The FOD Group had its largest attendance EVER for our National FOD/OAA Conference in Portland, OR at the Red Lion Hotel on the River! It was a beautiful setting and the weather cooperated! We registered over 130, although we had a few late cancellations due to emergencies and other reasons. We had Families from Greece, Australia, Canada and the US! We had several TEEN/ADULT FODers attend—it was terrific that they connected immediately and then shared their experiences with many of the younger Families.

On behalf of ALL of our Families, I want to personally THANK Kathy Stagni of the OAA for being my teammate in planning all the activities and for soliciting funding—without these donations we would never be able to host such a diverse gathering! I want to also thank ALL of our Sponsors—our main Host/Sponsor was the Oregon Health & Science University with Dr Melanie Gillingham not only speaking but helping with coordination of their local Speakers and volunteers for the Kids’ Activity Room — and thank you to all of our Speakers that shared not only their knowledge and expertise of FODs and other information, but were all so generous with their time as to talking in-between sessions and meals with as many Families as possible.

I will have all of our Speaker powerpoint slides up on our Conference page soon, along with their pictures and bios. You can view our Conference Hosts/Sponsors, Agenda and Speaker Bios in our Conference Program.

We also had several volunteers assist us in securing the Hotel [Eileen, MCAD mom], set up the Online Registration Form [Terrie, GA2 mom], help with buying kids’ activity supplies and handling our mailed boxes [local Oregon OAA mom, Janet], selling our FOD items [Gwen, GA2 mom & Brenda, SCAD mom], and designing our ending ceremony slideshow [OAA mom, Raymonde]. THANK YOU to all!

If you forgot to complete the Conference Follow-up Survey, you can go to regonline.com where you originally registered and complete it there.

If there is a Clinic or University that would like to Sponsor/Host our 2014 Conference please contact Kathy or myself!

Please also continue to create awareness of FODs with your family, friends, and medical professionals, as well as create your own ways to raise funds, via ‘Family Fundraisers,’ so we can continue to spread the word about FODs via our website, Conferences, speaking at hospitals, and other various ways that allow us to offer all of our services free of charge. Also, when buying online please remember when you use the iGive link on our site, the FOD Group gets a percentage of your sale. We also earn funds by using GoodSearch as a search engine, or using the Donate button on our site or on our facebook Cause page. You can also order your very own embroidered or screenprinted FOD polo shirt , cap, or any other item of various colors from the same embroidery company that I purchased our Speaker shirts from the 2010 Conference! They have our logo on file.

Families ~ We welcome ALL new or updated Family Stories and pictures and we encourage Families dealing with the less common FODs (i.e. HMG, GA2, Carnitine Uptake Defect, TFP, CPT 1&2 etc.) to share their experiences. We’re also always looking for more low fat recipes, poems, ‘Silver Linings,’ pictures, and ‘Reach for the Stars’ accomplishments of our kids/families.

Professionals ~ we need to hear from you too! New Medical, Research, Nutritional, Counseling/Coping, etc articles are always appreciated.

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... DLG
We were given the wonderful opportunity by USA TODAY to create worldwide awareness of Fatty Oxidation Disorders on July 16, 2012! Our black & white banner ad, created by MCAD dad, Keith Widmann, was printed in the Life section. It was seen by millions of people and hopefully many felt compelled to check out our website and learn more about FODs.

This being our 1st ever ‘FOD Awareness Month’ I shared Kristen’s picture [Oct 6, 1983 - July 21, 1985, Undiagnosed MCAD], as well as Kevin’s [age 26, MCAD diagnosed at Birth]. With expanded NBS we are now adding MANY NEW Families to our Group every year — it truly SAVES LIVES!

So please share our website and brochure with ALL in your Family and your Professional contacts!

And those that would like to create FOD Awareness year-round by having your own fundraiser, PLEASE DO — donations to the FOD Group are tax-deductible!

~ Deb Lee Gould, MEd FOD Director
I want to start by saying that Deb and the FOD Support Group has brought an immense amount of support to our family. I was led to the group after meeting with our genetic doctors for the first time. So up front, thank you Deb!

My husband, Evan, and I decided in early 2010 that it was time to extend our family. After recently, getting married, buying a house and finding our church home it was time to start a family. We had a bit of trouble getting pregnant and started on Clomed and the very first month was a success! That is just how the women in my family work – our bodies need a ‘jump start’ and then we hit the ground running!

The journey of pregnancy was so much fun for Evan and I. Well, maybe me more than Evan; I might have always wanted the house freezing cold, scrambled eggs and absolutely no corn dogs! I enjoyed every part of the pregnancy. I didn’t experience much morning sickness, was active, all labs and medical items were always right on track and over the holiday season I could eat whatever I wanted in stretchy pants! We attended classes for breastfeeding and natural births; as I wanted to have a natural birth using Hypnobabies techniques. In the spirit of our ‘stubborn’ family, with about three weeks until our due date Lucas, was turned the wrong way. We scheduled an external cephalic version (ECV) and a caesarean section. I had my heart set on a natural birth and that was just not how Lucas wanted to enter the world.

On January 25, 2011, we arrived at the hospital and prepared for the coming procedures. I had two OBGYN’s performing the ECV and caesarean, with our family doctor/pedestrian waiting to grab Lucas once he was out. My OB’s attempted the ECV procedure twice and Lucas simply went back to his original position each time. So, since Lucas didn’t want to come naturally, we went in and got him! He was born at 12:55 p.m., weighing seven pounds and ten ounces and 20 inches long. He was so beautiful and perfect. Following all the perfect evaluations from the doctors, Lucas and I were wheeled from the operating room back to a room to start our new journey with family waiting!

During our hospital stay, Evan, Lucas and I learned the basics of diapers, talked to all the nurses about care and blood draws (Newborn Screening), put our latching and feeding techniques to work, and got to know our perfect son! We had all the emotions, excitement, questions, fear and nerves of all new parents. We signed all the proper paper work and installed the car seat correctly and made our first ‘scary’ five minute car ride home with our son! We had all the normal visitors, started our new routines and began to learn life as the three of us!

