From the Editor

The New Year Begins!

We hope everyone had a safe and healthy start to the New Year! Now it’s time to get down to business as far as planning for our upcoming joint National Metabolic Conference with the Organic Acidemia Association (OAA) in Atlanta, Georgia on July 30-31! But first, I’d like to welcome Carol Barton back into the ‘ranks’ of being an Executive Director for the OAA. Carol will be working with me, along with Kathy Stagni, OAA’s past ED and presently their Administrative Director, to help put on another terrific Conference! There’s more information on our developing plans on page 2.

In the meantime, we are trying to raise as many funds as possible ~ so please share our ‘2010 FOD Letter of Giving’ on our homepage with your Families, Friends and Medical Professionals. Also, if you’d like to have your own FOD Awareness projects as ‘fundraisers’ please let me know. Tap your creativity and help raise awareness of FODs, as well as funds for our Conference! We also have other ways of fundraising that are posted on the right sidebar of our homepage — they include our awareness bracelets and window ribbons, shopping online by using the iGive site linked on our homepage (we get a % every time you shop one of the 700+ stores that participate), using GoodSearch as a search engine, or using the Donate button on our site or on our facebook Cause page. If we raise enough funds we might be able to offer ‘scholarships’ to help defray some of the costs for Families to attend the Conference.

Several times this year we will be displaying our poster board and/or sharing brochures and info sheets at various conferences. Last August I was supposed to display at the International Congress of Inborn Errors of Metabolism conference in San Diego, but we had a family emergency so I was unable to personally attend. Kathy and Carol (OAA) thankfully shared our brochures/info with those attending. This year I am seeking Volunteer Families to help with the Society for Inherited Metabolic Disorders (SIMD) Conference on March 28-31st, in Albuquerque, NM. Fortunately we have an OAA mom that is also familiar with FODs that will be sitting at our joint booth for the 2010 GMDI (Genetic Metabolic Dieticians International) Meeting titled ‘Navigating Changes in Nutrition Management of Genetic Disorders’ on April 15-17 in Baltimore, MD. If any FOD members would like to help out with either conference by sitting at our joint booth with OAA reps, please contact me soon. Often, you are able to sit in on a few sessions, as well as ‘man’ our booth, meeting and talking with all the medical professionals interested in learning about our disorders. I also hope to attend a Newborn Screening meeting in Atlanta on Feb 19. Emory University and several other organizations have partnered to develop an interactive clinician-supported patient registry. I will have more info on that in our July newsletter. This meeting will also give us and OAA the opportunity to view the Emory Conference Center Hotel, which is where our Conference will be held.

Thank you to our Families that shared their struggles and challenges with us in this issue by way of their stories, commentaries, and pictures. We welcome ALL of your stories and pictures and we will try to either print them in the newsletter or place them on the Family Stories, Newborn Screening, or Love Messages page on our site. We would especially like to encourage families dealing with some of the less common FODs (i.e. HMG, Carnitine Uptake Defect, TFP, CPT 1&2 etc.) to share their experiences. We’re always looking for more low fat recipes, poems, and pictures.

We also would like to hear from our Professionals ~ we always welcome new Medical, Research, Nutritional, Counseling/Coping, etc articles. 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
I cannot urge you enough to attend our 2010 Conference in Atlanta, Georgia on July 30-31st ~ you will have a ‘Peach of a Time!’ Because we have our Conference, in conjunction with the Organic Acidemia Association (OAA) every 2 years, it’s a wonderful opportunity for you and your families/professionals to not only learn about the various FODs but also to NETWORK and meet other FOD members face-to-face.

Vitafo USA is presently our premier Sponsor and Emory University School of Medicine/Department of Human Genetics will be the main Host. Those that are familiar with Emory know Rani H Singh, PhD, RD ~ she will not only be speaking, but will help us coordinate some of the other experts in the Atlanta area. We are actively soliciting more financial sponsors—please contact Carol (see below) or me (Deb) if you have any suggestions of whom we might be able to contact.

The meetings and sleeping accommodations will be at the Emory Conference Center Hotel (ECCH).

We are just starting to plan for Speakers and Topics so we don’t have any of that information yet. We will try and utilize many of our local Atlanta experts first, but we can also bring some outside experts in to speak. Tricia and Calvin Luker, special education advocacy and legal issue experts, who had to cancel for the 2008 Pittsburgh Conference due to medical emergencies, will be with us in 2010— their information is so valuable it is worth the wait!

Soon, we will be posting the Registration Form on our website which will have the Hotel Reservation phone # and a Tentative Agenda — and I also will be mailing a postcard reminder in February to our entire Mailing List, since some do not have internet access and are not on our Email List. They will then be aware that we are having a Conference and can possibly have a family member or friend print the form or go to the library to print off the Registration Form!

We will have a $50.00 per person Registration Fee — and $30.00 per person fee if you HAVE the FOD or OA [or for a child age 5 and up or a sitter for that child that want access to the Conference meals/snacks] and that covers Friday and Saturday’s continental breakfast/Lunch/snacks, Friday night Reception, a Group folder (for those attending sessions), and a yellow FOD Tshirt (adult sizes only—smaller shirts can be purchased through the FOD cafepress site on our homepage, right sidebar). Dinner will be on your own. We also may be able to offer ‘scholarships’ to help some Families offset some of their travel and hotel costs IF we get more donations. We were able to help @8 Families for the 2008 Conference in Pittsburgh and the OAA (Organic Acidemia Association) also helped some of their Families.

So if you are thinking about doing a FOD Family Fundraiser (Family Project for FOD Awareness Form on our homepage) PLEASE start planning and spreading the word. It would be terrific if we can get as many donations as possible to help with this conference. I know many like to give to the Research Fund, but our most immediate need right now is for the Conference. And I’m sure when we get closer to the date, we will also need some FOD and OAA volunteers to help with various tasks.

You will be responsible for making your own Travel reservations and Hotel reservations (ECCH can take reservations now—special rate good until July 8th or when our room block is full). We will have a special rate of $99 per night plus tax for the Emory Conference Center Hotel (offered 2 days before and 2 days after the conference to accommodate family vacations). We will be working with the chef, as we have at past conferences, so we can offer FOD and OA friendly meals - there will be a variety of foods to choose from, but keep in mind it’s not all going to be lowfat or low protein and you may want to bring some of your own snacks, etc to have on hand. There is a space on the Registration Form to list specific Food requests/allergies etc. Some rooms may have a refrigerator, but you will need to ask about that when making your reservation.

We will have a children’s activity room set up like we did in 2008 in Pittsburgh - but you will need to bring a grandparent or someone else to watch your children (if you decide to bring them) while you attend the Conference. If they are to join us for breakfasts/lunches/snacks they will need to be registered as well, for the $30.00 fee.

So let’s all get onboard and help spread the word ~ I KNOW it’s been a few tight years economically, but if everyone helped out a little bit we will be able to put on another terrific conference for not only our Families, but also professionals that are interested in learning about FODs and OAs!
Adam just turned 19 this month and it’s time for an update! Adam graduated from his very competitive all boys’ high school at the end of May 2009. Probably over 90% of the graduates from his school go straight to a 4 year college. However, with state budget cuts in education, a larger than normal graduating class, and Adam’s desire to attend one of the top UCs in the state, Adam wasn’t accepted to a university he wanted. We were sad for him since he so much wanted to go directly to a 4 year university. But actually we were relieved. Since he has LCHAD deficiency (Long Chain 3 hydroxyacyl Co enzyme A Dehydrogenase Deficiency), we thought it would be beneficial for him to attend a local junior college for 2 or more years and live at home. There are a lot of adjustments going to college – in peer relations and in academics, and remaining at home for now will minimize the pressure on him.

Adam started attending West Valley College in the fall. He is in a regimen to complete classes in 2 years that will qualify him to attend a University of California or California Polytechnic College. He wants to major in Biomedical Engineering. Maybe someday he will be designing prosthetic retinas for LCHADers suffering from advanced RP (Retinitis Pigmentosa), or some other state of the art device. So far he’s completed Intro to Engineering, Calculus, English, and Animal Behavior classes and says junior college is easy. We’ll believe him when we see his grades!

Adam finished his last summer on our local cabana swim team. He was awarded a “Golden Gator” award as were 5 other seniors. This award is given to those swim team members who were on the team every year from age 5 or 6. Adam was never the best swimmer but he was always at the meets to compete, especially in freestyle and butterfly, and sometimes backstroke. And he was in the championship meet each year. He had fun, made many lifetime friends, and was a good example to the younger kids on the team.

