The FOD Communication Network Newsletter was created by and is currently edited by Deb and Dan Gould PO Box 54 Okemos, MI 48805 [phone] 517.381.1940 [fax] 866.290.5206 [website] www.fodsupport.org [email] deb@fodsupport.org | deb@bereavedparent.com [(backup) fodgroup@gmail.com [Skype overseas internet calls/voicemail] username: fodgroup

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2012 FOD Account Balances [before FOD accountant examination/calculations]

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2012 Expenses: @ $43,000
2012 Donations: @ $25,000

[$4900 in checks were rec’d after 1.1.13 and deposited 1.5.13 as 2012 Donations]

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/adults/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

FOD Support
fatty oxidation disorder communication network
As we move into our 23rd year of existence, we continue to encourage ALL of our Families to be proactive about creating FOD awareness around the world and advocating for more comprehensive/universal Newborn screening and insurance coverage for various treatments and supplements with the help of other larger Groups [ie., Genetic Alliance, Baby’s 1st Step, etc]. But more work is yet to be done ~ so keep on sharing with any and all that will listen!

With the power of the internet, we have been able to reach many Families in other countries, as well as get our young people involved in advocacy and fundraising. Below, one of our international MCAD Families shares how she personally created awareness of her son’s disorder via a blog. And a SC MCADer unselfishly gives up his 12th birthday gifts to raise money for an LCHAD Family and for the FOD Group!

♥ To my extended FOD family,

I recently had the chance to tell my Family’s (MCAD) story to a sympathetic reporter and celebrate Deb and the community she’s built here. I know this story is familiar to so many of you in this Group, so in case it’s helpful to you to see out in the public domain, I wanted to share the link.


Anne annemorriss@gmail.com

♥ My son is a sixth grader, with MCAD, and just celebrated his twelfth birthday. I wanted to share that instead of receiving presents this year, he decided to raise money for Emily that has LCHAD and for the FOD Family Support Group. We hope that these funds will help with some of the cost to continue to provide your wonderful services to families that have these rare disorders.

I was doing my usual cleaning and running around like a mad woman the morning of Colton’s birthday party. He, of course, wanted to go on my Facebook page to play games. When I logged him in that morning Oct 6th, the first post we saw was yours (Deb), of Kristen’s photo, remembering her birthday. It completely brought tears to my eyes and just seemed like a God sign. I did not realize that she and Colton’s birthdays are just two days and seventeen years apart. I was able to explain to him that because of Kristen we were able to find out about MCAD. However, it would take the hard work and dedication of Kristen’s mother and father, FOD Support, many doctors, and state testing, and his sister, Haley, being born until we got a diagnosis in the expanded Newborn Screening in Ohio.

Without FOD Support, I am completely convinced that we would have lost at least one of our three children, if not all of them by now. While that is all so scary, it gives us hope to keep awareness alive and keep striving for a better tomorrow for FOD families. Thank you for all that you have done and all that you continue to do for these rare disorders and all parent’s that have lost a child. God Bless you and your family.

P.S. Colton thinks he wants to be a doctor someday. He has been saying that since 2nd grade. He says he wants to be an Anesthesiologist, but I am hoping that he chooses Genetics!

The Huber’s
Chad, Kelly, Colton (12), Haley (8), Carter (6) - All MCAD kids
South Carolina chhuber99@gmail.com

So please share our website and brochure with ALL in your Family and your Professional contacts! I can also mail out brochures.

And for 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!
On August 9th, 2012 at 10:16 AM, a beautiful healthy (or so we thought) baby girl was born. Maisyn's father and I immediately fell in love with her. She was our first child and we couldn't ask for a more perfect baby girl. The nurse let me breast feed her as soon as she was cleaned up and when she was done, she was taken to the nursery for her routine tests. The nurse came back and told me that everything was great but her blood sugar was a little low (30's). She asked if it would be okay to give Maisyn a bottle to boost up her sugar and I immediately gave her permission. The bottle helped bring it back up to normal range and she was brought to my room shortly after.

We had a great day with her and I chose to keep her in my room that night considering the fact that I would be breastfeeding her anyway. Around midnight, I tried to feed her but she was very lethargic and would latch on but wouldn't suck at all. The nurse came in to check on her and I explained to her what was going on. She went to get a pump for me and I was able to pump enough to give to her some in a bottle. She took the bottle with no problems and fell back asleep. The nurse left us alone for the rest of the night.

The next morning the nurse came back to do more routine tests and from that point on I kept pumping and she was taking everything I would pump by bottle. They checked her blood sugar and it was back low again. This time I believe it was in the 20's. It was almost time for her to eat again so they waited for me to feed her and they checked her blood sugar immediately after she ate. It went up but was still low. It was in the 30's again. The nurse had to take her from me and bring her in ICU to put her on IV fluids until they could figure out what was wrong. I was completely devastated. What I didn't know is that this was just the beginning of the worst nightmare I have ever experienced.

The ICU Drs called my husband and I into ICU to let us know what was going on. They ran numerous tests including a spinal tap. They thought she had a bacterial infection. Everything came back negative and they could not figure out what was wrong. Meanwhile, she started improving and her blood sugar was staying in normal range. On the third day, the doctor lowered her dose of IV fluids and started letting us bottle feed her 30 ML. She would take the entire 30 ML in 5 minutes with no problem at all. All her tests would come back in normal range except for her ammonia levels. It was always elevated but at that point she seemed perfectly fine and would eat really well and also cry very loud. The doctor didn't believe the test results were accurate. On day 4, she was finally taken completely off the IV fluids and we started feeding her 60 ML every 3-4 hours. The doctor passed by and was still not sure about her ammonia levels. She told my husband and I that she would take a urine sample and a blood test and have it shipped to a geneticist’s overnight. If those test results came back good, we would be able to room in with our daughter the next night and finally bring her home. We were THRILLED!!! We stayed with Maisyn in ICU until midnight so that we could feed her before heading home. As usual, she did really great with her bottle and was in a good mood.

