FOD Family Support Group ~ Communication Network

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FOD (Fatty Oxidation Disorders)
Family Support Group

PO Box 54
Okemos, MI 48805

517.381.1940 phone
866.290.5206 fax

deb@fodsupport.org
www.fodsupport.org

Non-profit Tax ID 83-0471342

From the Editor

We have a Conference city for next July ~ Minneapolis, MN! Kathy Stagni (OAA) and I are exploring some of the hotels, along with Eileen Shank (our fabulous MCAD mom event planner), and we will let everyone know the dates and the location in the next several months and more info will be posted in our January 2018 Newsletter. We are **excited that a major Sponsor is Mayo Medical Laboratories! However, we are still searching for more major Sponsors to help us fund our Conference for ALL of you!**

Since we only offer this wonderful learning and networking opportunity every 2 years for our FOD and OAA Families and Professionals, please seriously consider attending. We have a full day of presentations on a Friday and half day on Saturday. As of now, there is no registration FEE for Families, but Professionals will pay a minimal fee. EVERYONE, including children age 2+, will need to Register for the Conference (that form will be on our site after Jan 2018) so we have an accurate food count. The only major cost for Families is the reduced hotel cost and your travel costs, and any other meals we don't provide. We may have breakfast on both days (unless the breakfast is provided with your hotel reservation - depends on our contract) and a lunch on Friday and then an evening Reception (usually a cash bar and food is free) where Families can mingle with both Families and Professionals. Kathy and I are looking forward to another terrific Conference! We had 300 attend the 2016 Conference in Colorado. Let's break our record!

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

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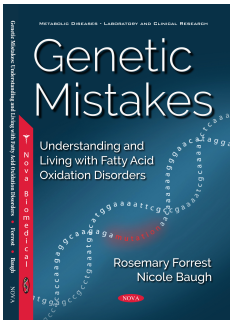
Editorial

Our entire FOD Family is so proud of Rosemary Forrest and her daughter, Nicole Baugh, for writing a book about FODs ~ Please read Rosemary's comments below and think about either purchasing and/or sharing this with your professionals, libraries, metabolic clinics etc.



When my grandson was born in 2014, my family knew nothing about FODs. His pediatrician knew little more. As we struggled to understand his condition, I knew that as a science writer, I could make a difference in the lives of other families if I could assemble enough information about the topic and explain it well. I began working on Genetic Mistakes, Understanding and Living with Fatty Acid Oxidation Disorders. It is published by Nova Science Publishers. [From Deb: It can also be purchased through our FOD amazonsmile link!]

My scientist daughter joined me as co-author and together we read hundreds of academic, medical papers and book chapters, and spoke directly to those working in the field as well as to many families in the FOD community. The resulting book is our best effort to help both doctors and families understand what it means to have a FOD.

What my family wanted when my grandson was born was accurate, accessible information that would not unnecessarily alarm us or dismiss our concerns. I have tried to make Genetic Mistakes exactly that. The first part deals with the science and genetics of FODs, both in general and individually. The second part speaks to the experience of having a FOD in the family, and the third part provides some helpful references as well as a how-to on doing one's own research. It does not attempt to answer every question that may arise, rather it is meant to give the reader a greater depth of understanding and confidence in seeking and evaluating those answers. It is the book I wish I had had.

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). As they are an academic press, the book is expensive, so I am asking every affected family to request that it be purchased by your local library so that it is available for all. And if you live in a college community or near a medical school, please request that those libraries order it as well. Please mention it to your primary care doctor or pediatrician. The more we know, the better off we all are.

FAMILY STORIES

Mitchell ~ VLCAD

I will never forget the day I received the news that Mitchell had VLCAD. It was a hot day in July and we had just been released from the hospital. I was trying to adjust to the new (non) sleep schedule, breastfeeding and managing a newborn in my household. I was resting with Mitchell in my room when I saw unknown number calling. I decided to ignore the call because I did not want to be bothered with work or telemarketers. A few minutes later, my phone alerted me that the caller left a voicemail.

I picked up the phone and listened to the voicemail. A male voice began telling me he was a genetic specialist and my son had screened positive for a disorder. I listened for a few moments longer until the doctor said, "it is potentially life threatening." I immediately hung up. I did knot know what was going on, and I did not want to listen to any more of what he had to say.

