia at the age of 4. No one really could pinpoint why he was having the pain. So when we were back in the ER, we repeated the panel of tests. Some of them came back a 'little elevated' and after six hours we were sent home. Two hours later I received a call from one of the pediatricians, saying that Michael's CPK was astronomically high, she thought maybe he had Muscular Dystrophy and we had to get him to Dartmouth-Hitchcock Medical Center, where a room was already waiting for him. Fortunately, MD was ruled out pretty quickly. Although Michael had a lot of pain and needed carrying, he was still strong and passed all the tests for muscle strength. The doctors started throwing around other potential diagnoses: myositis, polymyositis, dermatomyositis, etc. I had my laptop with me in the room and was looking up everything as they said it. I knew they didn't have it right, he didn't have the symptoms. They kept searching. When we arrived, the nurses got a sample of Michael's urine, and it was the color of coke. It was terrifying for me, as a mom and an RN, to see the urine that color and know that something was desperately wrong with my son. His fever kept getting worse but with the test results being what they were, the doctors couldn't give Michael anything more than Tylenol to keep his temperature down. We were using washcloths soaked in ice water and wrung out, laying them on his body to cool him down.

He was on oxygen soon enough, as he couldn't maintain his oxygen saturation on his own. He was later moved to the PICU where they discovered part of his right lung had collapsed. A new doctor started running a lot of odd tests, and by the end of our 8 day stay, we had a presumptive diagnosis of CPT 2 deficiency. We were sent home with a letter to give people in a crisis situation, and set up for follow up appointments. I asked about testing Ariella and opinions were mixed on whether or not she needed to be tested. A year later she finally had her blood drawn and was also diagnosed.

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Today, almost four years later, the kids are doing pretty well. Michael has been in the hospital one time in the last two years for IV fluids but not a full hospitalization. Ariella has yet to be in true crisis, other than an incident at 15 months old that we are investigating. The kids are managed with MCT oil at this time and will hopefully switch to Liquigen soon. Ariella is anxious to participate in clinical trials because she wants to do what she can to help other children like her. Michael has already participated in one trial and we hope to do another one soon so he can be put on Triheptanoin. With MCT oil/Liquigen, and a low fat diet, the kids are thriving. They have much less pain and discomfort. They were having difficulty in school between getting sick and missing classes and misbehaving. Their father and I made the decision to pull them from public school and homeschool them. Now they are excelling in their work and they get sick much less often because they are not constantly exposed to all the other kids’ germs. As Ariella has said, with a healthy diet, they do well.

Vanessa Godfrey  Vermont
I started working out as part of an outlet from my son’s FOD. Since Mikey was diagnosed with SCADD almost 6yrs ago, I have tried many different ways to lose my weight to be healthier. I am now a runner primarily, but started obstacle course racing 3yrs ago as part of my weight loss journey. I have now lost 80lbs! A couple years ago I found Spartan racing.

Spartan has what’s called a trifecta - a Sprint race of 5miles and 15 obstacles, then a Super race of 8 miles and 20 obstacles, and a Beast race of 15 miles and 25 obstacles. These are military type things, climbing 10’ walls, climbing 20’ ropes, barbed wire, fire jumps, etc. I never thought I’d ever even think about attempting it.

Then one day I was on the Spartan race website, and they mentioned becoming an ‘Everyday Hero’…raising funds for a cause. And the FOD Group just happened to be on the list! Then I decided to go for it!

I did the Sprint on a ski mountain in Tuxedo, NY in June. I did the super in Boston, MA in July. Then, I did the beast on a ski mountain in Killington, Vermont in September. That one was 11 hrs, all straight up climbs, and I was sick as a dog. But, I just knew I had to do this for my Mikey bug!!

In November, a friend of mine who saw a flyer for this fundraiser, decided to open his gym for a live fundraiser for Mikey - we had tons of Spartan friends come for the event, some as far away as Philadelphia and NYC to the coast of CT!!! We raised $900 I think that day.

The Total I raised was over $2100.

This helped me bond with my five-year-old, because he became my trainer through the year. He also now knows every workout and move by heart! It’s also gotten him healthier. And, we have tons of support from the local community, at the obstacle course racing community, and rare disease community as well.

