From the Editor

How can it be 2018 already?! That means it's Conference time! We will be converging on Bloomington, MN on July 6-7, 2018 at the Embassy Suites by Hilton Minneapolis Airport for our next FOD/OAA International Metabolic Conference for affected children/adults, their Families and for Professionals. Over the years, Kathy Stagni (OAA Director) and I try to find locations that not only can accommodate our numbers but also has quality medical care nearby in case our Families run into an emergency (Univ of MN and Mayo Clinic). Many Families bring their children along and make it not only an educational and networking experience but also a family vacation. You can make Reservations online – do them soon because there is another event in the area and rooms may fill up. If you call 952.854.1000, be sure to tell them it's for the FOD/OAA Conference - code FOD. Every person age 3 and up will need to Register for the Conference so we have an accurate food count. I will post the form in mid-January 2018. There is NO cost to Register for Families, but Professionals will pay $50 each.

We are still confirming our FOD Speakers, but we have already confirmed Dr Jerry Vockley, Dr Stephen Kahler, Dr Piero Rinaldo (keynote for beginning of Conference), Dr Susan Berry, and Dr Chris Boys. We will have opportunities to also network with same disorder Families (ie., MCAD, LCHAD etc) and have Professional and teen/adult FOD panels. As with past Conferences, we will have a Kid’s Activity room, but each child will need their own family member/sitter watching them. We will have some volunteers assisting in the room, but every family is responsible for their child/ren. So we HOPE to see many of you ~ read more on page 3-4 and keep checking our site for Updates and the Agenda! And refer to our past Conference info to get a better idea of our format.

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

‘All in This Together’
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**EDITORIAL**

“Deb Porter... You looked wonderful on Dr. Phil. I hope people that saw it, who are caretakers, listened, and will realize that they DO have to take care of themselves and often need to put themselves first, in order to stay physically and mentally healthy.”  
*Mary Thorson/TFP Parent*

I totally agree with Mary’s poignant comment ~ living with and caring for a child or adult with an FOD is challenging and exhausting and everything in-between. Deb put a face on ALL of those things even though much of what she said in the taping was edited out! Deb shared with our closed facebook Group what she actually said. Unfortunately they cut out so much VALUABLE information in order to put more focus on another group’s book and another person’s comments on caregiving (even though this person is/was not in that role!). I am personally not a fan of Dr Phil’s show style, yet it was an opportunity for Deb to create awareness of how living with and caring for someone with a chronic disorder impacts EVERYONE in the family. And that we HAVE to take care of ourselves in order for us to stay FUELED (emotionally, cognitively, physically, relationally, and spiritually etc) for the short and long run, just as our FODers have to stay fueled within their bodies in order to function every day. So THANK YOU Deb for getting out in front of the world and sharing your and Rodney’s experiences with living with an FOD!
Our 2018 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 Host/Sponsor is Mayo Medical Labs, as well as many other invaluable Sponsors.

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 or call her at 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 6-9pm for Families and Speakers. Saturday we will 1st meet in our separate rooms for networking & breakout sessions, and then finish up jointly with our Speakers and Professional Panel Q & A time and Ending Video Ceremony.

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 a Buffet Lunch and snacks are provided to all Registrants on FRIDAY and there will be Breakfast on Saturday AND possibly a Box Lunch - the Conference possibly ends at @2 pm - if we have enough funding.

There is NO registration fee for FOD/OAA Family participants for the 2018 Conference - but you will still need to complete an Online Eventbrite Conference Registration Form (Online in late Jan - due by JUNE 15th) for each member (age 3 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 will be Online SOON.

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, 2018.

Booth Exhibitors do NOT register on the eventbrite site. Please contact OAA Director Kathy Stagni 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 3 and older MUST be registered. All sitters MUST be registered. This is to provide advance accurate numbers for meal preparations. ***
Hotel info & Conference:
Embassy Suites by Hilton Minneapolis Airport
7901 34th Avenue South, Bloomington, Minnesota, 55425

Online HOTEL Reservations: Attendees are responsible for making their own hotel reservations by June 13 to get the lower rate. There is another event in town so don’t wait to reserve your room.

