

# FOD

Support

fatty oxidation disorder communication network



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## From the Editor



It seems like yesterday that we were planning our 2006 Dallas Conference ~ and here it is 2008 and we're once again planning for another GREAT conference! **Kathy Stagni (OAA Director) and I have contracted with the Hvatt Regency Airport Hotel in Pittsburgh to host our National Metabolic Conference this July 18-19, 2008.** We will have a special room rate of \$99 (plus tax) per night. **Dr Jerry Vockley**, one of our leading experts at Children's Hospital of Pittsburgh, **has offered to sponsor this year's Conference.** THANK YOU Dr Vockley ~ if we didn't have a sponsor we wouldn't be able to offer this great opportunity for Families and professionals to listen and learn together!

We are still in the process of asking speakers so once we have everyone verified we will post over the website and because **we raised enough donations this year** I will also mail out the Conference info to our US and Canadian Families and Professionals. This is mainly a Family Conference but we've had several health professionals attend over the last few conferences ~ it's always great to hear about their experiences with FODs and OAs and they also might learn a few NEW things! The Conference Registration Form hopefully will also be posted by March on the website to fill in online and a PayPal link to pay the Registration Fee (usually @\$50 per person). Those forms/checks can also be mailed to me via the US mail as well.

We will once again have yellow FOD t-shirts with our blue logo for every paid registrant. Our block of rooms (discounted rates) at the airport hotel will be open for RESERVATIONS SOON but we are waiting to confirm our speakers before we open the reservations to everyone. You will then be responsible for making your own reservations. The hotel will have a breakfast buffet and as part of the Registration Fee, each person will get lunch on Friday and Saturday. Dinners will be on your own. Once we get more meal information we will post it, and as in Dallas, if you have special needs we will have a contact person in the kitchen to discuss those needs ahead of time.. It's difficult to please everyone as far as the menu is concerned but they are aware we are trying to have lower fat and healthy meals planned for those 2 days. For those that attended the Dallas Conference, the format will be very similar ~ except this year we will have 2 full days instead of a day and a half. We hope to have enough time for individual FODs/groups of disorders to get together and talk. In Dallas we ran out of time to do that! So keep your eyes open on the site ~ we will let you know when we get more details.

Speaking of donations ~ this year has been a very good year, considering it's our 1<sup>st</sup> being a 501c3 nonprofit organization! I have posted our financial standing for 2007 and of course I have listed everyone that donated (some wanted to remain anonymous however) on the last page of this issue. Some have inquired how they can create awareness and raise funds for the Group in the process ~ please look over the Family Project Form on our homepage for further information. Members that want to do their own projects acknowledge that the FOD Group is not an official sponsor of their project and that only THEY would get the tax deduction when one check is mailed to the Group. Because of laws and nonprofit logistics, **the only FOD-sponsored 'fundraiser' is our 2008 Annual Letter of Giving** ~ you can print that off the homepage and share with EVERYONE if you like!

**Families and Friends ~ all donations are tax deductible** and a receipt will be mailed acknowledging your donation. Please make checks (US currency) out to the 'FOD Family Support Group' and mail to our Michigan address above. You can also donate directly from our homepage ~ we have a PayPal link on the right sidebar. You can donate to the General FOD Fund (covers day-to-day costs and conferences), a Clinical Trust Fund (to raise funds to help clinically train new Drs/professionals in the field of metabolism and genetics), a Research Trust Fund (to raise funds for FOD research), and an option for grief support/consulting donations ~ all of these options can be given in honor or memory of a loved one. Every donation counts ~ small or large! We hope you will be as generous as possible ~ since we are an ALL volunteer Group no one has a salary ~ **every cent raised helps our Families!**

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 Acylcarnitine Translocase, TFP, CPT 1&2 etc.) to share their experiences. We're always looking for more low fat recipes, poems, and pictures.