I went to the living room and found my husband on the phone. He was speaking with the doctor who had just left me the voicemail. My husband put the doctor on speakerphone and we listened to him explain what our sons test revealed. He explained that there are false positives to this disorder, but he asked us to prepare for the fact that Mitchell probably had it. He stated the marker for this disorder was very elevated in our son's blood test and he believed that he really had VLCAD.

To say I was devastated is an understatement. Here I was, hormonal and sleep deprived, and there was a man telling me that my perfect baby could have a life changing diagnosis. A diagnosis I had never even heard of. A diagnosis that he stated could be "life threatening".

After the call, we went online and searched every article we could about VLCAD. Some articles made the disorder seem like a death sentence and some articles were so technical, that it was hard to really grasp what this meant for our son.

We took Mitchell for additional blood tests and we waited for the results. Some days I felt optimistic that the first test was wrong. Some days, I knew that Mitchell had the disorder. We received the call from the specialist's office saying that Mitchell's second test had come back positive for VLCAD and we needed to come in right away to get him on special formula. I was only allowed to exclusively breastfeed my baby for the first two weeks of his life. I cried as we drove to the office to pick up the special formula. I cried when I fed him his first bottle. It took me several weeks to accept that I would not be able to breastfeed him the way I had planned or for as long as I had planned. I felt as if an important part of my bonding time with my son had been ripped away from me. I knew it was for the best, but I took it really hard.

We got Mitchell on his special formula, and he took to it like a champion. As the months went on, he was gaining weight appropriately, his tests for cardiomyopathy came back negative and everything was going extremely well for him. You would never know that he had any issues just by looking at him. He was happy, healthy and thriving.

Then in January, our sweet baby boy got a common cold – RSV – and had to be hospitalized for five days. While we were there, one of the nurses did not check his IV in the middle of the night and when it was checked the next day, they realized his vein had blown and he was not receiving his D10. Mitchell had been lethargic the entire night and for most of the morning, but I figured it was because he was tired and sick. I did not realize it was because his body was getting close to a metabolic crisis. Once they replaced his IV, he perked up and became himself again. That was the moment that I finally accepted that he had VLCAD. I think I had been in denial before because he always seemed so healthy…but watching him go from limp to playful just because of the IV fluids really gave me a wakeup call.

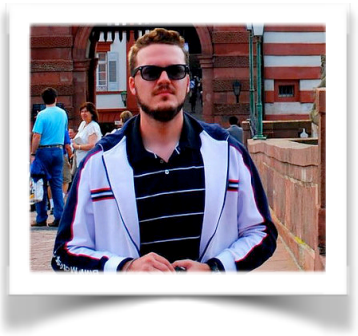
Mitchell is going to be turning one at the end of July and he still continues to thrive. He has been extremely healthy and happy, despite the VLCAD.

Moving forward I think our biggest adjustment will be the lack of convenience (food wise) this diagnosis presents. I find myself overwhelmed from time to time thinking about all of the meals I'll need to cook, all of the fats I need to calculate and the MCT oil I need to measure and get him to eat.

All in all, we are very thankful for our team who takes care of Mitchell's special body, we are thankful that he has not had any serious issues because of his disorder and we are thankful that we found out about it early. We know that this is a long road and there is no cure available…but we are thankful that he has been healthy and happy as we figure this entire thing out together.

