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Happy New Year everyone ~ welcome to 2009! I don’t know about you, but as I get older, these years seem to fly by faster and faster! It was only ‘yesterday’ when I was married ~ and it’ll be 30 years this July!

2008 was a successful year as far as our terrific National Metabolic Conference last July in Pittsburgh, creating more awareness of FODs and raising funds for future FOD Clinical Training and FOD Research. Since we have another 18 months before our next Conference, please try and share our Annual Letter of Giving with your Families and friends whenever you can. I realize this is a trying time with the economy the way it is, yet many have given this past year despite the crisis. Donations don’t have to be in the thousands to be significant ~ every penny counts! You can also view our Financial update on the last page of this issue.

As for creating awareness as well as funds, some Families have held their own ‘fundraisers’ ~ from Silpada jewelry parties to having family/friends send donations in honor of their child’s birthday or Baptism! These events not only raise funds for us they also get the word out about what FODs are and how they’ve impacted each Family. If you are interested in having your own ‘Family Fundraiser’ please be sure to look over the ‘Family Project Form’ on our homepage ~ it’ll explain how you can plan for an event and how to send the donation.

Every cent raised helps our Families!

Changes abound in 2009 ~ Mary Lingle (MCAD Parent, FOD Boardmember/Secretary, and our webmaster extraordinaire!) will be updating our website over the next several months. So look for a new look some time this year! I think it looks terrific right now but Mary wants to freshen it up a bit and add some new pages.

We also hope to have our Family List online some time in 2009. That way Families can update their information as it changes. It will also be password protected so only registered Families will have access to it. Mary and Erika Wallace (MCAD Parent and coordinator/collator all of our mailing lists) are working on that together. I know there are some kinks that need to be worked out but we hope to have that up in the near future.

The FOD Group is not the only Group making changes this year ~ the Organic Acidemia Association (OAA) has just named a new Executive Director and Board. Kathy Stagni, whom I’ve had the pleasure of working with at conferences over the last 10 years will now be their Administrative Director and Jana Monaco will be their new Executive Director. Jana has been a staunch advocate for ENBS for years and knows firsthand the benefit of ENBS and the consequences of NOT having ENBS ~ her son, Stephen, had a major crisis when he was 3 and then diagnosed with Isovaleric Acidemia, but the lack of early diagnosis and that crisis caused major medical complications for him ~ then when his sister, Caroline, was born they found out from birth that she too has IVA and has been doing well. To Kathy I say ‘THANK YOU for all of your hard work over the years and your passion/compassion for your Families’ and to Jana I say ‘Congratulations on your new position with OAA and I look forward to working with you in different capacities’!

Thank you also to our Families that shared their struggles and challenges with us in this issue by way of their stories. 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 also 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, 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
Even though the holidays are behind us, it doesn’t mean that the spirit of those special days, like Thanksgiving, has to be put away for another year. In this most difficult economic time, some may just want to curl up and cover their heads and come out when everything is back to ‘normal.’ Yet all of us that are living with an FOD in our Family KNOW that our lives are anything but ‘normal!’ But that’s not a bad thing ~ it’s all about perspective ~ and one’s perspective can make a HUGE difference in these stressful times. We DO have a lot to be thankful for despite all the challenges we face as individuals, as Families, as communities, and as nations around the world. So if you’re feeling as if you can’t make a difference because you’re ‘just’ a mom, dad, child or grandparent etc ~ THINK AGAIN!

Even though NBS month is now over (was last September), make every month NBS month by spreading the word about ENBS and FODs (and other metabolic disorders that can be screened for) to anyone and everyone that will listen! You may be one person but there are A LOT of us ‘ones’ out there that can make a HUGE difference if we’re all on the same page and speak as a whole ~ and we ALL know the importance of screening and diagnosing these disorders EARLY so treatment/followup can begin EARLY!

[As an aside ~ my husband, Dan, has this recurring dream that we won the lottery and then gave it all away—who hasn’t had THAT dream?!] But don’t think of yourself as insignificant in this ‘fight’ to create awareness just because you don’t have millions of dollars, a home in several locations, or wear fancy clothes (sweatpants are the mainstay of MY closet!) ~ you DO have a VOICE and it’s going to take a lot of individuals and our grassroot organizations working together for state and national legislatures/organizations/schools to listen, as well as your own local medical professionals and hospitals. We all know examples of what happens when they DON’T listen to us ~ we HAVE to continue being proactive and make sure those experiences don’t happen again!

Because we are ALL important just by ‘being’ ~ I believe every one of our Families has an important message to share ~ so take that first step and SHARE your story ~ it WILL save a life!

On a similar note (as far as being heard) ~ I have added the information below on our Medical Information page. Share it with your medical professionals and suggest that some of it (the medical info) be added to your emergency protocol. I wrote the 1st paragraph (we’ve been there!) but the 2nd one was suggested to me by some of our medical and legal professionals who know all too well the sometimes fatal consequences of medical/health/other professionals not listening to parents!

***When FOD Families call 911 or come into an ER please FOLLOW the EMERGENCY PROTOCOL LETTER IMMEDIATELY that their specialist has given them and LISTEN to the PARENTS! We are having our Families thrust into BEREAVEMENT all because someone CHOOSES to BLATANTLY DISREGARD the Protocol and send Families home because their child 'looks' okay or they think the blood sugar is sufficient! DO NOT ASSUME you know how to treat FODs, especially if you have never treated an FOD individual in crisis ~ it is NOT treated like diabetes! FOLLOW THE PROTOCOL that their specialist has individualized specifically for them! We are NEEDLESSLY burying too many children because of arrogance, ignorance, and downright negligence!

[From our FOD Experts] A plasma glucose in the "normal range" does not mean it is safe to skip a D10 bolus if a medical protocol instructs that a bolus is necessary. When a patient is ill, some FODs require a glucose infusion even in the face of a glucose level that is normal or near normal as toxic metabolites can still accumulate. Sometimes only a glucose bolus will reset the metabolic "thermostat" which regulates breakdown of endogenous (stored) fat. If a physician has concerns about a glucose bolus for a sick FOD patient based on a normal/near normal plasma glucose level, the answer is NOT to ignore the protocol. The patient's treating metabolic physician must be consulted immediately or, if unavailable, another metabolic physician should be paged. For many FODs, it is much easier to deal with transient hyperglycemia than the consequences of continued decompensation.