We also **would like to hear from our Professionals** ~ we always welcome new Medical, Research, Nutritional, Counseling, 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



## Editorial

### A very proud mama...

In this issue I am pleased to announce a new Family section called '*Silver Linings*' that one of our MCAD parents, Kim (5-yr-old son, MCAD), suggested a few months ago. Its purpose is to provide a way **to show that living with an FOD CAN have a positive impact on the child/adult, as well as for their Families.** Well, I thought I'd share our own 'silver lining' after living with an MCAD son for over 21 years. In other words, I feel the urge to 'brag' a little after all these years! I'll gladly do that in a minute, but first ~

As stated on our homepage, there have been some critics of our site, saying that it's 'all negative' and that new Families shouldn't contact us. Of course I take exception to that opinion in that what we try to provide is a **TRUE representation of what our Families have been through** ~ and yes, some have had major tragedies and some have been fortunate enough to be diagnosed AT BIRTH and treated AT BIRTH. We still have a long way to go in some regard to expanded newborn screening in that the results HAVE to come back sooner ~ we've lost some babies because they didn't get back in time. And that brings up another whole issue we've discussed in past issues ~ about having medical professionals advocating supplementing infants (and not just have them breast-fed) while waiting for results. Often it's that 'fast' that infants go through right after birth when mom doesn't have a full supply of breast milk available that they go into metabolic crisis. So even though we've come a long way in diagnosing infants sooner which increases the odds of a more positive prognosis, we still have a long way to go in other areas.

Our Family is an example of both extremes of Family experiences ~ our 1<sup>st</sup> child, Kristen, did not have that benefit of EARLY screening/diagnosis/treatment and she died over 22 years ago at the age of 21-months during her one and only episode (initially MISdiagnosed as Reye's Syndrome). Yet, with Kevin, we fortunately had read about MCAD before he was born and took action to have him tested at BIRTH (just as the expanded nbs test was being developed by Dr Roe and colleagues), despite our Dr telling us he most likely didn't have it 'because MCAD is so rare!' After his positive diagnosis, I think his Dr learned that he should LISTEN to parents! And then fortunately, when testing Brian, our 3<sup>rd</sup> child, 17 months after Kevin was born (our now 20-yr-old sophomore here at Mich State), we learned he was a carrier.

So I am here to tell you that **YES one CAN live with an FOD and THRIVE to live a 'normal' life (whatever normal is!) especially when diagnosis and treatment BEGIN AT BIRTH.**

On Dec 15, 2007, our 21-year-old son, Kevin (MCAD, diagnosed at birth) graduated in 3 ½ years magna cum laude (Business/Marketing and Leadership) from the University of NC at Wilmington! **This is a HUGE testament to the power of being screened/diagnosed/treated at BIRTH and having good follow-up and ongoing care!** As stated in previous issues, it hasn't been all easy-going (especially when a Dr totally disregards an emergency protocol that's been in place for 2 decades!), but Kevin has weathered several hospitalizations, continues to take care of himself by eating healthy foods daily and OFTEN throughout the day (60% carbs, 20% fat, 20% protein) and he takes his Carnitor®. He has really been on his own while away at college, so he's learned A LOT of what he knows he needs to do in order to stay healthy and be active in physical activities. Besides graduating from college, over the course of the last few years he has also become a certified fitness trainer, a fitness model, and a licensed NC real estate agent (inactive right now until he decides whether he's going to stay in NC)! And add to that all the sport activities he's been able to enjoy his entire life ALL because we knew about his MCAD AT BIRTH and what adjustments to make to his treatment when active/under stress.

Many of our new Families have concerns with what the future may hold for their child/children ~ **ALWAYS remember ~ ANYTHING IS POSSIBLE!** NEVER let someone tell you that it's a fact that ALL those with FODs with NEVER do well in school or will NEVER participate in sports or will NEVER be able to do this or that ~ **one thing I can say is NEVER UNDERESTIMATE YOUR CHILD and his or her abilities to surprise us all!**

I know we have a lot of Families that live with the residual medical/cognitive/physical/emotional complications due to metabolic crises BEFORE a diagnosis took place ~ EVERY child/adult is unique and special and important and no matter what the CHALLENGES, each and every child/adult has something to offer in THEIR OWN WAY! We just need to acknowledge those ways and encourage strengthening whatever their abilities may be. That's where the personal definition of 'normal' comes in ~ try not to compare or focus on what a child/adult CAN'T DO ~ rather **focus on what they CAN DO, CHERISH them for who they are and LOVE them with your whole heart till the end of time!**

