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FOD (Fatty Oxidation Disorders)
Family Support Group

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FROM THE EDITOR

Welcome to FOD Awareness Month! Years ago we designated July as our month to create GLOBAL AWARENESS of the various rare FODs. One way that we create awareness is by our FOD Banner ~ and for the 2019 FOD Banner we have chosen to honor Ysabel (adult LCHAD 1999-2018, California) and Canaan (VLCAD, 3 yrs old, Georgia). Also refer to page 6.

You can help to create Awareness around the world by promoting and sharing your Family Stories with your family and friends, as well as co-workers, professionals and everyone else that is willing to listen. Please also share our banner on your social media sites. Another way to create awareness is to purchase some of our Awareness items and wear them with Pride! Also when you shop amazon be sure to bookmark and shop every time from our FOD amazonsmile link ~ we benefit from all of your purchases ALL year round by earning a certain percentage of your total purchase! Donations made to the FOD Group are tax-deductible and will help us as we begin planning for our new Regional Meetups! More info on those Meetups is on page 2.

Also as stated in previous Newsletters and in the facebook Group, I am 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

www.fodsupport.org

‘All in This Together’
EDITORIAL

As stated in our Jan 2019 issue, we have decided to change from having a large 2 day Conference with the OAA group every two years, to doing 2-3 FOD sponsored Regional Meetups throughout the year. We are in the process of planning a 4-hr one in Pittsburgh for Oct 2019. Mitoaction is actually going to be coordinating our 1st one so we can learn how they set things up. We hope to have more info on this Meetup soon so you can begin to plan ahead. We will also try to videotape the Meetup so others around the world that can’t attend can hear our Speaker (possibly Dr Vockley) and a Q & A session.

Even though we will have FOD sponsored Meetups we will still NEED VOLUNTEERS in those cities to help plan. I am transitioning from doing a lot of the planning etc to having our Families take over! So once we set up dates it would be great to find local Families to help setup the actual meeting.

Along with Pittsburgh, we are exploring doing one in Boston and 1 other city (possibly out west) for 2020. However, ANY FOD member can really set up their own Meetup in their local area. It won’t be an official FOD sponsored one, but you can still get local FOD Families together to meet each other and share experiences! Or you can also try to have a local FOD professional speak and/or answer questions from Families. A good resource for planning your own Meetup is on the mitoaction.org site - Social Playbook for Guide on Hosting.

So please think about ALL of the above and share your comments/suggestions in our closed facebook or google Group.

Our FOD facebook Group is the more active one so it’s where we will post all the Updates. Please also view my Welcome Video ~ it explains our Group’s Mission and the future events we hope to plan.
The day had finally come. The day we were to bring our long-awaited, beautiful baby boy home from the hospital. It couldn’t have come any sooner. Between the constant monitoring of his low blood sugar, regulating of his body temperature, and the time he spent away from us in the warmer, we were ready for some quality time alone with our little Promise. That’s what his name means, promised one. Our sweet Canaan. We finally get the green light for our departure from Northside Hospital, formerly known as the Baby Factory. We get home and settle in with our newest addition, my brother and my husband’s mother. It was an exciting and exhausting first night. No one could have warned us how quickly that excitement would turn to paralyzing fear and helplessness. We wake up the next day to a phone call from the Emory Genetics Clinic. I answer the phone and everything from the moment I said hello is a blur. I do recall an explanation of a disorder I had never heard of, strict instructions to stop breastfeeding immediately, and an urgent request to go to the local children’s hospital. They would be waiting for us. We needed confirmatory testing as some children in the past have received false positives on the newborn screen. The statement that was stamped in my mind was, “I am pretty confident that your child has VLCAD because his CKs are so high. We like them to be under 300, and his are 5,000.” Cue the uncontrollable tears and my husband taking the phone to continue the conversation. The next hours and weeks really, were a complete whirlwind consisting of blood draws, echos, IVs, conversations with doctor after doctor, research, explanations to close friends and family, and prayer. So. Much. Prayer.