I hope this information helps.
Have a great New Year and I hope all stay HEALTHY!

Deb Lee Gould, Director
Our baby’s MCAD story is very different than most MCAD stories. Thomas was comprehensively screened at birth, but the results just did not reach us in time. Thomas Wood Shannon was born Tuesday, March 14, 2006 to James and Melanie Shannon. He was a beautiful full-term baby boy weighing 8 pounds 1 ounce and was 21 inches long. He nursed beautifully right after birth and was considered healthy after his post-delivery examination. That night Thomas’s brother, Tucker, was so excited to hold him and finally get to be a “Big Brother” after many months of anticipation.

On the day of discharge, Thomas was circumcised and had the heel stick for newborn screening. We live in Mississippi, a state which has mandated comprehensive newborn screening. We left the hospital before noon on Thursday, March 16. Thomas was not nursing well when we left and many thought it was because he was tired and ill from the morning’s circumcision.

As the afternoon progressed, we became very worried about Thomas’s lack of eating during the day. As we searched for answers over the phone from different medical personnel, Thomas became lifeless and his body temperature dropped. We rushed Thomas to our family doctor where attempts were made to revive him. He was carried by ambulance to our local hospital where further attempts were made at resuscitation. Within an hour, doctors had informed us that Thomas was gone.

We received word from the pediatrician’s office on Saturday, March 18 that Thomas’s newborn screening results came back positive for MCAD. Doctors believe that the combination of breastfeeding and the fasting before the circumcision sent Thomas into crisis so quickly.

A memorial service and a private family graveside service were both held for Thomas on Sunday, March 19, 2006. It is still hard to believe that a family’s life and future can change so drastically in one short week. We continue to educate ourselves and our extended families about MCAD. It is our hope that research and information will continue to progress so that parents do not have to face MCAD related deaths.

Written and submitted by:
James & Melanie Shannon
Parents to Thomas Wood Shannon (MCAD 3/14/06-3/16/06)
Tucker Douglas Shannon (6 years old - unaffected)

We lost a child, Thomas, to MCAD in March of 2006. Although he was comprehensively screened at birth, we did not receive the results of NBS in time to save him. He died a few hours after leaving the hospital and we received word two days after his death that he had screened positive for MCAD.

My husband and I decided that we should have another child, not to replace Thomas or even take away a portion of the pain. We thought it would bring more happiness into our lives and give our 6 year old added joy of getting to experience being a big brother.

Although we chose not to proceed with any prenatal testing, we took all other necessary precautions with our baby. On November 27, 2007, Lilly was born. Because of our history with MCAD and because of very caring health professionals, Lilly was placed in NICU while we awaited test results. She was on IV carnitine, glucose and was given formula every 2 hours. On Friday, November 30, NICU doctors notified us that Lilly too had tested positive for MCAD. My original gut feeling was that this baby would not have the defect. It was quite a blow to our family, however, we realized this was treatable and knowledge is powerful.
**Thomas and Lilly...cont’d**

Lilly is doing well now. She is 8 months old and is meeting all of her milestones. She has had more than her share of hospitals stays in her short little life. When she was 12 days old, she was not taking enough formula, fighting her bottles, taking quite a bit of time to complete a feeding, etc. After about 8 hours of this routine, I called genetic specialist and he told me to head to the local ER and meet my regular pediatrician there and put the emergency protocol he had written for us into place. IT WORKED. We were very pleased at how well the doctors, staff, and ICU handled the protocol even though most of them had never heard of MCAD. The reason Lilly could not take her bottles correctly was because of trapped gas. Yes, trapped gas (it even showed up on the chest x-ray) prevents babies from getting enough in-take and can put them in trouble fairly quickly if you don’t get them the help they need. At 3 ½ months, Lilly went back to the hospital. This time for a twelve day stay because of poor feedings. Doctors did not find anything that would prevent her from eating. We put her on a different schedule, added cereal to her diet, and were discharged after she adapted to those changes.

Two weeks later, Lilly refused to eat at one of her scheduled feedings, so we went back to our local hospital and stayed four days. Lilly was transferred to our state's only Children’s Hospital. It was determined there, after extensive procedures, that she had some ulcerated areas in the stomach and was experiencing some problems due to acid reflux. Lilly was discharged with an NG tube and us having the knowledge on how to put the tube in and how to use it. In May, Lilly had to go back to the local hospital and stay a week because of an upper respiratory infection. That’s four hospitalizations in a six month period.

Lilly now has a NG feeding tube so that she can get her needed calories each day and we can feed her through the tube when she just can take all of her bottle. We know there will be more hospitalizations but we are happy to have the knowledge needed to take care of her. We are very happy that many health care professionals have received the proper education to provide medical attention to Lilly. We know that is why Lilly was sent to us with MCAD so she could make a difference for someone else.

Written and submitted by:
James and Melanie Shannon
Parents to:
Lilly (MCAD Born November 27, 2007)
Thomas (MCAD 3/14/06-3/16/06)
Tucker (Unaffected – 6 years old)

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**Rebecca’s Story ~ MCAD**

Rebecca was born on April 2, 2005, but this story begins well before that. The fact that Rebecca was tested and that her MCAD was detected is, to us, truly a miracle. At some point during my wife’s pregnancy, an article in the *Wall Street Journal* happened to catch my eye. The piece explained that all states test for the three “most common” (e.g., PKU) of the known rare genetic disorders, but only a handful test for the full battery of the 30 or so conditions, and the test to run them all (through Tandem Mass Spectrometry) is simple and very inexpensive.

Having no knowledge of any such disorders on either side of the family, but figuring, “it can’t hurt,” I contacted one of the test providers (Baylor Health Care System Institute of Metabolic Disease) and ordered the $25 test kit. The kit arrived in the mail, and got shuffled in with the baby stuff, almost to be forgotten.

As Rebecca’s birth neared, my wife experienced some complications that caused her to be hospitalized on and off the two weeks prior to delivery. Things got quite hectic during that time, and during one of my trips between the house and the hospital, I remembered the test kit and initially couldn’t find it. Something kept bugging me, though, and I eventually located it and brought it to the hospital.
But that was only half the battle. The hospital’s staff and in-house pediatrician refused to draw the blood for the test! In most cases, I think my wife and I would have given up on having this test run, but something compelled us to keep trying.

