From the Editor

I hope everyone had a very special and healthy holiday season and Happy New Year to ALL! It’s so hard to believe that we are beginning a new year already.

Last year was extremely busy with our July International Metabolic Conference in Minnesota so this year should be a bit quieter ~ although we hope to increase our exposure and create awareness of the various FODs via social media and Facebook and other Family Fundraisers. It really takes ALL of us to be proactive and persistent in regard to spreading the word about our rare disorders. If you decide to do a Fundraiser please be sure to share that info with me so I can place the donations in the Fund you would like (ie., General, Research, or Clinical Training).

Kathy Stagni (OAA Director) and I have had some discussions about future joint Conferences ~ please refer to my Editorial on the next page. We are having to make some difficult decisions and we hope all of you understand where we are coming from. AND also help us focus on where we can go in the future and how we might get there as a Group.

As stated in previous Newsletters and in the facebook Group, I am also looking for someone to help with the 2x/year Newsletter (Jan & July) ~ I have the main template on Pages for mac (most up-to-date format) so if you’d like more info or help let me know!

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
EDITORIAL

After much deliberation and talking with OAA Director, Kathy Stagni, we have decided to take a break from a Conference in 2020. This very difficult decision was based on several factors ~ that both of us have been running these Conferences for many years and we feel it’s time to pass these responsibilities on to some committed members, as well as the high cost of running the events! I am getting some interested members in helping with specific tasks, but not anyone that is willing to fully commit to taking over the entire Conference. And that also includes picking up all of Kathy's tasks ~ over the years we have divided the various tasks between us so neither of us would have to do everything. Well, now we are in a position that we WILL have to do everything. At this moment in time, I do not feel we have what we need in order to take that great task on.

However, I am exploring some other options so our Families can still network and share their triumphs, challenges, and if possible, hear expert information about our disorders. It would not be as difficult to plan or as extensive as a 2-day Conference, but it would still be wonderful to have Families connect with each other and share experiences. Yet it still means we NEED VOLUNTEERS!

One possibility is to have some local Families volunteer to setup and host a Regional FOD Family Meet-Up for a half day/day at a local hospital, hotel, restaurant, community center or other facility (possibly for no fee or a low fee). For 2020 we may try this concept in 2 cities across the US on different dates, say for instance Pittsburgh or Boston and then possibly Portland. These are cities where most of our FOD Research is being done and we do have some of our experts there.

I found some very good resources on the mitoaction.org site that would be very helpful to those Families that might be interested in planning one of these meet-ups. Please refer to mitoaction’s Social Playbook for Guide on Hosting.

I would give some funds to help with the cost of catering a lunch in and for xeroxing etc., but that would be determined after we know how many would be interested in coming. We would have a registration process. However, the Host Family would need to run the whole meet-up. I may or may not actually be present. It could strictly be a networking event and/or a local Speaker or Speakers can be asked to attend and share their expertise.

I am also exploring cost effective videotaping programs/softwares so we can then share with others in the Group that cannot attend the meet-up (ie., zoom or webinarjam). So if anyone is familiar with these or has other suggestions for filming our meet-ups PLEASE contact me.

So please think about ALL of the above and share your comments/suggestions in our closed facebook or google group. ~ DLG
In 2014 our first child, Henry, was born. After he became very sick at 48 hours old, we began the roller coaster journey of having a child diagnosed with a rare and life threatening disorder. Henry was diagnosed with LCHAD Deficiency when he was around 2 weeks old.

Overwhelmed, I searched online for support. That's how I came across the FOD Family Support Group - a lifeline for us! And also how I came across the Children’s Medical Research Institute.

CMRI is a fundamental medical and biological research facility in Sydney, Australia. One of our metabolic doctors moved on to become the head of the gene therapy research unit at CMRI. We wanted to know how we could help families like ours in better treatments and possible cures for FOD disorders.

In 2018 we were invited to be a part of the national campaign, Jeans for Genes Day, and represent metabolic disorders. My son Henry, who has only just turned 4, was a part of a television advertisement showing children with genetic disease and asking people to ‘fight with them, fight for them’ and raise funds for CMRI and their vital research. His cheeky smile and lovely personality shone through.

What an amazing opportunity! Henry was on TV, billboards, posters, magazines and newspapers. We shared our story and spoke about LCHAD Deficiency to a national audience. I was invited to speak at fundraising events and was able to tell our story and spread awareness of FODs.