Mother Nature was not cooperating because just days after bringing Lucas home, we had an ice storm that sealed us up in our house for about four days. Evan and I were scared we would lose power, but by the grace of God we did not. On day eight, mid-afternoon the phone rang. Lucas and I were feeding and Evan was talking with the Pastor’s wife about the last few days. It was the pediatrician on-call since ours was on a mission trip. She informed me that the newborn screen results were in and a few things were showing abnormal and we needed to call Doctor Hainline at Riley Children’s Hospital to make an appointment tomorrow. I was unable to speak, started crying and handed Lucas to Evan. The on-call doctor was trying her best to comfort me and also give me names and phone numbers and said to call her back after I had spoken to Riley, to ensure we got in. So with courage and strength that I now know only a parent can have, I pulled myself together and called the hospital to make the appointment. Riley Children’s Hospital is the best around and is not a place you ‘get in tomorrow’ unless something is very wrong.

The first appointment with Hainline’s office was one of the scariest meetings we had ever been in. First, they asked us if we had any questions and I replied “Um yes, why are we here?” In the room was the genetic counselor, the nutritionist, metabolism nurse and Doctor Hainline, the genetic counselor started to tell us what was going on. They wanted to take blood and urine samples to perform a few more tests and said that Lucas has a rare genetic disorder called Glutaric Acidemia Type 2. She told us of the common medications, the common developmental status’, the unknown life expectancy, dietary requirements, the rareness of the disorder and basically scared Evan and I to death as new parents. Here I was holding my nine day old baby boy, crying my eyes out, thanking God for my miracle, and praying he wouldn’t die in his sleep that night. This meeting was about three hours long. We had questions but mostly it was simply us just listening to what they were saying. At the end of the meeting we set up an appointment to get the lab results, were given a script for Carnitine, an emergency protocol letter, and handed a couple of packets of information to read. Then they showed us where to go to get Lucas’ blood drawn. That Friday afternoon our lives, yet again, changed forever.

We stopped by the pharmacy on our way home in silence, mostly because I could not speak, and wondered what this all meant. Over the next couple of days, I breastfed Lucas every two hours around the clock, started his medicine, watched for all the different signs we were told about, took shifts watching him sleep and wrote down all the questions we had. We informed the pediatrician and she also got in touch with the metabolic team to get a summary of the diagnosis. The two doctor’s visit with the pediatrician went well, from a newborn baby stand point. Lucas had gained a bit of weight, physically looked well from a newborn
baby stand point. Lucas had gained a bit of weight, physically looked well and he was measuring well with a slightly larger head. He looked and seemed to act like any normal newborn baby. No one would have ever known what was happening on the inside.

The lab results finally came in confirming GAII. We were still allowed to give him breast milk, but I started pumping in order to measure his intake. We started a Poly-Vi-Sol Multivitamin with Iron, CoQ 10 and increased the Carnitine dose. We set up an appointment for an echocardiogram and were told to hold off on all immunizations until the next round of blood work. After that he could have them, just not all at once. We arranged the time intervals with the pediatrician.

Evan and I were doing our best to stay strong and figure everything out. We have a wonderful church family that was caring for us, our best friends and family were there every day to help with small tasks around the house, to let us sleep or just to listen to us cry and vent. Prior to the ‘phone call’ I was already struggling with post-partum depression and this situation only intensified that. So we were trying to make our way through that part of the journey as well. In the spirit of having to know everything always, I started researching online. Anything and everything I could find I read. Most of it was extremely fatal and depressing and not at all encouraging. I would call and email the genetic counselor with questions and articles. When I asked her if I was bothering her will all my inquiries, she kindly replied “No, and said to contact her with anything.”

Since then we watched Lucas and tried to learn everything we could about his actions, behaviors, and his temperament, as any parent does to try and discern normal baby/toddler things from symptoms of GA2. At three months of age Lucas came down with RSV and pneumonia, which landed us in the hospital for eight days (five in the NICU). We were on IV fluids, Vapotherm, oxygen, NG tube and steroids. He was in the lower reference range of being acidic, but thankfully never got there. He did though have a terrible time breathing and his oxygen saturation was dangerously low. We took this opportunity to get the gene sequencing done on all three of us to figure out exactly what the mutations were. These were sent off to Denver for analysis. We did go home on oxygen and a NG tube.

The DNA results came in about three months later with a positive ETFDH mutation, with the ETFA and ETFB genes showing no mutation at all. This mutation is riboflavin (B2) responsive, so 50 mg was immediately started. Side note: B2 is extremely nasty tasting.

Skipping ahead to look back.....

Lucas is 18 month old now and growing and developing beautifully. Around nine months old we enrolled him in a program called First Steps and began to get him PT, OT and nutrition therapy. And this fall we will get him evaluated for speech therapy. He has met all of his milestones in a timely manner, but the help from First Steps gave him the confidence to attain our goals for him with much more ease. Since the first hospitalization with RSV and pneumonia at three months old, we have been admitted five other times through the ER and directly to the NICU for croup, HMV, pneumonia, and an asthma attack.

We have come home twice on oxygen and additional breathing treatments. We have even had “T” tubes placed in his ears right after his first birthday because of the drainage and ear infections. We have had barium swallow tests to check for aspiration, because of all the congestion. The techs only were successful with a handful of swallows, so we might end up repeating this test. We are followed very closely by the Ear, Nose, Throat and Allergy doctor as well. Pulmonary is also following us closely since Lucas has never really been able to completely recover from all the respiratory distress.

Evan and I have been very blessed to have wonderful jobs and fantastic insurance, which has taken a great deal of pressure off our shoulders. I have been lucky to have had so much vacation time and most of all Evan’s job...this past March when Lucas was hospitalized with what we are calling a severe asthma attack. We were scared to send Lucas back to the sitter’s house in fear of another illness. Evan was able to become a stay at home dad and will return to work mid-August. This has allowed us to get Lucas’ health back on track. We are off oxygen, breathing treatments and inhalers now and only a simple nose spray before bed.

During this time we concentrated on furthering Lucas’ development and started some baby sign language techniques for communication since he doesn’t use words yet. It’s as if all the ear infections affected his hearing and we lost the first year of sound, but we are trying to catch up since the tubes were placed. This summer has presented some problems with controlling his body temperature in the 100 degree heat and humidity, but with ice packs and Gatorade we have keep him regulated with no real scares.

Again, during the last 18 months and the roller coaster of life that we have been on, Lucas has been the happiest child. With oxygen tubes in his nose, IV’s in his head/hands/feet, he always smiles, wants to play and is happy to see everyone. He absolutely loves bath time and to swim. He has no fear of new things and he loves to eat Pop Tarts and bananas.