So, at Rebecca’s first office visit, we asked her pediatrician to run the test, and thankfully, he agreed. We dropped the completed kit in the mail, assuming we would never think about it again. A few days later, my wife received a call from the pediatrician. He said the test came back positive for MCAD.

The FOD Family Support Group was one of the first resources we were referred to, and has been a trusted knowledge-sharing base ever since. After the initial shock and fear wore off and as we became more educated (through the Group and Rebecca’s geneticist), we began to accept and understand MCAD and realized how blessed and lucky we were to have learned about this when we did.

In fact, we believe that the early detection through the supplemental screening may have saved Rebecca’s life. You see, she underwent two surgeries in the first 13 months of her life ~ the first at only two months of age. Local anesthesia was acceptable, but general was preferred – and seriously pushed – by the hospital. But because of our knowledge of the MCAD, my wife and I successfully fought against the use of general anesthesia (which, of course, would have required overnight fasting) for the first surgery. Had we not known about the MCAD (and followed fasting orders), we wonder if Rebecca would have made it through that surgery.

For the second surgery, which required general anesthesia, we worked closely with the surgeon and anesthesiologist, who took all of the necessary precautions (most importantly giving her a D10 IV drip throughout the procedure to maintain her blood sugar). Again, we cannot bear to think of what could have happened had we not been armed with the knowledge of Rebecca’s disorder.

MCAD is a very manageable condition, but clearly, knowledge is key. While Rebecca has been sick a couple of times, we have been able to manage her care at home and have not needed to bring her to the ER. We have taken special care to be prepared and have supplies on hand for trips and vacations. Again, we have been extremely lucky thus far that she has not needed hospitalization – yet. Unfortunately, our guard comes down sometimes since we have been so lucky for so long. But every time she does get sick we immediately remember how important proper preparation is.

In summary, we have truly been blessed with the knowledge of Rebecca’s condition. Thankfully, our state recently passed legislation that now requires the full panel of genetic testing - so many lives will be saved in the future. But because this testing was not mandated at the time of our daughter’s birth, we believe that God played a part in the fact that she even got tested in the first place and we are thankful for that every day. We also know that so many other families have not been as lucky, but through their advocacy, they should know that they are saving lives every day.

2008 Update: We have a new addition to our Family ~ Emily! After waiting almost a MONTH, we FINALLY got the results from Emily’s NBS today and...it is NEGATIVE. We are so relieved and thankful. Of course, Rebecca’s geneticist had us re-test Emily to be sure, and those are negative as well. Rebecca, now 3½ yrs old, is doing great. She is in preschool and is adapting well to being a big sister.

Thanks for thinking of us and for all the support getting us through Rebecca’s diagnosis 3½ years ago.

Dave and Chylynn Bastian
davidbastian@bellsouth.net
Family Stories

Logan’s Story ~ MCAD

Logan was born on August 12th, six weeks early. He was diagnosed with MCAD through Newborn Screening. We are truly blessed that he did arrive early because after he was born he was put on a glucose IV.

I had gestational diabetes which was a shock because I have always been very thin and had a modest weight gain during my pregnancy. This too was a blessing because at the hospital it was protocol to check the blood glucose three times a day in infants of mothers with gestational diabetes. When he was ready to come off the IV he was fed breast-milk in a bottle every three hours.

We are so blessed that we received the NBS results before we took him home. It took seven days for the results and two days to confirm them. There are two other MCAD kids in our town and one of the mothers told me that Connecticut just started testing for MCAD two years ago.

We owe our son’s life to all of you that fight for states to have the expanded newborn screening. Logan is now four-months-old and 14lbs. He is nursing about every 2 hours on his own and we do not let him go more than 3 hours. We test his blood glucose once a day per our specialist.

Thank you for everything ~ I really do not feel alone in this!

Melinda Beever
Norwich, CT
melindabeever@gmail.com

Story behind our FOD Colors ~

Some may wonder why royal blue and yellow were chosen as the FOD Group ‘colors.’ The power and meaning of these colors represent many facets of my life (Deb) experiences before and after our lives were changed forever with the sudden death of our daughter, Kristen, from undiagnosed MCAD in 1985.

Before starting our family, Dan and I had both graduated from the University of Illinois (‘The Fighting Illini’) in Champaign, IL and the school colors are blue and orange. I wanted to incorporate our loyalty to Illinois by having blue as one of the colors ~ but probably more poignant for me is that Kristen’s eyes were the bluest of blue ~ thus I chose royal blue. And even though I grew up in the south suburbs of Chicago, I consider Champaign to be home ~ and it’s also where Kristen is buried.

As for the yellow ~ I have always loved small yellow roses and Kristen came to love them as well. Yet after Kristen died, they became even more significant to me (as seen on http://fodsupport.org/rose.htm). They not only symbolize my journey through grief, they also symbolize Kristen’s love and eternal light ~ a light that will shine forever...
Last year Valerie Fulton (LCHAD mom to teen Adam) attended a professional Conference for Inborn Errors of Metabolism in California and was our representative in a meeting of professionals and family advocates, as well as attended some seminars and a luncheon. It was a great opportunity to share our Group’s brochure and info about our family support services. Both the professionals and the advocates were excited to have a chance to talk with each other because there are similar interests ~ working together to create awareness of various inborn errors of metabolism and to work on issues such as getting the rest of the states onboard with expanded NBS and formula legislation, just to name a few. Both professionals and advocates are trying to find ways to collaborate and work as a united front rather than all on our own.

This year, I (Deb) hope to attend (if we have the funds) the 11th International Congress on Inborn Errors of Metabolism, hosted by the Society of Inherited Metabolic Disorders (SIMD) and being held August 29 – September 2, 2009 in San Diego, California. I will be able to pick up where Valerie left off and meet again with professionals and family advocates, as well as sit in on the seminars. It’ll be interesting to hear how metabolic professionals from all over the world treat/research the various FODs. I will also display our FOD poster that has been displayed at a few events last year (ie., our 2008 National Conference, the UMDF conference, and a local MI event) and have brochures and other info available. We most likely will share a booth with the Organic Acidemia Association (OAA) due to the high cost of the conference. You can view the FOD & NBS Awareness info/display (in pdf form) on our website on the Medical Info page, right sidebar. It would be an informative handout if you happen to have the opportunity to speak with medical students!