Justine Scott
Rocklin, CA

"LCHADAttacks" ~ Information on when Adam's body is in distress due to LCHAD



When Adam has an LCHAD attack his metabolism is out of balance. His body is in need of energy sources to perform the voluntary and involuntary activities that keep his body functioning. Normally, short-term energy needs are taken care of by eating carbohydrates. When the body is in a state of continuous physical activity it will use these short- term energy sources (carbohydrates) first to give the body energy. After all the carbohydrates are used up, the body then moves on to fat, and will breakdown the fats in our body for energy. However, patients with LCHAD lack the enzyme used to break down fats. If LCHAD patient's carbohydrates become depleted due to excessive activity or unusual stress on the body, the body's first instinct will be to use fats to break them down for energy, but since they are lacking the enzyme to convert the fats to energy, the body produces a toxic by-product instead of energy. Next, the body will then move to the muscle, and break down muscle for sources of energy. The extreme case of this metabolic crisis is called Myoglobinuria. There are several reasons why Adam develops Myoglobinuria; a slight viral infection, bacterial infection, excessive exercise, long fasting periods, and dehydration. Unfortunately, Adam has suffered many of these attacks, which results in hospital stays for 2-6 days. During this time, he is given an IV solution of 10% dextrose at over 100 ml/hr to re-hydrate his system and protect his kidneys from the effects of Myoglobinuria. As a young child, Adam would complain of "hurty legs", and this was an indication that he was on the verge of an attack. This is a severe aching in his legs that usually begins in his calves and works quickly up to his thighs and other parts of his body. The severity of the pain doesn't always lead to hospitalization. Once, we spent about one hour on a brisk sunny afternoon at the ocean soon proceeded by about a one-hour visit with a friend. After the visit we proceeded to go eat, and as we were sitting down to eat, Adam began complaining of leg pain. The pain moved to his arms, neck, and chest. He complained it hurt to breathe or talk. Even after having fluids at our dinner, we took him to the car where we continued to hydrate him with sugar fluids and water. He was able to overcome the incident without hospitalization!

We are quite frustrated by these sometimes seemingly random LCHAD attacks. Sometimes when we expect them, they don't occur, and other times out of the blue he gets sick. This is very difficult for us and even though we try to monitor his activities, sometimes all of our attentiveness fails. Over the years Adam has learned how to hydrate and fuel himself before strenuous or long events, in order to prevent these attacks. However, even now at the age of 25 he still has attacks. Our main concern is the long-term effects of frequent breakdown of muscle tissue in Adam's body.

Valerie Fulton, mom Adam's page

Welcome to FOD Awareness Month!

Several years ago we created 'FOD Awareness Month' so the world would become more aware of these rare Fatty Oxidation Disorders. One way that we create awareness is by our FOD Banner ~ and this year we have chosen to honor Chelsea (adult LCHAD 1992~2016) and Josh (14 yrs, GA2/MADD from Australia). Thank you to their parents, Sonia and Lynda, for sharing your wonderful children in our Mission to create Awareness!

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 located on fodsupport.org/awareness.htm 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 July 2018 Conference in Minnesota.

So please keep us in mind if you are able to donate anytime throughout 2017 and beyond!

Family Fundraisers

Sarah Dawn, one of our LCHAD Families in MD, has friends who have a nonprofit called Adventures for the Cure that wanted to raise money for the FOD Group. They did a biking event called Everesting - Biking up and down a steep hill until they reach the height of Everest. Sarah suggested our Group as a 50/50 beneficiary of their cycling event! They **raised over $5000 for our Research Trust Fund!**

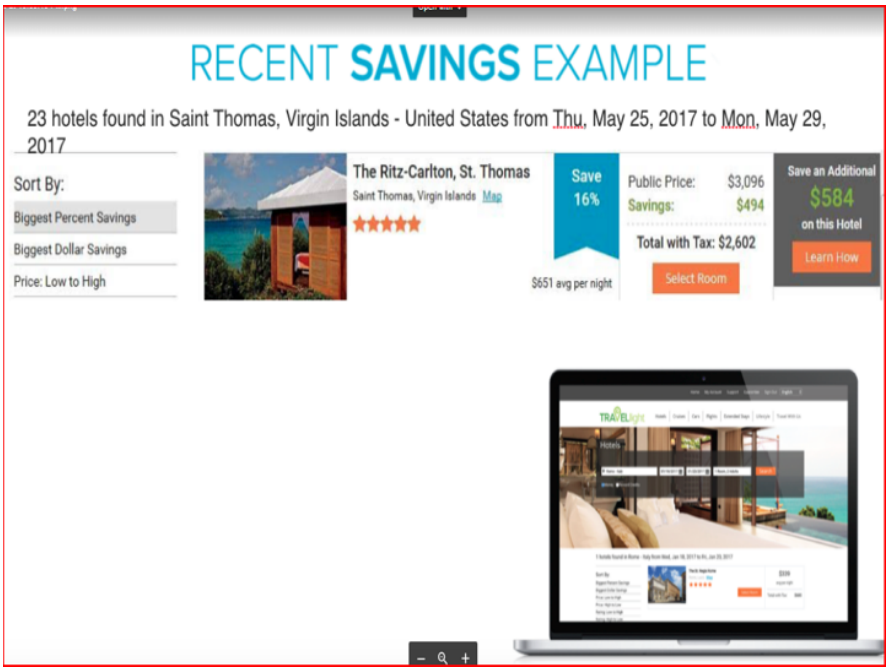
THANK YOU to all!