So I am now a personal trainer, and healthier, have had an awesome experience, and feel better at 41 than in my 20’s! And in 2016 I now have an obstacle course racing company to sponsor my races! It’s helped everyone, all around.

In 2016, I hope to do a Sk in Mikey’s name, to raise more funds. I am also on the rare disease council for the state of CT, to get the word out. And, I’m starting a class in a couple weeks to become a child advocate, to teach others how to navigate 504s and such.

Thanks everybody for your support!! [Mikey is in the red t-shirt on far right, on his dad’s shoulders!]

Michelle Cotton, B.S. RT(R, M, CT, MRL) ILST CPT CFN
Member, State of CT Rare Disease Task Force
Obstacle Maniac Associate, Obstackerma.com, obstacle course racing
2015 Triports.com sponsored triathlete
Orange Avenue School Community Outreach Chairperson
Personal Trainer and Fitness Nutritionist
203.521.7824 ctmkiki@hotmail.com

What a fitting day to receive our bear and button in the mail. We just got home from seeing her Dietician and Geneticist who say Bekah is absolutely perfect and is the poster child for how well VLCADD babies can do when newborn screening allows for the earliest diagnosis and treatment. I’m so lucky we have a team of doctors who truly care about my little girl.

Lauren Beauchamp

I am excited to announce I created some t-shirt designs to raise awareness about metabolic disorders. Please visit our store on Etsy (Typul) and share with your friends these cool designs. Make sure you indicate which disorder you are raising awareness for or would like on your t-shirt and we are donating $3 for every shirt purchased for metabolic disorders to fodsupport.org. There are six designs so far. Some of these were ones that were recommended in the past but if you have other ideas just let me know I would be happy to create it. You can like us on facebook - just search for Typul. Wishing you and yours good health!

Kelly Schroeder Huber mom to 3 with MCAD ~ 4, 11 and 9 yrs old

www.fodsupport.org

'We are All in This Together'
**Medical Update**

Professionals: Please contact Deb if you’d like to write an article/summary for our next issue. Our Families are really interested in learning what research and/or clinical issues you are working on!

---

**One Good Thing**

Have you ever tried to explain what a fatty acid oxidation disorder is to someone and have them say "Oh, so it’s just like diabetes but with fat!” I have. Frequently. In my head I’m thinking – no – it’s not like diabetes at all.

Diabetes is a disease where the ability to MOVE glucose (a form of sugar in the body) from the blood into the tissues (like into muscle) is impaired. People with diabetes can use the glucose to make energy if it gets into the cell – they just can’t move it from the blood stream into the cell. They also make more glucose in their livers and put that into the blood, which makes their blood sugar high.

With a fatty acid oxidation disorder, you can move the fatty acids into the cells just fine but you can’t use the fatty acids to make energy. In fact some of those fatty acids can come back out of the cells and show up in the fatty acid or acylcarnitine profiles that are measured in blood. People affected by an FOD use glucose very well because with very low use of fatty acids, it becomes the primary energy source in the body.

In fact the conversation about diabetes and FODs might be highly relevant. Type 2 diabetes is rising in the population at an extraordinary rate. There are many factors that increase the risk for developing diabetes like excess body weight, higher fat stores, increased fatty acids in blood among others. Some people with a FOD have these factors but so far, the risk of developing type 2 diabetes among people with a FOD is very, very low. A mouse model of VLCAD is less likely to get diabetes than a comparable mouse without VLCAD[1]. This led us to think that maybe people with a FOD are less likely to get diabetes than the general population; that people with a FOD may be protected from developing diabetes. That’s a good thing. We are currently recruiting people to test that idea. If you are over 18 and have VLCAD, LCHADD, TFP or MCAD and are interested in participating, send us an email or give us a call.

Muscle pain, lethargy, recurrent rhabdomyolysis are constant realities of living with a FOD. Maybe one good thing is a lower chance of developing of diabetes.


Melanie B. Gillingham, PhD, RD
Associate Professor Oregon Health & Science University Portland, OR
gillingm@ohsu.edu

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**Dr Charles Roe**, our very 1st Medical Advisor, has recently co-written an article summarizing 15 years of his research – *Anaplerotic treatment of long-chain fat oxidation disorders with triheptanoin: Review of 15 years Experience*

It is also listed on PubMed. Dr Roe has retired from his practice.