The main point I'm trying to make (amidst all the proud mama stuff!) is that **THERE IS HOPE ~ and HOPE to SAVE LIVES** is made possible by getting all states/countries on board for expanded and universal Newborn Screening and follow-up care! So **get out there IN YOUR OWN WAY, CREATE AWARENESS, EDUCATE, ADVOCATE and BE HEARD!**

Deb Lee Gould, MEd  
FOD Director



Deb, Brian, Kevin, girlfriend Ashley, and Dan  
December 15, 2007 UNCW Graduation



## Family Networking



### New FOD Email List (Google Group) Reminders

From our homepage, if you are an FOD Family/member or a professional working with FOD Families, you can sign up for our NEW Listserve. Once you create a google account you can join – and all of your lists (we have subgroups for MCAD etc) will be under you're 'My Groups' heading so you'll be able to move within all of them easily. You won't need to sign in every time you want to switch to a different list. Of course this is all from the List's webpage. You can change your mail preferences, email address, password etc on the List's webpage.

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. Create an entirely NEW message if you want to change topics. You can also send messages via the List's webpage for those that choose that option—it's also easier to red the archives of past topics from the List's webpage.

The List Webpage address for the **MAIN FOD List** is <http://groups.google.com/group/FODsupport>

The email address for the **MAIN FOD List** is [FODsupport@googlegroups.com](mailto:FODsupport@googlegroups.com)

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 some **subGroups that you can choose to join in addition to our MAIN FOD List**. Please note that these are NOT substitutes for the MAIN List. They are offered as a complement to the Main List. Most in the subGroups will be living with that specific FOD 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>

**MCAD subGroup List email address:** [fodsupport-mcad@googlegroups.com](mailto:fodsupport-mcad@googlegroups.com)

**VLCAD/LCHAD/TFP subGroup List web address and signup:** <http://groups.google.com/group/fodsupport-vlcad-lchad-tfp>

**VLCAD/LCHAD/TFP subGroup List email address:** [fodsupport-vlcad-lchad-tfp@googlegroups.com](mailto:fodsupport-vlcad-lchad-tfp@googlegroups.com)

**SCAD/GA2/CPT 1& 2 subGroup List web address and signup:** <http://groups.google.com/group/fodsupport-scad-ga2-cpt>

**SCAD/GA2/CPT 1& 2 subGroup List email address:** [fodsupport-scad-ga2-cpt@googlegroups.com](mailto:fodsupport-scad-ga2-cpt@googlegroups.com)

PLEASE save these links in your bookmarks/Favorites.

Enjoy this great way to network!



### FOD Family Questionnaire

If you would like to be listed in our future online FOD Family Listing please be sure and complete the FOD Family Questionnaire on our 'Online Forms' page. Many of you have done it in the past for the printed Family List, but if you have recently moved please complete a new questionnaire. In the past we have mailed the printed Lists to over 900 Families/members on our Mailing List, but with copying and mailing costs these days we are exploring a password protected page on our homepage. It would **ONLY be for FOD Families**. We would also list Medical Professionals and Clinics around the world. So **if you would like to be listed** for networking purposes, please go to '**Online Forms**' on our website ([www.fodsupport.org](http://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** ~

see page 1 of this issue for Deb's address. We will let everyone know when the Listing goes live! It could be AFTER the July Conference so PLEASE be patient!





# Family Stories

## Adam's Update ~ Teen LCHAD

The big event for Adam, once he turned 16, was getting his Driver's License. It gives him the independence to drive himself to and from his high school and to our swim club and other nearby places. It's a huge relief for mom and dad, who don't need to do as much chauffeuring!

Adam is now beginning his junior year at an all boys very competitive Jesuit high school. The first two years, for the most part, he thought his classes were easy. This wasn't good because he just did a minimum of work to obtain a 3.4 GPA. He spent most of his time on Xbox 360 playing games with others around the world. In my day it was pen pals but now it's on line gaming....