On day 5 at 5 AM, I was awake pumping and I received a phone call from the hospital. It was the nurse practitioner asking us to get to the hospital as soon as we could. Maisyn was in cardiac arrest. We rushed over to the hospital which is a 45 minute drive from home. We got there and there was someone waiting outside of ICU to take us in immediately. My heart dropped. I asked the nurse if my daughter was still alive and she wouldn’t talk to me. She brought us to Maisyn's bedside and she was just lying there with respiratory nurses all around. She was in cardiac arrest for 45 minutes and her ammonia levels were 700+. We don’t exactly know how high her ammonia levels were because at that particular hospital the highest number they could test was 700. It took a while but they finally got her stable. She was still in very critical condition and we were told she might not survive. She was transferred by Air Med to Tulane Hospital in New Orleans, LA (approximately 2.5 hours from home) where they have a genetic team. She was at Tulane for approximately 5 weeks but the genetics team there was awesome and were able to figure out her diet and disease.

She has CACT and as of 2010, there were only 30 reported cases. It affects 1 in 250,000 children. A lot of information is still unknown about this disorder but considering how great Maisyn is doing today, I truly believe we can get through this. She is now 4 months old and is meeting all of her milestones great considering the fact that she went into cardiac arrest. We were told we would have to monitor her development and growth very carefully. She rolled over for the first time at 2 months old and I cried! She is such a blessing to our family and I thank God every day for blessing us with a little miracle.

Krystal Boyer
Mom to Maisyn- 4months old-CACT
klrobin@hotmail.com
Louisiana
I wanted to post an update now that Jake is 10 years old and it is now 2013. Jake is doing very well with his LCHAD...dare I ever speak too soon...knock on wood! He went from being in the hospital every few months as a baby and toddler to now probably having one hospital stay per year when he is acutely ill with anything that causes him to have diarrhea, vomiting or a high fever mainly. Also his hospital stays are much shorter now usually only lasting a day or a few days tops where when he was little, they were several days to a week and even longer in some cases.

I mainly credit his g-tube to letting us manage him at home if he isn't too sick and just doesn't feel like eating. We don't have to stay in the hospital with IV fluids sometimes if he can at least tolerate g-tube feeds if he is refusing to eat. Also he isn't very hypoglycemic now that he is older and his liver is bigger which is a huge relief. As much as I hated to make the decision for Jake to get his g-tube, it was the best thing I ever did. I also went to nursing school and changed careers so I could best care for him at home and make good decisions about his medical care. I have become pretty darn good at learning the signs when he's sick and catching things early so we can avoid hospital stays most of the time.

Jake’s Retinitis Pigmentosa has been stable...dare I say that either. So far he has a lot of pigmentation in the back of his eyes that shouldn’t be there; however, it has not seemed to affect his vision much so far. Currently he doesn’t even need eyeglasses.

I must say people who meet Jake are surprised to hear that he has this rare disease at all because he looks so healthy thankfully! His height and weight are perfect for his age and he’s an extremely handsome boy if I do say so myself. Unfortunately on top of his LCHAD he does have autism (which started as pretty severe) but after years of therapy and a lot of diligence from me to copy at home what the teachers do he is very high functioning now with more quirkiness. He also has Tourette’s Syndrome which is mainly controlled by meds with some breakthrough twitches (no he doesn’t have the kind where he blurts out swear words). I believe that is pretty rare but it’s often what people think of, although now that he is a pre-teener Id like to use that for an excuse for some of the things he blurts out at times! ha ha.

He sure has a lot of challenges for a little boy but does pretty well with it all. To boot, sadly after 10 years of marriage to his dad when Jake was only about 5 years old, we got divorced. Having a child with so many challenges was surely hard on us. He now lives out of state and doesn’t see Jake much but is still involved when he can be and at least we get along. I have heard the divorce rate for parents of children with any special needs is astronomically high.

If I can ever be of help to any LCHADer or LCHAD parent feel free to contact me anytime. If I can help even one child avoid the amount of hospital stays that Jake had I would be very happy.

Regards,
Michelle Cincotti
Billerica, MA
michelle.cincotti@yahoo.com
Jake’s mom  (written in Sept 2012)

The following is Anna’s story that first appeared in the July 1998 FOD newsletter with an update following.

1996 ~ Stomach virus - just what we needed with a seven-week old baby in the house. Our oldest daughter, Callie (4.5yrs), had had it. Now our middle child, Anna (1.5yrs), had it. We were concerned that baby Ben would be next.

From the start, Anna had always been our little eater. She had been through ear infections and bronchitis, but never missed a meal or a snack. This time though, she just could not eat. Anna seemed tired and slept most of the day. That night, Dell stayed in the room with Anna. She was up with vomiting and diarrhea several times. The next morning Dell went to work. I was going to let all the children sleep. I decided, though, to check Anna’s diaper. She moaned but did not put up the usual fuss over a diaper change. I called the doctor.
We went straight to the emergency room. Emergency. Triage failed. We were told to wait. Anna was moaning and not responding to us. I took her up to a nurse who finally realized that we needed help immediately. Anna’s blood sugar was at 15. We were asked several times if there was any way that Anna could have taken an insulin pill. We told them “no!” several times. After dozens of tries, an IV was finally started in her hairline. After getting Anna stable enough to travel, she was transferred to Cook Children’s Hospital in Fort Worth. Once again we were asked if Anna could have gotten into someone’s insulin pills. They could not explain what was happening. (Later, hospital notes show that possible diagnoses were 1. Infectious origin, i.e., sepsis or encephalitis or meningitis; 2. Reye’s syndrome possibility; 3. Ingestion of unknown origin; 4. Hepatic encephalopathy or met hemoglobinemia. These were in the typed notes. There was a written note added – 5. Metabolic defect.)