The Conference rate will also be in effect 2 days before the conference dates of July 6 and 7, 2018. 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 $129/night + tax for a king size bed or $139/night + tax for 2 Double beds - this is the group discounted rate.
Guests can access the FOD/OAA Conf link to book, modify, or cancel a HOTEL reservation

Reservations by Phone: 952.854.1000 and state your reservation is for the FOD/OAA International Metabolic Conference to ensure you are billed at the reduced conference rate. Code is ‘FOD’
Airport: Minneapolis-St Paul International Airport
4300 Glumack Drive  St Paul, MN 55111  612.726.5555
Amenities & Free Courtesy Bus to/from MSP airport and Mall of America

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 and possible Box Lunch 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. There will be a special FOD presentation on both days for 2nd-5/6th grade FOD kids and their sibs - I will post more info in the Facebook Group and on our website. 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 and Reception must be registered.

ANYONE age 3 and older MUST register. All sitters MUST be registered. This is to provide advance accurate numbers for meal preparations.

Registration Form: Online or by mail (the regis form will also be on www.fodsupport.org and www.oaanews.org by late January)

REGISTRATION DEADLINE - JUNE 15, 2018
[IF you have to CANCEL please email Deb so we can keep accurate counts]

Printed forms [and Professional checks made out to OAA] can be mailed to:
Deb Lee Gould/FOD Group
PO Box 54  Okemos, MI 48805  517.381.1940
Family Stories

Aline ~ Trifunctional Protein Deficiency

The life of our family changed on February 25th - exactly 6 days after the birth of my daughter. The doctor from the Newborn Screening and Metabolism Centre called: "The screening was positive and you must come to the clinic immediately, we have already reserved a bed for you in the intensive care unit."

We were really lucky that Aline did not decompensated during her first days of life. When we came to the clinic, Aline was half-fed with the special formula "monogen" and half was breastfed. This only applied for the first three months, until the results of the genetic test showed that Aline had not only the homozygous characteristic LCHADD mutation, but also a rare deletion mutation.

So the revised diagnosis was TFP- deficiency. But since the treatment is the same, I just reduced the amount of breast feeding and from the age of 4 months, Aline only got the formula.

It has been almost 4.5 years since this special call, and we spent a lot of time in the hospital, often triggered by bronchitis and coughing- induced vomiting. Aline already had 4 periods of metabolism crisis with bad rhabdomyolisis accompanied with very strong muscle pain in the whole body. These episodes were very awful for us as parents – to see our little girl suffer by just touching her.

We carry out all regular controls at the Metabolism Centre every 3-6 months and constantly monitor her heart, nerves and eyes. Until now she is a normal athletic girl/daughter/younger sister with a special diet and the need for more caution in case of infections. We are really lucky with our kindergarten. They are willing to get involved. They cook for her and take care of her as we would do it.

In Germany fatty acid oxidation disorders (FAOD) are screened since 2005. In the last 12 years 150 children were born with long chain FAOD and many more (approx. 850) with MCAD. In the first time after the diagnosis, we found help and information from other families only online. Until now, there is only one German-speaking online platform (macd-infos.de) where most of the families are connected. After a children-rehabilitation last summer with other TFP and VLCAD families, we noticed how helpful it was to meet other families personally; but it was especially important that the kids had the chance to meet others who have to follow a stricted fat-reduced diet. So we (a befriended family and us) organized the first meeting for LC-FAOD families in Germany and Austria. In preparation for this meeting, I also contacted German researchers and it became clear that self-help need to be more professionalized, also in order to support these research- groups.

We are very glad to share our thoughts with your community and also to learn from you. We would like to keep you updated in case we know anything what makes the life of our kids easier.

Hopefully, we are going to be as successful as you in the future and can link all interested families with all kinds of FAOD.

Maren and Erik
Berlin, Germany
parents of Aline, TFP deficiency
www.lchad-mtp-vlcad.com
info@lchad-mtp-vlcad.com
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!