Since Adam obtained his driver’s license at 16 ½ years of age, driving cars has become a passion for him. He does have some abnormal retinal pigmentation in his eyes that produce black spots that he must look around, but he is still able to drive well, even at night. Initially he had a few scrapes with small trees and fences. He totaled our 1985 Volvo wagon, sliding into a small tree on wet pavement on the first rainy day of the season in 2007 (which he claims is our fault for not buying new tires). But now along with his two older brothers and his dad, he enters at least 1 autocross a month. These are races against time with vehicles in the same class. One car races at a time. The races take place in a large empty parking lot with orange cones arranged to make the course. His times have been slowly creeping down, and at the race this past weekend he, for the first time, beat his dad (by 2 seconds). Besides good vision, this sport requires quick reflexes. Adam does have some peripheral neuropathy in the bottom of his feet but neither this nor his RP, has so far hindered his accomplishments. I ride with him one time around the track a few months ago. It was scary for me as Adam tore down the straightaways and slammed on his brakes at the turns. One lap was enough for me! Young men love to race and speed, and this is a much safer way to do it (they wear helmets too) than on the streets.

Adam now is in charge of his own diet. We hope we’ve taught him the right things to eat to keep him feeling well and healthy. I know he occasionally strays off course, especially when he goes to Panda Express for shiny (greasy) Chinese food. But he seems to know what to do for himself when he starts feeling bad. He has been fixing his own bottles since age 16. He still drinks 3, or sometimes 4 6-ounce jelly jars of fat free milk per day. Each has 1T of MCT Oil and 1t of Carnitine. He also takes the following vitamin supplements each day: 1 multi vitamin with minerals, 1 500mg vitamin C, 1 Bausch & Lomb Ocuvite with Lutein, 1 Solaray Bio E Gamma Plex, and 1 GNC DHA 250.

Adam gets a flu shot every year. This year he also got the H1N1 shot. He has been having the flu shots since a toddler with no side effects. He may have had the H1N1 Flu even before it was a pandemic in the US. He had a fever of up to 106 for one day then 102 for several of the following days. He was listless but still could drink his usual fluids and Gatorade. He didn’t have to be hospitalized. He didn’t seem to have an LCHAD episode and just rested and slept more than usual for about 1 week.

I know a lot of the families on the FOD list, question traveling with their FODer. First you should always consult your doctor for his or her advice. We didn’t travel with any of my 3 sons until they were over 6 months of age. Adam’s first big trip was to Hawaii at about 18 months. We tried to be very prepared by finding out the names, addresses, and phone numbers of doctors in our health plan at each place we visited. We were prepared for the big island of Hawaii but it was on Kauai that Adam came down with an ear infection. There was no Kaiser clinic there so we had to just see a random pediatrician there. We did luck out by missing Hurricane Iniki by 1 week. Had we been there then, Adam would have had to have been

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in the hospital as there was no electricity for weeks on the island = no refrigeration. We were tube feeding him at the time. Since that trip we’ve traveled with him to Florida, the Bahamas, a driving trip across the US, a 52 day trip to Europe, a 14 day trip to Japan, a 12 day trip to Africa (with Make a Wish Foundation) and Hawaii several times. On the last 2 trips he traveled at least one way alone, carrying his own bottles, MCT Oil, and Carnitine in a cooler bag. He has a protocol letter from his doctor he shows to security when they look in his bag. At his age no longer wants to travel with us so he usually stays home.

When we’ve traveled with Adam, besides getting the name and number of local doctors, we always have the cell and home phone number of his main metabolic doctor who answers our calls at any time of day or night. If we will be away a long time (3 weeks or more) we always try to send his MCT Oil ahead so we don’t have to carry gallons of it with us. Also, we TRY to stay at places that have refrigerators and or preferably kitchens so we can easily make his bottles and wash them etc.

Some people say it’s a waste of money and a bad investment to buy a time share. For us, though with an FODer it’s been a godsend. We always know we will have a place with a clean working order kitchen and a beautiful resort for recreation. We usually go to our place in Hawaii (the big island) but we have also gone to ones on Maui and Kauai. We’ve made exchanges to Oregon, Florida, and Colorado, and more recently, when Adam was invited but opted to stay at home, to Arizona. Another option is to rent a house, like on the Home Away site. The quality and consistency isn’t the same as a timeshare but also, you will have a kitchen.

When we can we’ve visited and even stayed with LCHAD families – in Southern California, Utah, Missouri, Wisconsin, Sweden, and Germany. Since LCHAD is so rare we can’t just drive up the street or even to the next county (although there is one about 40 miles away) to visit another LCHAD family. It is SO WONDERFUL to meet other families, which some of you have been able to do at the FOD/OAA Conferences. Now with the technology of email, Adam regularly communicates with 2 LCHAD girls in Ireland around his own age. He says he’ll visit them if we pay for the airfare...Well, maybe when he’s older.

Enough for now, I’ve babbled away enough. Please feel free to call or email me, or visit us when you’re in the area.

Valerie Fulton, Mother to Adam LCHAD 19 years
vallchadmom@yahoo.com

Melea’s Story ~ MCAD
‘Melea ~ my Dream come true’

On November 22, 2002, having children wasn’t something I thought I would ever want. This was our wedding day, full of hope, aspirations, and dreams coming true. We were a complete set needing nothing else. Or so I thought.

It was during our third year of marriage I was looking at my husband, whom I loved and adored, that I wanted something to share together. I wanted a family. My husband couldn’t agree more. So we started the venture of the unexpected. Unexpected indeed, a year and a half went by and no baby. Disheartened I went to the doctor to see why we didn’t have a little one yet. After some tests he informed me that I wouldn’t be able to conceive. The doctor in his efforts to comfort me said I could take some fertility medication to help in the process of having a baby. After a long and lengthy talk with my husband we opted not to take the medication for fear of multiple babies. Filled with such sadness, I held my chin up and tried not to think about it anymore. But yet, I was reminded and felt an emptiness I could not fill. I had a friend who had already had a couple of children and was expecting their third child. The news of this sent me into tears and a depression. I wanted to be a mom more than anyone in the world.

Finally in October of 2007 I had gotten pregnant! With no medication! This was the happiest day of our lives. I went to my doctor and we got to see our little one on the ultrasound screen. At the time I was only 2 or 3 weeks along. All we were able to see was a blinking dot. Its little heart was already beating. I had never felt so good in all my life! A life was inside of me! Everything was so far so good from that doctor’s visit. So they had us come back once I was almost four months along. Waiting was the hardest thing to do ever.

Time went by and I was ready for my appointment. Laid back on the table to hear a heart beat... and we didn’t hear anything. The nurse said, “Well maybe you’re not as far along as you think you are, so let’s do another ultra sound.”
Melea...cont’d

Not thinking anything could be wrong I went along with it. They couldn't find anything. The nurse left and got the doctor. He came in and looked everything over. He looked down at me, and said “It looks like you've had a missed miscarriage.” I had never heard of such a thing! I immediately started to cry and cry. “How could this be? I did everything I was supposed to... is it my fault?” He reassured me it wasn't.

Over time I pulled myself together. I was thinking...“If I got pregnant once on my own surely it can happen again.” And sure enough, eight months later I was pregnant! Everything was going very well with this pregnancy. No sickness or anything. I truly loved being pregnant, I remember thinking to myself, “Yes I was meant for this.” I can honestly say I glowed the whole time and I felt wonderful! I wasn't one of these women that act like they’re dying...lugging around a big belly. No, I enjoyed every moment of it!

My darling little girl came into this world on May 14, 2009. A moment we had waited for a very, very long time. I must say it was the happiest day of my life! I felt so fulfilled! “This is what we're made for” I thought as I held her in my arms for the first time. I had never known “love” like that.

We took her home when she was three days old. I'm sure my husband's cheeks were sore from smiling so much driving home with his little family. We stared at her for hours!

Things were pretty normal the next few days until on the sixth day we got a disturbing phone call from her pediatrician's office. They said to bring her up there right away, that something came back on her newborn screening test. I was in shock, threw down the phone and starting crying. Scooped her up and loved on her, and told my husband about the call.

We ended up over-nighting our bundle of joy at the Children's Hospital in Lexington, KY. That night changed our lives forever. The doctor told us our seemingly perfect daughter had MCAD. We had never heard of such a disorder. I didn't want to believe it! “How unfair! After all we've been through!” I thought. They took blood and sent it to a genetic lab to make sure the diagnosis was positive. It was.

This was like a death sentence...the child I wanted for so long has a life threatening disorder.

All I could do was educate myself about this and take care of her the very best I could.