In writing this letter, I just returned from the 2012 FOD Conference in Portland and had an amazing experience. I was able to personally meet Deb, GA2 moms, other FOD families and some of the top metabolic doctors in the world. The conference weekend is beyond words. Being able to learn other’s stories, good times and bad times and speak with the doctors on a personal one-on-one level was priceless. The medical knowledge, the practical knowledge and the encouragement from this weekend was love and passion at its purest. Thank you Deb for making this all possible and providing a canvas for all of us to paint our stories on.
Sadie’s Story ~ UK Adult VLCAD

I was diagnosed when I was 30 after running a half marathon in 2010. I was admitted to hospital that night as they thought I just had muscular pain from running the race. The muscle spasms were actually full muscle breakdown and I was admitted to the HDU with a CK level of over 400,000. I have been told what happened as I was unconscious for 10 days. I spent 3 weeks in total on dialysis to restart my kidneys as they had failed and had a few other serious complications. After a 5 week stay in hospital it led to the Doctors discovering I have a ‘mild’ form of VLCAD (that didn’t seem a mild way to find out!).

I haven't been told to follow a strict diet as such, (so no MCT oils etc for me), however I am much more aware of what I eat and can seem to control things before it gets to the hospitalization stage. Despite having this condition I do lead a pretty normal life — I work full time, have my own house and even manage to go to the gym again in my lunch hour. It took a lot of recovery to get over my stay in hospital as that was a life or death situation for a long time.

I know a lot of people find out they have this condition with screenings or constant trips to the Doctor etc. It seems I decided to be a little different to that, so if you have any questions about my hospital stuff please feel free to ask!

Sadie :) United Kingdom
sadie_fennell@hotmail.com

Harper’s Story ~ SCAD

At 30 weeks pregnant it was discovered that I had preeclampsia. A pretty severe case. I was sent to Nortons, in Louisville, KY to await the arrival of baby Harper. We thought she was going to have to come early due to complications with my diabetes and preeclampsia. My sugars were uncontrolled and my blood pressure was unpredictable. I held on for 6 more weeks. The ordeal of being hospitalized the last 6 weeks was grueling; I was just ready to get this baby out so I could start being a mommy. I’m an Aunt of several, and I couldn’t wait to get the experiences that my sisters got with their children. Unfortunately, it didn’t work out that way for me.

Harper was born on December 31st 2010, New Years Eve. Me and Daddy were so ready, I lost a lot of blood during delivery, almost passed out and felt pretty ‘dead’ for awhile. My hemoglobin didn’t come up for several weeks. So, to say the least, I wasn’t feeling too well. But, I was ready to meet my little wonder.

Harper was 7lbs 2oz. Pretty hefty for being 4 weeks early. She was healthy, and we were happy. After being situated into a room they brought her to me. I got to feed her. She wasn’t much into breastfeeding, I tried my best, and pumped as much as I could, but she opted for the bottle.

Because I have diabetes, they came in to check her sugar, this is the first sugar check Harper has ever gotten. It was 28. They didn’t seem too concerned. They said that while she was in my tummy she relied on my glucose and insulin to control her sugars as well. So once she got out, it had to regulate itself. This was expected. After taking two of the little two ounce bottles, they came in to recheck her sugar. It was 30. They were getting a little concerned and said that she probably needed to go to the intermediate nursery (between the regular nursery and the NICU) for the night. Just to be safe. I was so weak and sick, I went to sleep, and waited to see her again.
Her sugars over the next five days finally regulated. After being in the intermediate nursery for 5 days, she got to come home. We were so happy. It seemed like those five days took forever. I couldn’t wait to get home and be a mommy, finally. Life was amazing for a couple days. I was still a little nervous about her sugars but knew it was because of my diabetes.

On January 8th, at around 1pm, I got a phone call. You know what I’m talking about. The call. I answer. “Mrs. Anthony, we were just calling to tell you that Harper tested positive for something on her Newborn Screening.” They go on to tell me there is nothing to worry about and that most of the time, these come back okay, and babies don’t even have the disorder. To be safe, they said to feed her every 3 hours.

I cried. For days. Weeks even. I wasn’t able to function, eat or sleep. I was useless. This is before it was even confirmed.

After a couple of tests, we waited, and finally found out that yes, she does have SCADD. We got into a geneticist office immediately and started treatment. Eat every 3-4 hours and take carnitine, and all should be well. At this point, I feel better. I feel like I know what to do, I can take care of my child now.

I couldn’t take care of her. Whatever was going on inside her body was out of my hands. It did what it wanted. We would feed her every 3 hours around the clock, we had multiple alarms set to feed her. We were ritualistic about the way she was being fed. And if someone thought we were crazy, well, it was certainly okay for them to go to hell. I was doing what needed to be done to keep her alive.

Harper had a lot of issues. We found out she had kidney reflux. Which wasn’t much of an issue in itself, but with the SCADD, if Harper were to get infections, we were in the hospital. Which seemed to be all the time. Out of Harper’s first year, four months of it was spent in the hospital. She was always at Kosairs. We’ve come to be regulars. They know our names, and they’re like family.

Harper’s sugars were crazy. They had a mind of their own. No matter what we did, her sugar seemed to want to drop. She would be on her normal schedule, eating great, acting fine, and her sugar would be in the fifties and sixties. She would be in the hospital for weeks at a time, waiting for her sugar to regulate. Eventually it would, and we would go home. We would be back in another week. This all happened so fast, we didn’t have time to be devastated. We only had time to feed, check sugars and wait.

I knew something wasn’t right. We’re doing what we’re told, and she’s sick. I expressed this many times. They said that the first year was usually the hardest and it would get better. But in my mind I thought ‘What if we’re asleep? The alarm doesn’t go off. What if we get a flat tire and it’s time for her to eat? We don’t have enough for another bottle.’ It was always what if.

When she was about 9 months old, she went a full week with her sugars not being above 70. She was eating and getting Dextrose 10, but her sugars weren’t following.