Braylee Jo Pridal was born on April 3, 2012 in Sioux Falls, SD. On the 3rd day of life she was diagnosed with LCHAD. She was granted her precious angel wings on November 13, 2017 after a brave and courageous battle. In her short, yet very memorable life she touched many hearts.

Braylee’s life would seem too short to many, but those who knew her understood that the quality of existence far exceeds that quantity of time in which one lives. She never let LCHAD define who she was. Her infectious smile could melt the heart of anyone around her. She had a heart of gold and wouldn’t leave without hugs from everyone.

Even though she is no longer with us on earth, we will forever be FOD parents. It is dear to our heart and we will continue to advocate and help other families and researchers with any knowledge we can contribute.

Please Note: Dr Melanie Gillingham, associate professor at Oregon Health and Science University shared this information with me after Braylee’s passing when I asked about any information that could be shared regarding my daughter.

***They have a data repository which is a fancy way to keep medical records in a HIPPA compliant research way so they can compare patients across the US and beyond. She is working with a cardiology group to review cases of cardiac failure to look for similarities or differences, to describe biochemical parameters and genetic mutations and see if they can discover a pattern specifically to LCHAD. The cardiac complications of LCHAD are devastating and they are not sure where to begin to find answers except looking at medical records for clues. Any medical records of deceased or living LCHAD individuals would be very helpful in this work.

Melanie Gillingham, PhD, RD
Assistant Professor
Oregon Health & Science University
Department of Medical & Molecular Genetics
Graduate Programs in Human Nutrition
Mailcode L103
3181 SW Sam Jackson Park Road
Portland, OR 97239
phone: (503) 494-1682
FAX: (503) 494-6886
email: gillingm@ohsu.edu

‘If I know what love is, it is because of you’

~ Herman Hesse ~
PUBLIC RELEASE: 24-OCT-2017

New clinical care guidelines issued for patients with mitochondrial disease

*CHOP clinician co-leads consensus statement for managing complex group of genetic disorders*

**CHILDREN’S HOSPITAL OF PHILADELPHIA**

*IMAGE: AMY GOLDSTEIN, MD, IS THE CLINICAL DIRECTOR OF THE MITOCHONDRIAL MEDICINE FRONTIER PROGRAM AT CHILDREN'S HOSPITAL OF PHILADELPHIA. [view more]*

*CREDIT: CHILDREN'S HOSPITAL OF PHILADELPHIA*

Physicians who see patients with mitochondrial disease now have a practical new tool—a set of guidelines for managing and caring for those patients. Occurring in at least one in 4,500 individuals, mitochondrial disease is caused by defects in genes affecting the function of mitochondria, crucial energy-producing structures found in every cell. This complex disease can affect nearly every organ or system in the body.

"Standards of care are not uniform across centers or clinicians. To take just one example, clinicians need to know how often to order laboratory tests to monitor the health of patients with mitochondrial disease," said study co-leader Amy Goldstein, MD, newly appointed clinical director of the Mitochondrial Medicine Frontier Program at Children's Hospital of Philadelphia (CHOP), and current president of the Mitochondrial Medicine Society (MMS), which issued the consensus statement. "Our guidelines reflect expert consensus based on our current knowledge of mitochondrial medicine."

The MMS patient care standards for primary mitochondrial disease appeared online July 27, 2017 in *Genetics in Medicine*. The study leader and corresponding author is Sumit Parikh, MD, of the Cleveland Clinic Children's Hospital.

The MMS previously issued consensus criteria in 2015 to guide diagnosis of mitochondrial disease. It subsequently surveyed over 200 clinicians worldwide who see mitochondrial patients, and found that 99 percent of those practitioners, including neurologists, geneticists and metabolic experts, wanted additional guidelines to assist in managing patient care. In addition, said Goldstein, "patients and families have been asking for a guidelines document to bring to their own physicians."

For the current study, the MMS appointed an international panel of 35 mitochondrial medicine specialists to review current knowledge and develop recommendations. Reflecting the systemic impact of energy deficiencies caused by impaired mitochondrial function, the group's recommendations address a broad range of medical specialties, including cardiology, neurology, critical care medicine, nephrology, endocrinology, audiology and ophthalmology.