Time has passed and my little dream come true “Melea” is now seven-months-old. And is a very active sweet snuggly little girl, who now gives me kisses! In fact we call her “snugs” because she loves to snuggle with you. Every day she amazes me with new things she's doing. I feel so incredibly blessed to have had her. There isn't anything in the whole world that could make me any happier.

Her diagnosis was something that is very rare but manageable. The more I learn about it the better I can deal with it. I often think to myself, there are many other things in this world she could have had. MCAD isn't that bad and I'm just glad they found it when they did.

I've found this wonderful website for group support and I've learned she's not the only one and there are many others that have lived a normal healthy life. I see her in the future now, going to school and growing up like every other child. Looking back on all that my husband and I have been through, I know it was a hard time for us but look at what we have....Our little Melea, she truly is our dream come true!

Robin Funk
robinfunk@gmail.com

Allyson’s NBS Story ~ MCAD

Allyson Jennifer was born on February 5, 2009. She was born after I was put on bed rest for 5 weeks because of preterm contractions. When the day finally came for us to meet her it was very exciting.

At Baylor University Medical Center in Dallas it is standard to run the newborn screening test. I never thought about why they did the test or how the results could impact your life. We have 2 other boys, Jacob and Brooks, and their test results were normal so I just assumed Allyson would be the same. When she was a week old I answered a call from my pediatrician that will forever be etched in my mind. He told me that there was an abnormality in her newborn screening test and that he needed me to come to the office immediately to discuss what they found. Thankfully my husband was home at the time and was able to go with me to process the information we were given. Our doctor told us that she had MCAD and explained that it was rare disorder and sent us on to a metabolic geneticist. He also told us that we don’t need to need to worry about what she has as much as we need to be thankful that these test results just saved her life. That is what we needed to stay focused on. I tried really hard to concentrate on what he was telling us but I remember looking at her thinking that she looked normal and how could she be sick with something?

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I had no idea of what a metabolic disorder was and thought there has to be a cure for this and she will get better. I spoke to a metabolic counselor that day who informed us that as long as she stayed healthy and continued to eat often, she would be fine.

We were sent to Ft. Worth with a few pieces of paper explaining what MCAD was and orders to have more blood and urine samples taken from her to make sure that the initial test was right. I started to pray that Allyson’s first test was wrong and that we would hear soon that this was a crazy nightmare.

Allyson is now 11 months old and I can’t believe how amazing she has done. Over those months there have been so many cherished memories of all the milestones that she has crossed. Even now she is learning to walk and saying so many words and mimicking so many sounds. She has been a trooper on a couple of plane trips and a few road trips (one of which was 15 hours). It’s really true that kids with MCAD are normal kids that deserve a little extra attention to make sure everything goes well. There have definitely been the challenging times of sickness, checking her blood sugar levels and avoiding people with known sicknesses. And twice daily as part of her normal routine, she takes 3ml of carnitine – and thankfully she doesn’t mind a bit! But, overall Allyson is happy, healthy and is a joy in our family!

Kathleen, mom to Allyson
kathleenmcraven@gmail.com

Here's Sean's story in a nutshell ~

Seanie is now 16, soon to be 17. She had her first incident when she was 6 months old. She was diagnosed with an unclassified FAOD when she was four. She is still unclassified but we appear to be close to getting a definitive diagnosis.

Sean is very, very active and has been training as a competitive athlete since she was three years old. She started with gymnastics, went on to All Star Cheerleading and finally found the sport that she truly loves, diving.

...and Sean's popular with the other divers because she's the kid who has the biggest cooler filled with lots of juice, fruit and all sorts of great snacks!

That's it ~ If I tried to go into the ENTIRE story, it would take forever!

Eileen McMullin
eimcmullin@gmail.com
I was just reflecting on life with a FOD child today. It sure has its challenges and stresses, but I have to look for all the good I can. I have always been a persistent person, but not a very consistent one. It’s always been easier for me to walk fifteen miles in one day then for me to walk one mile every day for fifteen days.

Living with an FOD requires consistency. You have to consistently feed your child at the right times. You have to consistently give them their carnitine or other medicines. You have to consistently wake up to feed them at times. You have to consistently watch what they eat. You have to consistently watch them for signs of illness.

Somehow, knowing that Caitlin’s well-being depends on my being consistent has made it easier. I am not consistent in every area of life, and I screw up with Caitlin sometimes, but I’ve gained more ability to be consistent.

This year we have a real Christmas tree, and I have consistently given it water everyday. That is a first for me. It’s green and the needles aren’t falling everywhere. I have to chalk that up to a lesson learned from caring for Caitlin. It’s a small thing, but there you go!

Becci in Grovetown, GA
mom to Caitlin, 3, MCAD

Stephen just had his 8th birthday last weekend. Please indulge me for taking a few moments to reflect. It’s hard to believe how fast the years are flying now. The first few years of having a FOD baby seemed so intense; it was hard to believe that things would get easier. They have. Now the hard things are getting through homework and keeping the peace in our house between the oldest and the youngest! I’m grateful for a relatively uneventful year. No hospitalizations. Only two flu-type episodes, and they were weathered fine using Stephen’s g-tube to help keep him safe when he didn’t really feel like eating.

I’m so grateful for Stephen’s older siblings and Dad who help take some of the pressure off me by stepping up to help him with homework, to entertain, or to get him in bed. I think when we are alone as a parent, we can, and do step up to do whatever we have to do to make it all work. But it sure is a blessing when there are those around who can relieve us from time to time. Though it’s a little tough when expectations get me into trouble!

Sometimes I wonder: do kids who have special needs have more incidence of anxiety and insecurities? Stephen seems to be much more anxious about being alone and being independent than my other kids. Stephen seems so mature in many other ways, but he still struggles with bad dreams and being alone. Another thing I wonder is if Stephen is capable of building muscle strength and being as strong as other kids. I understand and accept that endurance will always be an issue. But it’s been harder to figure out why he still has a hard time getting in and out of the car, balancing to put his clothes and shoes on, and constantly seems to grab onto me to keep his balance. I thought that by this time he would have caught up. I don’t really know how to address that issue since he seems so uninterested and resistant to doing active things.

All that aside, Stephen had a great birthday. We had a "mad scientist" party because Stephen loves science and wants to be a scientist when he grows up. I was very proud of myself because I made a birthday cake in the shape of a volcano that actually erupted, thanks to the science of what happens with dry ice and very warm red/orange colored diluted marshmallow cream. I’m still basking in the pleasure of tackling the unknown and having it be a delightful success! Here’s hoping for another year of health!

Diane, mom to Stephen, age 8, TFP
3 sisters ages 11, 14, 16
Kent, Washington
Nutrition Update

Professionals/Metabolic Nutritionists: Please contact Deb if you’d like to write an article/summary for our July 2010 issue.
Our Families are really interested in learning what research or clinical issues you are working on!

Q: Does anyone have an opinion on the difference between using glucose gel and cake icing to administer a blood sugar boost in an emergency situation?

A: Good question. Glucose gel doesn’t have to be swallowed to be effective. It can be absorbed starting in the mouth. Even in the stomach, the sugar in cake icing would be absorbed more slowly than glucose. The sucrose in the icing has to be broken down into glucose (+ fructose) to be absorbed, and fat may also delay the absorption. Go with glucose gel.

Diana Pantalos, MS, RD, LD
Metabolic Nutritionist
Weisskopf Center for the Evaluation of Children
University of Louisville
571 S Floyd Street, Suite 100
Louisville, KY 40202

Q: What are complex carbohydrates?

A: Complex carbs (carbohydrate) foods are basically those in wholegrain form such as wholegrain breads, oats, muesli and brown rice. Complex carbs are broken down into glucose more slowly than simple carbohydrates and thus provide a gradual steady stream of energy throughout the day. I took this off the web, but the thought behind Complex Carbs is that it takes longer for our FOD kiddos to digest and break down. Therefore giving them energy through-out the day for longer than regular foods.

The food list below shows good sources of complex carbohydrates. The best way to provide the diet with complex carbs is to consume foods in their most natural state such as oatmeal, bran and brown rice. Also Pasta, Macaroni, Spaghetti, Brown Rice, Potatoes, Root Vegetables, Whole meal breads, Granary Bread, Brown Bread, Pita Bread, Bagels, Wholegrain cereals, High Fiber breakfast cereals, Porridge oats, All bran, Shredded Wheat, Ryvita Crispbread, Cassava, Corn, Yams, Oatcakes, Peas, Beans, Lentils, and Pretzels.