Possible Future Family Fundraiser

Hello Fellow FOD Families,

My name is Joe Pizzimenti and I am the father of Gianna Pizzimenti (5 years old LCHAD). My wife Kristy and I have been involved with this unbelievable group since we learned of Gianna's condition when she was born. We have been to the last 3 conferences and are so grateful for the relationships we have built and look forward to meeting so many more families in the future. We truly appreciate everything that Deb and the team does to provide so much information and to put together the conferences so that we could learn and meet so many people that we can relate to.

I have recently gotten involved with a great company called Viridian Travel Light and thought of how we can give back and help the FOD Group and the all of the FOD families. Deb and I are working to roll out a website soon that will provide some great savings for all the families in the group for travel. We provide a **FREE private booking site to book hotels and car rentals at wholesale prices.** The families will **HAVE ACCESS TO THE FREE site** to book any of their family vacations, business trips as well as any future FOD Conferences. The best part of this opportunity is that when anybody **books their hotels or car rentals and completes the trip through the FOD link provided, 80% of what you save will go to the FOD Group!** For example, if somebody books through the site and they save $200 off of the best online public price, the FOD Group will receive $160!!! We are working to get the site up and running as well as a short video showing you how to sign up for the site and they will soon be posted to the FOD Group page so look out for that from Deb.



MEDICAL UPDATE

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

I wanted to share a very special article honoring Dr Charles R Roe, one of our clinical and research experts in the field of FODs (now retired) and on our FOD Medical Advisory Board ~ it's a wonderful compilation of his life and work in medicine and presents some of his important contributions.

He MOST definitely impacted our lives (Dan and myself) in 1986, when Kevin was born, one year after the sudden death of our daughter/his 21-mos-old sister, Kristen, from what the IL medical examiner said was reye's syndrome (which we KNEW it wasn't!). Before Kevin was born we had read about MCAD (my sister's Ped had sent us an article by Dr Roe and others that she read in one of her journals ~ talk about synchronicity!!!) and we INSISTED that he be tested after birth. Even when our Drs initially dismissed our request as 'that is very rare and he probably won't have it and that's not what Kristen died from,' we still insisted.

After Kevin was born and within 24 hrs of sending blood to Duke University where Dr Roe was at the time, Kevin was diagnosed with MCAD. AND because the IL medical examiner had THANKFULLY saved some frozen liver tissue from Kristen's autopsy a year before, we sent that as well and she too was CORRECTLY diagnosed with MCAD by Dr Roe. Our 2nd son, Brian, was thankfully a carrier and not directly affected.

So Dan and I are eternally grateful to Dr Roe and so very glad to share this Special Honor Issue! *DLG*

Medical Articles/Info of Interest

Late presentation of medium-chain acyl-CoAdehydrogenase

Clinical Trials, Studies and Registries for Mitochondrial Disease

A Study "which assesses the burden of rare diseases in Australia, using innovative techniques that are applicable globally"

SPECIAL FAMILY ARTICLES

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

April 3, 2017 was World Autism Day. Kristi Wees was honored to write about some of the root causes of "autism" in this month's issue of Autism Notebook Magazine Pittsburgh.

NEWBORN SCREENING UPDATE

Making Sense of Newborn Screening Cut-off Values

Posted on February 28, 2017 in Newborn Screening and Genetics

[**Thank you to Association of Public Health Laboratories for allowing us to reprint their blog post**]

Newborn screening is the practice of screening every baby in their first 24-48 hours of life for certain harmful or potentially fatal conditions that are not otherwise apparent at birth. For babies who have abnormal screens for one of these conditions, rapid identification and treatment makes the difference between health and disability – or even life and death. Every year more than 12,000 newborn lives are saved or improved through newborn screening. It is the largest and most successful health promotion and disease prevention system in the country.

How is a screening test different from a diagnostic test?