Anna started doing better after a few days of glucose IV’s. Tests were done. She came home from the hospital. A week later we received a call from our family doctor. He said that a doctor at Baylor in Dallas had been contacted about Anna’s test results. Dr. Charles Roe had an explanation for us. Anna had MCAD. DNA testing showed that our other two children were carriers for MCAD.

Anna has no lasting complications from her first metabolic crisis. To help prevent future crises she takes an enzyme supplement, restricts fat intake, and avoids periods of fasting. We keep an emergency protocol sheet with us at all times. Not all doctors and emergency room staff know how to treat MCAD. Awareness and early diagnosis of metabolic diseases can save lives. Supplemental newborn screening can save lives.

Fast forward through sixteen years...

What a long strange trip it has been. We have moved twice since Texas (Tennessee and Georgia). With each move, we have found pediatricians who have been willing to learn about MCAD. We have been fortunate in finding pediatricians that listened to us and educated themselves (and staff) on MCAD. Anna went eleven years without a hospitalization (kindergarten through eleventh grade). She had to go in for an overnight stay due to a virus combined with stress. A month later she came through wisdom teeth extraction with no problems. Activity in the heat has been a concern. Anna tends to melt in really hot weather but with a sharp eye and keeping the fluids in her and a snack at the ready, she has been able to enjoy several days at amusements parks and touring Washington DC, San Antonio, and Charleston in the heat of summer.

Enough about MCAD......... On to Anna

Anna has blossomed into a phenomenal young lady. She has participated in Girl Scouts rising to the rank of Senior Girl Scout. She passed her driving test on the first try. She graduated high school in May 2012 (ranked in the top ten and with honors, French, Sociology and Physics Awards, Georgia Certificate of Merit). Although she is the most athletic of our kids, she did not go out for sports. It’s just not her thing. She is a bookworm and anime fanatic. She has just finished her first semester as Armstrong Atlantic State University with a 4.0 / Dean’s List (majoring in History). The daily commute has not been a problem although we do worry about her zooming around in her little Civic.

At the Atlanta FOD Conference, Anna participated in the general discussion for MCAD. She was able to talk to parents of the younger children and provide some insight on growing up with this disorder.

As parents, we were very proud (and are) very proud of her.

Dell & Melanie Ruff - Richmond Hill, GA
Parents of
Callie – Carrier
Anna – MCAD
Ben – Carrier
druff60@comcast.net
Clinical Trials for FOD Patients and Families
Jerry Vockley, MD, PhD
Professor of Pediatrics and Human Genetics
University of Pittsburgh School of Medicine and Graduate School of Public Health

Introduction. Advances in treatment of rare disorders have been slow and few. In contrast, dramatic improvements have been made in the treatment of equally rare childhood cancers over the past 30 years. Much of the difference can be traced directly to organized, national clinical trials that provide all patients diagnosed with cancer the opportunity to participate in clinical research. The treatment of rare disorders has instead been driven by experience and expert opinion rather than formal clinical trials because of the significant barriers in place to conducting traditional random, placebo controlled, national studies. This observation is certainly true for fatty acid oxidation disorders (FODs). In spite of the fact that FODs represent the most common group of disorders identified through expanded newborn screening, only one medication (carnitine) for treating them is currently approved by the Food and Drug Administration (FDA); and even its use is controversial in many FODs. What is a clinical trial, why are they so important in guiding therapy, and should you participate in them? This article will explore these questions and discuss how to best advance our knowledge in treatment of FODs.

A Brief Example. Everyone has been “talking” on the internet about a new supplement. It’s available over the counter and from a variety of suppliers. Some families have tried it and rave that it gives their child more energy. Others have questioned its effect. There doesn’t seem to be much published information in the medical literature on the compound. Which statement best describes your feelings on trying the new supplement?

I have to try it because it might make a difference.

I’ll do some more reading and make up my mind about trying it after that.

I’ll ask my doctor his/her opinion on trying the new supplement.

I can’t see how something like this will work so I won’t try it.

I would be very interested in participating in a clinical trial.

While the first four answers are the ones we most frequently hear relative to trying new therapies, the last one is in reality the one that provides the best path forward to new therapies. Let’s examine why this is true.

Evidence Based Medicine. The idea of clinical trials is grounded in evidence based medicine, which holds that therapy should be based on firm scientific investigation rather than expert opinion. It presupposes that alternative treatments for a disease can be compared through direct testing in a large enough number of patients to discern if one or the other is better. This process is more complicated in FODs and other rare disease, but it is still critical to adhere to the guidelines as much as possible in order to advance clinical knowledge in these disorders. Insurance companies are also increasingly demanding documentation of clinical efficacy before authorizing payments for therapies.

Barriers to Clinical Trials. Because of the clinical complexity of FODs, much of our current therapy has evolved from clinical experience supported liberally by theoretical biochemical considerations (i.e., expert opinion). Unfortunately, in an era when “evidenced-based medicine” has become a political rallying cry driving health care reform, essentially no controlled trials have been conducted for FODs.

There are three major barriers to conducting clinical trials in FODs. First, the treatment ethic in rare disorders often borders on “miss no chance” rather than “do no harm”. New suggestions for treatment that are logical are embraced by families and physicians alike without insisting on proof of efficacy. Both should recognize that resorting to unproven treatments is counterproductive, and interferes with true progress in advancing therapy. Second, FODs are sometimes viewed as not being amenable to clinical therapeutic trials because of their rarity. This is not true. Advances in the treatment of even rare tumors have been facilitated by organized, national clinical trials that would have been impossible to conduct at any single institution. The ultra rare disorders that include FODs present special challenges and perhaps require a unique infrastructure, but the concentration of most patients in the hands of a relatively small number of practitioners provides a fertile substrate for collaborative studies. Thus, for ultra-rare disorders, developing and promoting innovative approaches to small size clinical trials becomes a priority.