Absolutely nothing could have prepared us for Canaan’s first crisis. Or his second. Or his third. No amount of research prepared us for the arguments we would have with hospital staff who assumed to know more than us about a disorder they have never even heard of. Or how assertive we would have to be with insurance companies refusing to cover Canaan’s lifesaving metabolic formula. No one could have prepared us for the financial strain we would experience due to week long hospitalizations, ambulance rides, ER visits, specialty doctors appointments, or the expense of buying food that he can actually eat. But we also weren’t prepared for the amazing connections and friendships we would create with other FOD families. Or how the need to stay home with Canaan as opposed to sending him to daycare would create a bond between us that is stronger than I’d ever imagine. And never in a million years would I expect Canaan being born with a serious and rare, metabolic disorder actually strengthen our faith and trust in God and His oftentimes mysterious plans for our lives. But it did. And I am forever grateful.

Sharickah
Atlanta, GA

www.fodsupport.org

‘All in This Together’
Ethan was born on September 8, 2013 and appeared to be a healthy baby. It was not until day 3 that my husband and I started noticing that Ethan was a very sleepy baby. Ethan went into metabolic crisis on day 4 of his life. It happened very quickly and Health Care Professionals were unable to revive Ethan. We lost our baby boy at only 4 days old. We did not learn that Ethan had MCADD until 8 hours after he passed away. We got the results from his newborn screening after it was too late.

We have created the Ethan James Wyne MCADD Organization, Canadian Registered Charity, to spread awareness and help facilitate education. This organization has helped us cope with the loss of our son and helps us keep Ethan’s memory alive. The support we have received from family and friends as well as the community has been heartwarming. Everyone has shown us such great support in creating and running the Ethan James Wyne MCADD Organization.

Ethan James Wyne MCADD Organization
Facebook group: Ethan James Wyne MCADD Organization
Rebecca Wyne, mom

2019 FOD Awareness Banner
Canaan, 3, VLCAD Georgia
Ysabel, LCHAD, California, (1999-2018)

JULY is Fatty Oxidation Disorders Awareness Month
Expanded Newborn Screening Saves Lives!
**Medical & Research Update**

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

**The Metabolic Crisis: Recognition, Diagnosis, and Management ~ Chicago and Atlanta**

Other seminars presented by VMP Genetics and Dr Korson and Dr Fran Kendall are listed as well ~ enlarge pics to better read the info

~SAVE THE DATE~

**THE METABOLIC CRISIS: RECOGNITION, DIAGNOSIS & MANAGEMENT**

CME ACCREDITED

Saturday, Sept 14th, 2019
8:00 a.m. – 5:00 p.m.
Loyola University Chicago - Lake Shore Campus
Damen Student Center
Chicago, IL 60626

Presented by: VMP Genetics – Dr Mark Korson & Dr Fran Kendall

**Recognize patterns of symptoms**
- Order appropriate tests
- Implement practical treatment strategies

We especially welcome our colleagues in:
- Neurology
- Gastroenterology
- Hospital Medicine
- Emergency Medicine
- Intensive Care
- NICU/PICU
- Genetics/Genetic Counseling

There exists an ongoing severe shortage of metabolic geneticists. Since patients present to a wide array of specialists before they meet a geneticist (if they ever do), this workshop is an educational opportunity for MDs, RNs/PAs, genetic counselors and trainees who see acutely ill patients and who need to consider metabolic disease in their differential diagnosis. The most successful patient outcome generally occurs when disease recognition and implementation of treatment happen early in the course of a disease.

Comments from past attendees included the following:

“The whole program was great ... I would get up at 2 AM to listen to this ... It was presented in a manner that gave logic to a very complex, confusing topic ... all the lectures were top notch ...”

“The ease of use of algorithms and presented approach to these patients—should be taught to all pediatric residents!”

“The presenters were engaging and incorporated active learning in the form of interactive case studies with polled question and answers throughout the presentations that helped the audience remain engaged and master concepts covered.”

“The speakers broke down complex, metabolic diseases to more easily understandable diagnoses.”