Her geneticist decided that he thought something else was going on. She was tested for hyperinsulinism, and a couple other endocrine disorders. They wanted to test her for Growth Hormone Deficiency. This meant a fasting blood test. And of course, we waited, and waited. They wanted her sugar at 50 before they would draw the blood. The one time when we WANTED her sugars to drop, they wouldn’t. She went 20 hours without eating, and finally, 50. Blood was drawn. They gave her a glucogen shot, and she perked up right away. This was the hardest thing I’ve done in my life. Waited. It’s not natural for a mother to let her child not eat, it felt wrong and abusive. I watched her deteriorate. Her eyes were glossy, but her sugar was 65. She was acting lethargic, but her sugar was 55. Finally, after ‘falling asleep’ her sugar reached 50.

The results came back, she had Growth Hormone Deficiency. GHD and SCADD are not usually extremely severe disorders. But together, they were killing my baby.

After two central lines due to frequent IVs and over 15 hospitalizations, Harper now has no cords coming out of her, and she is ‘normal.’ She takes her carnitine, and an injection of Human Growth Hormone daily and she’s healthy. Since being treated for GHD, she’s like a different child. She’s growing, and she’s happy. We’re happy.

I’m 22 years old. When I got married I couldn’t wait to have a child. People need to think about the child they’ll be having. It isn’t all fairy tales. Reality is that anyone can have a child with a disease. Luckily, we caught hers. The reason she is alive is because I didn’t give up. I drove myself, my body, my family, and the doctors crazy making sure my baby was safe. Now she is.

Erica Gibson  Leitchfield, KY  ericagibson2007@hotmail.com

[Update July 2012— It was determined that Harper now also has 2 benign brain tumors and if they start to cause a problem they will be drained...story to be continued in the future]
Medical Articles as resources:

A Rough Guide to Acylcarnitines

Clinical and Genetic Characterisation of Lipid storage myopathies

Medical ‘Bits of Info’:

● Free carnitine & Total carnitine are the two things needed to determine a carnitine deficiency. Free is the type our body can use to aid in getting rid of organic acids etc., like EMA, which can be elevated sometimes in SCAD deficiency.

Total carnitine represents the stored amount, however muscle carnitine levels can be many times higher (or lower) than what we measure in blood. If the total is OK the muscle stores are likely to be Ok as well.

Lynne A. Wolfe, MS, CRNP, BC  lynne.wolfe@nih.gov  Genetic Nurse Practitioner  Undiagnosed Diseases Program  NIH/NHGRI

● Pancreatitis has been reported in many of the organic acidurias, including MMA, PA, IVA, MSUD, disorders of long-chain fatty acid oxidation and the carnitine cycle, many forms of mito disease including GA II; rarely in PKU or urea cycle disorders, or MCAD deficiency. Abdominal pain due to vomiting and ketosis in most of these disorders is common; so the pancreatitis (which can cause abdominal pain and vomiting) is hidden or overlooked. Mild increases in pancreatic enzymes amylase and lipase are common do not necessarily mean pancreatitis—ultrasound showing edema of the pancreas and nearby structures (bile ducts, gall bladder) can be very helpful. Recurrent pancreatitis can lead to destruction of the pancreas, and inability to make enough insulin (= diabetes). It’s a bit late here for a longer reply—sorry for the brevity.

Stephen G. Kahler, MD  KahlerStepheng@uams.edu  Professor, Genetics and Metabolism Section  Department of Pediatrics  University of Arkansas for Medical Sciences

● Many patients with defects of long-chain or medium-chain fatty acid oxidation can produce some ketones. Negative ketones with low blood glucose is of course a major clue, but the presence of ketones doesn’t rule out an FOD. In my experience the ketones are never very large (4+) in such patients, but certainly can be present during fasting, and will be suspiciously low considering how low the blood sugar is. This is where you’ll find the term hypoketotic hypoglycemia. My comments are based on experience--someone with real data (Dr. Vockley, for example) could probably add more details--what % of patients have had no ketones detectable when they've gotten ill, for example.

Stephen G. Kahler, MD  KahlerStepheng@uams.edu  Professor, Genetics and Metabolism Section  Department of Pediatrics  University of Arkansas for Medical Sciences

● FOD Parent Suggestion—Emergency Protocol Letter

I copied part of Jordan's VLCAD emergency protocol letter [written by her Drs] that deals with D10 and hyperglycemia:

"Neither should the IV rate be lowered because of mild to moderate hyperglycemia, because elevations of blood glucose may occur as a physiological response to relative intracellular hypoglycemia, a common phenomenon in metabolic diseases.

If there is a need to control hyperglycemia, insulin at 0.01 to 0.02 units/kg/hr should be started and adjusted to maintain blood glucose between 100 and 150 mg/dl. In addition, if Jordan is seriously ill, insulin should be started promptly to block lipolysis and thereby reverse metabolic intoxication more rapidly. Dopamine and related pressors should be used cautiously because of their lipolytic effect. If she receives intravenous fluids for more than 8 hours, serum phosphorus should be monitored carefully and corrected intravenously as needed. In addition, if Jordan must remain NPO for more than 24 hours, intravenous amino acids @ 1 g/kg/d should be given. Because of its effect to raise plasma free fatty acids levels, agitation should be treated with sedatives."

I hope that helps! Many positive thoughts,

Dawn

Jordan, 19, VLCAD
dawnd39@comcast.net

[*** from Deb—be sure to discuss protocol additions/deletions with your Metabolic Specialists before making any changes]
NBS Advocacy from a Parent’s Perspective

Kristi Wees@gmail.com

For the last 3 years we have been searching for answers for our little girl. The first time "mito" was mentioned to us nearly 2 years ago, I set out to research all I could about it (with a background in chemistry, I dusted off my rusty skills!). I came across your Email List and website and remember reading for the first time about universal newborn screening. Last fall it was on this board also that I learned about a grant for parents to get involved with newborn screening and applied and was chosen for the BABYFIRSTTEST Consumer task force.

This past week I had the amazing opportunity to go to Washington DC to participate in the meeting where disorders are reviewed for addition (or not) to the Recommended Screening Panel. This meeting is called SACHDNC (Secretary's Advisory Committees on Heritable Disorders in Newborns and Children). This group makes the recommendations to the states for newborn screening disorders, HOWEVER, NOT ALL STATES screen for all the disorders that are recommended. EACH STATE IS DIFFERENT...meaning that where a baby is born, and which screens they receive may determine their quality (or length) of life. You can check what your state screens for here: http://www.babysfirsttest.org/newborn-screening/states

I learned one KEY thing at this meeting and that is without parent involvement at the national and state level, very little of these changes would be made. So if you have a bit of time or energy this is a great way to spread awareness not only about FODs and mito but also about newborn screening. Check with your state and see what you can do to ensure they are screening for the ENTIRE recommendations (including SCID and pulse Ox for CCHD1): http://www.hrsa.gov/advisorycommittees/mchb/heritabledisorders/recommendedpanel/uniformscreeningpanel.pdf

Here is my blog post about my trip and what I learned: http://babyfoodsteps.wordpress.com/2012/05/20/what-i-learned-about-newborn-screening-at-sachdnc/

I am sure many of you are already advocates for newborn screening and have been instrumental in getting legislation passed! I would love to hear your stories and learn how I can be a better advocate in this arena.