In addition, the guidelines address special issues encountered by patients during pregnancy and high-altitude travel, and also compile a list of medications, such as statins and acetaminophen, that must be used with caution or avoided in patients with mitochondrial disease. While the current guidelines are the first set of published recommendations for patient management and clinical care decisions, the authors recognize that as mitochondrial medicine continues to evolve, the guidelines will need to be updated.
These guidelines represent an important step in the effort to standardize health care and optimize health outcomes for mitochondrial disease patients. They also establish a baseline from which meaningful clinical trials can be launched to evaluate new treatment interventions.

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About Children's Hospital of Philadelphia: Children's Hospital of Philadelphia was founded in 1855 as the nation's first pediatric hospital. Through its long-standing commitment to providing exceptional patient care, training new generations of pediatric healthcare professionals, and pioneering major research initiatives, Children's Hospital has fostered many discoveries that have benefited children worldwide. Its pediatric research program is among the largest in the country. In addition, its unique family-centered care and public service programs have brought the 546-bed hospital recognition as a leading advocate for children and adolescents. For more information, visit http://www.chop.edu.

**Articles of Medical Interest**

June 9, 2017  By: Rosemary Forrest

**An Inborn Errors of Metabolism Collaborative (IBEMC) exists for long-term follow-up of conditions found through the newborn screen**

January 25, 2017

**Children's National, NORD Partner to Create Rare Disease 'Centers of Excellence'**

Synergistic heterozygosity: disease resulting from multiple partial defects in one or more metabolic pathways

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**Dr Mark Korson Joins VMP Genetics Expanding Metabolic Medicine Services to Physicians, Hospitals, and Institutions Worldwide**

VMP Genetics and Dr. Fran Kendall, pioneers in rare genetics and telemedicine, are pleased to announce that Dr. Mark Korson has joined VMP as the Director of Physician Support and Educational Services divisions. Expanding these two divisions extends our reach beyond current direct patient care and remote second opinion services into medical consultation to hospital systems worldwide and allows for the development of educational platforms ranging from live medical conferences to rare disease eLearning modules.

As the Physician Support and Educational Services divisions expand, VMP Genetics will seek to add physicians as consultants to create a roster of unparalleled talent and expertise in rare diseases. Throughout their decades of dedicated careers, Drs. Kendall & Korson have consistently blazed new trails in genetic medicine creating innovative ways to improve the quality of life and care for children and adults affected with rare diseases.

By utilizing the latest technology, this unprecedented and powerful collaboration of world leaders in the field of Inborn Errors of Metabolism under the VMP umbrella will extend decades of expertise in highly specialized medicine to health professionals in far reaching corners of the world.

To learn more, please contact Dr Korson at vmpgenetics.com.
Dealing with Medical Curveballs  
*By ~ Stacie Poole*

(Written from the perspective of a caregiver, the following information can also be incorporated into caring for yourself.)

You're trucking along, dealing with what you know about your kiddo and all of a sudden, they change the game. Trouble eating. Stomach pain. Trouble walking. Several families within the FOD community have experienced these changes, all of which can go beyond the description of just an FOD.

Coping with medical curveballs is challenging. Reigniting past fears of times when your child (or affected adult) was sick, caregivers have a strained role. Advocating for, protecting, and normalizing their child’s life is easy for the heart to do but takes time and energy. And often times, parents and providers are confused, confuzzled and left with uncertainties.

When you or your child experiences new and challenging issues, a few things may help to provide valuable information for your care providers, allow you to communicate better for yourself or your loved one and to keep yourself in tip top shape. Below are a few ideas to make this time easier on you and the one you care for.

**Journal, Journal, Journal!**

Any illness can bring sleep deprivation. Even typical families will be up late with a vomiting child or if they have a high fever. Loss of sleep is real and can do a number on your memory and ability to recount important details for your care provider. Keeping a daily journal with dates, times and short descriptions can offer a way to release your brain from holding all the details, details that matter. It sounds simple but when you’re running on 4 cups of coffee, some string cheese and an apple, you forget to do stuff. If the person who is medically affected can, offer them the journal so they know where it is kept and can write down what they think is important. Having in-home care providers also use the journal is helpful as they may have information to add but forget before they leave your home. Journaling is a great tool for clear communication and providing critical pieces of the puzzle to the doc!
Sleep, Sleep, Sleep!