**VMP GENETICS EDUCATIONAL APPROACH**

- Teaching that is practical, symptom-based, case-oriented, specialty-relevant, interactive, and pitched appropriately to the audience
- Principles taught, followed by their application in clinical cases
- Approaches provided to help clinicians investigate symptoms they see in their daily practices
- Key take-away messages made clear and reinforced
- Teaching that occurs in a variety of formats to maximize learning and interest
- An audience response system encourages interactive participation without intimidation

NEW FOD CLINICAL TRIAL

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.oahsu.edu
Articles of Medical Interest

- Ciprofloxacin has dramatic effects on the mitochondrial genome
- The Use of Vitamin E in Mitochondrial Antioxidant Cocktails
- Carnitine palmitoyltransferase II deficiency: A new cause of recurrent pancreatitis
- Using RNA Import to Repair Mutations in Human Mitochondria
- Dysautonomia: Too Hot, Too Cold, Too High, Too Low - Blame it on Dysautonomia!

Medical grade Genetic Testing ~ Invitae offers a variety of tests

“Invitae is a leader in advanced medical genetics. Our company was founded with a singular mission: to make genetic information affordable and accessible to everyone who can benefit from it. The Invitae team includes pioneers in genetics, medicine, technology, and genetic counseling, and is trusted by experts to provide the most comprehensive, reliable genetic screening and support available.”
MEDICAL FOOD INSURANCE COVERAGE TIPS FOR ALL TYPES OF INHERITED METABOLIC DISEASES AND RARE GENETIC DISORDERS IN THE USA

~ Raenette Franco ~

The complexity of the health care system can overwhelm even the savviest patient and/or clinical professional. That is why Compassion Works Medical was created to hold hands with patients and alleviate the clinics time through the difficult process of medical food insurance coverage.

Compassion Works Medical is founded by Raenette Franco, CEO and Certified Billing and Insurance Specialist. Raenette has been inspired to share her hands-on experience with medical foods insurance coverage specialized in all types of inherited metabolic diseases and rare genetic disorders. Compassion Works Medical works with you and for you, providing guidance and supporting you with compassion and integrity. Ms. Franco specializes only in medical food coverage and has been battling insurance coverage for medical foods for over a few years in addition to fighting for the Medical Nutrition Equity Act on Washington's' DC Capitol Hill. Compassion Works Medical collaborates with patients’ current insurance policies, and fights for state mandated coverage.

Every case is unique and different. Understanding your options and insurance terminology is essential to obtaining the coverage that you deserve!

Let’s start with the basics…………..

What is a Medical Food? You may hear these words often and could be confusing to the words “formula” or “dietary supplements”.

- Medical foods are foods that are specially formulated and processed (as opposed to a naturally occurring foodstuff used in a natural state) for a patient who requires use of the product as a major component of a disease or condition’s specific dietary management (i.e. designed for a certain disease) and intended to be used under medical supervision. In reality,

- Formula is basically the same thing as a medical food as they are made from the building blocks of foods.

- Dietary supplements are not generally designed for a certain disease, but are used in contribution to maintain a disease such as added vitamins. Dietary supplements are sometimes added to patient’s dietary management.

- What is Enteral? Enteral is a medical term used for a feeding method either oral or tube feeding; Hence Enteral formula.

- What is the difference between medical foods and dietary supplements? A supplement implies that it’s optional, like a vitamin. Formula is the required MEDICINE for people with Inborn Error of Metabolism Diseases. It just happens to be in the form of medical food versus medication.

Overall Medical foods, dietary supplements and enteral formula are common words used for insurance coverage.

Coverage for medical foods and dietary supplements are generally covered under medical benefits and supplied by a durable medical equipment (DME) distributor by using the description of coverage. However, medical foods are also covered under pharmacy benefits by product only, just a little tougher to maneuver insurance coverage.
There are many different types of Fatty Oxidation Disorders (FODs) genetic metabolic deficiencies and some dietary management could differ according to the type of FOD. Coverage for FOD's ICD-10 codes range from E71.310, E71.318, E71.41, E71.1, E71.3.

A typical dietary regimen for Very Long Chain Acyl-CoA Dehydrogenase (VLCAD) Deficiency, Long Chain 3-Hydroxyacyl-CoA Dehydrogenase (LCHAD) Deficiency has a special type of Medical Food (Formula) prescribed to help maintain a patient's health. Coverage for these medical foods (Formula) is defined by description codes also known as HCPCS Codes such as B4150 and B4158. These codes are used for medical benefits.