If possible, we will also have a family rep display our poster at the United Mitochondrial Disease Foundation annual conference in Washington, DC June 26-27, 2009 (family meetings). If anyone lives nearby and would like to sit at our booth for those 2 days (if we have one) please email me at deb@fodsupport.org.

Although it is 18 months away, we are already beginning to think ahead to our next conference, hopefully in conjunction with the Organic Acidemia Association. We do not have a planned Host as of yet (Children’s Hospital of Pittsburgh and Dr Jerry Vockley were our Hosts for the 2008 conference), but we are hopeful that an institution will offer to help sponsor this vital event for our Families and interested professionals. Because these conferences cost @$30,000 for facilities, food, equipment etc, we would need some financial assistance/commitment from our host and then the FOD Group and OAA would solicit funding (@$20,000) from various places such as pharmaceutical companies, Foundations, and other corporate businesses. A year before a conference is also a great time/opportunity for Families to help out by planning their own ‘Family Fundraisers’ (see our Online Forms on the website for info). We try to host it in various cities across the country (ie., easy access to an airport, entertainment/restaurant sites for families, nearby hospitals in case of emergencies, etc) so we can attract as many as possible. Past sites included Pittsburgh, Dallas, Detroit, Orlando, and Columbus, OH.

If anyone is interested in helping with our next conference please email me at deb@fodsupport.org. The biggest help all of you can offer is talking with your own specialists and letting them know that we have this Family Conference every 2 years ~ they might be able to assist us in some way, if not by hosting, possibly through a sponsorship donation.

By knowing so far in advance they may be able earmark a donation!

We will have more information in our July 2009 issue as well as the Jan 2010 issue. But start thinking about cities, speakers and topics now ~

**2010 will be here before we all know it!**
Medical Update

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

Floating Hospital for Children
at Tufts Medical Center

TEACHING MEDICAL STUDENTS & DOCTORS ABOUT
FATTY ACID OXIDATION DEFECTS

The Metabolism Service at Boston’s Floating Hospital for Children has launched the METABOLISM OUTREACH SERVICE

This innovative program represents the largest and most comprehensive program to date to educate medical students and physicians about metabolic disease. At this time, it serves 6 academic medical centers in the northeastern U.S., and provides:

- Seminars & workshops about metabolic disease and abnormal test findings;
- Opportunities for patients/families to help teach medical students and doctors;
- Consultative assistance to physicians as they assess their patients;
- Long distance support for these medical centers during more urgent situations.

WE ARE LOOKING FOR PATIENTS AND FAMILIES TO BECOME INVOLVED IN THE TEACHING PROCESS!

If you are interested in speaking to a medical audience as part of the Metabolic Outreach Service, or if you will allow your/your child’s record to be reviewed and used as a teaching case (anonymously) during an Outreach workshop, please let us know!

Please call:
Isabel Matos
Tufts Medical Center
Metabolism Service
617-636-5443

Or visit our website -
http://www.floatinghospital.org/OurServices/Genetics_Metabolism/theMetabolicOutreachService

THANKS!

The Metabolic Outreach Service (MOS) includes: Baystate Medical Center, Vermont Children’s Hospital/Fletcher Allen Health Care, Dartmouth-Hitchcock Medical Center, Eastern Maine Medical Center, Boston Medical Center and Maimonides Medical Center. One of the major goals of the MOS is to get health professionals and medical students interested in metabolic disease. Other goals include: Developing mechanisms for long distance consultation as far as diagnosis and treatment are concerned and providing educational opportunities in metabolism for medical residents and students. Please check out the site above if you are interested in helping toward that goal!
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!

The Children’s Hospital of Philadelphia
34th Street and Civic Center Boulevard
Philadelphia, PA 19104-4399

RESEARCH STUDY ADVERTISEMENT

Mitochondrial disease consists of hundreds of different energy-related, genetic-based disorders. No single laboratory test can accurately diagnose mitochondrial disease in most patients. Furthermore, no effective treatments exist for many mitochondrial disease patients. An NIH-sponsored study at the Children’s Hospital of Philadelphia entitled, “Metabolic Consequences of Primary Mitochondrial Disease,” is recruiting subjects with definite biochemical and/or genetic causes of mitochondrial disease to identify a “signature” of metabolic changes that may offer the opportunity for improved mitochondrial disease diagnosis and treatment.

This study is designed to primarily evaluate previously collected muscle, skin, and blood from individuals with definite mitochondrial disease. New blood and/or skin specimens will only be requested if no prior specimens are available. Tissue sample(s) will be studied to detect patterns of secondary biochemical and/or genetic alterations that occur in mitochondrial disease.

To learn more about participation in this study, please contact the Research Study Coordinator, Emily Place, MS, directly at (267) 426-9650 and/or placee@email.chop.edu.

Second day-long Regional FAOD Meeting

with Dr Margreta Seashore
Director, Genetic Consultation Services and
Director, Biochemical Disease Detection Laboratory, Yale-New Haven Hospital, Yale University School of Medicine
And
Dr Jerry Vockley
Chief of Medical Genetics
Children’s Hospital of Pittsburgh of UPMC

Sponsored by: Team Ella and Yale-New Haven Hospital Department of Genetic Consultation Services

Date: April 1, 2009
Place: Mercy Center, Madison, CT

Meet the Speakers Reception March 31, 2009
Complimentary supervised Children’s Room available for children traveling with parents

To receive a registration brochure and more information as it becomes available, please contact Team Ella at GoTeamElla@aol.com or by mail at 22 Woodland Dr, Clinton, CT 06413.
**Q:** What are ketones and what role do they play in diagnosing FODs?

**A:** Ketones are a product of using fats (lipids) for energy, which mainly happens after the carbohydrate sources of energy (glucose from a meal, and its storage form in liver and muscles, called glycogen) are depleted. Some tissues run very well on fats—muscle (after the first several minutes) and heart (at all times). They can use all of a fat molecule, so they don’t release ketones. Fat molecules are typically 16 or 18 carbons long. Two carbons at a time are split off. The liver can’t split the last set of four carbons, and releases them as acetacetate and hydroxybutyrate, for other tissues to use. SO, when your liver is needing fuel, and you haven’t eaten in a while, it will be running on fats (from your fat cells), and releasing ketones, or “ketone bodies”. There is a third ketone, made by splitting the other two, called acetone—the active ingredient in nail-polish remover and the solvent in airplane glue. It is quite noticeable on the breath.