“Complex carbohydrates are chains of three or more single sugar molecules linked together. Long chains of sugar molecules are called starches and they serve as the storage form of energy in plants. Branched complex carbohydrates called cellulose form the structural components that give plants their shape. Starches are fairly easy to digest. However, your body doesn’t digest cellulose, which is an important component of dietary fiber. Complex carbohydrates are found in fruits, vegetables, nuts, seeds and grains. Some examples of foods high in starchy complex carbohydrates include bread, cereal, rice, pasta, potatoes, dry beans, carrots and corn. Green vegetables like green beans, broccoli and spinach contain less starch and more fiber. All grains include starchy carbohydrates. However, whole grains -- such as whole wheat pasta -- are better for you because they also have more fiber. Complex carbohydrates should be a major part of your diet; about half of your daily calories should come from carbohydrates -- mostly from grains, cereals, fruits and vegetables. Only a few of your daily calories should come from simple carbohydrates like table sugar. Simple carbohydrates are made up of one or two sugar molecules linked together. Examples of simple carbohydrates include glucose, fructose (fruit sugar), sucrose (table sugar) and galactose (the sugar found in milk). Simple sugars are used as ingredients in candy, ice cream, cookies and other sweets. Plus they occur naturally in fruits and lesser amounts are found in vegetables."

Hope this helps...

Cheers,
Tamara
Mom to Hunter 3.8 years & MacKenzie 2!!!
Mackenzie - SCAD - originally diagnosed with LCHAD at 9 months (but now ruled-out completely)
Hunter has not yet been tested (but He AND Mac had a negative ENBS)
lchadmacsmom@gmail.com

(Cont’d on page 9)
A tasteless, microencapsulated, powdered form of Riboflavin for individuals over the age of 1 year with Mitochondrial Cytopathies or Glutaric Acidemia Type II.

**Cyto B2 powder** is a Medical Food specifically formulated using a proprietary microencapsulation process. Tasteless Cyto B2 powder represents a practical solution to the dosing of riboflavin for metabolic and mitochondrial patient, without the offending taste and staining of the compound.

**Product Form**
Powder

**Indications**
Diagnosed Mitochondrial Disorders
Glutaric Acidemia Type II

**Advantages**
Tasteless – promotes better compliance
Does not stain

**Nutrition Information**

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</table>

**Ingredients**: Riboflavin, mono - and diglycerides

**Legislative Advocacy Update**

[Taken from www.umdf.org and from a letter from Chuck Mohan, CEO/ED]

“On July 31, 2009, Rep. Jim McDermott introduced in the House the Mitochondrial Medicine Research and Treatment Enhancement Act, known as H.R. 3502. On December 10, 2009, Sen. Barbara Boxer introduced S.2858, a companion bill in the Senate called The Brittany Wilkinson Mitochondrial Disease Research and Treatment Enhancement Act. H.R. 3502 directs the National Institutes of Health (NIH) to establish an Office of Mitochondrial Medicine. The newly created office will be directed to improve the coordination of research related to mitochondrial medicine within the institutes at the NIH and with outside researchers. It also calls on the NIH to annually award five grants for multi project research programs related to mitochondrial medicine and five grants annually for integrated, multi project research programs related to mitochondrial medicine. In addition, H.R. 3502 calls on the NIH to establish a “Mitochondrial Medicine Centers for Excellence” to promote interdisciplinary research and training related to mitochondrial medicine. It also calls on the NIH to establish a national registry for the maintenance and sharing for research purposes and creates a biorepository for DNA and tissues collected from patients with mitochondrial disease and dysfunction for research purposes.”

Write your Representatives and Senators to support these bills!
New Research in Treatment of Fatty Acid Oxidation Deficiencies

Jerry Vockley, MD, PhD
University of Pittsburgh
Professor of Pediatrics, School of Medicine
Professor of Human Genetics, Graduate School of Public Health
Chief of Medical Genetics
Children’s Hospital of Pittsburgh of UPMC
Pittsburgh, PA 15224

Nicole Payne, RD, LDN
Metabolic Dietitian
Children’s Hospital of Pittsburgh

The recognition of disorders of fatty acid oxidation recently passed a 35 year anniversary and newborn screening for these disorders has just expanded to all 50 states. As a result, disorders of FAO are now among the most common inborn errors of metabolism diagnosed world wide. Unfortunately, resources focusing on the development of new therapies have lagged behind the recognition of affected individuals. Mostly our therapeutic options still center around avoidance of fasting with use of some supplements such as carnitine and medium chain triglyceride (MCT) oil. The good news is that the tide may finally be turning with a number of new initiatives underway to further study FAODs and develop new treatments for them.

One key to the development of new treatments for these disorders, is the ability to coordinate the efforts of the many centers around the country caring for patients with FAOD. While few metabolic centers care for enough patients to carry out adequate clinical trials for new therapies by themselves, coordinating efforts provides the opportunity for all patients to participate in trials and benefit from new treatment protocols. Two new national efforts are important in this regard. First, the National Institutes for Health (NIH) and the Health Resources and Services Administration (HRSA) have begun to develop national collaborative consortia to follow babies with metabolic diseases identified through newborn screening as well as create an infrastructure to empower careful clinical studies in patients with metabolic disorders. The NIH Office of Rare Diseases Research has also begun establishing rare disease networks focused on groups of disorders with the goal of identifying patients with them, understanding the full spectrum of their symptoms, and developing new therapies. A national consortium for the study and treatment of FAODs coordinated by the Children’s Hospital of Pittsburgh has been organized in collaboration with the FAOD support group and Saving Babies through Screening but is still seeking funding to begin operation. In the meantime, a number of the centers involved in establishing the FAOD consortium are independently pursuing pilot projects in newborn screening follow-up (University of Minnesota), developmental outcomes in MCAD deficiency (Boston Children’s Hospital and Children’s Hospital of Pittsburgh), and a comparison of triheptanoin and MCT oil in the treatment of long chain fatty acid oxidation defects (Oregon Health Sciences University and Children’s Hospital of Pittsburgh).

Two therapies are likely to receive more attention in the near future. Triheptanoin (often referred to as C7 oil) is an artificial fat that has been used for over 10 years to treat some patients with a variety of FAODs. Studies conducted by Dr. Charles Roe during that time have suggested benefit for muscular symptoms in patients with long chain fat defects and improvement in heart symptoms in some individuals. However, Dr. Roe has retired prior to accumulation of enough data for Food and Drug Administration (FDA) approval of the medication. We have recently received approval by the FDA to use triheptanoin as an experimental drug at the Children’s Hospital of Pittsburgh while we organize a definitive clinical trial. Initially, patients will need to travel to Pittsburgh at least annually to participate. We are attempting to engage other sites around the country to participate in this study as well. The evaluation involves an outpatient visit and blood draw. Individuals currently being followed by Dr. Roe for triheptanoin use should contact our study coordinator Nicole Payne (nicole.payne@chp.edu) or 412-692-5099 to participate in the Pittsburgh study. Over the next several years, we will plan a multi-center study that will meet the requirements for FDA approval of triheptanoin.

Bezafibrate is a second new therapy for treatment of long chain FAODs. This is a drug originally used to help treat high blood cholesterol and lipids. It has since been shown to increase the body’s ability to perform fatty acid oxidation by increasing the amount of fatty acid oxidation enzymes made by their genes. Individuals with mutations in FAOD genes that result in a small amount of protein still being produced may benefit from this therapy. A preliminary study in France has shown promise and a larger European study is underway. No U.S. sites currently participate in this study but interest in doing so is high (including at Children’s Hospital of Pittsburgh) and likely to occur in the next year or two.

A number of more experimental therapeutic options for FAODs are also under investigation. Gene therapy has long been a goal for many genetic disorders including FAODs. Unfortunately, while there has been progress in using gene therapy to correct FAO enzyme deficiencies in tissue culture cells in the laboratory and in mice with FAODs, the options for reliably delivering gene therapy in humans

(Cont’d on page 11)
and establishing long term efficacy of the new gene have not been successful in most cases. While the allure of gene therapy remains high, the reality likely remains many years away. A variation of this technique may hold more immediate promise. Liver transplantation has been used for many years to treat individuals with some metabolic disorders. It has not been attempted for FAODs because of the chronic problems related to the long-term immune therapy that must be continued indefinitely after transplant. Also, while liver transplant may eliminate hypoglycemia, it is not clear that it would improve the muscular, heart, or other system problems seen in some FAODs. At the Children’s Hospital of Pittsburgh, investigators are now studying new techniques to make stem cells for an individual from their skin cells that can then be transplanted back without the need for immunosuppression. In patients with FAOD, the goal is to use genetic techniques to correct the stem cells prior to transplanting them back to the original donor. Since stem cells can theoretically be induced to become any cell type, it would be possible to give multiple cell types as needed to address the specific metabolic needs of each FAOD. Clinical trials for other metabolic disorders are soon to begin and will be expanded to include FAODs if successful.