A screening test looks for abnormal levels that may indicate signs of a disease when no symptoms are present. It tells a patient their risk – normal levels indicate low-risk and abnormal levels indicate high-risk. A diagnostic test determines if, in fact, the disease is present allowing the healthcare provider to make a definitive diagnosis and initiate treatment.

Newborn screening is not a diagnostic test but rather a screening test – it determines whether the baby has a high or low risk of having that disease. If a baby has abnormal screening results, the baby's levels were out of normal range. This immediately cues the healthcare provider to pursue additional diagnostic testing in order to know whether or not the baby has the disease in question.
If a baby has symptoms or family history of a disease, parents should not rely entirely on newborn screening to rule it out; healthcare providers should be consulted for additional diagnostic testing.

What are cut-off values?

As in many scientific tests, cut-off values are used to determine which levels are normal and abnormal. Newborn screening looks for markers of disease and the cut-off levels tell scientists if the amount of markers indicates high or low risk. Determining the precise cut-off values is extremely nuanced and always being evaluated.

How are cut-off values determined and why do they vary from state to state?

Every state newborn screening lab determines the optimal cut-off values for its population. The values are set using a number of factors and considerations such as:

- The disease's prevalence and severity in the state's population,
- Race and ethnic differences in the state (again, relating to a disease's prevalence),
- Environmental factors in the state (temperature or altitude, for example) which can affect testing,
- Differences in the way the laboratory test is performed (methodology),
- And other factors unique to the laboratory and its equipment.

For these reasons, a value in one state newborn screening lab cannot simply be compared to a value in another lab. The value associated with a normal screen in one state's population may differ significantly from the value associated with a normal screening at another lab. That is, the line between normal and abnormal could be different in each state.

For example, Baby A gets a value of 14 which is normal in her state where the cut-off is 16. In a neighboring state, the cut-off is 10 so a 14 would be considered abnormal. However, because of differences in how cut-off values were determined and how the test was performed, Baby A's sample would have screened at 8 in the neighboring state and been considered normal as well.

What are false positives and false negatives?

Sometimes newborn screening will show that a baby has abnormal levels of markers for a disease, but further diagnostic testing is negative. This is a false positive. In extremely rare cases, newborn screening will show normal levels of markers in babies who will eventually develop diseases. This is a false negative or delayed diagnosis.

False positives can be extremely stressful for families. In some cases, the diagnostic process can take several months leading to distress and hardship for the baby and family. False negatives, on the other hand, mean that a baby might begin experiencing symptoms of a condition before being diagnosed. Depending on the condition, these symptoms could cause life-long development delays, permanent disability or even death.

If cut-off values are thought of as a filter, state newborn screening programs work to find the optimal filter to catch as many babies as they can. That may mean catching more babies who are ultimately determined to be healthy to avoid missing others who may later receive positive diagnoses. . So while some false positives are necessary to avoid false negatives, states strive to keep them to a minimum.

What happens when there is a delayed diagnosis (aka, false negative)?
While delayed diagnoses (aka, false negatives or missed cases) are extremely rare, they are not nonexistent. State newborn screening program staff work to save babies' lives and they take this job extremely seriously. It takes just one delayed diagnosis reported to a newborn screening program to trigger a comprehensive examination of the system. Every effort is made to understand why the case was missed and what, if any, changes can be made to prevent additional delayed diagnoses.

When a delayed diagnosis is reported to the state newborn screening program, the laboratory scientists begin repeating the test to see if they get different results. They retest the baby's bloodspot if it is still available and revalidate the testing equipment to make sure it is functioning properly. If everything is still the same upon retesting, newborn screening laboratory scientists will reevaluate the state cut-off values for the condition, consider altering the sensitivity of the testing equipment and/or determine whether the baby's biology (fluctuating hormone levels, for example) may have affected the screen.

What has been done to prevent delayed diagnoses? Is there more than can be done?
Many states have implemented processes to prevent delayed diagnoses while keeping false positives to a minimum. In most states, when a baby's newborn screening results are abnormal, the test is performed again to confirm that the results are consistent. In cases where the value is abnormal but is close to the cut-off, second tier testing may be used. Second tier testing employs a more sensitive test that can eliminate some false positives and delayed diagnoses. But second tier tests are also more expensive, more complex and take more time than the primary method of testing. For these reasons, they are reserved for supporting or refuting a borderline abnormal result.