●   ●   ●

Mitoaction family socials — for more information on our next social contact me at kristiwees@gmail.com

Here is a photo from our last get-together

We are having another one during Mitochondrial Disease awareness week on Saturday September 22nd from 10-1pm at Memorial Herman Hospital in Memorial City in Houston, Tx.

Please refer to the link below for more info on the socials http://babyfoodsteps.wordpress.com/2012/04/05/mitoaction-family-socials-houston-2012-support-for-those-on-the-mitochondrial-disease-journey/
THANK you to Jennifer Guillory (VLCAD mom) for being our FOD representative for our booth at the Genetic Metabolic Dietitians International (GMDI) Conference on April 19-21, 2012 in New Orleans, LA!

We shared a booth with Kathy Stagni of the OAA. We displayed our new Banner designed by Keith Widmann (MCAD dad) and passed out our brochures/cards to professionals attending the Conference. It was a great way to create awareness of our Group and its free services.

Deb also displayed at the March 10, 2012 Meridian Area Business Association EXPO and created awareness of FODs, as well as her probono Grief Consulting private practice in the local East Lansing, MI area.

Stephanie Harry, LCHAD mom, has written a paperback book (shared at our Conference too!) that will help educate many about Fatty Oxidation Disorders and how it feels to be a child living with a long chain disorder. The book comes out of her experience with her son, Christopher, whose story is in the Jan 2012 issue, pg 3.

My Special Body is specifically geared toward 3-6 year olds with LCHAD, TFP and VLCAD. The book showcases Andy, who shares with the reader about his “special body”. He shares his condition’s name, the foods that are good for him, the difference between medium and long-chain fats, the importance of MCT oil and medical formula in his diet, how to read nutrition labels, and how to sort through which foods he can eat. The book has engaging questions on the left for parents, with the main text on the right. There are also activities in the back of the book to continue conversation about diet as your child gets older. Note: This book discusses a lot about the importance of MCT oil in the diet and medium chain fats being good, so unfortunately, this book would not be appropriate for children with MCAD or SCAD.

"If you enjoyed this book please consider sharing it with your metabolic team, as many metabolic facilities are still unaware that this book exists! And we would like all families who have children with LCHAD, VLCAD and TFP to have access to this resource!"

Welcome to New Babies!

Dacie Adelaide Craig
April 27, 2012 9:00 pm
9lbs 6oz 20” long

VLCADD free!!! Nursing like a pro and getting lots of love from her older siblings!

Rebecca Croteau
April 20, 2012
7 lbs 12 oz

Order Form

"If you enjoyed this book please consider sharing it with your metabolic team, as many metabolic facilities are still unaware that this book exists! And we would like all families who have children with LCHAD, VLCAD and TFP to have access to this resource!"
The Newborn Screening Translational Network (NBSTRN) has developed a centralized, web-based dried blood spot (DBS) virtual repository. The system represents information about the stored samples in participating states in a consistent and virtual manner to allow researchers to browse and query the DBS universe. The virtual repository provides NBSTRN members with the tools to review and manage sample requests, configure approved orders, track shipments, and view researcher responses to the samples they have received. To promote the Virtual Repository of Dried Blood Spots (VRDBS), the NBSTRN will be hosting one hour monthly training sessions which will cover a variety of topics and provide time after the demonstration for questions. Please visit our website at www.nbstrn.org to see a complete list of webinars. While each webinar is geared toward an intended audience, anyone is welcome to join the webinar to learn more about the VRDBS.

Amy J. Hoffman, MPH  ahoffman@acmg.net
Project Manager - Newborn Screening Translational Research Network
American College of Medical Genetics & ACMG Foundation
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Medical Genetics: Translating Genes into Health®  http://www.acmg.net

http://www.gemssforschools.org/

Genetics Education Materials for School Success (GEMSS) is a new website featuring information that schools can use to support students who have genetic conditions. If you are a teacher, parent, paraprofessional, or have a special interest in genetics and education, visit the site to learn more.

From academics to athletics and from the classroom to the cafeteria, experts in the field have contributed a wealth of information in a well-organized, colorful, and easy to use online resource.

GEMSS was developed by the New England Genetics Collaborative which is funded by Cooperative Agreement No. U22MC10980 with the Health Resources and Services Administration/Maternal and Child Health Bureau/Genetic Services Branch
‘Texas Meet and Greet’

FOD/Mito moms ~ Janet Longmore and I are planning a meet and greet at Yogurt Fusion the weekend of Labor day—Sept 1, 2012! Time is TBA. Place is Yogurt Fusion in Denton Tx! We hope to see you there!

Brittany Henagan

209 West Hickory Street, Suite 101
Denton, Texas 76201 [on Denton Square, across Campus Theater intersection of W. Hickory St and Cedar St]
Phone: 940-387-4906

Parent to Parent Suggestions
[Always check with your specialists before making any changes to your/your child’s diet or supplements]

Adding calories to your/your child’s diet—cornstarch vs polycose and extend bars

[***always check with your metabolic RD and/or Dr before making changes]