Finally, at the Children’s Hospital of Pittsburgh, we are using computer aided drug design and screening to develop a new medication to treat MCAD deficiency. 90% of individuals affect with MCAD deficiency have at least one copy of a gene that has a single mistake, the common A>G 985 mutation. This mutation allows production of a normal amount of MCAD protein, but because of the genetic defect, the protein cannot be processed normally and is quickly destroyed by the cells. We have recently received funding from the NIH to develop a drug that will stabilize the abnormal protein, which it turns out likely functions well enough to prevent symptoms. Such a medication could be used on a daily basis or even just when a patient is otherwise ill and at risk for the development of a metabolic crisis. If successful for MCAD deficiency, similar technology can be used to search for drugs to treat other FAODs.

Newborn screening for FAODs has been a welcome addition to our clinical set of tools but it is a beginning not an end. Screening brings with it new promise to identify patients prior to the development of symptoms. It also brings new obligations for clinician scientists to develop new and better treatments. But patients and families must also help to reach this goal. How? The most important avenue is to participate in clinical trials. Experimental protocols will always be designed to provide standard of care while safely changing one unknown variable. Much of our standard of care has been driven not by data but by anecdote and expert opinion. Backtracking to reexamine these therapies as well as testing new ones will require close collaboration between metabolic physicians, patients, and investigators. Keep your eye on this newsletter for new opportunities!

Medical Update...cont’d

Effectiveness of a Clinical Pathway for the Emergency Treatment of Patients With Inborn Errors of Metabolism
Dina J. Zand, MDb,a, Kathleen M. Brown, MD,a,c, Uta Lichter-Konecki, MD, PDb,a, Joyce K. Campbell, RN, MSNd, Vesta Salehi, MDe, James M. Chamberlain, MDa,c
aDepartment of Pediatrics, George Washington University School of Medicine and Health Sciences, Washington, DC; Divisions of bGenetics and Metabolism and cEmergency Medicine and dCenter for Hospital-Based Specialties, Children’s National Medical Center, Washington, DC; eDepartment of Pediatrics, Weill Cornell Medical College, New York, New York
The authors have indicated they have no financial relationships relevant to this article to disclose

OBJECTIVE. The goal was to measure the effectiveness of a clinical pathway for the emergency department care of patients with inborn errors of metabolism.

METHODS. Two years after the implementation of a multidisciplinary clinical pathway for patients with inborn errors of metabolism in our urban, academic, pediatric emergency department, we compared measures of timeliness and effectiveness for patients treated before the pathway with the same measures for patients treated after implementation of the pathway. Measures of timeliness included time to room, time to doctor, time to glucose infusion, and total emergency department length of stay. Measures of clinical effectiveness included the proportion of patients receiving adequate glucose infusions, proportion of patients admitted, inpatient length of stay, and proportion of patients requiring PICU admission.

RESULTS. A total of 214 emergency department visits for patients with inborn errors of metabolism were analyzed, 90 before and 124 after initiation of the pathway. All measures of timeliness except total emergency department length of stay demonstrated significant improvement in comparisons of values before and after initiation of the pathway. Measures of clinical effectiveness also demonstrated significant improvements after initiation of the pathway. There was improvement in the proportion of patients who received adequate glucose infusions, with a decrease in the proportion of patients who required admission to the PICU. Emergency department length of stay, inpatient length of stay, and the proportion of patients admitted to the hospital were not affected.

CONCLUSIONS. Most measures of timeliness and 2 measures of effectiveness showed improvement after implementation of an emergency department pathway for patients with inborn errors of metabolism. Therefore, a clinical pathway can improve the emergency care of patients with inborn errors of metabolism. *Pediatrics* 2008;122:1191–1195
Parent Commentary ~ Thoughts on medicating...or not...for ADD/ADHD

Q: I'm interested in how those of you who deal with an FOD and ADD type problems in your children have dealt with it. Have you successfully medicated without side effects? Have you found any attention problems associated with taking carnitine? Have you dealt with it successfully other ways?

Parent Response: The decision to medicate was the most difficult decision we ever made. Katie had most of the symptoms you're describing, and she was on dexedrine for several years. Dexedrine is very "old school" but our doctor felt it was best since dexedrine had been used for different things for sixty years, and side effects were documented. The dexedrine did help her focus and completion of school work improved. However, there were side effects—loss of appetite (which we had to watch closely because of the MCAD), repetitious behaviors (pulling eyelashes and/or hair, peeling skin off her lips, etc.), becoming very withdrawn. Her writing and her concentration were much improved, though.

Katie has learning disabilities due to the lack of oxygen during her first episode. The difference medication made was enough to put her over the pass/fail line. If repeating a grade would have resulted in more learning, we would have been willing for her to be retained. At that time, though, Katie's memory problems kept her from retaining info very long. IF she passed her spelling test on Friday, she was likely to forget the words by Monday. For Katie, the medication made a difference between passing and failing, and we felt the trade off was necessary. The constant struggle of school also began to wear on her mentally and emotionally, and our psychologist, who we saw regularly, was worried about her and felt the medication was needed.

Be very clear about what you want from the medication. Studies have shown in the long run students who are medicated do not retain any more knowledge than non-medicated counterparts. Medication does not guarantee everything's going to be okay academically at the end of school. A new study about this was released when we were having to make the decision for Katie, and it really made us look at why we were doing this. If the situation had not been a matter of pass/fail, I do not know if we would have tried the medication, and I certainly do not think we would have continued after the side effects surfaced. We were worried about the effect retention would have on her, especially since her teachers, doctors, and psychologist all felt like repeating would not be beneficial.

Katie had to be removed from dexedrine 2 years ago due to some problems she was having. (Unsure if related to dexedrine.)

Before putting your child on any medication, go to your local library and get Dr. Frank Lawlis' "The ADD Answer Book." It is one of the few books out there written by someone who is not supporting a pharmaceutical company. It has quizzes and suggestions to help you decide what is best for your child.

Our psychologist used neurofeedback with Katie, and the results were wonderful! The psychologist hooks electrodes to Katie’s head, and Katie does PacMan-like games with her brain—no hands. It teaches her self-relaxing techniques. Dr. Lawlis covers some of this, using temperature sensitive stress dots, in his book. The neurofeedback can be controversial, but for us this has been a blessing.

Also, remember there are lots of techniques for dealing with ADHD besides medication. You may need to get a 504 or IEP in place allowing your child to get modified assignments (Katie often does every other problem), or to have extra time. Sitting near the front of the class helps, having a piece of paper to hold under a line of reading, having tests and/or assignments read, etc. Also, the two things we have found VITAL to helping Katie stay on track are a predictable schedule (this was hard for me, because I am a very unorganized person) and LOTS AND LOTS of sleep. Though she’s almost fifteen, Katie goes to bed between 8:00-9:00 every night. If she fails to do this, she is out of kitler. I would try increasing sleep as a starting point and see if that helps.

After a lot of years and struggles, Katie is now doing a little better in school, the ADHD is not as bad, and her memory has improved some. No one is quite certain how or why these have improved, but we’re counting our blessings.

I would encourage you, if possible, to find a psychologist or psychiatrist who can advise about testing. Even if the school tests, you want your own person to make certain the results are correct. If your insurance has a hotline number, call and discuss with them and see what they advise—maybe then they’ll cover it.

The info above is info from our lives, but each child and each family are different. Making this decision is difficult because people who talk about the issue seem to be extremes—either "Absolutely I'm not medicating my child", or "Here, have another pill." I found out, though, there are a lot of people on the middle road struggling with this issue who are embarrassed to say so. See if there are any support groups in your area for ADHD.

Follow your heart, research all the options, and do what you feel is best for your child. Don’t let anyone bully you into making a decision you don’t feel comfortable with. I don’t know if you are a religious person or not, but for my husband and I, prayer was a huge help to us when making this decision. You're obviously a caring mom, and I know you'll do what's best for your child.

Good luck! Sending prayers your way!

Gail
hdgwnwhite@aol.com
Katie, 14, MCAD
How Families are creating awareness for metabolic disorders!

This past year we had several Families plan their own FOD Awareness projects and not only raised awareness but funds for our Group! We even had Families have friends send donations into the Group in honor of their child’s birthday or baptism. Another Family, in honor of their granddaughter, hosted several Silpada jewelry parties and raised over $1000!