Coverage for special injectable vitamins: Are you or your family member on injection vitamins such as cyanocobalamin/hydroxocobalamin ML (B-12)? If yes, coverage for this special vitamin could be challenging. This special injectable vitamin may or may not be covered under pharmacy benefits. Some pharmacy benefits do not cover these products and considered over the counter. To obtain coverage, it requires jumping through loop holes. However, the health insurance benefits for cyanocobalamin/hydroxocobalamin ML could be covered under your medical benefits. Since the skin is pinched or broken such as with an injection and the place of service is at your clinic. If your clinic could administer the vitamin and bill your insurance company, it would be the best affordable route.

The insurance language under medical benefits for Hydroxocobalamin ML use HCPCS code J3420 and for Pharmacy benefits it is under an NDC number (i.e. 00591-2888-30). The place of service is at the office – Usually injected at the physician’s office under medical benefits.

Insurance coverage tips…

To start investigating coverage for your dietary management, it is recommended to start with your medical benefits first. Sometimes when we get a prescription we automatically think it’s a pharmacy benefit and that’s natural, however, if you have a prescription for medical foods or dietary supplements it’s best to check with your medical benefits first.

Here are eight tips below to better understand your medical food and dietary supplement insurance coverage:

**Rule No. 1: Never take NO for an answer!**

1. **Insurance Terminology**
2. **Difference between Medical and Pharmacy coverage**
3. **Reimbursement issues between insurance company and supplier**
4. **Verifying Insurance Benefits before placing an order**
5. **Medical Food Exclusion Removal**
6. **Gap Exceptions for policies with no out-of-network benefits**
7. **Be prepared for a prior authorization before covered services**
8. **Got Medicare or Medicaid? Best Avenue for medical food coverage.**

It's important to understand your health plan's guidelines for medical food coverage by thoroughly reading through your health plans summary of benefits to find out if your medical foods and dietary supplements are covered. Start by looking under durable medical equipment benefits (DME) and non-covered services including exclusions. Key words: **ENTERAL, MEDICAL FOODS, NUTRITION, FORMULA, SUPPLEMENTS.**
1. **Insurance Terminology:** Medical food and dietary supplements coverage is a complete foreign language to the health insurance industry. There are certain terminologies used to help obtain the most accurate coverage details with your health plan's benefit specialist such as:

   * Service codes (also known as HCPCS codes) used to describe the medical foods, enteral formula, dietary supplements and vitamins (i.e. B4155, B4157, B4162, B9998, S9435, S9435, J3420). These codes could be administered orally, tube feeding or vitamin injection. Injections are usually done at the clinic and not at home for proper coverage.
   * In-network and out-of-network to help determine the most affordable way to obtain your dietary needs. Also known as participating or non-participating.
   * Know the difference between prior authorization and predetermination. Prior authorization is required before coverage and predetermination is not required before coverage, but helps avoid any future denials.
   * Diagnosis driven plan: This is a plan that will only cover if the diagnosis code such as your medical condition(s) matches the description of service. Your diagnosis codes starts with a letter (i.e. ICD-10: E71.121). If it matches then you are covered. Diagnosis driven plans are easily mistaken as not covered, so if your benefit specialist mentions that it’s not covered, ask if your plan is diagnosis driven.
   * Other words are exclusions, out-of-pocket, state mandated plans, deductibles, fully insured, self-funded, allowed amounts, suppliers, gap exceptions.

2. **Difference between Medical and Pharmacy coverage:** Typically medical foods and dietary supplements are generally covered under your medical benefits and provided by a DME distributor. The medical benefits cover by using the service codes and the diagnosis code. Pharmacy benefits cover by the product alone and not the service. Medical foods and dietary supplements could be challenging for coverage under pharmacy benefits, if the product is not listed in their system and considered over the counter it's not covered. If you pharmacy plan does not cover your product, then use you medical benefits or file for an appeal.