Adam is still on a summer cabana swim team that meets May through July. Like most teens in his age group of 15-18 year olds, he rarely goes to the 1 ½ hour 6:30am practice sessions. When he does, he has 1 tablespoon MCT Oil and 1 teaspoon of Carnitine mixed in 6 ounces of fat free milk before and after he swims. He doesn't have the endurance to swim for more than 30 minutes of the practice. It is pretty embarrassing for him now because he's the slowest on the team in his age group. But his friends are wonderful and never criticize him for being slow. At least he doesn't DQ (disqualify for doing a stroke incorrectly). He loves the socialization of just hanging out with the team. He has discovered girls and between events can usually be found sitting on towels in some shady place surrounded by four or more girls.

Adam is the first to make "blind jokes" about himself. At his age he doesn't talk to us about feelings so I don't know if he's really afraid he will go blind. In the past few years he has noticed more blank spots in his right eye. But he is able to turn his head to work around these and still see well. He even can see well at night. We took him to one meeting of the Foundation Fighting Blindness (a national or maybe international organization that supports people of all ages with diseases of the retinas). The meeting he went to separated into groups – parents of teens, teens, etc. so he was able to be with a group of teens suffering RP just like himself (Retinitis Pigmentosa). Most of these FFB 16 and older teens have their driver's licenses too but wonder if there will be a time when they will have to give up driving. I think it is a great support group but Adam doesn't think he's really ready to be in such a group yet. And, as I said before, he doesn't talk about his feelings. This also applies to when he's in a group.

For most of the year, Adam is pretty inactive. His nutritionist and metabolic doctors would like him to be more active, maybe riding a bicycle or going to the gym on a regular basis. This would strengthen his muscles and give him some reserve should he have an LCHAD Episode. Perhaps I need to explain an LCHAD Episode. This is when he starts feeling severe pain in his limbs, particularly in his legs. This is caused by a breakdown of his muscles as they try to provide his body with energy when his sources of the small amount of fat he can metabolize and carbs are depleted. Of course muscles don't give him energy, so they break down (Rhabdomyolysis). The broken down muscles leave the body through the urine (Myoglobinuria). When he was younger, Adam usually had to go to the hospital for an IV when this happened. Since the age of 13, he's been able to overcome LCHAD Episodes with just drinking massive amounts of Gatorade.

Since he was initially diagnosed with LCHAD at 6 months of age, Adam is seen every 6 months at the regional metabolic clinic. There he meets with a psychologist, his nutritionist, his metabolic doctor, and others. He completes blood work and a diet record before going so that the staff can analyze his metabolic control. After the appointments, the metabolic staff meets in a group and discusses their patients, sharing information between them that will help others. Since Adam's health plan has a lot of members, in Northern California, there are actually two other LCHAD kids seen at the same metabolic clinic.

Adam has been in two additional studies since I last updated. He was in a two-week diet study at Oregon Health and Science University in Portland, Oregon. There he stayed in the hospital for 2 weeks, having blood work done and stress tests while eating a high carb diet one week and a higher protein diet the next. There is a tendency in LCHAD deficient individuals to become obese, which can lead to Diabetes 2. Being overweight isn't healthy for anyone but for the LCHAD person it is worse. With Diabetes they would have to limit carb intake (which turns to sugars). For LCHAD deficient patients, carbs are a MAJOR source of energy. If they got Diabetes 2, their main energy source would be compromised. LCHAD kids are always told to eat carbs for energy. Adam LOVES rice and as an individual, probably eats more of it than someone living in Asia. Unfortunately too many carbs can easily make a person fat. He was very overweight at age 9 – 12 years, until puberty. He was always told he could NOT diet because it would be toxic to him to lessen calories. But at puberty he lost 17 pounds without dieting. This was probably not healthy for his body, but I don't know how we could have stopped this from happening when he was eating the same amount of food.

The study at OHSU determined that there is less of a tendency for LCHAD people to become obese if they decrease carbs for energy and increase protein (the low fat type). This summer Adam entered a follow up study related to the first. There are around 14 LCHAD participants who make an initial 4 day visit to OHSU for base line blood work, stress testing, and an MRS fat scan. They are then sent home and told either to continue on their usual high carb diet, or to be on a higher protein diet. After 4 months, they will return to OHSU for more blood work, stress testing, and an MRS fat scan to see the results. Ideally, the researchers want to find that those on the higher protein diet will have more energy and less fat. Adam is in the carb group so he is continuing his usual diet.