This brings us to the final barrier. Well-controlled, multi-center, national collaborative studies are expensive. Biotech and the pharmaceutical industry have stepped up to meet the need for some diseases and have been responsible for developing many of the clinically validated medications for inborn errors of metabolism currently on the market. But well-intentioned investigators (academic and industrial) may find themselves stalled before they can start by FDA regulations designed for drugs that treat thousands or millions of patients. Moreover, the financial incentives provided to companies under the auspices of the Orphan Drug

[cont’d on page 7]
Act have opened them to criticism over the high prices of their products, and the single producer model has sometimes led to bottlenecks in supply.

**Solving the Problems.** Recognizing these challenges, a number of concrete measures can be taken to improve our clinical science with the ultimate goal of improving our clinical care. The most obvious is to increase federal resources dedicated to dealing with rare disorders. With trillion dollar deficits and health care reform looming on the horizon, now may not be the most opportune time to lobby for funds. However, the savings to the health care system by prevention or reduction of chronic care needs, along with elimination of expenses associated with needless therapies, should facilitate this discussion. But money isn’t the real (or at least only) answer. The development of a national collaborative infrastructure that provides a framework for clinical trials is crucial. There are some promising initiatives already underway. The Office of Rare Disease Research (ORDR) and the FDA Office of Orphan Products Development have played key roles in much of the development of drugs for treatment of inborn errors of metabolism to date. The NIH-funded ORDR Rare Disease Clinical Research Network, HRSA sponsored newborn screening regional collaboratives, and the related HRSA rare disease Translational Research Network are good examples of attempts to move beyond the isolation of individual institutions. While these programs represent a beginning, the ultimate goal should be the offer entry into a clinical trial for all patients diagnosed with an FOD, rather than being started on whatever treatment regimen is currently in vogue. While individual investigators will by need and interest develop and coordinate specific protocols, all metabolic centers should be able to enroll patients and participate in all studies.

**Clinical Trials in FODs.** The number of clinical trials for FODs will likely be growing in coming years. Not all trials will be suitable for everyone. Clinical trials are by definition experiments in medical care. Risks are carefully managed to be as low as possible, but they can’t be eliminated completely. Clinical trials often involve comparison of a test medication to a placebo (an inactive compound made to look like the test medication). Some families and patients find this a difficult concept to accept, wanting rather that they or their child get the “real treatment”. It is critical in this setting to remember that the clinical investigators really don’t know if the new treatment is better (or even worse) than the old one. So there is no intent to withhold an effective new therapy for an older one. The trial is necessary to prove one or the other is better. Patients and families should always feel comfortable with all aspects of a clinical trial before agreeing to participate. Investigators in a trial should be willing to take as much time as necessary to explain exactly what will happen in the trial. You should know what procedures or treatments are involved and if any expenses might be incurred. Most (but not all) trials will cover all expenses related to the trials. In the end, a clinical trial is a partnership between the study team and the patient and family.

When exploring clinical trials, patients and families should be familiar with [www.clinicaltrials.gov](http://www.clinicaltrials.gov). This site compiled by the National Institutes for Health accumulates information on existing clinical trials and allows on line searching for those related to specific diseases. The FOD Family Support Group web site and listserv should also be aggressive in updating information for families and providing access to investigators enrolling studies. **Currently, my program is conducting clinical trials on the use of triheptanoin (c7) to treat long chain fatty acid oxidation defects, and enrollment is lagging behind projections. Patients older than 7 are eligible and families can contact Stephanie Deward (Pittsburgh, PA; Stephanie.DeWard@chp.edu ) or Julie Martin (Portland, OR; martijul@ohsu.edu) for information on participating. A trial for a new medication to treat MCAD deficiency will be starting soon.**

**Conclusion.** A move to evidence-based medicine in the treatment of FODs is not only desirable but will be necessary to move forward in a changing medical economy. Therapies based on compassion without knowledge will inevitably promulgate confusion. The ready accessibility of clinical trials to all patients and metabolic physicians will dampen the immediate urge to do everything possible and instead, redirect the considerable energy of both groups into doing everything known to be effective, while identifying additional new therapies that work. And always remember that without clinical trials, no new medications to treat FODs will be developed and the effectiveness of new therapies will never be proven.

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**‘Texas Meet and Greet’**

FOD/Mito moms/Professionals ~ Janet Longmore and I are planning a meet and greet at Yogurt Fusion

March 30, 2013 at 1pm—we may also go to dinner as well 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
4 January 2013

Dear Patients and Families,

We are writing to announce a new National Institutes of Health sponsored study to learn about the function of the immune system in patients with inborn errors of metabolism (IEM), especially fatty acid oxidation disorders (FAODs). As many of you are aware, infections can play a significant role in triggering life-threatening acute metabolic crises in children and adults with IEM, especially in those with FAODs. While the standard of care for IEM patients is routine vaccination for childhood and seasonal illnesses in most US centers, there have been no studies to investigate whether the response to vaccination is normal in FAOD patients. We know that the enzymes deficient in FAOD are also present in immune cells and may be important for developing immunity to vaccinations. We wonder whether FAOD enzyme deficiency can affect immune system function.

The NIH MINI Study: Metabolism Infection and Immunity in Inborn Errors of Metabolism (www.genome.gov/mini) is an exciting new study at the NIH Clinical Center (clinicalcenter.nih.gov). The main goal of our study is to learn about the function of the immune system in metabolic disorders, especially FAODs. Participants will be invited to the NIH Clinical Center in Bethesda, Maryland for an evaluation. Travel costs will be provided for patients and their families. Additional visits may be suggested dependent upon the level of subject participation. The visits will typically be 2-3 days long. At the first visit, we will perform a physical exam and do a detailed nutritional and immunologic assessment for all study participants. We will offer Hepatitis A vaccination, which is part of the current Pediatric Vaccination Schedule (http://www2.aap.org/immunization/IZSchedule.html).

These recommendations are relatively recent, coming in 2005, and many children over the age of 8 years may have missed getting vaccinated against Hepatitis A. Therefore, you or your child would potentially benefit from receiving this vaccine. During “flu” season, the influenza vaccine is recommended for all children with chronic illness, including those with FAODs, and will also be offered. As part of the assessment, we will measure whether or not you or your child’s immune system was able to respond appropriately to vaccine(s).