3. **Reimbursement-Billing issues between insurance company and supplier:** Receiving bills from your providers could be scary. Don’t panic! First make-sure you if you’ve received a bill from your provider or is it an Explanation of Benefits- EOB statement (not a bill) from your insurance company. Check your EOB and match it with your invoice to determine if the bill is for your deductible or co-insurance. If not, contact your provider immediately and go over your invoices. Look out for any unnecessary charges.

4. **Verifying Insurance Benefits before placing an order:** The best way to avoid delays with your medical food orders are to try to verify your benefits and coverage "first" with your insurance carrier before placing an order. Contact your insurance carrier and ask for benefit coverage for Medical Food/Enteral Formula or nutritional supplements. Include diagnosis code (ICD-10). Mention it’s “usually covered under DME’. Remember to ask if the plan is diagnosis driven to avoid any misunderstandings.

5. **Ask for any exclusion on your policy for medical foods:** if there are any exclusions that does not cover your medical foods, it is not the insurance company that you would fight with. This is out of their hands. You will have to go to you employers HR department and ask for a medical food exclusion removal and present your letter of medical necessity explaining your rare genetic disease. Medical food removal template letters can be found at Compassion Works Medical. **To make a request, email raenettef@compassionworksmrs.com.**
6. What is a Gap Exception? A coverage gap exception is a waiver from a healthcare insurance company that allows a customer to receive medical services from an out of network provider at an in network rate. Usually HMO or EPO plans do not have out-of-network benefits, but if you can’t find an in-network provider to supply your medical foods, you could ask your insurance carrier for a gap exception. Also, your out-of-network supplier could request a Gap exception to your insurance company directly. This way is easier!

• One of the best reasons for your waiver is that there aren’t any other in-network providers within 100 miles of your residence that can supply your medical foods. Another is that you prefer to use the out-of-network provider because of a strong long-lasting and trusting previous relationship.

• Any request is worth a shot! This also saves time for your out-of-network supplier as well as providing faster medical food service.

7. Be prepared for a prior authorization that is required by your insurance carrier: some policies require prior authorizations from your insurance company before they will cover. Prior authorizations need to be identified as “medical necessary”. This is usually provided by your clinic or medical food supplier. Make sure your clinic provides you a letter of medical necessity (LMN) with a prescription and recent progress notes (A.K.A. clinical notes). Your provider usually makes these requests.

• Stay on top of your prior authorization approvals. When they expire, you or your provider will have to request a renewal. This depends on your policy; i.e. month to month, every 3 months, yearly, etc.

8. Do you have a government plan such as Medicaid or Medicare? As most of you already know, Medicaid usually follows all of the state mandated laws and covers 100% for in-network providers and may require a prior authorization. Medicare straight from your state does not cover medical foods “UNLESS fed by a feeding tube and is the sole source of nutrition”.

• Want Medicare Coverage?: If you have already have Medicare you can switch to a Managed Medicare Plan in your state such as AARP, UHC, BCBS, Humana, etc. and they could provide your medical food coverage. You may not have to pay any extra premiums. Many patients are able to be covered through their managed Medicare plans. This is NOT a Supplement Plan; it is a Managed plan that has leniency for medical food coverage. Supplement plans only follow the Medicare straight state plans. Supplement plans will have the word “supplement” on your card or “Complete”. Make sure that your plan is not a supplement as they follow Medicare guidelines. To find a managed Medicare plan in your state by visiting https://www.medicare.gov/find-a-plan/questions/home.aspx. Or simply call member services listed on the back of your Medicare card for assistance.

The tips above are based on actual experiences. I believe there are no true experts with all of the answers.

So let’s face the facts, patients NEED an Advocate, preferably someone with a medical food-insurance background. Patients need champions who can: (1) TRANSLATE what’s being told (2) ASK THE RIGHT QUESTIONS that patients ‘don’t know to ask’ (3) COMMUNICATE upwards, downwards and sideways.

For support and questions on medical food insurance coverage for all types of Inherited Metabolic Diseases and rare genetic diseases, please contact Compassion Works Medical at (973) 832-4736; Fax. 973-387-1223, email raenettef@compassionworksmrs.com.