Additionally, newborn screening short-term follow-up program staff review reports from clinicians of babies' final diagnoses. This information, even if consistent with the baby's newborn screening results, helps the program continue to improve the quality of their testing.

Newborn screening programs around the nation routinely evaluate and examine their processes from beginning to end. There is always room for improvement, and newborn screening programs will continue to seek new advances in technology and methodology while looking to other scientists, clinicians and parents for input.

Nutritional Update

New Cookbook

The Fatty acid Oxidation o Disorders Kitchen

This is a cookbook designed for patients with a long-chain fatty acid oxidation disorder. The recipes are low in fat with added MCT oil. There are some great ideas about how to use MCT oil in cooking everything from main dishes and salads to desserts.

The project was a collaboration between Claire Held, BS in Nutrition and Dietetics and living with LCHADD, Melanie Gillingham, PhD, RD, the Graduate Programs in Human Nutrition, and OHSU Bionutrition. Enjoy cooking some new recipes that are designed specifically for you.

All proceeds from this book will be donated to the OHSU foundation to fund additional research for novel treatments of fatty acid oxidation disorders.

Order here:
http://www.ohsu.edu/tech-transfer/portal/technology.php?technology_id=2373373

Be sure to check out this new book and order here!

Also there's a new food app that was talked about at our 2016 Conference in Denver

Parent to Parent Suggestions

Melissa Carey suggested Substitutes and Techniques for Fat-free Cooking

[Please Note: Read the full fat content of the substitutes carefully – they may not be appropriate for your/your child's specific FOD]

Will You Be Able to Help Your College-Age Child in a Medical Emergency

Stephanie Harry's Blog (LCHAD)

"This blog shares our journey, hopes, and fears. We also want this blog to contain practical information! Entries will include: yummy recipes, how we manage his LCHADD, conversations about medical issues, educational tools, and useful links on the side of the blog! If you are ever curious about something I have shared feel free to contact me personally!"

Reach for the Stars

Hi everyone! Please help support my ten-year-old son, Max Heizer, who has LCHAD, in supporting his new YouTube cooking channel for low fat meals. For years he had an eating aversion and would only eat by G-Tube, and we are to the point where he now eats everything my mouth. I am teaching him how to cook low-fat, high carb meals. He just started his cooking channel, and is posting weekly recipes. He now wants to be a chef!

Please show your support for him by subscribing to his free YouTube cooking channel! Thank you!
J. Lisa Heizer (mom)

For all you new FOD parents who worry about the future, there is no reason to give up hope on a "normal" future for your FOD kids. This is my son Zach, 16 with MCADD. He has played sports his entire life and is very active in other activities as well. Stay strong everyone!

Alicia, mom

RESOURCES

Invitae Announcing expanded services/tests for genetic testing ~ FODs are included

As an Advocacy Partner using our Patient Insights Network (PIN) and registry services we aim to keep you up to date about offerings that may be relevant to your community. We are pleased to share the announcement of a **recent test menu expansion from Invitae.** [Invitae (formerly was AltaVoice) is the company that offers the FOD Group the free REGISTRY that may eventually help FOD researchers!]

At Invitae, we are committed to **providing high quality genetic testing easily and affordably.** We are excited to release 80 new panels and update 24 existing panels centered on our **metabolic disorders & newborn screening** clinical areas.

This release is another step toward our goal of ensuring you have the tools to provide your patients with the answers they need.

Our expanded metabolic disorders & newborn screening offering includes:

- Updated metabolic disorders newborn screening confirmation panel
- New and updated panels by analyte
- New panels focused on defects of carbohydrate metabolism, including glycogen storage disorders
- New and updated ketogenesis and ketolysis disorders panels

Highlights of this expansion include:

- Expanded metabolic newborn screening confirmation panel that includes X-linked adrenoleukodystrophy, LSDs, and acidemias
- Panel testing to enable earlier diagnosis
- New panels covering peroxisomal, neurotransmitter, glycogen storage, and other rare metabolic disorders

You can view the full press release with additional information on our website.

With our flexible menu, you can easily select a pre-curated panel, combine multiple panels, or customize your own panel from scratch. In our continued mission to make genetic testing more accessible and affordable, prices and services remain the same and include clinical consultations with genetic counselors and help with ordering, billing, and interpreting results. All of the new tests include complete gene sequencing and exon-level deletion/duplication analysis in a single assay.