Additional tests may include:
- body composition testing, including a DEXA scan
- energy expenditure testing

To be eligible, participants must:
- Be at least 2 years of age
- Have a definitive diagnosis of an IEM
- Be able to travel to the NIH Clinical Center in Bethesda, Maryland

Results of all clinical testing will be provided to the participant and if desired, their home medical teams. Research findings, when available, will also be communicated to participants.

Important: You are still eligible to enroll in the protocol and be evaluated at NIH even if you or your child have already had HepA or “flu” vaccines or do not want to receive a vaccine. For those patients not undergoing vaccination in the study, we will be able to determine whether you or your child have made an immune response to other vaccines such as measles, mumps, and rubella (the “MMR” vaccine).

The NIH MINI team is available to discuss eligibility for this protocol with anyone that may be interested in participating and welcomes all inquiries.

In order to participate in the study, please contact the either myself or the MINI study coordinator by phone or by email. See our contact information below. Thank you for reading our letter and we hope you will be encouraged to investigate study participation further. Please do not hesitate to contact me with any questions or concerns.

Sincerely,

Peter J. McGuire MS, MD
Principal Investigator
Genetic Disease Research Branch
Metabolism and Immunity Section
Phone: 301-451-7716
Email: peter.mcguire@nih.gov

The NIH MINI Study
Study Coordinator: Janet Shiffer, NP
Phone: 301-451-9145
Email: janet.shiffer@nih.gov
INTRODUCTION
Recently Vitamin D has gotten a lot of interest because of its function beyond bone health. With the recognition that Rickets could be cured with vitamin D its role in the prevention of disorders associated with bone health has dominated the research to date. However, new research has identified vitamin D metabolism may be different in different cell types, is involved in calcium and phosphorus homeostasis in multiple tissues and important in other body functions. It is now known that vitamin D levels positively correlate with conditions such as cancer, immunity disorders, diabetes, muscle disorders and cardiovascular disease.

The vitamin D metabolite 25-hydroxy vitamin D (25-OH) is one vitamin D status indicator. The serum level is determined by skin synthesis through sun exposure and/or dietary intake. Sun synthesis of vitamin D has been limited by changes in sun exposure because of concerns about skin cancer. Skin synthesis of 25-OH vitamin D is limited by skin pigmentation, age, angle of the sun, poor air quality, and the percent of the skin exposed to direct sunlight at any given time. Wearing long sleeves or staying in the shade reduces vitamin D synthesis in the skin however the use of sunscreen, even with high sun protection factor (SPF), did not block the skin’s ability to synthesize vitamin D.

Today, dietary contributions of this vitamin are most important and foods, such as Orange juice are now fortified with Vitamin D. Vitamin D3 is considered the metabolically active form of vitamin D and supplements should be with vitamin D3 not Vitamin D2. The scope of vitamin D deficiency is a new focus. Two publications have identified the problem specific to children and adolescents within the US. On the basis of a sample of US children aged 1 to 11 years, millions of children may have suboptimal levels of 25-OH vitamin D, especially non-Hispanic black and Mexican American children (Pediatrics 2009;124:1404–1410). A disproportionate burden of vitamin D deficiency in the non-Hispanic black adolescent population. Females and overweight adolescents are at increased risk (Pediatrics 2009;123:797–803).

ENDOCRINE FUNCTION
For the endocrine functions of vitamin D, the kidney is the main site for changing 25-OH vitamin D to its active metabolite 1,25-OH vitamin D. Once made in the kidney, this active metabolite enters the blood stream and is circulated to all cells and organs in the body. The two main functions of circulating 1,25-OH vitamin D are; 1) to increase intestinal calcium and phosphorus absorption, and 2) to stimulate bone metabolism. Other important functions include; decreasing renin production in the kidney that helps to regulate blood pressure and increasing insulin secretion in pancreas that helps keep blood sugar levels normal. Other organs (muscles, colon, prostate, immune system and pancreas) can also change 25-OH vitamin D to 1,25-OH vitamin D.

IMMUNE SUPPORT
Vitamin D is important for stimulation of normal immunity. Current research demonstrates that 1,25-OH vitamin D improves the function of several white blood cell types that fight infections. It also turns on several pathways that make proteins that can destroy bacterial cell membranes.

CANCER PREVENTION
1,25-OH vitamin D appears to stop the growth and differentiation of cancer cells. It can also support apoptosis – cell death in cancer cells.

MUSCLE HEALTH
Vitamin D deficiency has been associated with muscle atrophy (wasting) and poor muscle contraction. 1,25-OH vitamin D helps muscle cells maintain normal calcium balance. Calcium is essential for normal muscle contraction and relaxation. 1,25-OH vitamin D also improves muscle cell growth and function by interacting with multiple other hormones and enzymes.

Vitamin D has a benefit on muscle function in hyperparathyroidism that can cause several muscle tissue and functional abnormalities.
HEART HEALTH
Vitamin D may be beneficial for preventing cardiovascular disease. Hyperparathyroidism is associated with high blood pressure. 1,25-OH vitamin D can indirectly impact on high blood pressure by decreasing parathyroid hormone levels. Vitamin D also interferes with the renin–angiotensin system (RAS) that regulates blood pressure by decreasing renin production. Some evidence also suggests that vitamin D status can impact on heart muscle contractions as well.

WHAT LEVELS OF VITAMIN D ARE NEEDED?
Two types of vitamin D are currently described “deficiency” and “insufficiency”. Deficiency corresponds to a level of 25-OH vitamin D level below 25 nmol/L, a level that was set to prevent rickets or osteomalacia. The Institute of Medicine (IOM) defines the desired serum 25-OH vitamin D level at 50 nmol/L for promoting bone health. This level is considered too low to support the functions of vitamin D beyond calcium metabolism and bone health.