- We’ve used polycose. You can order it from MetroMedical online. They ship it to you quickly and their prices are better than local prices, IF you can get a pharmacy to buy it for you. Our insurance refuses to pay for it...FYI. The only way we can use the polycose, though, is with the enteral pump. Having a GA2er who lived most of her life NOT knowing what was causing her health problems, she has eaten according to her preferences for 17 years. Breaking the dietary habits of a 17 year old Aspy is more task than I’m up to. Well, not entirely true, but we have had to make our changes V-E-R-Y slowly. So when I tell you all that your GA2er CAN eat a lot of “normal” things, I speak what our 22 & 1/2 year experiment has taught us. What is most critical for us is avoiding fasting and then logging our daily plan & keeping to it. Of all the stuff we’ve tried and failed at, fasting is our biggest enemy in this house. Our secondary battle is keeping Mal’s fat levels below 55 grams/day. She tends to be a very poor eater. I cannot tell you how much having extend bars has made a difference in our lives. And NO, I do not get paid for my endorsement. But in all seriousness, this product has made managing night fasts a piece of cake. NO MORE getting up in the night to eat. NO MORE running the pump all night to avoid fasting. Seriously, folks, these products are wonderful. They have a great variety of products, too, so those of you with younger children could likely find something to add to juice or formula, or whatever. Mallory will only eat the bars, and only the chocolate. But our metabolic dietitian is the one who found these bars and she’s the one who highly recommends them for all her metabolic patients who need to avoid fasting. When I asked her about cornstarch, several years ago, I got the same sort of response, “No, not ever for Mallory.” That’s when she recommended polycose and the even more fantastic extend bar.

Terrie, St. Louis mom to Mallory, 22 & 1/2, GA2/MADD & Maisey, 8, blissfully unaffected evanandterrie@hotmail.com

- I’m going to answer this using some basic math. Forgive me if you already know how to do this. But in case you don’t then I thought this may help you out. I don’t know how many calories to count for, but some calorie counting and label reading can help you figure the percentages out based on what you’re currently feeding your child.

This food item has 143 calories ( 20 + 96 + 27 ).
The percentage of calories from fat = 27 / 143 = 18.8%.
The percentage of calories from protein = 20 / 143 = 13.9%
The percentage of calories from carbs = 96 / 143 = 67%

If you add the fat grams and calories of all the food eaten, you can figure these numbers out.

If in a day one eats a 1000 calorie diet, then 300 calories could come from fat if 30% fat is the goal. That would be about 33g fat - 300 / 9.

If one eats 1500 calories, then 450 could come from fat. That would be about 50g fat.

Hope this helps you out.

Laura
Ohio
Gabrielle 5 years ( MCAD) gabmom648@sbcglobal.net

1 gram of fat = 9 calories
1 gram of protein = 4 calories
1 gram of carbs = 4 calories

A food that is 100 calories with 4 grams of fat ( 36 calories worth of fat ) is 36% fat.

Here is another example of some random food item...
If the food contains
5 g protein = 20 calories
24 g carbs = 96 calories
3 g fat = 27 calories

If the food contains
5 g protein = 20 calories
24 g carbs = 96 calories
3 g fat = 27 calories

[cont’d on page 12]
Parent to Parent...cont’d

● Laura gives some great numbers. Something to remember, though, if you have both an OA & FOD, like GA2, these numbers are probably not spot on. Mallory is NOT allowed a percentage of fat, rather an absolute # of grams, regardless of her total daily caloric intake. Her protein allowance is pretty rigid, also, but she’s less inclined to max out on her protein allowances----picky eater. When she is active, or there is changing weather, Mallory sometimes must get 3500-4000 calories to make it through the day without a crisis...yet on these days, her allowances do NOT change with the caloric intake so she much load with empty calories to do this.

Terrie, St. Louis Mallory, 22 & 1/2, GA2/MADD & Maisey, 8, blissfully unaffected evanandterrie@hotmail.com

Alternatives to high fat peanut butter—

● Check http://bellplantation.com/ - they have a low fat peanut butter, I think it has about 1.5g of fat. Also they even have it in Chocolate & it’s a very good alternative. With this alternative you can get the protein and other nutritional benefits yet eliminate most of the fat of regular peanut butter. Hope this helps.

James D Jenkins/Amy Jenkins Cameron 7 (CPT 2)(Chromosome Deletion/Duplication)(Development Delay)(Anxiety) Jacob 5 (unknown) Louisville KY Jjenkins1974@insightbb.com

● Lexie doesn’t like to eat right away in the AM either. I make her drink juice when she gets up and that’s enough to get her going for the day until she needs to eat at hour or so later. She is too out of it like me in the AM to eat right away :-) I do have to change up what she eats a lot so she doesn’t get bored. She is also gluten free and lactose free. Toast with jam, egg beaters, egg whites, cereal, “chocolate milk”, smoothies, fresh fruit, frozen waffles, french toast sticks. Are great to have around.

Peanut butter--This one is a good one too - http://www.betternpeanutbutter.com/index.php
Julie mom to Lexie MCAD MN jmhagen23@hotmail.com

IEPs and SSI -

● As a special educator, your school is bound to follow the IEP. It is good that you are getting support from an advocacy group - they can help guide you through the process that is laid out in your procedural safeguards that is part of your Parent's Right's in Special Education for your state. There must be an avenue for you to make a complaint and have your son's educational issues addressed. Most states have a conflict resolution system in place. Your child's exceptional learning needs must be met as described in the IEP -- or changed — ignoring it should not be an option!

Kate mom to Shannon, 18 MCAD Matt, 23 not affected kmckinnonpsu@gmail.com

● Most of the time, hospital social workers can help you through the paperwork to establish eligibility for SSI and any other state or county programs you and your child may be entitled to. It can be a bit overwhelming. The best recommendation I can suggest is to keep a very organized file of your taxes from the previous year, your current income (pay stubs) and any hospital/Dr bills you have already accumulated. Plus copies of the papers with the diagnosis. In Ohio, we not only have ssi but also a Bureau for Children with Medical Handicaps, that is based on parent income, but once you are on it, it covers the baby 100% after your insurance and if you have no insurance then it covers the child 100%. I don't know if other states have it. You have to make sure that your Drs are on the list to be paid by them, but most are. We had this for years for Kayla as my husband made just a little too much for SSI, but not too much for BCMH! IT WAS GREAT! They even paid for a stroller/wheelchair for her as she got bigger! They also paid for her AFO (Foot/ankle braces) and other supplies we needed at home like Therapy balls, IV poles, Video Monitors. I had to get letters of necessity from her Dr but that was pretty easy. I just carried this certification letter with me every where and handed it in with our insurance card and we NEVER PAID out of pocket! Now of course, my husband makes too much for that and our insurance covers less and less for her as she is HIGH RISK and so we pay A TON out of pocket! But check into it with your hospital. That may be the easiest way as they should have ALL the different paperwork you will need.