All new and updated panels are available to order online or using a paper order form.
If you have any questions, please do not hesitate to contact Client Services.

Invitae is very transparent with their pricing, in fact, the two price tiers are promoted on the Invitae homepage. Here's the link that gets into the details about insurance billing

US testing inquiries
US customer assistance is available Monday through Friday, 5:00 am to 5:00 pm Pacific

Phone: 415-374-7782
Toll Free: 800-436-3037
Domestic Spanish: 415-423-3277

Fax: 415-276-4164
Email: clientservices@invitae.com

International inquiries
International customer assistance is available Monday through Friday, 4:00 am to 5:00 pm Pacific
International email:
globalsupport@invitae.com
International phone:
+1 415-930-4018
Local phone numbers, for English, Spanish, and Portuguese:
Argentina: +54 11-5032-0180
Brazil: +55 11-3181-4924
Canada: 1-888-332-6039
Chile: +56 2-2599-4386
Colombia: +57 1-486-4863
Mexico: +52 554-777-2190
Peru: +51 1-705-9827
Uruguay: +598 000-4019-0910

Feeding Tube Awareness Foundation

"Our mission is twofold. First, we would like to help other parents by sharing practical experience tube-feeding infants and children. Secondly, we would like to raise positive awareness of tube feeding so that families have the support they need.

The success of this effort relies heavily on the many parents who have shared their stories, knowledge, and support."

The Children's Medical Nutrition Alliance (CMNuA), a 501(C)3 nonprofit organization, was developed out of the explicit need for a unified voice to empower, educate, assist, advocate for and support **ALL patients** who require medical nutrition. CMNuA exists to provide an effective national coalition of parents, healthcare providers, advocacy groups and corporations dedicated to a common overarching mission. That mission, simply stated, is to improve the lives of patients and families dealing with digestive disorders, diseases and other medical conditions that requires medical foods and formulas to survive and thrive. CMNuA creates that positive change through direct support, information, education, advocacy, and community.

Pharmaceutical Update

Sigma-Tau Pharmaceuticals, Inc. Changes Name to Leadiant Biosciences, Inc. And Reaffirms its Commitment to Rare Disease Communities

Celebration and Launch of www.Leadiant.com Commemorate Rare Disease Day 2017

February 28, 2017 07:30 PM Eastern Standard Time

GAITHERSBURG, Md.--(BUSINESS WIRE)--Sigma-Tau Pharmaceuticals, Inc., a leader in the development and commercialization of medicines for patients with rare diseases, today announced that the company has changed its name to Leadiant Biosciences, Inc. reaffirming the company's continued strong commitment to the patient communities
it serves.

"In 2017, Leadiant Biosciences will realize several important and exciting milestones in our product pipeline, as well as continuing multiple ongoing clinical trials."

The announcement coincides with Rare Disease Day 2017, a global campaign to raise awareness of rare diseases and improve access to available treatments and medical representation for people, and their caregivers, whose lives are impacted by these conditions. Now in its 10th year, Rare Disease Day is an annual celebration organized by the European Organization for Rare Diseases (EURORDIS) and the National Organization for Rare Disorders (NORD). This year's theme, *With Research, Possibilities Are Limitless*, underscores the importance of collaborative research in the drug-development process and recognizes the contributions of patients and families in advocating for increased investment in rare disease research.

Rare Disease Day is the perfect time to unveil our new name and reaffirm our commitment to the study of rare diseases, which has been an integral part of our heritage dating back to 1984 when we became only the fourth company in the world to receive an Orphan Drug Designation in the U.S.," said Michael Minarich, chief executive officer, Leadiant Biosciences, Inc. "In 2017, Leadiant Biosciences will realize several important and exciting milestones in our product pipeline, as well as continuing multiple ongoing clinical trials."

For more information about the vision, mission and work of Leadiant Biosciences, Inc. visit www.leadiant.com.
For more information about Rare Disease Day 2017, visit www.rarediseaseday.org or www.rarediseaseday.us.