Having Henry diagnosed with LCHAD deficiency was life changing for us. The grief and confusion, the questions about his future, they are a big part of the journey of having a child with a rare disease. To be able to be involved in Jeans for Genes day to support CMRI was empowering, exciting and humbling. It connected me to other Australian families living with FOD as they came across our story in the media. Henry gained amazing confidence seeing himself in a campaign celebrating his resilience and bravery.

The main thing this experience taught me, was to use my voice. So many people want to listen and there are organizations that want to support research into better managements and cures for FOD. We are proud to be a part of the FOD family and we will always advocate for research, better treatments, and possible cures.

Jessica Gowans
Surviving Inborn Errors of Metabolism with Diet: Multiple Acyl CoA Dehydrogenase Deficiency

By: Gwen Abele
First printed online in Hormones Matter Aug 29, 2018

For DES Daughters, Conception and Pregnancy Are Difficult

My first pregnancy, now 30 years back, was difficult. I am a DES daughter and after years of trying to conceive naturally, we tried in-vitro fertilization (IVF), which was pretty new at the time. The first IVF attempt led to a miscarriage. The second IVF attempt was successful and I gave birth to triplets. The pregnancy was difficult. I was on bed rest throughout the pregnancy and in hospital from week 26 through 30 when the babies were born prematurely. Although they were preemies and had to stay in the NICU for five weeks before coming home, they had few problems once they were home. They were all good nursers after they developed the sucking reflex at about thirty two weeks of age – two weeks after delivery. I nursed all three of them for the first six months and when they went onto solids they were great eaters.

A Miracle Baby but Something Was Wrong

Fast forward eight years, I became pregnant naturally. Something I NEVER in the world expected. This baby was such a miracle. To my surprise, the pregnancy was normal. I delivered what appeared to be a healthy baby boy via c-section. Early on, however, it became obvious that something was wrong.

My son, Austen had no interest in breast feeding and although the nurses said it was not an uncommon thing for a baby not to eat for the first few days. I remember being very concerned about his crying. Since, I had c-section, I stayed on at the hospital to get back on my feet. Austen wailed like only a hungry baby could. When he was taken from my room so I could get some rest, I could hear his cries in the little nursery down the hall, louder than all the others. The second day was like the first. Now I was worried. The staff seemed indifferent. He still wouldn’t eat and he was clearly unhappy.

That evening lying next to my bed in his little bassinet, his wailing forced me to get out of my bed to pick him up. The nurses were all busy and because it was a Friday there were a lot of visitors, noise, and rejoicing the birth of all the new babies.

Once I got Austen settled in my arms and I was comfortable, I tried once again to nurse him. Nothing. His crying turned to a sound that a little kitten would make. The light was low and I held him and tried to soothe my sweet little man. I don’t know if I fell asleep or we both became one again and my breaths were his and finally he was at peace. Suddenly my dream turned into a nightmare. I stroked his head and it was cold. I called his name and he didn’t move. I screamed at the top of my lungs for help and my baby didn’t flinch. I recall screaming forever until the room was full of people and lights and the hallway was silent. Austen was a strange blue color. They took him away and I knew he was dead and I still kept screaming.

My writer’s block is kicking in. This is where I always stop the scene running in my head. I can’t keep writing because I feel sick and clammy and the tears make it hard to see. I need to finish this story because maybe it could have a happy ending.

Austen was eventually revived. The nurses said he was without oxygen for twenty minutes. I think it was longer because no one came to my room to tell me anything and I was very hoarse from wailing. He was transported by ambulance to New England Medical Center, (also known at the time as The Floating Hospital for historical Boston reasons), where he was stabilized from the seizures and put under oxygen. Once again I had a baby hooked up to wires and tubes, but there was no excitement this time. He had suffered serious brain damage and on the third day of his stay in the NICU. I was asked to sit down with the doctors who had been following him.

The Diagnosis: Multiple Acyl CoA Dehydrogenase Deficiency (MADD)

Dr. A, the metabolic doctor who had been spending a lot of time with him, told me that he had a serious genetic defect. She called it Glutaric Acidemia type II or otherwise known as Multiple Acyl CoA Dehydrogenase Deficiency (MADD). She told me that it was a fatal disease and explained...
that he could not metabolize fats or proteins. She said that no other child born with this disease had lived for longer than six to eight months. She was patient with me when I cried. She said that she wanted to send a muscle fibroblast to a doctor in Iowa who would confirm the disease. She said that he could be brought home once he was taken off the tube feeding him through his nose and suck on his own. He should be given the best life possible in the next few months. It was “best not to resuscitate” should he stop breathing again, because of all the damage that he had already sustained. He was not to drink breast milk, too much fat and protein, so he needed a special formula.