“"It is with great excitement I share the release of much awaited Nutrition Guidelines for VLCAD. A big thanks to many who volunteered hours to make this a reality. We do plan to work on the consumer summaries.” [read page 12]
Rani H Singh PhD, RD, LD
Introducing the Nutrition Management Guideline for VLCAD

**Purpose**

The Southeast Regional Genetics Network (SERN) and Genetic Metabolic Dietitians International (GMDI) are proud to announce the Nutrition Management Guideline for very long-chain acyl-CoA dehydrogenase deficiency (VLCAD). This is part of a multi-year project to develop evidence and consensus-based guidelines for nutrition management of inborn errors of metabolism (IEM). The VLCAD guideline is now publically available online to all metabolic dietitians, physicians and other clinicians.

**Features**

The Management Guideline Portal is a tool for development of guidelines of genetic metabolic disorders for which there is little published scientific evidence.

SERN and GMDI partnered to develop nutrition management guidelines based on our evidence and consensus DNDF\(^1\) methodology. The resulting VLCAD guidelines are freely available on this portal.

Management Guidelines cover the assessment and management of patients known to have a particular metabolic disorder.

The practice recommendations are an effort to increase standardization of care and enable outcomes studies within and across centers.

When warranted by developments in VLCAD research and clinical practice, these guidelines will be updated periodically and will be maintained through a dynamic process.

Explore this resource at: [https://southeastgenetics.org/ngp/guidelines_vlcad.php](https://southeastgenetics.org/ngp/guidelines_vlcad.php)


*Many thanks to the contributors of this guideline, especially the VLCAD Workgroup Chairs, Sandy van Calcar, Ph D, RD and Mary Sowa, MS RD, as well as the workgroup members, web developer, project manager, project coordinators, reference librarian, project consultant, project advisor, evidence analysts, dietitians, physicians, researchers, parents of children with VLCAD, adult patients, and reviewers. This collaborative effort has resulted in guidelines to improve the nutrition management of individuals living with IEMs.*

For more information please contact:

**Rani Singh, PhD, RD**
**Frances Rohr, MS, RD**
Professor and Principal Investigator Nutritionist and Co-Principal Investigator

SERN and Guidelines Project GMDI and Guidelines Project

\(^1\)DNDF - Delphi-Nominal Group-Delphi-Field Testing

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**State-based Laws Provide a Flawed Patchwork of Coverage For Medical Nutrition**

[www.fodsupport.org](http://www.fodsupport.org)  'All in This Together'
Help For All Types of Tube Feeders

By Stacie Poole

FOD Families and members find themselves in a variety of situations and sometimes, having multiple health needs. Some of our FOD members have been using feeding tubes to supplement nutrition, safeguard caloric intake and deal with feeding ups and downs. Known as HPEN (Home Parenteral and Enteral Nutrition), some members may use feeding tubes that bring nutrition to the stomach or jejunum (an area past the stomach and into the intestine). Some members may also use or instead use IV nutrition through a port or picc line. (Parenteral nutrition is the use of IV based nutrition or fluid replacement. Enteral nutrition is the use of the stomach or jejunum as a way of providing nutrition.)

The FOD Group is all about families, consumers and people who need support through the FAOD journey. Learning you or a loved one has a fatty acid oxidation disorder can be very upsetting and challenging, to say the least. If the decision to add an alternative feeding route like a feeding tube is reached, it can add an additional layer of complexity to an already challenging world. For some, having a way to feed beyond the mouth also provides a much needed layer of safety, improving quality of life and minimizing hospital stays...but it is not without it’s learning curves.

FODsupport.org would like to make you aware of The Oley Foundation, an advocacy organization specifically in existence to support the needs of HPEN consumers and their loved ones. Through education, advocacy and networking, Oley strives to help ease the challenges of all tube feeding, advocate for better products and safety measures, as well as offer avenues through which to receive camaraderie, support and peer-to-peer help.

Our family had the distinct pleasure of attending our first Oley Conference in Lincolnshire, Illinois this month. Sessions were recorded and are available at oley.org.