If you don’t feel comfortable doing your own fundraiser/project, you can help raise FOD funds by using Goodsearch as your browser or shop online using the iGive site – a portion of your purchases benefit our Group (see our homepage, right sidebar for links)

As for raising awareness – sharing your story at a local hospital or teaching hospital during grand rounds would be terrific ~ we NEED more clinical professionals in the field of metabolism and this would be a way of exposing them to the challenges of this exciting field!

We also added our information on Facebook.com in order to raise Funds ~ check us out and join the CAUSE!

ATTENTION FOD FAMILIES ~ FUNDRAISING EFFORT AT ITS BEST!

I will donate 100% of my proceeds to FODSUPPORT toward our RESEARCH FUND!

Ever hear of Silpada Jewelry? No, well let me introduce you to the beautiful fine sterling silver jewelry we have to offer!

All our products are .925 fine sterling silver. What’s that you ask?

.925 is 92.5% pure silver mixed with 7.5% COPPER!
(NOT nickel or brass, which makes many individuals’ skin turn green or black)
This will NEVER happen with Silpada jewelry.

EVERY piece is handcrafted and exclusive in design!

AND, we just received the 2009-2010 new products!
Please go to my website and check out over 450 pieces in the new catalog! Then send me an email with your order and your phone number and I will contact you personally for payment information. Every order is shipped directly to you for just $4.00!

LET’S REALLY MAKE THIS HAPPEN! THE OPPORTUNITIES ARE ENDLESS WITH SILPADA!

Brenda Goodman (FOD mom)
Independent Representative for Silpada Jewelry
Fine Sterling Silver Jewelry

doublebn@aol.com
my silpada website

home: 216.292.5938
cell: 440.655.2793
*Under ordinary circumstances, the defect appears to be silent.*

*However, a severe and life threatening crisis may be provoked by prolonged fasts when the body ordinarily begins to depend heavily on fatty acids as a fuel, and are particularly likely to occur during intercurrent illness when food intake is reduced, or with mild fever.*

*If this patient presents in the ER with any of these symptoms, treatment aimed at providing sufficient glucose to reverse the fasting state must be begun immediately and urgently.*

*Hypoglycemia may occur, but the symptoms and significant disease progression have usually begun while the plasma glucose is still quite normal.*

*If treatment is begun early, recovery should start to occur fairly rapidly, within 2-4 hours.*

[Note: ‘recovery’ does not necessarily mean the patient is sent home in 2-4 hrs, it just means most start to ‘turnaround’ because they are getting what their body needs – immediate calories through the dextrose 10% IV]

*We have found that a one-pager is much more effective than too much information! Short and sweet! Also bolded is always the statement that D10 is started even before lab results are available, even if child “looks” ok. Also I don’t think a lot of docs know about the insulin drip (severe case for long chain). When BS is too high they just turn down D10 rather than adding insulin to drive the sugar into the cells to stop fat mobilization.

And again, I stress the shorter the better. Anything else (treatment for leg pain, etc.) can be discussed later. People are usually not interested in that at this time, and if handed a 2, 3 or 4 page document, it is overwhelming and will usually be overlooked or ignored.

Submitted by: a very experienced VLCAD mom!

[Always check with your own FOD specialists for individualized wording on your own/your child’s protocol]
Pioneering HHS HRSA Grant Funds Establishment of First National Newborn Screening Clearinghouse

WASHINGTON – September 16, 2009 – The nation’s first Newborn Screening Clearinghouse (NBSC), connecting millions of parents and healthcare providers with resources and information relevant to more than four million newborns screened annually, will be created through a $3.75 million cooperative agreement from the U.S. Health and Human Services, Health Resources and Services Administration (HRSA), Genetic Services Branch. The project will span five years.

Genetic Alliance and the National Newborn Screening and Genetics Resource Center (NNSGRC) at the University of Texas Health Science Center at San Antonio, will develop the NBSC with the Genetics and Newborn Screening Regional Collaborative Groups, March of Dimes, the Association of Public Health Laboratories and many other partners.

For more than 40 years infants born in the U.S. have been screened for an increasing number of congenital conditions, yet parents are often unaware of the number and quality of screening their children received or how options may vary from state to state. The NBSC will increase awareness of newborn screening, and improve understanding and informed decision-making capacity of expectant and new parents, health professionals, industry representatives, and the public. The project will connect state and regional public health groups in these efforts and facilitate data and resource sharing. It will provide a central linkage location for access to informational resources and data on quality indicators of newborn screening. The NBSC will be responsive to emerging technologies and the public health challenges these technologies will present. It will also take advantage of newly established and promising communications technologies that allow just-in-time and point-of-service access for parents and providers alike.

“The National Newborn Screening and Genetics Resource Center is the robust core of the new NBSC,” said Bradford Therrell, Jr., Ph.D., director of NNSGRC. “The current national newborn screening data reporting system will be taken to the next level in this project. We look forward to collaborating with Genetic Alliance in the development of this resource.”

“The nation’s newborn screening (NBS) programs are a phenomenal, unsung, public health success,” stated Sharon Terry, president and chief executive officer of Genetic Alliance. “NBS offers an unparalleled opportunity to integrate electronic health technologies, data standards, data collection, and consumer-focused educational materials all in one coordinated system. Essentially every child in the nation is screened, and enters the healthcare system in a place where the system is working. The NBSC will allow for appropriate data transparency, integrated tools, technologies and education, and provide the basis for follow-up.”

“Newborn screening touches the lives of millions of families and hundreds of thousands of healthcare providers each year,” declared Natasha Bonhomme, NBSC project director and the vice president of strategic development at Genetic Alliance. “The NBSC partners’ goal is to transform information sharing within newborn screening in the interest of each child born in America. Parents will better understand which newborn screens are required and options for additional screening, while state newborn screening programs will receive needed support in their mission to serve the newborns of our country.”

The NBSC partners plan to develop the electronic and outreach components of the NBSC simultaneously. Terry serves on the Office of the National Coordinator’s Health Information Technology (HIT) Standards Committee, so development of the NBSC will model new HIT/exchange guidelines as they are created. Due to the consumer focus of Genetic Alliance, the project will balance privacy concerns and the informational needs of the public and providers. Therrell has served on both the American Academy of Pediatrics and American College of Medical Genetics Working Groups, defining current and future national activities in newborn screening.

About Genetic Alliance – Genetic Alliance transforms health through genetics, promoting an environment of openness centered on the health of individuals, families, and communities. Genetic Alliance brings together diverse stakeholders that create novel partnerships in advocacy; integrates individual, family, and community perspectives to improve health systems; and revolutionizes access to information to enable translation of research into services and individualized decision making. For more information about Genetic Alliance, visit http://www.geneticalliance.org.

About National Newborn Screening and Genetics Resource Center – The National Newborn Screening and Genetics Resource Center (NNSGRC) is a cooperative agreement between the Maternal and Child Health Bureau (MCHB), Genetic Services Branch and the University of Texas Health Science Center at San Antonio (UTHSCSA), Department of Pediatrics. The project is funded by the Health Resources and Services Administration (HRSA). The mission of the NNSGRC is to: 1) provide a forum for interaction between consumers, health care professionals, researchers, organizations, and policy makers in refining and developing public health newborn screening and genetics programs; and 2) serve as a national resource center for information and education in the areas of newborn screening and genetics. For more information, visit http://genes-r-us.uthscsa.edu/.

For More Information Contact: Tiphané Turpin, Communications Manager – tturpin@geneticalliance.org or 202.966.5557 x212
Q: Does anyone have suggestions for sleep issues?

A #1: I just want to mention that there are MANY things which go into helping your child sleep through the night, and we went though a similar thing around 2-1/2 with Katie - she had been sleeping through the night (almost all nights) and putting herself to sleep happily, and then, bang, it all stopped. We were able to trace it to gradula changes in our routine and other inputs, I really don't think it was at all related to her LCHAD. (though you never do know what impact blood draws and other stressful LCHAD related things have on sleep/dreams, etc.)

In any case, we pulled our hair out for a few months, and then found a great resource - the No Cry Sleep Solution by Elizabeth Pantley (Toddler version) - This book lays out a lot of the research on sleep drawing conclusions on what it means for children, and then gives just TONS of different ideas about how to help your child sleep better. It doesn't give you one inflexible routine that you have to follow, but rather MANY, many different ideas to try in different situations. It took us awhile to get into a routine that worked for Katie and our family, but eventually, through trial and error (and for us, it was partially getting back to earlier naps when most of Katie's local friends take very late naps, and making sure that our bedtime routine started early so that Katie could be asleep by 7:30-8:00 at the latest...that's just us - Katie wakes up at 6am whether she goes to bed at 7pm or 10pm...in fact, the later she goes to bed the earlier she wakes - we found that the earlier she goes to bed, the better she sleeps!) Everyone's situation is very different, but this book gave just a plethora of tips and ideas to help your child sleep better. I hope it might be helpful for you!