So far, so good. If you can’t metabolize long- or medium-chain fats you will not make ketones adequately, and you will suffer from the shortage of energy/fuel. Your liver needs the fuel to make glucose, so one of the features of the long- and medium-chain disorders (VLCAD, MCAD def, etc) is nonketotic hypoglycemia. Some patients make some ketones, so we call that hypoketotic hypoglycemia. Either way, the amount of fat being metabolized is inadequate for the situation, and the blood sugar is too low. Some patients need very frequent feeding to stay out of trouble, others can go many hours without difficulty unless they have a fever, are infected, etc.

The short-chain disorders are different, because those patients can get plenty of energy from the first 12 or 14 carbons in the fatty acid (fat) molecules, so hypoglycemia isn’t such a problem. Also, they may be able to release ketones from the liver, so they can get ketogenic. Ketones in that situation would mean the patient was fasting, and his body was trying to use fats for fuel. Since those patients have trouble with the 4-carbon molecules, they can be a biochemical strain for them, toxic products may build up, etc., and when the ketones show up it’s time to get medical attention, or at least check with your doctor. If someone seems to have problems with both short- and long-chain molecules, that will be a very tricky situation that probably has a deeper explanation than the usual deficiency of a single enzyme.

SO, ketones are just a sign of fasting for most of us. Patients with long- and medium-chain defects will not produce them as well during prolonged fasting, etc., when anyone else will be producing plenty, so finding them is an indication that the patient is under excessive metabolic strain, and should be getting more glucose. Testing ketones (if you do make them appropriately) is hugely helpful for finding out what’s going on in many other situations including diabetes, as lack of insulin will lead to ketosis; many of the organic acid disorders, and others, etc.

Now to prolonged exercise: Your heart runs happily on fats, so it doesn’t really notice what the blood sugar is. Your body stores a lot of glycogen (in liver and muscles, mainly), which it uses for fuel, as glucose. After this starts to be depleted you’ll start using fats for fuel in the muscles, and the liver will use fats to make more glucose for the tissues that really rely on glucose (brain especially). And you will make ketones. Hence we may find ketones after prolonged exercise. Prolonged exercise—marathon, for example—can certainly damage muscle, but I don’t think this is because of the ketones, as such. Ketones and muscle damage are both signs of major metabolic work. One of the proteins in muscle, CPK (creatine phosphokinase, sometimes called CK—creatine kinase), will leak out of injured muscles, and the blood CPK level will rise. Normal CPK is up to 100 units or a bit more. If there is SEVERE muscle injury, the CPK level might be well over 20,000 (or even ten times that), and there is a risk of kidney damage from high blood levels of another muscle protein, myoglobin, that will make the urine brown. Mild muscle injury from major exercise, even from a marathon, won’t cause kidney damage. Dehydration will increase the risk of kidney damage from myoglobin, so we emphasize being well-hydrated.

Some of our children with long-chain defects have ongoing muscle damage despite our best treatment, so the CPK tends to be high, and can go higher with fever/infection/cold/exercise, etc. Most patients don’t have pain if the CPK is less than 1000; a level of 10,000 might be associated with very painful muscles (most of my patients), but might not be. (One young man I care for, a baseball pitcher, says he feels absolutely fine, even when his CPK is 15,000).

CPK (or CK) is not the same as creatinine. Creatine is a substance in muscle that is used to store energy, as creatine phosphate. It leaves the body through the urine as creatinine. The creatinine level is a good general measure of kidney function, as it isn’t influenced very much by hydration. Urea, another substance that the kidney excretes, reflects hydration as well. Urea is usually measured as Blood Urea Nitrogen (BUN)—it goes up with dehydration or kidney problems, so the creatinine is used to help distinguish between those two possibilities.
Q & A...cont’d

I'll continue to chime in when I think I can help clarify some of these daunting and confusing technical issues. Hope this helps.

Stephen G. Kahler, MD
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Department of Pediatrics
University of Arkansas for Medical Sciences
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Mail:Division of Clinical Genetics
Slot 512-22
Arkansas Children’s Hospital
800 Marshall St.
Little Rock, AR 72202-3591

Q: I have been searching for a diagnosis for my child for years and have recently been accused of Munchausen's. I am extremely frustrated and angry but I will continue to search for a Dr that will listen to me. Can anyone offer suggestions for what I can do or ask for at the next Dr’s appointment and how do I respond if they ask about the Munchausen accusation?

A: I've been accused of Munchausen's also, and my daughter has spent 15 years without care for her LCHAD which was diagnosed at 8 months. I found a month or so back that the doctor who diagnosed her gave my ex-husband a set of instructions for her to be taken to a metabolic specialist "within two months" for follow-up but those instructions never made it out of a file folder in our home office. The pediatrician never knew, and I never knew, that she was supposed to have follow-up care. Anyway, that's a whole other story and the important thing is what do you do at your appointment, so here goes:

♥ Stay calm. No matter what, don't get angry and out of control. To help you do that…
♥ Make lists of questions, number them - double-space the list and give a copy to the nurse for the file, and hand a second copy to the doctor. Keep your own copy in your hand and start checking things off as the doctor answers. If there is no answer, ask "what do we have to do to find out what the answer is?" and start adding the responses to that secondary question on a new list for the next visit.
♥ Describe a typical day, from waking to next morning. Feedings, vomiting, how long it takes to feed, behaviors, everything. What he plays with or looks at. Show a typical day in total.
♥ For the future - inform the doctor that you intend to videotape or photograph any episodes you can't describe or that s/he doesn't seem to understand, such as the listlessness or "spacey" behavior (if that's the case) some kids get when they're very sick. If the doctor doesn't know the patient well, it's almost impossible to make that doctor understand how "off" a behavior is, and why as a parent you're concerned. Pictures tell stories which words can't express.
♥ Also for the future - keep a large calendar on the wall and note changes or strange behaviors. If there's a constant vomiting series, note what foods were given before, or if the little one has been out in the sun just prior to it - anything that is not part of a typical day. Actually, describe a typical day first, then note the differences and whether or not his behavior or symptoms change afterwards.
♥ Make friends with the nurse. And make sure s/he knows you as a concerned parent, not as a panicked one.
♥ If you've already had suspicions of Munchausen noted in the file, be extra careful and don't *tell* the doctor what the diagnosis should be unless it's already been noted as a possible. I know that sounds unfair, but you have to be super-careful of how you word things to make sure your child doesn't get ignored because of what the medical staff thinks might be *your* problem. Use words like "he used to do this and now he doesn't" instead of "he can't do xyz" so that the doctor knows you are comparing a before and after, and not assuming something from one behavior only.
♥ Compare and refer to measured quantities - if he used to drink 8 ounces and now won't drink more than 4 at a time, or if he *always* throws up after more than 4 ounces, state that in your notes and questions.
♥ Bring a file folder or notebook and keep every tiny scrap of paper you ever get from the doctors or nurses. Make sure that everything you hand the nurse at the start of each visit is put into the file; make a note on your copy "gave copy of this to Nurse Suzie on 8.3.08" so you'll know later on who you gave what information to, and when.
Q & A...cont’d