---

**RESEARCH Open Access**

Clinical and genetical heterogeneity of late-onset multiple acyl-coenzyme A dehydrogenase deficiency

Sarah C Grünert

Mitochondrion-toxic drugs given to patients with mitochondrial psychoses

Josef Finsterer
Medical Update...continued

The Genetic Metabolic Center for Education (GMCE) has a multi-faceted educational focus - we aim to advance a mission "to improve access to quality care for children and adults with inborn errors of metabolism, GMCE is dedicated to developing practical, symptom-based, and specialty-relevant services and programs for all members of the metabolic community." This mission also works toward seeing 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 provides 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 are made available through technologically-advanced communications and distance learning.

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

GMCE provides a depth of educational resources to expand availability of physician training in topics related to the care of metabolic patients. These services are 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.

The newly formed GMCE is increasing awareness about metabolic disease among those in the medical community, including: clinicians, health professionals, medical students, and post-graduate trainees.

Contact Info: 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

This is Sara Khangura writing from the Canadian Inherited Metabolic Diseases Research Network (CIMDRN) at the University of Ottawa. I’m writing in follow up to our telephone conversation last year during which you [Deb] participated in a research interview regarding child and family experiences with inborn errors of metabolism (IEM).

The important contributions that each of you made to the study have been analyzed, summarized and reported, and as discussed, I’d like to share those results with you. Firstly, in the past couple of months, we’ve had the opportunity to share the research findings at two conferences: 1) the American College of Medical Genetics meeting in Salt Lake City, and; 2) the Canadian GENLS and Health Services & Policy Research Conference in Vancouver. The poster summarizing results can be viewed here.

In addition, the results have been published in the Journal of Inherited Metabolic Diseases (JIMD) or pdf.

Once more, and on behalf of myself and the study investigators, I would like to thank you for your valuable time and dedication to advancing an understanding of the experiences, challenges and priorities of children and families affected with IEMs. For information on CIMDRN, its program of research and other studies, please visit our web site at www.cimdrn.ca. For questions and/or more information, please feel free to contact myself (khangura@uottawa.ca) or CIMDRN’s Principal Investigator; Dr. Beth Potter (bpotter@uottawa.ca), anytime.

SundayReview | OPINION
The New Child Abuse Panic
By MAXINE EICHNER
JULY 11, 2015

2015 Research Article: Kupffer cells modulate hepatic fatty acid oxidation during infection with PR8 influenza
Medical Update...continued

Research Update from OHSU

Triheptanoin: There continues to be ongoing research on the benefits of Triheptanoin, an odd-carbon medium chain triglyceride, for patients with long-chain FODs. Two recent publications suggest a positive benefit of triheptanoin for hypoglycemia and cardiac function [1, 2]. We recently completed a large clinical trial of triheptanoin compared to MCT. Thanks to all who participated! The results are being analyzed and prepared now. As soon as they are complete, we will let the FOD Family Support Group know. Stay tuned!

Retinopathy of LCHADD: We have an active research program to develop a treatment for LCHADD retinopathy and we are making some great progress! Thanks to hard work and support from many dedicated families, we have funding to devote more time and resources to this effort. Right now we are working on developing an LCHADD retinal cell culture model and testing novel treatments in these cells.

Thanks to all who participate in our clinical studies and who help with funds to support ongoing laboratory studies. We are excited about new treatments on the horizon for FODs.

Melanie B Gillingham PhD, RD
Cary O Harding, MD
Oregon Health & Science University
Portland, OR
gillingm@ohsu.edu


Research Summary:
Correcting VLCAD enzyme activity by s-nitrosylation

Basic research in the laboratory of Paschalis-Thomas Doulias at the University of Pennsylvania identified a novel VLCAD protein modification by nitrous oxide that dramatically increased the enzyme activity in normal skin fibroblasts.

In a recent follow up study applying fibroblasts from four patients with missense mutations (simple amino acid changes) in VLCAD and VLCAD deficiency, Dr. Doulias and coworkers were able to correct the defective activity and acylcarnitine abnormalities by this process known as nitrosylation. This is a proof of concept study that is not yet ready for prime time patient application but generates future potential therapeutic approach using a very simple strategy. The process is unlikely to work in patients with the more severe mutations as it does require that some protein is present for the nitrosylation process to work.