And I REALLY sympathize - it is SO hard to be waking all night long and to try to function the next day (not to mention to maintain a patient, loving attitude towards our child who is dragging us out of bed in the wee hours when our eyes just want to be closed!) Sleep deprivation, to me, is one of the worst things in life!!! Wishing you luck, and SOON! :)

Warm wishes,
Taryn
Mom to Katie, 3, LCHAD
Queens, NY   tpaladiy@gmail.com

A #2: It's so tough at that age, when they're still just learning how to live on their own, and sleep deprivation makes every challenge seem larger than it is. I know in our case it exaggerated how overwhelming the idea of MCAD felt. We got to a "by any means necessary" place with sleep since it had such a big impact on our ability to care for him when we were awake. Sleep made it all seem possible. And the absence of sleep had the opposite effect.

A few things that worked for us:

-absolute darkness in his bedroom (black-out shades)
-swaddling (we actually used The Miracle Blanket quite a bit)
-white noise sound machines (the Sleep Sheep rain function worked best, although it only stays on for 45 minute at a time -- other machines you can plug in)
-removing all stimulants from his cribs (brightly colored pictures, etc.)
-clear, consistent pre-sleep rituals that minimized stimulants (lower lighting, calming music)
-Mozart for babies sleepstartyme CD
-learning how to let family members or babysitters help us with the overnight shifts (even when I was breastfeeding, someone else to change him, get him ready to feed, put him back down)
-pumping so that someone else could feed him at least once overnight, eventually supplementing breast milk with formula probably sooner than we would have for this same reason
-tips in the No Cry Sleep Solution book
-loose eat, activity, sleep schedule

Most importantly, hang in there! It does get better!

Anne
Mom to Alec, 15 months
Boston
sarahstucky@gmail.com
Please remember these families in your thoughts and prayers throughout the year

Joan and Tim Alberts  

Sandy and Howie Aitken  

Christy Axsom  

Jeanne and Mark Barilla  

Jodi and Wayne Barnes  
Amy - Birth Feb 20, 1995 Death Sept 27, 1995  
Baby Barnes - Death in-utero Oct 7, 1999

Delane and Althea Becker  

Sue and Jim Berneski  

Jennifer and Bill Boucher  
Alyssa - Birth Nov 18, 1999 Death July 22, 2000

Jacque and Mike Bradford  

Cynthia Brown  
Miranda - Birth Death April 3, 2004

Joseph and Barbara Brown  
Amber - Birth June 18, 1989 Death May 17, 1990

Barry and Julie Bryson  

Carolien Grooant - Callens  

Tom and Lynn Camino  
Stephanie - Birth June 28, 1995 Death Feb 6, 1996

Claudia and Atonio de Carmo  

Mark and Karen Carpenter  
James - Birth May 7, 1985 Death Dec 6, 1986

Jenny and John Carroll  
Sarah - Birth March 4, 1992 Death Sept 1, 1992

Mark and Diane Casey  
Matthew - Birth Apr 15, 1974 Death Jan 13, 1975  
Lori - Birth Aug 31, 1980 Death July 1, 1984

Tammy and Roger Clark  
Jenna - Birth Feb 17, 2002 Death Nov 22, 2002

Valerie & Chris Ciachette  
Benjamin - Birth Jan 12, 1987 Death April 18, 1987

Toni and Mark Cline  
Kasie - Birth June 6, 1990 Death March 10, 1991

Sandy and Jon Cooper  

Jill and Chesley Craig  

Martin and Kathy Davis  
Mary Katherine - Birth June 27, 1996 Death Nov 7, 1996

David and Amy Deshais  

Doug and June Evenhouse  
Marie - Birth Dec 15, 1985 Death Nov 19, 1986

Carolyn and Terence Finn  
Emily - Birth Feb 13, 2002 Death April 3, 2004

Andrea and Phillip Franklin  
Brandi - Birth Dec 2, 1986 Death Jan 1988

Lance and Dawn Goldsmith  

Deb and Dan Gould  
Kristen - Birth Oct 6, 1983 Death July 21, 1985

Shelly and William Grabow  
Noah - Birth Nov 18, 2003 Death March 23, 2004

Brandis Greichunos  
Madison Burchette - Birth March 8, 2001 Death March 24, 2002

Jeannette and Keith Guillory  
Dominique - Birth Jan 21, 1997 Death Jan 23, 1997

Nicole and Chris Gulinoello  
Alec - Birth Feb 21, 2001 Death Aug 24, 2001

Michael and Nicole Gumiel  
Michael - Born March 28, 1998 Death April 4, 1999

Carol and John Hall  
Sarah - Birth June 8, 1998 Death July 30, 2000

Robin and Vince Haygood  
Ben - Birth Feb 19, 1998 Death Aug 8, 2000

Ralph and Angie Hedrick  
Chelsea - Birth Jan 11, 1995 Death Apr 3, 1996

Nikki and Toby Hiatt  
Reece - Birth Aug 1998 Death April 18, 1999

(cont’d on page 18)
Love Messages...cont’d

Pauline and Bill Hill

Amy and Matthew Hoffman

Brad and Kim Holmes

Debbie and Dave Houk
Lauren - Birth May 4, 1988 Death Dec 15, 1989

Robert and Dixie Howard
Cody - Birth July 30, 1987 Death Dec 26, 1992

Stephanie and Doug Huber
Jace - Birth March 8, 2000 Death Feb 14, 2001

Meredith and Neil Hughes
Claire - Birth Sept 1, 1986 Death June 23, 1997

Karen and Steve Imhoff
Michael - Birth July 25, 1991 Death July 8, 2002

Miranda and Rick Jones
Jacob birth Nov 8, 1999 death Aug 4, 2009

Brian and Patricia Karhu

Vickie and Burnell Keller
Paul - Birth Mar 31, 1993 Death Sept 20, 1993
Annie - Birth Nov 26, 1998 Death April 22, 1999

Diane and Mickey Kennedy
Marie - Birth Dec 1, 1989 Death Oct 5, 1991

Andy and Temple Ketch
Nancey – Birth Feb 8, 1989 Death July 20, 1990

Robert Knoff
Teresa – Birth Nov 7, 1994 Death June 29, 1995

Sondra Koehn

Jamie and Tom Lazzaro

Lisa and Pete Leonard
Devin - Birth July 18, 1997 - Death July 19, 1997

Mary Lingle
Candice - Birth Feb 21, 1991 Death Nov 8, 1993

Darlene and Larry Lopez
Marissa - Death Feb, 1999

Heather and Phillip Marsella

Ron and Paula Matthews
Daniel - Birth May 19, 1981 Death Jan 12, 1982

Randy and Misty McDonald

Christine and Mark McFarland

Linelle and Matt Meadows
Cole - Birth Mar 21, 1999 Death Oct 18,1999

Elvira Melendres
Katherine - Birth Mar 6, 2000 Death May 3, 2000

Lori and Jeff Michaud

Simone and Michael Miller

Kristen and Ken Mitchell
Nolan - Birth Aug 8, 2004 Death May 16, 2005

Mike and Sheryl Mulhall
Justin - Birth April 22, 1990 Death April 22, 1990

Verna Parker

Diana and Kevin Patterson

Steve Bruski and Liz Pease
Caitlin - Birth July 10, 1989 Death May 10, 1996

Albert and Arleen Phang
Andrew - Birth Dec 7, 1989 Death April 17, 1991
Alexander - Birth Dec 3, 1994 Death Feb 8, 1995

Jennifer and Jason Pierson
Alexander - Birth June 1, 1995 Death June 3, 1995

Stephanie and Andrew Plaisted
Drew - Birth May 7, 1997 Death Dec 27, 2000

Louise and Michael Ramos

John and Sally Reichelder
Zachary - Birth March 24, 1997 Death March 27, 1997

Tanya and Pat Robitaille
Richard - (stillborn) June 24, 1993
Rachel - Born August 13, 1995 Death December 29, 1995

Brian and Cherryl Rosenberger

Janice and Steve Rowland

Litzy Sanz de Solis and Jesus Solis Sanchez
Jesus - Birth Sept, 14, 1996 Death March 16, 1998
Love Messages...cont’d