The Power of a Mom Fighting for Her Child

Up to this point, I was in shock and depressed and felt very alone and defeated. But as I spent days with him watching as he came out of his long sleep and when he finally looked up at me and took formula from a bottle, something changed in my attitude. On the day we were told we could go home I became an angry, assertive woman, a person I had never been in my whole life. I demanded an apnea monitor to have at home in case he stopped breathing. I insisted that I would breastfeed him and I didn’t want the formula. After all if he was to be given the best life in six quick months, shouldn’t he be allowed to breastfeed?

He went home and I pumped and he learned how to nurse. I got in touch with the FOO (Fatty Oxidation Disorder) Family Support Group and the Organic Acidemia Support group and got a home computer. Austen grew. He gained weight and I became more determined not to let the diagnosis defeat us. We got the confirmation from the fibroblast that he had “2% of controls… as low as enzymes get.” It was a mitochondrial disease and there was no cure except to continue with the carnitine and B2 supplements that were supposed to sustain him.

I read Dr. Andrew Weil’s book, “Spontaneous Healing” and was particularly affected by the chapter that addressed malfunctions in DNA. He says that it can be reversed through diet especially by ingesting natural enzymes. I changed my diet radically after going to see a naturopathic doctor who put me on a meat-free, dairy-free diet which included mostly raw fruits and vegetables and whole grains, (both Austen and myself still follow this diet). I didn’t stop there, I sought out a Native American shaman, a Catholic priest who was a faith healer, a chiropractor… and a second opinion from another metabolic doctor.

A New Doctor and New Hope

From the first time I met Dr. K, I knew that we would be in good hands. He believed in treating Austen the individual, not the disease. His approach was much more hopeful and that is what I needed to keep going, especially since I was a single parent at this point. He marveled at his weight gain and cognitive abilities. He was delayed but he seemed to be progressing. The one concern was that his head circumference had come to a halt. Dr. K prescribed CoQ10 and in the next few months after starting it, his little head started growing again. Although he is still considered to be microcephalic.

When we started with solid foods each meal was traumatic, because he would throw it up from reflux. I had to clean up the mess and start all over again. I knew if he didn’t eat we would end up in the ER. He came to recognize that he had no choice in this food business, he had to keep it down!

I weaned him very gradually off of the barbiturates that he had to take for seizures and he has never had another one since. Early on I recognized that Austen had a severe visual impairment and hooking up with Perkins School for the Blind got us involved with the infant toddler program, preschool, the ‘Lower School’ and last June he graduated to the ‘Secondary Program’. Social skills, PT, OT, sensory integration, mobility, music therapy, gym, arts, swimming and of course academics are only part of the total program. We had a skilled health care clinic on the grounds and were very lucky to live so close to the school and be part of this wonderful community.

Surviving Genetic Errors of Metabolism Through Diet

Today, at almost 22 years old, he is of normal height and weight, a handsome devil who is devoted to his older siblings, Nathan, Sasha and Taylor, and his loving stepfather, Joe. It has not been an easy road. We have had many bumps and starts. He stopped sleeping, (night and day) at about age three. Several trips to the ER after a vomiting bouts, severe sinusitis and airborne allergies, incontinence still to this day, but we persisted.

He has many food allergies which have been hard to decipher since he can’t really tell us ‘where it hurts’ and displays his discomfort through tantrums or negative behavior. Although once we got the nuts, legumes and lentils, etc., out of his diet, we have seen much less confusion and better spirits. The change in diet and recognizing that his behavior was on the autistic spectrum, (and getting the diagnosis of Asperger’s syndrome), has afforded me with much more knowledge of how to help my son deal with this world that he doesn’t really understand, and help others to understand his world. He is about to graduate from the Guild School for Human Behaviors where he has learned so much about how to express himself and keep his meltdowns to a minimum.

I feel strongly that the choices I have made for my son have been the right ones, but I could not have done it without the help of all the wonderful people I have met along the way, who now share a part of Austen’s world. Without them, I might not have made some of the connections that have made such a big difference in the quality of my son’s life. I cannot stress enough how important diet has been. The physicians in the NICU suggested that he would not live beyond 6 months and that we should not resuscitate should he stop breathing. I ignored them and with diet and persistence, he has lived and we have loved him for 22 years.
This summer the Harry Crew took a road trip from Atlanta, GA to Minneapolis Minnesota and then onward to Lake Superior! It was our first big road trip together that wasn’t to visit family and we stopped at several state parks along the way, and saw beautiful landscapes, boulders, and water. After all of our adventures, what does Christopher talk about the most? Where does he keep bugging me to go back? “Mom, when can we go back to the Embassy Suites Hotel?”