Michael J. Bennett PhD, FRCPath, FACB, DABCC
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Evelyn Willing Bromley Endowed Chair in Clinical Laboratories & Pathology
Chief, Division of Laboratory Medicine
Director Clinical Chemistry & Metabolic Disease Laboratories, The Children's Hospital of Philadelphia
5NW58, 34th Street & Civic Center Blvd
Philadelphia, PA 19104
bennetttmi@email.chop.edu
NUTRITIONAL UPDATE

One of FOD parents, Kayla, has created a website called eggwhitesonly.com, and it's primary focus is to provide a trusted resource of low-fat recipes for a person with a Fatty Acid Oxidation Disorder. They are on Facebook too.

“My name is Kayla. My son was diagnosed with LCHAD (a type of Fatty Acid Oxidation Disorder) when he was two weeks old. When Owen was a couple months old, I ventured out on my own and headed to Barnes and Noble. This trip was supposed to eliminate my underlying fear and guilt that I didn’t know how to cook one single meal my son could have. I had done a little research online but was disappointed with the results. This is why I was so excited about getting my hands on some low fat cookbooks and realizing I could do this! Instead, all I found was one heart healthy cookbook with low fat in the subtitle and although the recipes were low fat, they were not ones my son would be able to eat for a very long time. I was heartbroken. All I could think about were holidays and family wanting to cook food he could eat. And what about down the road when he has a girlfriend and her mom wants to make dinner for him? And what about me? Where was I supposed to find these super low fat recipes he could have?? I just stood there staring at all those depressing fat filled cookbooks and cried. My tears turned to determination and I knew I needed to do something. So the journey began.

I decided on creating a website that could host all the recipes our kids can have. I wanted it to be community driven and have the ability for the user to rate, comment, submit their own recipes AND search recipes based on fat per serving. I’m proud to say this website can do all those things. We’ve collected recipes from websites, blogs, low-fat cookbooks, genetic dietitians, moms and families from across the world. Trying to figure out what to feed our kids shouldn’t be this hard, and now, it doesn’t have to be.

My hope is that this website provides comfort for newly diagnosed families as well as a useful tool for FODers of all ages. If your family is anything like mine, cooking food together is a major joy of the holidays. I hope these recipes give your hesitant family members the courage to try a new recipe and help create memories that will last a lifetime. You are not alone in this journey and we’re here to help you any way that we can. Happy cooking!”

VitafloUSA has a new whiteboard video that explains using MCT Procal and mixing it in various liquids, as well as cooking with it. Also refer to their MCT Procal Recipe Guide.

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SPECIAL FAMILY ARTICLES
from those that live in the
FOD/Metabolic/Mito world!

‘Munchausen Syndrome By Proxy: A Plea for Patience & Objectivity’


Rachel Ragosa is an attorney and freelance writer based in San Diego, CA. With experience in family, civil, and business matters, she provides a unique prospective on a variety of topics that impact the healthcare community.

‘Preparing for Emergencies: Sweat the Small Stuff, Lead the Way to Empowerment via mitoaction’

By Julie Gortze RN, MitoAction New England Support Group Coordinator

Love

Please remember our Families in your thoughts and prayers throughout the year...

‘My son, Andy J Perrino (adult GA2) lost his longtime battle with illness July 26, 2015. The last 6 weeks were the best in a long long time he said. He was able to spend more time with his daughter, he golfed, he swam and he began to work. He was the most courageous man I will ever know!! His fight for life was phenomenal. I will love you ALWAYS Andrew!’ mom, Julie Perrino

‘Walk on, walk on
With Hope in your heart
And you’ll never walk alone’

~ Rodgers and Hammerstein, Carousel ~

www.fodsupport.org
Guest Article: Fatty Oxidation Disorders and Disability Benefits

The body's first source of energy is glucose or blood sugar, but once blood sugar has been used up, the body relies on the metabolism of fat to fuel all kinds of essential operations. Infants and children with Fatty Oxidation Disorders (FODs) have a genetic dysfunction in the breakdown and processing of fat for generating energy. This in turn can lead to all sorts of health complications in various body systems.