We met consumers who were enteral dependent and/or parenteral dependent. We met people who fed 24 hours per day and could not tolerate anything though the stomach or intestines. We met people who fed like a completely typical eater, 3 square liquid tube-fed meals a day with snacks. We met adults who even indulged in coffee and wine through their tubes! We learned about how to manage diarrhea, options regarding formula and blended diets, TSA, new products in development and new products available for purchase. Exhibitors talked with consumers about lipids, rehydration, feeding apparatus that provide a free arm (called FreeArm...very cool!), buttons and catheters. We tasted formulas and real food blends and much more. There were even oral rehydration snow cones!

We found Oley’s staff to be incredibly skilled at managing a neutral, safe space for opinions to be heard, validated and discussed. They were incredibly compassionate, open to feedback and put patient safety and comfort at the very TOP of their list. Oley also spends time involving themselves in national initiatives for formula coverage as well as safety efforts regarding tube feeding supplies.

Oley’s conference schedule kept in mind that some consumers were kids, some were adults. Kids’ club rooms included trivia, escape room afternoon, video game truck, crafts, movies (a special movie night with blankets and pillows in the big hall!), and age appropriate activities for two larger age groups.
A varied and excellent schedule was offered attempting to provide information that would also meet the different levels of needs for both enteral and parenteral consumers. There was an easy going “come as you are and when you can” atmosphere. Lunches were included, were delicious and allergen sensitive. Dinners were on your own with plenty of time provided. Wine, cheese, and desserts were offered in the evening and plenty of opportunities for first-timers to meet people. We felt part of Oley by the first day and it just kept getting better and better.

We left with many cards having been passed out with our phone numbers, conversations galore having taken place and lifelong friendships established. We highly recommend Oley and the Oley conference to anyone using HPEN in any way. (They also support those with ostomies!) Mostly, we left with a sense of belonging, support and as if a bit of the load had been lifted.

Oley conferences occur during the summer months. Rumor has it that the next Oley conference may be on the west coast, but that is not official. They do try to alternate between the coasts and always include somewhere in the middle to try and make attendance easier for families.

If HPEN effects your life, we encourage you to consider reaching out to the Oley Foundation. In the same way FODsupport.org provides much needed support, information, guidance and camaraderie to the FOD community, Oley helps those of us also effected by HPEN use. Together, these great organizations can truly help those of us affected by both FAOD and tube feedings. We hope by providing the additional resource of the Oley Foundation that you or your loved one can receive any additional help you may need to live the best life possible!

The Oley Foundation
Albany Medical Center, MC-28
99 Delaware Avenue
Delmar, NY 12054
518-262-5079
FAX 518-262-5528

Rare Patient Voice is in urgent need for the following: Long-Chain Fatty Acid Oxidation Disorders (LC-FAOD) 60-minute web-assisted phone interviews with 4-6 LC-FAOD patients and 6-8 caregivers (ideally an adult caring for a child) on July 9 and 10 ~ CLICK THIS LINK $100 Compensation

Get paid for your opinion and benefit the FOD Group 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!
Love Messages

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!

It is with an incredibly heavy heart that I share the devastating news of the passing of my nephew, Dominic Ray. Many of you have developed a special friendship with my sister Toni Forino Ray. She has gained so much knowledge from so many of you and has leaned on you all so much as you handle unimaginable GA2 challenges together. I have been a part of this group since Dominic’s diagnosis and have always observed from a distance so I could better understand what Toni & Tim were going through. I am constantly amazed at the tremendous support you all have for one another. I’m sharing a photo from Monday because this is how Toni would like to remember Dominic. He will always be loved and never forgotten.

💙 Dominic Forino Ray 12/25/13 - 3/8/19💙

‘Hope is the thing with feathers
That perches in the soul
And sings the tune without the words
And never stops at all’

~ Emily Dickinson ~
REACH FOR THE STARS

Our girl (Avery, 10 yrs, VLCAD) had 3 basketball games 🏀 this weekend (in Feb - 2 today 😊) and managed ok! This is her 4th year of playing basketball and her team won as division champs tonight! 🏆

We make sure to fuel before & after the games/practices and she has her ‘super juice’ during games (juice & Liquigen).
We’re so proud of her and how she pushed through, this season & today!