Vitamin D insufficiency is suggested by increased serum parathyroid hormone and markers of bone turnover, decreased intestinal calcium absorption and osteopenia by DEXA scans. Effects related to vitamin D insufficiency can be masked serum 25-OH vitamin D levels between 25 and 75 nmol/L. Thus, serum levels of 25-OH vitamin D in this range can be used to define a state of subclinical vitamin D deficiency. More than 70% of individuals can be at risk of subclinical vitamin D deficiency. Levels of 25-OH vitamin D above 75 nmol/L may be necessary to maximize musculoskeletal benefits. Several lines of evidence suggest that levels of 25-OH vitamin D above 75 nmol/L are associated with beneficial outcomes without toxic effects, such as elevated serum or urine calcium levels.

The US and Canadian governments requested the Institute of Medicine (IOM) to update its 1997 report on Dietary Reference Intakes (DRIs) of calcium and vitamin D so in 2010, new Recommended Dietary Allowances (RDAs) were published and recommended between 600 and 800 IU/day as “values sufficient to meet the needs of virtually all healthy persons”. There is considerable debate concerning what daily intake should be as the importance of vitamin D beyond bone health is getting more attention. Some researchers suggest 25-OH vitamin D levels should be above 75–80 nmol/L to support immune function and cancer prevention. The US Endocrine Society recommends an intake of at least 1,000 IU to raise the blood level of 25-OH vitamin D consistently above 75 nmol/L.

It is also generally recommended that high-risk populations that include obese children and adults, as well as children and adults on anticonvulsant medications, glucocorticoids, antifungal medications like ketoconazole, and many medications for AIDS should increase their Vitamin D3 intake by at least two to three times the recommendation for their age group.

Current scientific evidence suggests that 25-OH vitamin D serum levels should be over 75 nmol/L; otherwise, there is no beneficial effect beyond bone health. Though there is an ongoing controversy about changing the recommendations for vitamin D supplementation at this time. It seems apparent that the current RDA’s are based on preventing Rickets and maintaining bone status in primarily healthy children and adults; not for maintaining general health in children or adults with chronic illnesses who may also be on medications, such as seizure medications, that can have a negative impact on Vitamin D metabolism.

References are available upon request.

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~ NEEDED FOR THE JULY 2013 ISSUE ~

Medical Update ~ Please Submit to Deb

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!

Pharmaceutical Update

If your Physician needs more information about Brand name 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.
TEAM ELLA and Yale Genetics

2013 Regional FAOD Meeting

Date: April 24, 2013
Time: 9:00 am - 4:00 pm (Meet the Speakers Reception April 23 6-8 PM)
Place: North Haven Holiday Inn, North Haven, Connecticut
 Speakers: Dr. Margretta Seashore and Yale Genetics
Keynote Speaker: Dr. Georgianne Arnold, Pittsburgh Children’s Hospital

Ella
8 years old

MORE Information and Brochure on this
Regional FAOD Meeting:
Email GoTeamElla@AOL.Com

Reach for the Stars!

Ethan, 5, SCAD, Visalia CA, got the first reading award
of the year in his kindergarten class for being the best reader!
Proud mom, Christy daisy7843@hotmail.com

Dear Friends Old and New ...And those that I haven’t spoken to in a long time ~
The BOOK - The long awaited BOOK is now available on Amazon.com
The Survivor, the Hero & the Angel!
Let me know if you like it — better yet, send in a review online to Amazon

Love you lots
Wish you peace!
MaryAnn Raccosta
jraccosta@hotmail.com
It is with great sadness that we learned of 3 deaths within our ‘FOD Family’ in the last several months...please send your prayers and thoughts for our SCAD Family in Iraq...Zheen ~ born June 30, 2008 and died Nov 17, 2012. She is survived by her parents, Jwan and Sarkawt and older brother Zhiar.

Kathryn Burns (MCAD adult) ~ born Nov 11, 1990 and died July 12, 2012. She is survived by her almost 4 yr old daughter, Emma Janelle Burns and her parents, Dianna and Randy.

Leslie Whitt Williams (mito/GA2 adult) ~ born June 17, 1988 and died Oct 21, 2012. She is survived by her parents, Allisa and Roy, sister, Megan, and her husband, Jeff Williams.

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

My loving daughter, Leslie…

Hi, my name is Allisa Whitt and I would like to let everyone know that my beautiful daughter Leslie Cora Whitt-Williams passed away on October 21, 2012 at the age of 24. She was born on June 17, 1988. She meant the world to her parents Roy and Allisa Whitt, her sister Megan Whitt and her husband of 16 months Jeff Williams.

She was diagnosed with GAII at the age of 19 but, the further her disease progressed they were unsure which FOD she had. Her blood, urine, skin biopsy and muscle biopsy all showed a different type of FOD. They knew she had Mitochondrial Disease but they were unsure which one she actually had. Some doctors believed she had a Mitochondrial Disease as her primary diagnosis and then GAII as her secondary diagnosis. Whatever it was it took my very smart, funny, loving heart of gold daughter.

Leslie was such a fighter. The last 2 years her disease really progressed and fast. She started out with a g-tube for tube feeding, then went to a separate j-tube for feedings because her stomach could no longer tolerate the feeds. She then had to have a hickman catheter placed in her chest for TPN (total parental nutrition). She had been on TPN for 24 hours a day for the last 21 months. She was on oxygen 24 hours a day for the last year. She had a foley catheter in because of all the UTI’s and neurogenic bladder. She was on all IV medications because her gut had totally shutdown and the medicines were not being absorbed. She was always hooked up to something. She used a wheelchair for the last several years. Leslie was also hooked up to 2 different PCA’s (pain pumps). She had been receiving blood transfusions monthly for the last 16 months. With all that she was hooked up to and all that she had going on she never complained. She always had a smile on her face regardless of how bad she felt. She never said "why me."