(cont'd on page 5)

## Adam...cont'd

We have been very fortunate through the years to keep in touch with many LCHAD families around the world. We met families in Sweden and Germany in 2002. This summer we again met Jane Carroll, our initial LCHAD friend. She has always been in better metabolic control than most LCHAD individuals. At age 14 she ice skates competitively and has no retinal deterioration. Some of this may be attributed to her having a G tube until age 13 and having a very carefully monitored diet. Anyway, we met them in Colorado where she was competing in the State Games. She won 3<sup>rd</sup> place in her division. We're so proud of her!

We are now beginning to look for a university for Adam. Because of the expense, we want him to go to the University of California. However, the best campus location (Berkeley) is SO competitive. We don't think there is a possibility of him being accepted. That would be the best location because it is the closest (5 miles) from his metabolic nutritionist and the hospital. When you have a child with such a rare condition, I think it is best that he be near medical professionals who know him and understand his condition. Our second choice would be the University of California at Santa Cruz. This campus is about 45 miles (and a very windy road) away from the hospital. Public transportation there is poor and we would probably have to go get him if he needed care. What if we weren't home?? It is a big worry. We may just have him go to junior college for two years first and live at home. Of course he wants to move away like his middle brother, but that may not be the best for him.

I'll try to update when he's in college – maybe the first LCHADer to go to college? Someone can contradict me on this if I'm wrong.

### Adam's Diet supplements at 17 years

Multi vitamin daily, Ester C, Vitamin E, DHA, and Occuvite

3 – 4 6-ounce jelly jars of fat free milk. Each contains 1 tablespoon of MCT Oil and 1 teaspoon of Carnitine.

Limit of about 20 grams of long chain fat per day

Supplement with 20 + ounces of Gatorade when needed

### Sample of his daily (school day) diet

Breakfast: his 6oz milk supplement

Snack: Plain bagel

Lunch: Bowl of rice with soy or teriyaki sauce and his milk supplement

Snack: Bowl of rice, bagel, cereal or some carb

Dinner: Low fat meat, vegetables (he doesn't like many)

Snack: Dryers low fat ice cream

Bed: Milk supplement

He rarely eats fruit and just a few vegetables. I hope the vitamin supplements provide him with the necessary vitamins.

Valerie Fulton

[vallchadmom@yahoo.com](mailto:vallchadmom@yahoo.com)

California



## The Sarvas Family ~ CPT 1 x 3

### Finland

We live in Espoo, Finland in Northern Europe. Both of our sons have CPT1. In Finland we do not have NBS. Here is our family story.

One early morning in January 2004 I woke up to find out that my husband had a stomachache. I thought 'Oh no, now we all will be sick.' Later in the morning our 2-year-old son, Joonatan, came to sleep in our bed. He was very restless and I thought he had the same illness as his dad. I woke up to take care of our 4-month-old baby boy, Matias. Joonatan was still sleeping so I thought I'd let him sleep as he was probably sick too. Soon my husband called me and said he thought something was wrong with Joonatan. I tried to wake him up, but could not. I called my cousin who is a doctor and she told me to call an ambulance right away. I did and while waiting for it to come I wondered what to do. I had an unconscious 2 year-old, a small baby, and husband so sick he could not get out of bed.

Luckily I got hold of my father who came straight from a meeting to take care of the baby and my husband. The ambulance came before my father. They found out that Joonatan's blood sugar was very low – 1.4 mmol/l (25,2 mg/dL). He was put on an IV drip and started to recover. I left with him to the hospital where we were under control for rest of the day. But for the night we were sent home as he seemed to be getting better. He was very tired for next two days.

(cont'd on page 6)

## Sarvas Family...cont'd

A lot of tests were done, but no reason for the low blood sugar was found. We were told things like this could just happen and that it might have been a reaction to the stomachache.

Almost two years later November 2005, one morning Matias (on left in picture at age 4), now 2-years-old, was very sleepy and I could not get him awake. We gave him some honey as we suspected his blood sugar was low as his brothers two years ago. He started to recover. My sister is diabetic, so I know how to handle low blood sugar. I called her to come and check Matias' blood sugar with her glucose meter. Matias was very tired. We found out his blood sugar was very high 8 mmol/l (144 mg/dL) so we went to the local doctor. He did tests too and found out the same, high blood sugar. It was even higher than at home - 14 mmol/l (252 mg/dL). He sent us to the hospital. First they thought he had diabetes, but after lab tests that was ruled out. We stayed over night and left for home the next day. The labs also showed high ammonia levels.