♥ You're building a case here. You have to present evidence and be a credible witness. If you lose it in anger, even though it's understandable to people in this Group, it's not going to help the patient. You can, though, tell the doctor how frustrated you are. Tell the doctor what's at stake; just as you put in your post, "if this doctor doesn't refer us to xyz, then my son will not be able to receive the follow up care of (specify doctors needed) that was recommended by (give the name of the doctor who wanted the referrals to the neurologist, etc.). Make sure that you use the previous doctor's names, be clear about what the previous doctor told you to expect, and *Write It All Down* in the questions and comments you hand to the doctor. I don't know the doctor you're seeing, but often one doctor will not be willing to refuse to follow the recommendations of another, for reasons of liability. What if Dr #1 wanted referrals, and Dr #2 refused, and later it was found that the referrals would have prevented a serious illness? If Dr #1 has ever made such a comment, Write It Down and hand it to this new doctor.

Whew. Stay calm. You, for certain, should eat breakfast - no joke - you need to have all your brain cells fed and ready to roll! Good luck.

Janet
Theyamallama@aol.com
mother of Jena, 16, LCHAD?Mito?/low carnitine/cardiac/asthma/anorexia
and John, 17, ADD, Aspergers, dysgraphia

NBS Update

Be sure to visit the FOD website (In the News page) for the current articles on NBS efforts across the US and Canada. More states are getting on board (albeit slowly!) so check http://genes-r-us.uthscsa.edu/ every now and then to update yourselves on what your state is adding to their NBS panel of tests. Keep up the great work!

There is a new Parent Forum for parents to discuss their NBS experience with other parents and some healthcare professionals. I know some of you have had some ‘interesting’ awakenings to the field of metabolism – some were okay and others were nightmares! This is another way to let others know what happened to you and a way to offer some constructive suggestions to make the process more effective, informative, and less stressful. http://nnsgrc.forumotion.net/parent-to-parent-f1/

I have this link on our NBS page as well, right sidebar - this site stays up to date on which disorders your state/country screens for and all the happenings in the NBS world.

~ ~ ~

A natural outgrowth of advocating expanded newborn screening is short and long-term follow-up treatment and formula coverage/legislation. If anyone is interested in helping with any of these issues nationally or within their state please contact Jill Fisch at jill@savebabies.org. She is not only one of our Families (SCAD), but is also President of Save Babies Through Screening Foundation. She has been active on various committees to get these issues in the forefront since they so desperately affect all Families living with a metabolic condition.
• America's Compounding Center (takes out-of-state orders for riboflavin, coQ10, drug prescriptions etc and accepts most insurances, except most state Medicaid)  
http://www.acerb.com/home
866.222.7993

• I was in the bookstore this week and ran across a reference guide for IEPs - It's The Complete IEP Guide (How to Advocate for Your Special Ed Child) by Lawrence M. Siegel. Amazon.com allows you to look at the table of contents and the front & back cover. I looked through it at the store and it had a LOT of good info, and lots of forms that will help parents organize before and after their IEP meetings with the school. It looks like it would be really helpful for some of our parents with school age kids.
Thanks,
Hope Kelly
mom to Gwen (17 years) MCAD
Hopek@considertheheavens.com

• The Children's Cardiomyopathy Foundation (CCF) is a national non-profit dedicated to finding causes and cures for pediatric cardiomyopathy. CCF provides valuable information and support services to diagnosed families, including patient education materials, newsletters, resource listings, an e-mail discussion forum, local support groups, and physician and center specialty lists. Through CCF's research grant program, seed funding of up to $50,000/year is awarded to promising investigators studying aspects of pediatric cardiomyopathy. To learn more, visit CCF at www.childrenscardiomyopathy.org

• Basically every utility company out there offers what's called Medical Baseline, it's to help lower the energy costs to families with medical issues who may not be able to afford thier utility bills (your income level does NOT matter for this program). Here are links to 2 programs I have dealt with http://www.sce.com/CustomerService/RateInformation/ResidentialRates/MedicalBaselineAllocation.htm and http://www.pge.com/myhome/customerservice/financialassistance/medicalbaseline/ . It’s really easy to qualify, having someone in the home with an FOD qualifies, if your child has asthma and needs a nebulizer that runs on electricity you qualify, there's a lot of covered conditions. The FOD is covered under "A life-threatening illness or compromised immune system with special heating and/or cooling requirements to sustain the patient's life or prevent deterioration of the patient's medical condition" We really saw a drop in our bills when we got the additional allowance because we never go past tier 1 anymore because we have such a large baseline now. We cut our bills in half by getting CARE and Medical Baseline.
Heather
bluetaelon@att.net

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**FOD Family Questionnaire**

If you would like to be listed on our Family List (which we hope to get online soon, password protected for Families ONLY) for networking purposes, please go to ‘Online Forms’ on our website (www.fodsupport.org) and print out the Questionnaire. Then SIGN it and DATE it so I have your permission to list you. Please mail it to me via the regular mail or fax (see page 1 of this issue for address and fax #) so we can list you in the next List Update.
In our last issue we shared that Joey Ramos, 26, (Undiagnosed), son of Louise and Michael Ramos, and brother to Brian and Vince, died last spring. Louise shared with me his ‘Celebration of Life’ CD ~ it was a wonderful and endearing testimony of their love for their son and brother. And she also shared this touching poem in memory of Joey who will ALWAYS be remembered for never giving up and for being Joey!