What is sleep? HA! We’ve all had those times we don’t get enough or any sleep, especially during times of medical crisis. But sleep is critical to maintaining your own physical health, mental clarity and caregiving stamina. We are more patient, kind and effective when we’ve slept. It’s not always easy to do, but remembering newborn days and the old adage…sleep when they sleep…still remains true. Yes, if there is a nap occurring and you can do the dishes or run an errand, that’s tempting. But if you’ve been getting 4 hours sleep for the last week, take a nap yourself. Make yourself a priority as well so you can remain an important part of your loved ones support circle. Sleep!

Eat! Eat! Eat!

Now this is sort of a humorous topic for FOD parents since some also have a bit of symptoms, but if you are lucky enough to actually be able to forget to eat (what that must be like, who knows!), don’t. You need fuel. You’re not meant to run on fumes. Order the crappy hospital tray. Include a piece of fruit when possible with your fast food. Get a salad. Keep up your protein. Sounds easy, but it’s rough when you’re dealing with a vending machine, coffee stand snacks or fast food. Gaining or losing weight, energy loss and brain fog are real things when humans don’t eat well. When you’re low on energy, coffee is great, but remember to eat. Fuel up!

Spiritual Care!

Every person, even those within the same religion, will care for their spiritual needs differently. Whatever category you may fall into regarding your spiritual beliefs, religious or otherwise, this can be a powerful source of encouragement and grounding during a time that can feel very intimidating. Tapping into the beliefs you hold dear can bring you back to a place of comfort, easing your own worries and can be very calming. If you are the affected person or caregiver, reaching out to the hospital chaplain can be very helpful. Asking a local pastor to come and see you, even if you don’t have a home church, can be very uplifting. Again, whatever your belief system, tap into that source of relief, even if through a friend, a book or a show on TV.

Friends and Family!

Lastly, it can at times, be easy to isolate yourself when dealing with a medical crisis. It can feel like you are in a foxhole and you forget all the people who can come to help and support you are just a phone call away. Ask for help. Ask for support. Ask for visitors. Other people being in your room or with your child can be enough to help each of you feel more hope and quickly get back to your old self! Loving each other through these events is critical. And remember the FOD family! As evidenced by the massively supportive Facebook posts, we all seem to get one another and offer unfettered love and support. If FOD Support is all you happen to have, don’t underestimate its authenticity. It’s real and available 24 hours per day!

Above all, please remember that this too shall pass. Curveballs, even in baseball are tricky and happen quickly. They can fly by quickly, leaving everyone looking over their shoulder but they don’t linger. Sometimes they rattle the batter, for sure. Even if things never get back to your normal, you and your loved one will adapt, evolve and can accept the new normal. Time and time again, families and people are forced to deal with medical curveballs. It is very possible to get through this type of experience, heading back to the dugout happy, whole and sound. Never underestimate the power you have to adapt. Remember, above all else, you truly are never alone on your journey. Taking care of yourself and keeping lines of communication open with your care providers can go a long way to giving you the best chance at hitting a home run! Happy New Year!!!
Parent to Parent Suggestions

In case anyone is looking for emergency glucose gel, I found one on smile.amazon.com that is caffeine free, inexpensive and has a long shelf life. And my purchase benefits the FOD Group!

9 TSA Tips for Parents of Kids With Disabilities or Medical Needs

An OAA parent wrote this article

Cooling cloths from frogg toggs are amazing!

I know we often talk about snacks for our kids and just wanted to share this page of energy bite recipes. Our daughter (4, MCAD) especially loves the basic peanut butter and chocolate chip. We always add ground flax seed and rice cereal (like Rice Krispies) for a little extra crunch and substance. We also use peanut butter without palm oil or palm kernel oil, so that it's really good for her. The energy bites are wonderful frozen!! And you can change the nut butters, oil, sweets, etc to meet your child’s needs.