One-and-a-half weeks later Matias had a very restless night and in the morning he kept passing out. We were told to take the ambulance to the hospital if he would have any problems, so that is what we did. Now his blood sugar was normal, but ammonia levels were high again. He also had an ear infection (first ever). We stayed again for two days at the hospital and more tests were done, EEG for example.

A few weeks later we got a call from the hospital that they suspected CPT1 and Matias would be moved as a patient to the main children's hospital in Finland – Lastenlinna (Children's Castle). They have a specialist – Dr. Tiina Tyni, whom would take care of us. We went to meet her and she took more samples for the DNA test. She also told us that Joonatan most likely had the same disorder. Both boys' DNA results came back to confirm they had CPT1. They were the 4th and 5th diagnosed in Finland.

We finally got answers to our questions ~ why Joonatan was so tired at the daycare, why a stomachache had him in the hospital for 3 days when he was 1-yr-old, why Matias was so grumpy in the mornings (I had to give him candy to calm him down), and why the boys were sometimes so hard to wake up, why both seemed to be eating all the time when they were babies. I luckily fed them always when they wanted milk and both were night fed till over one-year-old. We also had a habit of having an evening porridge before bed. Our doctor said that probably had saved us many times.

Now they both can eat 12g (336 oz)/fat/daily, we eat every 3 hours and take Fantomalt (Maltodextrin) and cornstarch before bed. They also get Fantomalt with their meals and have omega 3 and walnut oil daily. With the right diet and regular feeding we have been doing great. No more times of unconsciousness or hospital stays. We meet our doctor every half a year.

Joonatan throws up or feels sick and tired if he does not eat probably or has too much exercise. Matias does not react that way. He is slowly learning new things, but still in the limits of normal. We are very very grateful that the boys were diagnosed in time and before any permanent damage occurred.

As we were told that every child we have has a 25% chance to have CPT1, we had to think really hard about future children. We have always hoped for 3-4 children. We thought about adoption, but that is quite difficult in our country. So we took the risk and I came pregnant in the spring of 2007. We found out in July that our third son also had CPT1. He had no heartbeat in August and I gave birth to him August 7th. No obvious reason for his death has been found. Our doctor told us CPT1 cannot be totally ruled out. We have obviously been deeply touched by this rare disorder and wanted to share our Family story. Thank you for listening.

Maikku, mom of Joonatan, 6, CPT1, Matias, 4, CPT1 and Nooa, most likely CPT1 (Stillborn 7<sup>th</sup> August 2007) and their father, Tero.

[maikku.sarvas@boksi.fi](mailto:maikku.sarvas@boksi.fi)



### **FOD and Expanded Newborn Screening Awareness Projects**

One of our Families (Chrissy, mom to Lacey (MCAD), Shelby and Jerrid) has created an educational and awareness tool to help spread the word about FODs ~

please check out her video montage at

[http://www.onetruemedia.com/shared?p=49b94039aed65a3efc74a1&skin\\_id=9&utm\\_source=otm&utm\\_medium=text\\_url](http://www.onetruemedia.com/shared?p=49b94039aed65a3efc74a1&skin_id=9&utm_source=otm&utm_medium=text_url)

Be sure to tell your Family and friends to view the montage as well!



## Questions & Answers



**Q: Can you tell me what actually happens during a newborn screen test and skin biopsies for FODs?**

**A:** Newborn screening for most metabolic problems is done by looking for metabolites – substances that are taking part in various chemical reactions in the body. These reactions occur through the actions of enzymes—special proteins that have particular shapes so as to fit around their particular metabolites. Enzymes typically put two molecules together, split one molecule into two components, and remove or add pairs of electrons. Genes are the DNA instructions for the sequence of amino acids that specifies each protein.