About Leadiant Biosciences, Inc.
Leadiant Biosciences, Inc. (formerly Sigma-Tau Pharmaceuticals, Inc.) is a U.S.-based, wholly owned subsidiary of Leadiant Biosciences S.p.A., a research-based pharmaceutical company dedicated to the development and commercialization of medicines for patients with rare diseases. Based in Gaithersburg, Maryland, Leadiant Biosciences, Inc. dedicates considerable scientific and financial resources to the research, development, and distribution of novel and effective therapies that address patient needs and improve quality of life. For more information, visit www.leadiant.com.

Contacts
Leadiant Biosciences, Inc.:
David Sandoval, 301-948-1041
Sr. Director of Legal Affairs & Chief Compliance Officer
or
SmithSolve LLC on behalf of Leadiant Biosciences:
Robert Murphy, 973-442-1555 ext. 116
Robert.murphy@smithsolve.com

If your Physician needs more information about Levocarnitine (Carnitor®), dosages, or has other questions, please have him/her contact Leadiant Biosciences (formerly Sigma-Tau Pharmaceuticals) and state that he/she has a question about levocarnitine. The phone number is 1-800-447-0169 or info@leadiant.com

The liquid and tablet **generic drug brand** for Levocarnitine was approved for distribution by the FDA many years ago. Please note that the generic drug form by HiTech/Akorn(as well as the brand name Carnitor®) needs a Prescription from the Dr for the oral solution and tablet .

Love Messages

We have had several 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!

Our hearts ache for Rob and Noreen Ryan-Weidener… their beautiful daughter Emma (TFP) and baby sister to Marissa and Andrew, died on March 26, 2017

WE ARE HEARTBROKEN. May perpetual light shine upon my niece, Ariana (CACT, age 3). May she fly freely with her angel wings. A little past 730pm Feb 2, 2017, she peacefully passed away & is now with God. Please keep us in your prayers, specifically her young parents, Lilly & Devon. Thank you all for being on this prayerful journey with Ariana. Your posts, suggestions, prayers have made a tremendous difference. May there one day be a cure! Amen.
Vanessa Sanchez

My precious LCHAD babe, Emily, turned 12 on February 19th this year...and sadly she left us all behind to be with God on April 14, 2017.

Danielle, mom

Charlie was an incredibly special girl. Now, I know a lot of people would say that about their kid who has died, but I really mean it. When she was diagnosed with a severe mutation of GA2, she was given a year to live and we were sent home on hospice. She thrived for a full three years. Her sense of humor was second to none. Her capacity for love and innate sense of empathy was incredible. She was my everything and I will always be honored that I was chosen to be her mom. I think her metabolic specialist put it best, "What she lacked in metabolism, she made up for in personality." We will miss you Chars.
Rachel, mom June 8, 2017

'Love is a fruit in season at all times, and within reach of every hand'

~ Mother Teresa ~

FOD Group Finances

2016 FOD 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 Bracelet and Ribbon Sales, Cafepress.com, iGive, Goodsearch, and any donation that isn't specifically designated for the other Funds. Once the Research and Clinical Funds reach a substantial amount (@$50,000) we will be able to offer grants to clinicians and researchers in the US. No FOD money is used for salaries - we are an ALL Volunteer organization.

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

Families and Professionals...

Please send all Submissions to ***Deb*** by Dec **15, 2017** for the January 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!

THANK YOU

Family Donations since Jan 2017:. John Collins. Natra Joyner. Brittany Sandoval. John Gibson. Kelly V. Mary H. Arnie Messing. Deb Bennett.

Tshirts, Bracelets, Ribbons, CafePress, GoodSearch browsing, MissionFish/eBay selling, iGive or Amazonsmile.org shopping etc: Terrie Breedlove. Debbie Guillory.

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.

Professional Donations : OneHope Foundation. Rare Patient Voice. United Way/Truist. KPMG. Maple City Savings Bank. Community Foundation of Central GA.Morgan Stanley. Adventures for the Cure.

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**

Mailing lists: Erika Wallace
Website Designer: Mary Lingle
Newsletter consulting: Brian Gould
Email/website consultants: Mark Heinz
Website slide shows &Graphic arts: Keith Widmann
FOD/OAA Event Planning: Eileen Shank
Newsletter formatting: Deb

'Being deeply loved by someone gives you strength, while loving someone deeply gives you courage '
~ Lao Tzu ~

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.