Michelle Little

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)

Rosemary is a CPT 2 grandma!
FAMILY FUNDRAISERS

CREATING AWARENESS & FAMILY FUNDRAISERS/MEMORY DONATIONS

‘Matt’s (CPT 2) sisters, Cecily and Clara, who helped me (grandma Rosemary Forrest) sell some of my brother’s photography as a fundraiser for the FOD Group. He left me his prints. They’re quite good.’

Rosemary Forrest

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 Conference costs, 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 included: Joe Pizzimenti, Kelsie Laillak, Alison Goldberg, Christy Taylor, Michelle Cotton, Debra Wagner, Christy Abrams, Evelyn Pence, Michelle Cotton, and the Pridal Family

REACH FOR THE STARS

Just wanted to share that Drew (5 VLCAD) completed his first Mud Run today and had no issues! Thankful for the days when he can do normal kid stuff!

Renee Stapley

Today we found out that Luke (12) was cast as Nib in his school’s spring production of Peter Pan. I’m bursting with pride that he was cast at all, much less in a speaking part, as this was his first ever audition. This is huge, everyone, because just a few months ago, Luke struggled with anxiety and depression, mostly because of his LCHAD. He had some serious confidence issues, so I was just thrilled he wanted to audition. I thank God that my boy is growing & thriving, and that LCHAD was not able to steal our joy today! Keep fighting the fight,

Beth Schrey Folcher
Pennsylvania
Emergency Contact Product:

“Know someone that travels a lot or drives a truck for a living? Be sure they have appropriate "Emergency Contact" information available in case of any emergency. This seat belt wrap is customizable, in your choice of several colors or add a name for true personalization!! Can be purchased on my Etsy store.”

Medical Tag sites:

www.medicalert.org
http://www.medids.com
https://www.universalmedicaldata.com/
https://www.stickyj.com/

Scholarship Info:

College accessibility for students with disabilities: Scholarships and financial aid
http://www.thebestcolleges.org/scholarships-for-student-with-disabilities/
http://livebellasoul.org

POTENTIALLY HARMFUL DRUGS FOR MITOCHONDRIAL PATIENTS VERSION 3

Learning without Tears

“Comprised of developmentally appropriate and multisensory instruction, Learning Without Tears promotes written communication success in the classroom from Pre-K to elementary school.”

This company may possibly be one of our Sponsors/Exhibitors at our 2018 Conference!

The Dr created a deodorant that helps with the sometimes fishy smell that some of our kids/adults experience when they take certain drugs to treat their FOD or OA. An Organic Acidemia (OA) mom used it for her 5-yr-old daughter and it worked wonderfully. It helps with all kinds of body odors and goes on like a regular deodorant but can be used anywhere on the body.

The interview is about 14 minutes into the podcast.

Genetic Testing resource ~ Invitae also has our FOD Registry [ a new link will be provided in late January - I will update then]
**KidsKorner**

Luke  
4 yrs old, CUD  
Ohio

Lydia  
2 ½ yrs old, CUD  
Ohio

Lexi, 5 yrs old, MCAD  and  
Peyton, 2 yrs old, MCAD  
Mom and dad  
Ohio

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

Mailing lists: [Erika Wallace](mailto:)  
Website Designer: [Mary Lingle](mailto:)  
Newsletter consulting: Brian Gould  
Email/website consultants: [Mark Heinz](mailto:)  
Website slide shows & Graphic arts: [Keith Widmann](mailto:)  
FOD/OAA Event Planning: [Eileen Shank](mailto:)  
Newsletter formatting: Deb  
Website slide shows & Graphic arts: [Keith Widmann](mailto:)  
FOD/OAA Event Planning: [Eileen Shank](mailto:)
Families and Professionals...

Please send all Submissions to Deb by June 15, 2018 for the July 2018 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!

FOD GROUP FINANCES

2016 FOD tax return [2017 return 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 2017]


Tshirts, Bracelets, Ribbons, CafePress, GoodSearch browsing, MissionFish/eBay selling, iGive or Amazonsmile.org shopping etc: Mark Human.

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 48865

Online Donations

Awareness Items

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.

www.fodsupport.org

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