Brenda Goodman Mom to Kayla, 11y, SCAD doublebn@aol.com

FODs and links between other disorders -

● We also have issues with some who do not see a link between FODs and Development/neurological issues in spite of strong evidence in the literature. The general problem as I see it, is that different areas of medicine do not work together—they have their own tunnel vision into their own field (speaking generally). If you put a team of metaboblic experts, immune experts and neuroscientists together to explore this you will likely find a different outcome. There are some strong hypothesis suggesting that the metabolic issues (FOD or other Mito disorders) results in susceptibility to oxidative stress in certain cells (immune system cells) that decrease its functional capacity thereby exposing one to opportunistic/persistent chronic infection states. The chronic infection states leads to an inflammatory response and when that happens in the CNS results in neurological issues manifesting itself as a disorder like ASD, Aspergers etc that is diagnosed clinically. This may not be the only path to the disease state but is a very likely path. I do not know about GA2 but things like SCAD where the population has varied clinical outcomes the likely trigger to tip one over are stressor events like bulk vaccinations or a very serious infection etc..

There are also some papers on the intersection of Mito dysfunction and Autism—
One of them is http://www.ncbi.nlm.nih.gov/pubmed/20818729

Kay SCAD Parent kp_mlist@yahoo.com
Love Messages

Condolences...

It is with great sadness that we learned of two deaths within our ‘FOD Family’ in the last few months...please send your prayers and thoughts for a CPT 2 Family in South America and a CACT Family in California

~ All of our FOD children will ALWAYS be with us in our hearts ~

‘Out of the ashes of our hopelessness comes the fire of our hope’

~Anne Wilson Schaef

One-on-one phone/email/skype and in-person Grief Support is available for our FOD Families and the Public that have experienced the Death of a Child or other loved ones and feel the need for extra support or are having a difficult time living with this reality.

To help me better understand your situation, please refer to the Grief Intake Form. It can be submitted online or mailed/faxed.

There is no charge for this grief support ~ however donations are always appreciated, and will benefit the FOD Group!

Deb offers free of charge face-to-face Grief Consulting to the local Lansing, MI community ~ specifically for Bereaved Parents, but other losses are supported as well.

Deb Lee Gould, MEd
Bereaved Parent & Grief Consultant
www.bereavedparent.com
deb@bereavedparent.com
517.381.1940

Pharmaceutical Update

If your Physician needs more information about L-carnitine (Carnitor®), dosages, or has other questions, please have him/her contact Sigma-Tau Pharmaceuticals, Inc., and ask for the Medical Information Department or state that he/she has a question about carnitine. The phone number is 1-800-447-0169.

The liquid and tablet generic drug brand for Levocarnitine was approved for distribution by the FDA several years ago. Please note that a generic drug form by Rising Pharmaceuticals, Inc. (as well as the brand name Carnitor®) needs a Prescription from the Dr. Additionally, a generic prescription authorized by Sigma-Tau is available from Hi-Tech Pharmaceuticals - as an oral solution and tablet.
ATTENTION FOD FAMILIES ~ FUNDRAISING EFFORT AT ITS BEST!

“The Next Best Thing to Fruits and Vegetables”
For those of you not at the conference, any orders from our FOD members and their families will benefit FODSupport.org
Whole Food Nutrition is extremely beneficial to those affected with FODs and those that are not!
Please take a look at my website and click on “watch the video” beneath the Juice Plus bottles. Then give me a call or an email to place your order. Please be sure to tell me you are an FOD family!
CALL OR EMAIL ME WITH QUESTIONS!

Have a healthy and blessed day!
Brenda Goodman
"Sharing Health Wealth!"
(866)280-5726
www.bgoodmanjuiceplus.com
doublebn@aol.com

Mom to
Kayla, 11y, SCADD, Unidentified Mito, Pulmonary Valve Stenosis (repaired), Epilepsy, SLD, PDD-NOS, SLD...who knows what else!!!
Naomi, 15y, unaffected, untested, GIFTED-HIGH HONORS STUDENT!
Pepper Pike, OH, USA

~ NEEDED FOR THE JANUARY 2013 ISSUE ~

Medical Update ~ Please Submit

PROFESSIONAL ABSTRACTS/ARTICLES OF ALL KINDS
(Drs, Nutritionists, Genetic Counselors, Social Workers, etc.)

FAMILY STORIES &
Pictures for KidsKorner

The ‘Silver Linings’ of FODs ~
What is your ‘Silver Lining’?

URGENT NEED for Medical Professionals

With more Families being identified with an inborn error of metabolism (through expanded newborn screening), our Families will need ongoing Clinical Care from knowledgeable and caring professionals. In addition to our Newborn Screening Advocacy by many of our Families, our Group is hoping to also bring awareness to medical schools and other medical organizations and facilities the need for educating and training new Professionals (physicians, metabolic nutritionists etc) in the field of Medical Genetics and Metabolism to treat our children, as well as our FOD adults. We are also raising funds for Clinical Training. [see our website for the donation box]

Once we raise enough Funds we will be able to offer grants to US Clinical Training institutions.
We NEED your help NOW and in the FUTURE so our children will thrive and grow into adulthood with the best of ongoing care!
2012 FOD/OAA Conference
‘Blazing our Trail to Portland!’

Patti, Megan and Gwen ~ GA 2
moms enjoying the Conference site,
Red Lion Hotel on the River!

Dr Vockley and some of
our VLCAD Families

Carmen (LCHAD) and her new young
adult LCHAD friends, Luke & Jai
(from Australia)

Ending Ceremony Slideshow ~
The FOD DVD is available to view or purchase through the One True Media
Created by OAA Mom, Raymonde DeGrace

1st song "When You Come Back Down" - by Nickel Creek
2nd song is karaoke version of that song
3rd song (angel song) is "Dancing With the Angels" - by Monk & Neagle
4rd song is "The Well of Healing" acoustic arrangement by John Morgan
I didn’t feel well after lunch. In fact, almost never felt well after lunch but I didn’t know why.

Part of my ‘eat healthier’ program, was to lunch at a cafeteria near my office. They had a wonderful selection of meals prepared on site. Each day there were six different salads, six entrees and six vegetables. But no matter what I ate, my belly would become swollen and I would begin to feel agitated. Before finishing lunch, I would get a craving for a candy bar.