Our little Joe Joe
How would we know
How much we would love you so
What you endured
Amazed us all
You stood strong
You didn’t fall
You are our hero
And we will never forget
The fight for your life
You never quit
You’ll remain forever in our hearts
Even though our lives are apart
You taught us life, love and joy
You were a wonderful gift and
You were our “little” boy
But God needed you up above
We have to believe it’s because of his love
He knew you were struggling in this temporary life
Now you are whole and without strife
We miss you so much...beyond belief
And we struggle now in our sadness and grief
But we know we will meet you again someday
So until then, we know you are okay

Love,
Mom and Dad

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

The ‘Silver Linings’ of FODs

All too often we are reminded of the difficulties associated with FODs. Hopefully our Email List support will help us remember the ‘Silver Linings’ to these disorders as well ~

What is your ‘Silver Lining?’
Complied by Kim ~ please send your ‘Silver Linings’ to Kim at gareths mommy@yahoo.com to be included in our July 2009 issue.
~ NEEDED FOR THE JULY 2009 ISSUE ~

**Medical Update ~ Please Submit**

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

**Pharmaceutical Update**

**Nutritional Update**

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**Just a few reminders for our 500+ member Email List ~**

If you would like to become part of our large network of Families, please 1st Register for our Group ~ that way we will have your mailing address etc in case we need to snail mail information (mostly during Conference time). Once you’re Registered for the Group (link is on our homepage), you can sign up for our Main FOD List.

First create a google account and then sign up for the List in the google box on our homepage or Join Our Email List page.

From the List’s webpage (see below) you can change your mail preferences, password etc. You can also read the Archives and send messages over the List.

If you want to send messages via your regular email server (ie., outlook, aol etc) you can – please make sure YOUR SUBJECT is in the SUBJECT AREA and it MATCHES what your message is actually saying - that way it’ll archive better.

The address for this **MAIN FOD List** is [FODsupport@googlegroups.com](mailto:FODsupport@googlegroups.com)
The List web address for this **MAIN FOD List** is [http://groups.google.com/group/FODsupport](http://groups.google.com/group/FODsupport)

You can choose your List and mailing preferences from this page.

**Please sign EACH post with 1st name/disorder/city/state or country.**

We also offer an **MCAD subGroup that you can choose to join in addition to our MAIN FOD List**. Please note that this is NOT a substitute for the MAIN List. It is offered as a complement to the Main List. Most in the MCAD subGroup will be living with MCAD, but you are welcome to join if you are any one of the FODs or you are still Undiagnosed or Unclassified:

**MCAD subGroup List web address and signup:** [http://groups.google.com/group/fodsupport-mcad](http://groups.google.com/group/fodsupport-mcad)
**MCAD subGroup List email address:** fodsupport-mcad@googlegroups.com

Because of inactivity on the other 2 subGroups, we have discontinued posting over them but you can still sign up for them if you’d like to read the Archives. We have some FOD families that started yahoo group lists several years ago so they are more active ~ you can post over our Main List if you’re interested in contacting those parents ~ they will get back with you once you post.

**VLCAD/LCHAD/TFP subGroup List web address and signup:** [http://groups.google.com/group/fodsupport-vlcad-lchad-tpf](http://groups.google.com/group/fodsupport-vlcad-lchad-tpf)
**SCAD/GA2/CPT 1& 2 subGroup List web address and signup:** [http://groups.google.com/group/fodsupport-scad-ga2-cpt](http://groups.google.com/group/fodsupport-scad-ga2-cpt)

**PLEASE save all of these links in your bookmarks/Favorites and Enjoy this great way to network!**
Welcome to New Babies!

Happy News!
Wanted to let everyone know the good news. Samantha was born via c-section 7.29.08 weighing 7 pounds 14 ounces and length was 19 1/4 inches. Her newborn screening came back negative for all FODs and she has been a very healthy happy baby thus far!!!
Lisa Casey (MCAD, 30) millij@yahoo.com and Anthony Moravac

♥

Kaitlin Marie Waak was born on 6.17.08 in Katy, Texas. She weighed 8 pounds and was 19.5 inches long. She has been diagnosed with Primary Carnitine Deficiency. She has 1 sister named Madeleine who will be tested soon.
Robin and Nick Waak Katy, TX robn515@gmail.com

♥

Serenity H Blume entered the world on March 17, 2008. She was 7lbs 3oz and 19 inches. She has MCAD. We also have Blake who is 13 and Gabriel who is 6. Neither of them is affected.
Kristy and Josh Blume Chula Vista, CA kirsty@iowaromancedivas.com

♥

We had our baby, Elise, on July 2, 2008 (7 lbs 7 oz, 19.5.” long) and by July 5th we had the screening results back ~ she too has MCAD like her big brother, Logan, 6 yrs old. All is going well though. She takes her carnitine no problem and Logan is excited to have another person with MCAD. He always thinks he is the only one. I remember talking with you (Deb) when Logan was just a few weeks old. How far we have come since then! This time around was so much less of a stress. Thank you for everything you do for all of us!
Amber Trudeau of MN, Ellie 7wks MCAD, Logan 6 yrs MCAD, Alex 13yrs Carrier amber.trudeau@gmail.com

♥

I wanted to share with you that Roger Clark and I are thrilled to announce the safe arrival of our baby girl Haleigh Clark weighing 9 lbs 5 oz on July 29, 2008. We feel really blessed to know that Haleigh is not affected by MCADD!!
Thanks for all your love and prayers.
Tammy Clark
Mom of Jenna (Feb 17/02 – Nov 22/02) Undiagnosed MCADD
www.savebabiescanada.org

♥

Ways to Raise FOD Awareness and Funds for the FOD Group!