So when newborn screening turns up something of interest we try to understand what is going on. In some situations we measure a whole sequence of enzyme reactions at once. This is most commonly done by using skin fibroblasts—the majority of cells just under the surface of the skin—because it is easy to grow them in culture and send them to other labs. They can also be frozen for many years, and when thawed they will start growing and dividing again. To get them requires a skin biopsy—usually done with a 3 mm (1/8 inch) punch.

Some enzyme assays can be done on blood cells. For fatty acid oxidation defects most labs prefer fibroblasts, but I believe a few are using white blood cells. The enzymes of fatty acid oxidation aren't present in red cells.

If a test can be done by analyzing the DNA directly for a change in a particular gene a blood sample will do just fine. (The white blood cells, which are part of the immune system, have DNA. Red blood cells, which are filled with hemoglobin for carrying oxygen, lose their DNA as they mature). The blood transfusions probably would have been to give red cells. They would use blood with very few white cells, and it would probably have been irradiated to make sure the white cells weren't able to divide. (This is done to protect the baby in case his immune system isn't able to recognize the new cells are different). So there is no reason to think that a DNA test would have analyzed the donor's DNA—if it did, the lab would have detected a mixture of cells, and reported that.

So if a disorder is caused by only a few mutations, looking directly for them is a good way to confirm a diagnosis. In the case of LCHAD deficiency, there is one very frequent mutation, so a DNA-based test is a good way to go.

Finally, if you need only a limited amount of DNA, this can be obtained with a small brush which is rolled along the inside of the cheek for 30 to 60 seconds. You won't obtain many living cells, but there will be enough DNA there for a few experiments.

• • •

**Q:** I use a beta adrenergic inhaler, which I believe is a form of steroid, to help my breathing. I found that it also gives me energy and strengthens my muscles. I also take a 10 mg tablet of cortef, a form of cortisone, daily which likewise helps with energy and muscle strength. I've been told by people with symptoms similar to mine, that Prednisone triggered bad side affects for them, so I asked the doctor to prescribe Cortef in stead of Prednisone. I assume that though they are both forms of cortisone, there is some difference in the formulation and perhaps in the side affects. Perhaps I get benefit rather than muscle spasms from cortisone because my epinephrine and dopamine are usually low. Cortisone might affect have a different affect if the neurotransmitters are normal or elevated to begin with. **Can you explain why longterm steroid use might be harmful to someone with a possible FOD?**

**A:** Adrenergic compounds mimic adrenaline, which is not a steroid but a neurotransmitter. Adrenergic compounds will cause mobilization of fat from fat cells to elsewhere (liver, muscle, and heart especially), where they are used for fuel. This process is one of the ways the body responds to low blood sugar (hypoglycemia)—that's why our hearts race and we sweat when the blood sugar goes too low. And it's one of the reasons why hypoglycemia leads to problems for our patients with disorders of fatty acid oxidation.

Steroid compounds, like cortisol, prednisone, and dozens of others, have many different actions, often overlapping. Some tend to raise the blood sugar, some influence the kidney's ability to retain sodium, some have activity like the natural sex steroids testosterone, estrogen, and progesterone, and many have anti-inflammatory properties which are useful for diminishing allergic reactions (asthma, etc.) Some alter the muscles' ability to use fats for energy. This last bit is somewhat unpredictable—some patients with metabolic myopathies have had a beneficial response to prednisone, for example, and others have gotten worse. We choose which steroid compound to use based on a lot of considerations—the problem, the various side effects we might encounter, ease of administration, route of administration, convenience, availability, cost, etc.

(cont'd on page 8)



## Q & A...cont'd

I'm not sure if the leukotriene inhibitors for asthma would pose any special problems for someone with an FOD.

Inhaled drugs for asthma are intended to have most of their action in the airways and lungs, but there may be mild or significant systemic response to these medications—rapid heartbeat, for example, and increased muscle excitability, from the adrenergic compounds — that might be a problem for someone with an FOD. The steroid inhalers typically don't have the systemic side effects we can see with prednisone or similar medications taken by mouth. We need to be thoughtful about using any of these substances, like other medications (including the non-prescription ones), in anyone with a systemic metabolic disorder.