Many children with a FOD are diagnosed early and successfully treated. Rarer forms of the condition can develop later and may not be caught as soon. If a child experiences any long-term or lasting health complications from a FOD, he or she may qualify for disability benefits from the Social Security Administration (SSA).

SSI Eligibility Rules

Supplemental Security Income, or SSI is the disability program under which infants, children, and teens most often qualify. This is a need-based program, which means children must meet both the medical and the financial eligibility rules in order to receive benefits.

- Basic medical eligibility requires a child has a formally diagnosed and severe disability that will significantly disrupt normal, age-appropriate activities for at least one year.
- Financial qualification for the program requires the SSA reviews the income and assets of the child and his or her parents or legal guardians.

Although the financial rules for qualifying may exclude some disabled children from receiving SSI, many kids are able to get benefits. The SSA only counts some household income and assets and also only assigns a percentage of those monies as available to the child. This means many children qualify for SSI despite strict rules governing income and assets.

Medically Qualifying for Benefits

In addition to meeting the basic technical eligibility requirements, children with FODs must also qualify by meeting or closely matching a listed disability in the SSA's Blue Book manual. There is no FOD listing, but the SSA will review applications under the body system that is most seriously affected by an infant or child's FOD.

FODs cause a range of symptoms and can result in serious health issues, including:

- Low Blood Sugar
- Muscle pain, weakness, and spasms
- Digestive complications
- Liver problems
- Heart complications
- Breathing issues
- Brain damage
- Seizures
• **Anemia**

• **Intellectual disabilities**

The Blue Book contains hundreds of listings for recognized disabilities. It is written for medical professionals and for technical use by the SSA though, which means it can be difficult for the average person to understand listing details and necessary medical documentation. Work closely with your child’s doctor to understand whether your child may qualify and under which listing he or she is likely to match the SSA’s eligibility requirements.

You can find the full Blue Book available online [here](#).

**Qualifying Without the Blue Book**

If your child cannot meet a Blue Book listing, he or she can still qualify for disability benefits. This can be done by showing that your child cannot perform any Activities of Daily Living (ALDs). ALDs are things that your child does every day. Some examples of ALDs include:

- Feeding herself
- Getting dressed
- Using the bathroom
- Playing with other children
- Understanding and listening to adult instructions
- Having good hygiene

If your child has difficulties with ALDs, he or she can still qualify for SSI benefits. Be sure to speak with your doctor about whether or not your child can qualify. You will need to have your pediatrician fill out a Residual Functional Capacity assessment (RFC), and you can also discuss what your child is limited to based on his or her FOD on your application. It is important to fill out an RFC and your application as carefully as possible. Leave no questions blank, and write on additional pages if necessary to describe exactly how your child is affected by a FOD.

**Applying for Benefits**

To apply for disability for a child, you must participate in an interview with an SSA representative. This can be done over the phone in some case, but most interviews take place at a local SSA office. Either way, you should be prepared to provide details of your child’s medical history and your financial situation. The SSA will additionally need contact information for all medical professionals that have treated your child so they can get copies of your son or daughter’s medical records for review.

**Deanna Power**  Boston, MA

[Please Note: Deanna contacted me about writing an article specific for FOD Families. It has some valuable information but due to the page constraints, not all info on SSI was included. Some Families have also checked out early childhood intervention sites for their states and have had a better chance at being accepted versus SSI - [http://ectacenter.org/contact/ptccoord.asp](http://ectacenter.org/contact/ptccoord.asp)]
Reach for the Stars!

Rosemary Forrest, (grandson Matt, CPT2, 13 months) is writing a reference book on FODs that will be of use to both families and their pediatricians or family practitioners. She would like to interview willing family members of the various FODS for inclusions in the book. She would also like to hear from anyone what they believe should be included in such a book.

The book proposal is available online at https://publishizer.com/fatty-acid-oxidation-disorders-and-you. Rosemary is a retired science writer and will be assisted in this effort by Nicole Baugh, a scientist at HiRISE, the group that studies Mars. Your privacy will be respected and your name need not be used if you do not want it used. Contact Rosemary directly at razz51@gmail.com.