The last several months I could see that she was progressing but, I didn’t want to accept it. She was in a lot of pain, having more and more seizures and infections that her body just couldn’t keep fighting anymore. She was such a mito warrior. She inspired so many people. Her Neurologist came to her funeral and even he was crying. He told me that Leslie was such an inspiration to him. She had so many teachers from all of her schools from elementary to high school attend her funeral. Leslie really touched a lot of people’s lives and I am so proud to call her my daughter. We had so many people come up to us at the funeral home that night and tell us what a wonderful and inspiring daughter we had. Leslie was valedictorian of her high school and went on to attend Case Western University for 1 1/2 years before leaving from failing health.

I still can’t even speak her name without crying. Her and I were so close. We did everything together. I took care of her even after she got married. I traveled 1 hour each way to her house to take care of her while her husband worked. I drove her to Akron, Ohio once sometimes twice a month for all of her doctor appointments which is 4 1/2 hours one way. The last 6 weeks when she was getting worse I lived with her and her husband taking care of her 24 hours a day. I would not change a thing. The only think I would change if I could would be to finding the right doctors sooner.

In August she had her dream granted from The Dream Foundation and she was able to meet Reba McEntire in Atlantic City. It was a wonderful experience that Leslie almost didn’t get to do. The night before she was to meet Reba she had a major seizure and was unresponsive for 3 hours. All the doctors thought she wouldn’t make it out of it but, she proved them wrong. She was so strong and such a fighter, she was bound to determine to meet Reba McEntire. The last several months we went on a lot of trips and accomplished quite a bit of items from her bucket list. I wanted to make sure that she had the best time of her life.

It feels like a part of my heart has been ripped out and I will never be whole again.

Leslie will be greatly missed, but she will always remain in my heart forever.

Allisa Whitt casemom0463@gmail.com
‘Letting go’ is NOT an Option
[Printed in several local community newspapers in Nov/Dec 2012 under different title]

When a loved one dies, you are thrust into disbelief, confusion, sorrow and pain with your head feeling disconnected from your shattered heart. What makes it even more difficult is having others tell you after a short time that you have to ‘let go’ in order to move on. That often stems from being uncomfortable with death and their need for you to get back to normal. And it totally disregards your need to hang onto your loved one’s physical image.

Working through and integrating grief is not a fast process and for some it may be a lifelong journey. Yet, in that process, there is NO need to ever ‘let go’ of your loved one…it’s more healing to create a new inner image and relationship with them, moving from a physical to a spiritual presence in your life.

Because everyone’s process is unique, there is no one answer for how long it takes for your head to reconnect with your heart. It feels like a tug-of-war between reality and what you truly want…you’re loved one back.

‘Letting go’ is not the answer, however. It’s more a matter of hanging onto your special memories while delicately ‘loosening your grip’ of not wanting to face your new reality in order to integrate your loss. It is only then that you may be more open and vulnerable to new relationships and experiences and to moving forward in your life by keeping your loved one’s spirit alive within you.

As much as you want to physically hug your loved one, you achingly know that is no longer possible. And as you move through the ups and downs and ins and outs of your grief and mourning in your own time and way, you may come to a ‘spiritual awakening’ whereby your once physical hug has been transformed to a ‘heart hug.’ It’s a hug that stays with you forever and hopefully will bring you comfort and peace the rest of your life and through challenging times.

If you are early in your grief, this moving through to the other side of grief may not even seem possible at this time. That’s entirely understandable. Yet, in time, by giving yourself permission to fully grieve, and being open to ‘love messages’ from your loved one, you will come to your own understanding of how ‘letting go’ is not necessary in order to heal.

So when someone tells you that you MUST ‘let go in order to move on,’ kindly let them know you KNOW what’s best for you in order to move forward…and that’s keeping your loved one WITHIN you close to your heart.

Have a blessed New Year ~ Our loved ones’ ‘lights’ will eternally shine brightly.

Deb Lee Gould, MEd
Bereaved Parent/Grief Consultant
Okemos, MI  www.bereavedparent.com  Nov 20, 2012
"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!"

I checked on the process of delivery and turn around with a variety people and it seems that the book typically takes about 1-2 weeks for delivery. So although there was an earlier concern apparently that was a glitch that has not been repeated (good to know!) So I don’t think we need to include any information about shipping.

"My Special Body" is a children's book that was written for children with LCHAD, TFP and VLCAD deficiency and was published one year ago. If your child has been diagnosed with these conditions and you have not yet received a copy please visit http://www.fodsupport.org/book.htm on our FOD website to fill out an order form. Currently, Stephanie (the author) is trying to reach out to the metabolic clinics and make them aware that the book exists! Her desire is that all families with these metabolic conditions can utilize the book and she can sure use your help! If your child visits a metabolic clinic throughout the year, if you would consider sharing with them information about the book or Stephanie's contact information this would be very helpful!

You and/or your clinicians are welcome to contact her at srharry374@hotmail.com
Stephanie Harry blog www.harryfamilyblog.blogspot.com

Dr. Robert Naseef's new book on Autism & Families shares wisdom from decades of personal and professional experience such as how to:
• Guide your child’s development from birth to adulthood
• Maintain a strong, supportive marriage
• Understand and provide support to siblings
• Navigate your complex emotional journey
• Collaborate effectively with professionals

Address meltdowns, sensitivities, sleeping, toileting, etc
rnaseefl@alternativechoices.com

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
de@bereavedparent.com
517.381.1940
Nutrition Update

**Glycosade**

**Description**
A medical food intended for use under medical supervision.
Glycosade™ is a hydrothermally processed high amyllopectin cornstarch.

**Indications**
For use in the dietary management of Glycogen Storage Disease (GSD) and other metabolic conditions where the use of a long acting starch is indicated, from 5 years of age.