Jackie Shears  

Lisa and Scott Sleezer  
Emily - Birth March 5, 1998 Death June 18, 2001

Leah and Paul Sofranko  
Kyle - Birth Feb 7, 1988 Death Feb 5, 1989

Rhonda and Matt Southard  
Trace - Birth May 2, 2000 Death Aug 26, 2000

Janna Sowers  
Kelsie - Birth April 23, 1993 Death April 23, 1993

Anne and Gary Stitt  

Lisa and Doug Tennyson  

Rick and Stephanie Thomas  
Trina - Birth July 1977 Death Jan 14, 1978

Mary Thorson  
Wendy - Birth Sept 20, 1978 Death Sept 10, 2005

S. Elizabeth & G. Douglas Turman  
Philip - Birth April 6, 1994 Death April 8, 1994

Darren and Karen Wade  

Sirpa and Jay Waananen  

Jenni Wagoner  
Lauren - Birth Oct 26, 1993 Death Nov 13, 1999

Richard and Amy Warner  
Andrew - Birth May 1978 Death Nov 18, 1979  
Scott - Birth May 1983 Death April 25, 1985

Denise and James Westman  
Benjamin - Birth March 11, 1987 Death Dec 20, 1988  

Bobbi-Jo and Duncan White  
Sophia McVey - birth Oct 23, 2008 death July 1, 2009

Mike and Darci White  
Brett - Birth June 14, 1993 Death June 17, 1993

Karen and James Whiteside  

Lori and Dean Williams  
Brennan - Birth June 1, 1999 Death June 6, 1999

Christi and Ronnie Williams  

‘Love is our true destiny. We do not find the meaning of life by ourselves alone ~ we find it with another’

~ Thomas Merton

Grief Support Services

Deb Lee Gould, MEd  
Director, FOD Family Support Group  
MCAD Parent and Grief Consultant  
PO Box 54  
Okemos, MI 48805-0054

Office/Cell Phone: 517.381.1940  
Fax: 866.290.5206

deb@fodsupport.org

Please know that all emails or phone contact with me will be confidential

One-on-one grief support is available for our Families/public that have experienced the death of a child or other loved ones and are having a difficult time living with this reality.

If you feel more comfortable just calling or emailing, please do ~ I do not want to miss anyone’s request for support.

However, in order for me to better understand your situation, I’d appreciate it if you could please complete the Grief Intake Form on our site. It isn’t required, but it will help me understand your situation. It can be submitted online or mailed/faxed.

There is no charge for this extra support ~ however donations are always appreciated!

Please note: As of 2010, Deb is expanding the Group’s Mission of providing free of charge face-to-face Grief Consulting to the local MI community ~ specifically for Bereaved Parents
Condolences...

It is with a heavy heart that I am letting you know that our son, Jacob Jones (TFP), died on August 4, 2009 after a short illness.

Forever in our hearts...

Miranda and Rick Jones
mjones_rn@hotmail.com

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

FOD Family Questionnaire and Survey — New ONLINE Format Coming Soon!

We will be making changes soon as to how Families can be placed on our ONLINE FAMILY LIST — years ago we used to have a written Family Questionnaire that needed to be signed (it is still on our Online Forms page on the website), however we are moving more toward having our Networking resources on our website. The FAMILY LIST will be password protected and ONLY Families will have access to it. We are also trying to consolidate forms so there will be a few more questions to answer on the new Form. The answers will all be CONFIDENTIAL, but they will help us tremendously in gaining valuable information about the makeup of our Families and will aid us when writing for grant funding. So keep an eye out for our New Family List signup!

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, 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.

Now that we are a 501c3 Nonprofit 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 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!
‘Reaching for the Stars’
Adventures and Accomplishments of our FOD Kids

Gabe Arveson
MCAD
King of Homecoming 2009!
Minnesota

John
Unclassified
Ferndale, MI
May 2008 Prom night

Resources

www.Disability.gov - A quality education sets the foundation for future success and should be within reach of everyone. This section of Disability.gov connects students with disabilities, as well as parents and educators, to information about a variety of topics from early childhood education to post-college and beyond, including making the transition from high school to post-secondary education or work, laws that protect the rights of students with disabilities, classroom supports and accommodations, and scholarships and other forms of financial aid. Many other topics are on the site as well.

http://www.namebubbles.com/labelpack/medical-alert-labels.html - Medical alert labels

Insurance Info from parent:
There is a patient assistance program through Sigma Tau for Carnitor® - I think you have to have a high deductible medical insurance plan but can have coverage with this. The phone number is 800-490-3262 and they will verify what you have for coverage. There is also NORD which may be the route that Sigma Tau sends you. Their number is 800-999-6673 Option 3, extension 1224 and the lady's name is Bunny.

For anyone with bleeding disorders or tendencies associated with mito or any other diagnosis like hemophilia or vonwillebrands, there is program called PSI, 866-367-4836, Rob is the contact. They cover vitamins, pain meds like tylenol, anything that would prevent bleeds from falls, like helmets and knee pads. I think you can just call them up and get renewals on whatever it is you need once your application is taken care of.

I also just ran into a mom (in Florida) who was telling me that if you have a child with special dietary needs that WIC was picking up her formula for her. I haven't been able to verify that yet however.

Mary-Ella
Jacob-9 and Noah-8, both undiagnosed fully yet
Florida
maryellafredrich@yahoo.com
My ‘question mark’ Reiley
Almost 4 yrs old
Unspecified metabolic disorder
Arizona

Luca
Almost 3 yrs old
LCHAD

Connor
6 mos old
VLCAD
Oklahoma City, OK

Gareth
MCAD
At July 4, 2009 flag ceremony
Pennsylvania

Katie
Wearing her ‘warm belly’
LCHAD
New York

Hayden (MCAD)
and Ashtyn
Grand Blanc, MI
(picture sent by proud grandma Brenda B)
**DONATIONS**


**Tshirts, Bracelets, Ribbons, CafePress, GoodSearch web browsing, or iGive shopping:** Nancy Hamm, Charles Stiles, Joleyn Law, Michelle Preston. Tia Jameson. Maria Yaney. Michelle Shahtout.

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 our homepage, right sidebar boxes.

**Professional Donations:** Sigma-Tau Pharmaceuticals, Inc., Microsoft Giving Campaign matching donation to (FOD Family) Virginia Luchau. OAA/Kathy Stagni, The Krez Group and ‘guys,’ and Haynes and Boone, LLP in memory of Gerry Lee Hogan. The David Geffen Foundation.

We greatly appreciate donations to help with postage and copying costs, website fees, supplies, conference costs, phone calls around the world, and raising funds for FOD Clinical Training and FOD Research. **US Checks can be made payable to ‘FOD FAMILY SUPPORT GROUP’ and mailed to Deb.**

We also have a PayPal link on our homepage. **ALL US donations are tax-deductible.** Our Tax ID # is 83-0471342.

**2009 Donations/Expenses for the FOD Group**

<table>
<thead>
<tr>
<th>Category</th>
<th>Amount</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Total 2009 Donations/Interest</strong> through 12.31.09</td>
<td></td>
</tr>
<tr>
<td>FOD General Fund</td>
<td>$ 4,900</td>
</tr>
<tr>
<td>FOD General Trust Fund</td>
<td>$9,300</td>
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<tr>
<td>FOD Clinical Trust Fund</td>
<td>$ 68</td>
</tr>
<tr>
<td>FOD Research Trust Fund</td>
<td>$ 2,400</td>
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<tr>
<td>FOD Petty Cash Fund (balance)</td>
<td>$ 76.84</td>
</tr>
<tr>
<td><strong>Total 2009 Expenses</strong> through 12.31.09</td>
<td>$ 9,700</td>
</tr>
<tr>
<td><strong>[These are rounded off amounts]</strong></td>
<td></td>
</tr>
</tbody>
</table>

Email Deb to view various Group tax documents

All Grief Consult donations are deposited into the General Fund, as are Bracelet and Ribbon Sales, Cafepress.com, iGive, Goodsearch, and any donation that isn’t designated for the other Funds. The General Trust Fund is to save/earn interest for Conferences and other annual costs. Once the Research and Clinical Funds reach a substantial amount, we will be able to offer grants to clinicians and researchers in the US.

Thank you to Erika Wallace - erikawallacepa@yahoo.com
(Mailing Lists), Mary Lingle - Mcartwrite@aol.com
(Web Page) and Brian Gould - gouldbr1@msu.edu
(newsletter) for all your hard work.

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.

**Communicate With Us**

Please **ADD** me to your mailing list
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

‘To accomplish great things, we must not only act, but also dream… not only plan, but also believe’

~ Anatole France