Yeah, sure, there was a pool, he got to watch soccer on a big screen, and he even got to eat something more than fruit at the continental breakfast (which is rarely the case). But the zinger was that the FOD Family Support Group conference was there and for the first time, that he can remember, Christopher was able to connect with kids his age and older with FODs.

This year at the conference, while the adults were learning about the latest research, and seeking to support each other through stories, their children were given the opportunity to do the same thing…in their own way. We had two sessions for youth.

The first day we learned about our body: how it functions, how it metabolizes the food we eat, and how cells break down fat for energy in the mitochondria. Our second day we did a science experiment discussing rhabdomyolysis (muscle breakdown) and then nine kids partnered up to role-play asking questions of doctors; confidently!

What touched my heart more than anything was watching Christopher connect for the first time with Luke, an older youth with LCHADD. I’m not sure that they had super deep conversations about living with LCHADD (although perhaps I shouldn’t put anything past my 10 year old son), but Christopher enjoyed getting to spend time with him so much! A space was created…a kind of space he hasn’t had before…where LCHADD existed outside of himself and his experience…and perhaps for a moment having LCHADD, counting fat, taking MCT oil, monitoring exercise; was a norm. Christopher came back after playing cards with Luke Saturday afternoon and said, “It’s cool to have LCHADD!” The door was open for him not to feel alone in this journey, and I still tear up thinking about it.

The conference plays an important role for every family who has a child with an FOD. It creates space for clinicians to disperse new information, while inviting families to ask questions and seek understanding. There is a tremendous feeling of support as you share your stories and listen to others. These stories are also helpful for the clinicians to hear because when you deal with rare inherited conditions sometimes overlap of symptoms are noticed for the first time in environments like these.

Thank you to Deb Gould and all of the volunteers that help organize this conference! And thank you to the clinicians and families that take the time to come! **Conferences like these are extremely expensive to put on!**
HELP US TEACH PHYSICIANS ABOUT FATTY ACID OXIDATION DEFECTS

FACT! Teaching about metabolic diseases in medical school and residency programs is poor.
FACT! Most patients live and die without a diagnosis being made, especially when the disease presents in adulthood.
FACT! Patients cannot access effective therapies unless a proper diagnosis is made.
FACT! The sooner a diagnosis is made and treatment begun, the better the outcome.

WE NEED YOUR HELP!

We at VMP Genetics believe in the power of “patient-teaching” and are bringing patients and families into lectures and presentations – at conferences and in the classroom. While doctors teach facts, patients tell stories. Story-telling is a more compelling teaching method with better recall over time than didactic lecturing. We also believe that doctors are more likely to make a diagnosis if they have already seen a patient and heard her/his story. Story-telling can be live or taped...

WE ARE LOOKING FOR...

* Patients and/or family members who are interested in telling their stories in local medical classroom settings… We are developing a Patient Teacher Registry. If a medical school faculty member is looking to introduce the patient story in a teaching session, the Registry can tell him/her if there are patient-speakers in the area and what diagnoses they have.

* Patients and/or family members who are interested in having their stories videotaped… As we secure funding, we are interested in recording stories that reflect the broader patient experience. The more variety in the stories, the richer the learning potential.

* Videos of patients and families telling their stories… A 5-or 10-minute clip can be downloaded into a lecture about that disease or relevant biochemistry to enhance the learning potential of the session.

Please help us in our efforts to raise awareness about Fatty Acid Oxidation Defects through this innovative educational outreach to the medical community. For more information about this project… please contact Jacob Athoe.

Mark Korson, MD
VMP Genetics
Director of Education
Voice: 404.793.7800
Fax: 866.744.5665
www.vmpgenetics.com

Jacob Athoe
Mark Korson, MD
VMP Genetics
Director of Education
Voice: 404.793.7800
Fax: 866.744.5665
www.vmpgenetics.com

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www.vmpgenetics.com

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Fax: 866.744.5665
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Fax: 866.744.5665
www.vmpgenetics.com

Mark Korson, MD
VMP Genetics
Director of Education
Voice: 404.793.7800
Fax: 866.744.5665
www.vmpgenetics.com