**Nutritional Information & Ingredients**
See Glycosade™ Datasheet available for download at the end of this page.

**Dosage and Administration**
To be determined by the clinician or dietitian and is dependent on the age, body weight and metabolic condition of each patient. **Each 60g sachet of Glycosade™ has an equivalent carbohydrate content to approximately 55g of uncooked cornstarch.**

**Guidelines for Preparation and Use**
To be determined by the clinician or dietitian.

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**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](http://example.com) 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

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

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**Easter Egg Suggestions**

Here in Denmark, Easter overflows with chocolate eggs, bunnies and all kinds of weird figurines. But luckily, licorice, hard candy and marshmallows can also be found in the shape of eggs (or otherwise wrapped to fit Easter). I guess every country has different candy traditions. This got me brainstorming...I'm thinking you could also go for baking egg-shaped low fat cookies or pancakes, and drizzle them with chocolate syrup. There must be Easter cookie cutters or sandwich cutters available somewhere online. Or maybe you could bake cocoa muffins and decorate them with little fondant bunnies or something :)
I have a growing collection of [recipes for low fat goodies](http://example.com) there, you can find it here:

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Fie Olsen
Mom to Viola, 2.5 yr old, VLCADD
Copenhagen, Denmark
fielundgaard Olsen@gmail.com
Welcome to New Babies!

Our heart!! Aiden Alexander Reyes
9.13.12 2 months old ~ VLCAD
Newington, CT
jennyf72@sbcglobal.net

Erin 4 (SCAD) is pleased to show off our new baby Emery born March 29, 2012. Love, The Perez family, Pedro and Christy parents to Ethan 5 SCAD, Erin 4 SCAD and Emery who isn't even a carrier.

Visalia , CA
daisy7843@hotmail.com

Drew Scott Stapley
2/9/2012 8:08 am
7lbs 6 oz
Honolulu, HI
VLCAD
renee.stapley@gmail.com

Julian, born Aug 23, 2012, with big sister, Melea (MCAD)
Kentucky
robinfunk@gmail.com

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

Sleep deprivation..... near and dear ~
My older children are not affected by any FODs - having a metabolically typical child that nurses frequently during the night is NOT the same as having an FODer that must have night time feeds. I say this not just to validate how exhausted you feel, but because it is absolutely true. I nursed on demand with my older unaffected children. Some were good sleepers some not so good. With my 4th child I even had to set a timer and nurse every 3 hours because it helped her reflux to eat smaller more frequent meals. At the time that seemed exhausting..

But, nothing was like the first year after Jack was diagnosed. I was a walking zombie. Sleep exhaustion + worry + the unknown FOD = a deeper exhaustion than I had ever experienced. My husband cannot take over the night time feeds because he works 2 jobs already.

To do that all with a first child? That has to be sooooo hard!!! At least I had some on-the-job-training by the time my affected children were born.

I don’t have real answers because everyone is so different. But here are a few suggestions:
Remind yourself that this is not permanent. It will get better.
Remind yourself that you are weepy or forgetful (or fill in the blank) not because you are a failure but because you need sleep.
Prune some activities. Cut out anything that doesn’t have a big payoff as far as your personal values.
Try not to fuel your body with sugar to make up for the lack of sleep.
Lower your expectations. This might mean your house isn’t as clean as you’d like, or you start using paper plates, or you don’t garden this year, or you don’t stay active in (fill in the blank).
Remind yourself that this is not permanent and this is just a season of life!!! My older affected child turns 6 next month. Though we still have periods of very little sleep, sometimes we go months with just our normal 1:30 am feeding. He doesn’t even wake up anymore. It takes me 15 minutes to give him his meds, his corn starch milk which he sucks up through a straw while still lying down, and then I get back in bed and fall asleep.
I will say try to get some gentle exercise everyday. It will really help boost your energy.

If you are young and hang out with other young mothers just plug your ears when they talk about night-time parenting and sleep and feeding, blah blah blah....Most of all don’t beat yourself up over the little things. I found that the more tired I am the more self critical I tend to get.
Oh, and love on your husband! Anyway - hope that helps some. Wish I could send you a box of sleep!

Susan Tipton rieshytipton@gmail.com
Please note that we also have an FOD KidsKorner/Adults Gallery and other Pictures on our homepage. To submit a pic please email Deb.
DONATIONS
[since our July 2012 Newsletter]


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


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. ALL donations go toward FOD efforts and programs.

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

Reminders

Families - Please send TYPED (preferably in word document) stories etc, by June 15, 2013 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 June 15, 2013 to Deb.

Be kind, for everyone you meet is fighting a hard battle

~ Plato

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

The 2012 FOD Group 990 tax return will be on our Financial page soon

The bulk of Expenses are for monthly phone, website fees, Conferences, and for our Grief Consultation office (rent, advertising, etc) to offer pro bono grief support to local Bereaved Parents & Families (and also via Skype to others in the US). We also donate FOD funds from undesignated donations to various FOD related entities (ie., for NBS issues, outreach) to support their efforts.

All Undesignated and Grief Consult donations are deposited into the General Fund, as are Bracelet and Ribbon Sales, Cafepress.com, iGive, Goodsearch, and any donation that isn’t specifically designated for the other Funds. Once the Research and Clinical Funds reach a substantial amount (@$50,000) we will be able to offer grants to clinicians and researchers in the US.

Because of a previous generous undesignated donation, we were also able to offer Family scholarships for our 2010 & 2012 Conferences! Additionally, we have a 1yr & 3yr certificates and long-term stocks/bonds earning interest and dividends for future FOD endeavors and programs.

Thank you to Erika Wallace - erikawallacepa@yahoo.com (Mailing Lists), Mary Lingle - Mcartwrite@aol.com (Website Designer) and Brian Gould – (newsletter consulting) for all your hard work, and to Mark Heinz mark@markheintz.com & Matt Pfeiffer pfeiffer@danhos.com for their pro bono consulting expertise on email/website information. Keith Widmann 4wdesign@gmail.com for our website slideshow pictures, the FOD Banner for booth displays, and the USA TODAY Charity Spotlight banner ad. Eileen Shank eshank@helmsbriscoe.com for helping us plan the 2012 FOD/OAA Conference. And all of our Conference volunteers.

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.