I’m officially on the advisory committee for the first rare disease council for the state of Connecticut. Only the third state to do such a thing. History is being made slowly!!!

Michelle Cotton

Hi there!! I’ve been appointed Parent Rep for the Genetic and Metabolic Disease Advisory Committee for the state of Illinois this year too!! Congratulations and good luck!!

Celia Teresa

Welcome to New Babies!

She was born on LABOR DAY;

Peyton
Sept 7, 2015
4:26AM
10lbs 9oz 😳
21.25 inches

Sister to Alexis (both MCADD)
Heather Little New Hampshire
**Someone Special ~ Uniquely Personalized Books**

From their site - “Choose a book from one of our Special Needs categories including Autism, ADHD, food allergies, Down Syndrome, Epilepsy, physical conditions, Diabetes, hearing and vision impaired, and neurological conditions. You can also personalize a story for any child wanting to go on a special adventure by choosing “Someone Makes a Friend.”

**Do It For The Love** is a global nonprofit wish granting foundation that brings people living with life-threatening illnesses, children with severe challenges, and wounded veterans to live concerts. Through the healing power of music, our goal is to inspire joy, hope, and lasting celebratory memories in the face of severe illness or trauma.

**Unique Opportunity for College age students affected by a mitochondrial disorder ~ Cooper Open Scholarship**

[This is a very competitive scholarship process - this was a Facebook post I recently found]

- To raise Awareness about Mitochondrial Disease and how it affects individuals and families in different ways:
- Mitochondrial Disease can be an invisible disease. Thus, since people do not ‘see’ your illness, they often do not understand. Mito families are always advocating with school systems, insurance, and the medical community all of whom may not understand the chronic illness and the patients needs.
- To help the Cooper Family cope with their daily struggles with Mitochondrial Disease and help lessen their challenges.
- To develop a scholarship fund for young adults with Mitochondrial Disease so they can attend college:

Young adult Mitochondrial patients have unique medical needs which can make attending college in a “typical” fashion difficult. Most scholarships require a specific amount of credits taken each semester in order to receive the funding. This scholarship fund would need to take their specific medical needs into consideration vs. requiring certain class load. That way, if the patient needs to take only two classes a semester, they can.

The Cooper Open will also work with MITO ACTION to promote the scholarship developing its potential in years to come, as the need is great.

Unlike medical evacuation insurance, our members are not hemmed in by preexisting conditions, service territories or restrictions on the amount or type of travel they take. The cost of a medical evacuation can range from $10,000 to $25,000, while international evacuations can cost $100,000 or more.

With MedjetAssist, if you are a member and become hospitalized more than 150 miles from home, we will get you from that unfamiliar hospital all the way home to the hospital you trust. And all you pay is your membership fee.”

www.fodsupport.org    'We are All in This Together'    page 16


Thank you to all that have bought products from companies on the Internet that support the amazonsmile, iGive, GoodSearch and GoodShop, and Cafepress.com programs of donating a certain percentage to Groups like ours. All of those links are on our website.


We greatly appreciate donations to help with daily costs, website fees, supplies, Conference costs, phone calls around the world, rent for Grief Consult office, and raising funds for FOD Clinical Training & FOD research and long-term investments. ALL donations go toward FOD efforts & programs.

**US checks can be made payable to the 'FOD Group' and mailed to:**

**FOD Group** PO Box 54 Okemos, MI 48805

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.

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The 2015 FOD Group 990 tax return will be on our Financial page by May 2016

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.

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. No FOD money is used for salaries - we are an ALL Volunteer organization.

Additionally, we have 1yr & 3yr certificates and long-term stocks/bonds earning interest and dividends for future FOD endeavors and programs.

**2015 FOD Donations & Expenses**  **2015 Balance of ALL FOD Accounts**

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**Families and Professionals...**

Please send all Submissions to Deb by June 15, 2016 for the July 2016 Newsletter! We are always looking for Family Stories, Professional Research and Clinical summaries, New Babies and KidsKorner pics etc. Also keep spreading the word about FODs and expanded Newborn Screening ~ it could save a life!

As we express our gratitude, we must never forget that the highest appreciation is not to utter words, but to live by them.’

~ John F. Kennedy ~