VirtualMedicalPractice, llc
5579 Chamblee Dunwoody Rd, Suite 110, Atlanta, GA 30338

www.fodsupport.org

>All in This Together"
Fatty Acid Oxidation and Insulin Sensitivity

Research Opportunity for patients with FAODs

A new study looking at the effects of fatty acid oxidation disorders (FAOD) on insulin sensitivity is being conducted at OHSU. Some types of FAODs may protect people from developing diabetes and we wish to explore this with further testing and see if it has implications for people without FAODs. If you have MCAD, VLCAD, LCHAD/TFP or CPT2 deficiency and are 18 years old or older, you may be eligible to participate. Participants must come to OHSU and stay at the Clinical Research Center for 3 days and two nights on two different occasions about 4 months apart. Travel to OHSU is covered and you may receive up to $1025 for completing the study.

For more information, please contact
Ashley Gregor, M.S. at (503) 494-5313 or gregora@ohsu.edu
Melanie Gillingham, Ph.D. at (503) 494-1682 or email gillingm@ohsu.edu

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www.ohsu.edu
Articles of Medical Interest

- **Primary Mitochondrial Disease and Secondary Mitochondrial Dysfunction: Importance of Distinction for Diagnosis and Treatment**
  Niyazov D.M. · Kahler S.G. · Frye R.E.

- **Evaluation and Treatment of Patients with Autism and Mitochondrial Disease**
  Richard I. Kelley, MD, PhD
  Division of Metabolism, Kennedy Krieger Institute
  Department of Pediatrics, Johns Hopkins Medical Institutions

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

- **Biparental Inheritance of Mitochondrial DNA in Humans**

- **State-by-state coverage of Medical Foods**

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**Invitae** is also sponsoring our **FOD REGISTRY** ~ it was created to build a comprehensive de-identified database of children and adults living with a fatty acid oxidation disorder

---

**We’ve lowered our patient-pay panel price to $250.**

Invitae’s mission is to make high-quality genetic testing affordable and accessible to everyone who needs it.
Get paid for your opinion and benefit FOD at the same time. Patients (14 and older) and Caregivers (family, friends) of any disability, disorder, syndrome, disease or condition are provided an opportunity to voice their opinions through surveys and interviews to improve medical products and services.

Join the community on-line and earn a Dunkin Donuts, Starbucks or CVS gift card. We receive $5 for each qualified signup. Refer others and we will benefit each time. Your information is confidential, and your email/name is never shared. You may be invited to participate in surveys from time to time, where you will earn cash.

Click on this link and join today! Fatty Oxidation Disorders

**KidsKorner**

Please think about sharing your children or adult self pictures for upcoming issues ~ email them with name, age, disorder, state/country to Deb

Adam (LCHAD) visiting Katie (LCHAD) in Ireland!

MaKenna
1 yr old
MCAD
Nevada

Sadie
2 ½ yrs old
VLCAD
New York

www.fodsupport.org
When someone you love becomes a memory… the memory becomes a treasure.

~ Unknown ~

We have had some deaths over this past year in our FOD Family…

Please remember our Families in your thoughts and prayers throughout the year ~ All of our FOD children and adults will ALWAYS be with us in our hearts!

💛 Ysabel ~ born Sept 29, 1999  death Nov 25, 2018 💛

Ysabel had a metabolic crisis at 3 days old and then was diagnosed with LCHAD at 10 days old.

We (mom and dad, Lisa and Gonzo), worked very closely with the March of Dimes and other families to get expanded newborn screening passed in the State of CA. Many babies lives have been saved by this testing. We were even in People Magazine in 2003.

Ysabel was very social, loved school, youth group & our church community. She loved to sit in the front row on Sunday and sing worship songs.

We have been told the Special Ed Jr & Sr class really miss her. She was the ‘glue’ in that class.

She lived a VERY full life and loved to travel – we traveled to Hawaii many times, Italy 3x, Switzerland 2x, in the US she visited New York City, Philly, Austin, Seattle, Portland, Los Angeles & San Diego.

She left an impression on just about everyone she met – we had close to 300 people at her Celebration of Life service in January.

We will ALL miss Ysabel and will keep her ‘fearless’ light alive!

Ysabel’s picture taken Oct 29, 2018

Watch the ‘Fearless’ Ysabel!
Colton (MCAD) – finished hours earning his SCRUBS Mentoring certificate at Bon Secours St. Francis Hospital. Colton attends Charleston Southern University studying Biology. His stated goal is “to apply to med school and fulfill his desire to help others.” All the best Colton!