One day, I selected liver and onions. I didn’t add a salad or vegetables or bread. I’d never had a problem with liver or with onions, but on this occasion, the familiar discomfort began before I had finished eating. I asked the manager how the liver and onions had been prepared. He said, “They are fried in 100% soybean margarine.”

Afterward, to avoid getting sick, I avoided foods that were fried. I would, instead, choose baked chicken or spaghetti or a salad. But the problem persisted. Again I approached the manager. He explained that the baked chicken was basted with soy oil; soy oil was used in the spaghetti sauce and in the pasta cooking water; and soy oil was the primary ingredient in the salad dressing.

I decided to write to the cafeteria to explain the situation and to ask what foods I might eat that would contain no soy oil. Their response was, “Jello, if the whipped topping is removed.” Their vegetables were ‘buttered’ with soybean margarine, soybean oil was an ingredient in the muffins and bread, and solid soybean shortening was used to make the biscuits.

I became a label reader. Most of the ‘vegetable oil’ sold in the grocery stores which I had assumed to be a combination of oils, was actually 100% soybean oil. In addition to almost all salad dressings, margarines and mayonnaise, most crackers, breads, flour tortillas, muffins, cookies, cakes and candy bars contain soy oil. Soy oil is also sometimes an ingredient in peanut butter (commercially prepared – not freshly ground), white chocolate, grated horseradish and the ground beef patties sold to hospitals, schools and restaurants. I had a bad reaction to the fish oil capsules I was taking and found that they contained gamma tocopherol, a form of Vitamin E that was derived from soy oil.

Soy oil is much cheaper than the next least expensive oil. Because of this, I thought it might be safer to purchase more expensive brands. But then I found soy oil as an ingredient in the chocolate of a prestige label ice cream bar.

For Christmas I received a rotisserie. I was delighted with the wonderful job it did on chickens. Soon, however, I started to realize that I became uncomfortable after eating the chicken. I was, in fact, having the same reaction from the chicken that I had from eating soy oil.

The good news proved to be that the chicken itself was not the problem. The problem was rather with the chicken fat. Most commercially raised chickens, cattle and pigs are now fed soybeans. Whereas the carbohydrates and proteins we eat are totally broken down by digestion, the same is not true of fats. The fats eaten are incorporated somewhat ‘as is’ into body fat. So when animals are fed soybeans, a form of soy oil will be incorporated into their body fat. It will also affect the fat in the yolks of the chicken’s eggs. It will be present in the butter, cheese and milk from soy fed cattle and will be in the bacon and sausage from soy fed pigs.

There is a specialized medical test known as a Red Blood Cell (RBC) Fatty Acid Analysis. For those who have seen the movie, Lorenzo’s Oil, this was the test used to identify Lorenzo’s problem. He had an excess of very long chain fatty acids. Fats have the potential to dissolve other fats. In Lorenzo’s case, the excess of the very long chain fatty acids was dissolving the fatty covering (myelin sheath) which serves as the insulation on the outside of his nerves. As the myelin sheath dissolved, Lorenzo lost neurological function.

In an RBC Fatty Acid Analysis, approximately twenty of the fats making up the membranes of the red blood cell walls are identified and quantified. Included are saturated, monounsaturated and poly-unsaturated fats of various chain lengths. Feed fats determine body fats. So this test would reveal the type of fat a person had been eating and the relative amount of each. Butter, for example, is largely a short chain, saturated fat, whereas margarine is a polyunsaturated, long chain fat. Below are photos of the bacon from two pigs. One pig had been fed soybeans and the other pig had not.

Below are photos of uncooked bacon.
The bacon on the left came from a pig that had been fed liberally on soybeans. Feed fats affect body fats. Whereas one can be allergic to proteins, the same is not technically true of fats. If you had a problem with the digestion or with the metabolism of fats, it would not show up on an allergy test.

Those who seem to be ‘allergic’ to many foods, might want to consider that they may be sensitive to just one substance that is common to many foods. Soybean oil isn’t the only ingredient that can prove troublesome. Monosodium glutamate (MSG) is another, as is gluten. Gluten is a form of protein found in wheat, rye, oats and barley. It is present not just in cereals and baked goods, but also in stews, gravies and puddings thickened with the flours of those grains.

If you often find yourself uncomfortable after eating or if you experience systemic type problems for which no cause can be identified, you may want to look closely at the food you are eating. The culprit may be sensitivity to a hidden ingredient.

**NOTE:** The author of this article is the founder and Executive Director of a 501(c)3 nonprofit by the name of “In Need Of Diagnosis, Inc.” (INOD). INOD advocates for more timely and more accurate diagnoses and is a resource center for those who suffer with illnesses that have eluded diagnosis.
Kids Korner

Helia
4 yrs old
MCAD
Greece

Christos on left & Kostantinos on right

Spencer
7 yrs old
MCAD
Massachusetts

Melody
‘I love blackberry picking!’
4 yrs old
VLCAD
California

Evie Grace
23 mos old
LCHAD
Louisiana

Ysabel
12 yrs old
LCHAD
California

Micah
13 mos old
MCAD
Minnesota

Stephen
10 yrs old
TFP
Washington

Rylee Jane
5 mos old
MCAD
Kentucky

Please note that we also have an FOD KidsKorner/Adults Gallery and other Pictures on our homepage. To submit a pic please email Deb.


Thank you to all that have bought products from companies on the Internet that support the iGive and Cafepress.com program of donating a certain percentage to Groups like ours. All of those links are on [www.fodsupport.org./Donate.htm](http://www.fodsupport.org./Donate.htm)


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

US Checks can be made payable to ‘FOD GROUP’ and mailed to: FOD Group PO Box 54 Okemos, MI 48805

We also have a Secure PayPal link on [www.fodsupport.org](http://www.fodsupport.org)

TYPED (preferably in word document) Reminders

Families - Please send TYPED stories etc, by Dec 10, 2012 to Deb. Continue to spread the word about FODs and the need for screening ~ it will SAVE LIVES!

Professionals - Please let us know about your research and/or clinical work with FOD Families. Send articles, summaries, etc by Dec 10, 2012 to Deb.

Communicate With Us

Please ADD me to your mailing list [Conference years]
Family Professional (please circle one)
Name/Address or Address Correction (circle one)

Please REMOVE me from your mailing list:
Name/Address:

Please include ideas for future issues or your questions

‘Statistics are for a population...
Treatment is for an individual’
~ Jerry Vockley, MD, PhD