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.
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 recently added our information on Facebook.com in order to raise Funds ~ so check us out and join the CAUSE!
Cookbook and Food Suggestions

For recipes, I started at the library looking for cookbooks that had low-fat and fat-free recipes. This way I could look at the cookbook, read through it and decide whether it was worth buying. I won't attest to any recipes, but things are worth a try. Here are some ideas:

- **Secrets of Fat Free Baking** by Sandra Woodruff. This book also talks about what one can substitute into a recipe to replace fatty items.
- **American Heart Association cookbooks - Large Red Cookbook in its 7th edition** - This has all kinds of meals and tells you the nutritional content of all.
- **Kraft Food and Family Magazine**. You can go to their site (www.kraftfoods.com) and see the recipes and subscribe to their free magazine. They have some low-fat recipes and they're marked with some kind of sunshine logo.

Other ideas....

- **99% Lean Ground Turkey** - Can use this in most things that would call for ground beef. You can make this into patties for grilling, but you usually have to add grated onion for some moisture.
- **Ballpark makes Fat-Free Turkey Franks.**
- **Here is a cake frosting/dip recipe.** We used this on an Angel Food Cake for Gabrielle's 1st birthday. It is great.

3/4 cup skim milk
1 package (3.3 oz) instant pudding mix
1/4 cup powdered sugar
8 oz container Fat-Free Cool Whip
-- whisk together milk, pudding mix and powdered sugar until thick. Then fold in the cool whip.

Laura
Mom to Gabrielle 19 months, MCAD
milhouse93@sbcglobal.net

Conversion Tips

I don't know how to calculate the carbs/protein, but if you add up all the grams of fat you add to a recipe, and divide by the number of servings (muffins/cookies, etc), you can get a # of grams of fat per serving.

1 Tbsp oil = 15g of fat, generally (5g per tsp)
(for margarine/butter, the amount of fat per Tbsp depends on the brand/type, so check the nutrition label)

So if you use 1/4c oil (4 Tbsp), there is 4 x 15 = 60 g fat from oil

Eggs - 1 large egg = 5g of fat or so (this is for the whole egg with the yolk; egg whites are nearly fat free)
So 2 eggs would add another 10g of fat, bringing the total to 60g

Confetti Spaghetti Salad

1 package (7 oz) uncooked spaghetti, broken into thirds
2 cups Green Giant® Valley Fresh Steamers™ frozen mixed vegetables
1/4 cup coarsely chopped red onion
1 medium tomato, chopped (3/4 cup)
1/2 cup Italian dressing (we use fat free)

1. Cook spaghetti as directed on package, adding frozen mixed vegetables during last 5 to 7 minutes of cooking time; cook until mixed vegetables are tender. Drain; rinse with cold water to cool. Drain well.
2. In medium bowl, gently toss all ingredients to coat. Cover; refrigerate at least 1 hour to blend flavors before serving.

Nutrition Information:
1 Serving: Calories 170 (Calories from Fat 30); Total Fat 3g (Saturated Fat 0g, Trans Fat 0g); Cholesterol 0mg; Sodium 260mg; Total Carbohydrate 30g (Dietary Fiber 3g, Sugars 3g); Protein 6g Percent Daily Value*: Vitamin A 40%; Vitamin C 4%; Calcium 2%; Iron 8%
Exchanges: 1 1/2 Starch; 0 Other Carbohydrate; 1 Vegetable; 1/2 Fat Carbohydrate Choices: 2 *Percent Daily Values are based on a 2,000 calorie diet.

Julie mom to Lexie, 20 months, MCAD
West St. Paul, MN
jmhagen23@hotmail.com

If the recipe made 3 dozen cookies (36), then there would be just under 2g of fat per cookie. (60 / 36 = 1.7)

Remember, certain ingredients such as chocolate chips, and even wheat germ (!) contain fat as well, so add in those fat amounts from the nutritional information labels on the product. And of course, using a greased cookie pan or sprays containing fat will add to the total as well.

Note: the specific breakdown of saturated/unsaturated fat can also be calculated - you just need to know how much of each is in each fat source you are adding to the mix, and add up the totals and divide by number of servings.

Maybe we could at least post total grams fat in the recipe (or total grams fat per serving, based on what # of servings), as this may be the most pertinent nutritional information that many of us are looking at for our FOD kids. (Of course the protein/carb counts come into play too, depending on what your Dr/Dietician recommends.)

Lynette, mom to Danica, 18mos, MCAD
Saskatchewan, Canada
lynette_epp@hotmail.com
Please remember our families in your thoughts and prayers throughout the year
[For entire list please refer to our Jan 2008 issue]

Jill and Chesley Craig

Louise and Michael Ramos

‘At this moment in your life there are people who need you, need your help, need your support, need your love. Do not be afraid to touch them, to talk with them, to listen with understanding, to give them hope. Do not be afraid to give them love! Their healing begins with you.’

~ Father Thomas J McSweeney

Grief Support Services

Deb Lee Gould, MEd
Director, FOD Family Support Group
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.

Additional grief support is available for our Families 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 welcomed!
Wayne (37, MCAD)  
and Molly (5, MCAD)  
Caplette  
New Hampshire

Olivia Krafft  
13 years old  
LCHAD  
Macomb, MI

Mackenzie Miller  
Still testing (possible SCAD or LCHAD)  
California

Molly Caplette  
5 years old  
MCAD  
New Hampshire

Gabriel and Blake  
Blume with Serenity  
(MCAD)  
Iowa

Alex McDonald  
MCAD  
Canada

Jacob Dupont  
MCAD  
and proud mom and dad  
New Orleans

Please note that we also have an FOD KidsKorner/Adults Gallery and other Pictures on our homepage.  
If you’d like to submit a pic please email Deb at deb@fodsupport.org]
DONATIONS


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.


We greatly appreciate donations to help with postage and copying costs, website fees, supplies, conference costs, phone calls, 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 donations are tax-deductible. Our Tax ID # is 83-0471342.

Reminders

Families - Please send TYPED (preferably in word document) stories by June 15, 2009. To be listed on the printed FAMILY LIST (refer to our website, Online Forms), please return the SIGNED Family Questionnaire 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 by June 15, 2009. Also, please return to Deb the Professional Questionnaire even if you are already listed on the printed Professional List. Refer to our website, Online Forms.

‘Life’s most persistent and urgent question is: What are you doing for others?’

~ Martin Luther King, Jr

2008 Balances for the FOD Group
[donations/expenses thru 12.31.08]

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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 the 2010 Conference 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. We need at least $50,000 for each Fund.

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. Special thanks to Sigma-Tau Pharmaceuticals, Inc. for their continued financial support.

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

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