Andrew’s Wish | World Wish Day 2018 | ALEX AND ANI

Andrew Calise, 14 yr old LCHAD, Make a Wish

Any Porter, Aug 9, 2018

Abstract

Title: Generalized Search Program to Find Correlations Between Medium Chain Acyl-Co enzyme A Dehydrogenase Deficiency and Other Conditions

Funding Source (s): Self-funded

Institution: University of Nevada, Reno, The Davidson Academy of Nevada

This project, written in the coding language of Julia, is aimed at finding articles in a database associated with the eutils functions that are linked to two or more imputed queries. A list of databases compatible with eutils is provided and the user queries are obtained. The program then runs the search and links to similar articles. The output of the program is the ids of articles that appeared in more than one search, which are returned to the user as a text file. Because it is generalized, this program not only helps find possible correlations between Medium Chain Acyl-CoA Dehydrogenase Deficiency (MCADD), it also can serve to find articles of interest for different studies.

[Creating MCAD Awareness is very important to Anya ~ THANK YOU Anya for your wonderful project!]

Genetic Mistakes, Understanding and Living with Fatty Acid Oxidation Disorders, by Rosemary Forrest and Nicole Baugh, is published by Nova Science Publishers (ISBN#978-1-53612-244-2) or on Amazon

Rosemary is a CPT 2 grandma!
Harry Family (LCHAD) Marathon

Ryan and I are running a Half Marathon on November 10th at Chickamauga Battlefield in North GA to raise awareness about FODs and money for possibly our next conference/event.

Ry and I have been steadily training...We ran about 11.5 last week. I am including a picture of my niece and nephew, they were helping to raise awareness about FODs and LCHADD a couple of weeks ago at her school's fall festival. Justice, our niece, drew pictures and sold them to raise money for the FOD Support group! They raised about $200! I had challenged friends and family that week to try and tell one new person about an FOD, and they did such a beautiful job!

The Race went great! We had t-shirts made that said, "moving these for FODs" and on the back it said, "Ask me about FOD"...so during the race people did! It was great! I ran 10.5 min miles...which was a huge accomplishment for myself...running with the long legs of Ry and his brother really pushed me!

Thank you to all that have done their own ‘Facebook Birthday Fundraisers or In Memory of Donations’ to benefit the FOD Group ~ all the donations are greatly appreciated and will assist us in either our General costs, Event programming, general FOD Research, LCHAD Research or other areas of the nonprofit that need funding!

Some of the Families that did facebook Birthday fundraisers or In Memory Of Donations since our last Newsletter included: Steph and Ryan Harry, Brittany Pridal’s sister’s facebook bday, Evelyn Pence Romano, Shawna Edwards, Kelsie Lallak and Allison Ruiz. All of our current donations are posted on our last page! If I missed anyone please let me know. Facebook sends the funds 30-60 after the end of the fundraiser so be sure to let me know when your Fundraiser ended and how much was raised. I will look for that in my automatic deposits ~ HOWEVER facebook never sends me names so I don’t have any idea which Fundraiser it was from - so please let me know!
RESOURCES

~ Facebook Groups for FOD Families ~

Main FOD Group for ALL FODs
LCHAD WARRIERS
Long and Very Long chain FOD food group
GA 2/MADD Families
Carnitine Deficiency (Primary and Secondary)
MCAD Deficiency
Raising Rare and Beautiful Children
with CPT 2 Deficiency
LCHAD Poland
Parents of VLCADD Kids
Adults with FODs
Metabolic Support UK
MCADD Families UK
The Metabolic Foundation - UK
MCAD Norge

NEEDED for JULY 2019 NEWSLETTER ~

KidsKorner Pictures, Recipes, Family Stories, Special Articles, Reach for the

Please think about sharing ALL of the above for upcoming issues ~ for ALL Submissions please email to Deb
Pictures ~ please include their name, age, disorder, and state/country and that you give me permission to print in the Newsletter

Thank You to all that have donated for the following ~


www.fodsupport.org

‘All in This Together’
FOD GROUP FINANCES

2018 Tax Return will be posted by May 2018

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 Awareness Item 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.


THANK YOU [Donations since July 2018]


THANK YOU [Donations since July 2018]


Online Donations

Awareness Items

Families and Professionals...

Please send all Submissions to Deb by June 15, 2019 for the July 2019 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!

‘No matter how dark the moment, love and hope are always possible’

~ George Chakiris ~

Disclaimer: 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 and for online networking groups.

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FOD Group PO Box 54 Okemos, MI 48805

www.fodsupport.org

‘All in This Together’