Jennifer Hill Edwards

Movin’ on up! I am so proud of Matthew (VLCAD sibling)! He earned his white belt with purple stripe this weekend! Keep it up buddy!

Megan McCarthy

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) and is on amazon

Rosemary is a CPT 2 grandma!

NEEDED for JAN 2020 NEWSLETTER ~

KidsKorner Pictures, Family Stories, Special Articles, Reach for the Stars, and Professional Articles etc

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

www.fodsupport.org

‘All in This Together’
Creating Awareness & Family Fundraisers

When Jack was a few days old we got a phone call from his pediatrician's office. We needed to go back in for blood work. He failed his newborn screen for a metabolic disorder. With panic, we took him in for blood work but the lab was closed. We took him in first thing the next morning. Several days later, we found out everything was good.

At eight months old, I got a phone call from a metabolic office saying Michigan had lowered the threshold for CPTII and they were retesting all babies who tested near the new threshold. When we arrived at the appointment, a week later, we were informed they had been studying Jack for six weeks, as he was the only child out affected by the lowering. We were completely blindsided, as I'm sure all FOD parents are. He seemed so healthy.

After testing, they decided he was an adult on set case. Several weeks later, we landed in the ER for his first stay. My husband and I decided to pursue further testing at an out of state hospital. Jack actually had a severe case of CPTII. (He has three older brothers who do not have CPTII.)

It was a relief to have concrete answers but the wait to get there was long and stressful. I found the FOD Support Group online and it helped our family tremendously. We have met other families like ours and gained wonderful, supportive friends.

For the first Rare Disease Day following Jack's diagnosis, I made our family matching shirts and handed out 250 zebra ribbons. Numerous friends and family members said they would love to wear a shirt too so the following year I decided to offer them shirts and ribbons. I made over 100 shirts with all profits donated to the FOD Support Group. It was amazing to see so many people share their pictures on Facebook in the matching shirts. I printed an album to share with Jack so he could see his amazing support system.

After attending the conference last July, we felt a huge sense of relief. We will always be grateful for all the group has done for us. I hope to make more shirts next year and donate even more!

Allison DeGrow Ruiz

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: Mary Lingle, Lindsay Johnston, Natalee Steed and Sara Trabucco and Memory donations for Matthew Koch, Dominic Ray and Tom Carmody, Sr. 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!

Also THANK YOU to the Committee members for the INFORM Network and the FOD Registry for all your work on FOD efforts~

Michelle Little, Dave Perritt and Brittany Leigh Pridal
Lindsay Johnston, Christy Perez and Brittany Leigh Pridal

www.fodsupport.org

‘All in This Together’
### Resources

#### Facebook Groups for FOD Families

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#### Additional Resources

- **FDA Launches New Video Series**
  - Featuring Testimonials from FDA Patient Representatives
- **Accessible Tools for Leadership and Advocacy Success**
  - from Genetic Alliance
- **Our Odyssey**
  - focuses on helping young adults with rare conditions

#### Mailing lists:
- Erika Wallace

#### Website Designers:
- Mary Lingle
- Jamie Payne

#### Newsletter consulting:
- Brian Gould

#### Email/website consultants:
- Mark Heinz

#### Website slide shows & Graphic arts:
- Keith Widmann

#### FOD/OAA Conference Event Planning:
- Eileen Shank

#### Website slide shows & Graphic arts:
- Keith Widmann

#### Newsletter formatting:
- Deb

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[www.fodsupport.org](http://www.fodsupport.org)
FOD GROUP FINANCES

2018 FOD Group Tax Return

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 January 2019]


Some of the above donors have purchased Tshirts, Bracelets, Ribbons, CafePress, or used GoodSearch browsing, MissionFish/eBay selling, iGive or Amazonsmile.org shopping etc

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 made payable to the ‘FOD Group’ mailed to:  FOD Group PO Box 54  Okemos, MI 48805

Online Donations  Awareness Items

‘You cannot swim for new horizons until you have courage to lose sight of the shore.’

~ William Faulkner ~

www.fodsupport.org

‘All in This Together’