### Both Questions answered by:

Stephen G. Kahler, MD

Professor, Division of Medical Genetics

Department of Pediatrics

University of Arkansas for Medical Sciences

Email: [KahlerStephenG@uams.edu](mailto:KahlerStephenG@uams.edu)

Office Phone 501-364-2966

Fax 501-364-1564

Mail: Division of Clinical Genetics

Slot 512-22

Arkansas Children's Hospital

800 Marshall St.

Little Rock, AR 72202-3591

### Q: Fat metabolism is confusing – does anyone have an easy way to explain it?

**A:** Jordan's specialist once told me that it's like a furnace. Jordan has VLCAD, but she has some enzyme activity, so she is able to process some long chain fats. For us, when we're not fasting (just eating and going about our normal day) our furnace is on "low." But for Jordan, her furnace is running "on high" just doing those things. So when she gets sick or stressed, her furnace is "overloaded" and things break down. He also gave me this very good analogy. The whole metabolism of fatty acids can be seen as a river...the enzymes work along the way to break down fatty acids into glucose, so the river runs with no problem. But...with our kids, there is a dam somewhere along the way - where it is, depends on the specific FOD (ie., MCAD, VLCAD, SCAD etc). So when they are "in trouble," fatty acids build up in their systems on the one side (which can in and of itself be dangerous), and then the other side gets nothing - you can picture the low water on the other side of the dam - meaning no glucose. I just thought that that was a very good visual, easy way to explain a complicated system to others who might have trouble with the medical explanation.

Dawn

Jordan, 15, VLCAD

[dawnd39@comcast.net](mailto:dawnd39@comcast.net)



### 'Reaching for the Stars' Adventures of our FOD Kids



Krystena Richards is proud of her 2 boys Caden and Carson (both GA2/MADD) who recently went to California to enter a modeling and talent competition. You can go to <http://www.aimmodelstalent.com/> and enter the site, then click on Contestant Preview. You will find them under kids or on the right, under "Images, Lexington, KY."

The week of Jan 7<sup>th</sup>, Carsen and Caden competed at <http://www.imta.com/home.aspx>.

Krystena will let us all know how the boys did with their monologues.







# Medical Update

## Australian Doctoral Study on Coping

Australian Catholic University Limited  
 ABN 15 050 192 660  
 Melbourne Campus (St Patrick's)  
 115 Victoria Parade Fitzroy Vic 3065  
 Locked Bag 4115 Fitzroy MCD VIC 3065  
 Telephone 03 9953 3000  
 Facsimile 03 9953 3005  
[www.acu.edu.au](http://www.acu.edu.au)

### INFORMATION LETTER TO PARTICIPANTS

**TITLE OF PROJECT:** Health of parents raising a child with a disability: Affect, help-seeking, spirituality, and coping.

**STAFF SUPERVISOR:** Professor Barry Fallon, School of Psychology    **STUDENT RESEARCHER:** Aaron Allen

**COURSE:** Doctorate of Clinical Psychology

**•• Link for Questionnaire ••**

<http://www.surveywizard.com.au/coping/>

Dear Participant:

***You are invited to participate in some research on the health of parents raising a child with a disability. The purpose of this study is to gain a deeper insight into the lives of parents raising a child with a disability. The current research seeks to better understand the variations in parental responses to raising a child with a disability. The research seeks to examine not only how parents cope with raising their child (which presumes that parents necessarily struggle to effectively manage their situations) but also how they flourish and grow.***

Information from questionnaires like this will help other families who are trying to cope with the added difficulties that a child with a disability gives rise to. This information will also help professional counsellors and psychologists working with parents who are experiencing problems in these areas.

If you agree to participate, you will be asked to complete an online questionnaire, which includes some questions where you rate the degree to which you agree or disagree to various statements. The topics covered in the questionnaire include your state of well being, help-seeking, coping processes and your spirituality. The questionnaire will take approximately 40 minutes to complete. You are requested to complete the same questionnaire approximately 6 months from now. Should you wish to complete the questionnaire at this time only, we would still be grateful for your support, and welcome your input.

Each parent/partner is asked to complete the questionnaire. The questionnaire is strictly confidential and anonymous, and your name should not be included. The questionnaire will operate through a secure website with restricted access, thus ensuring your anonymity. No other person other than the researcher will have access to your questionnaire. The questionnaire can be completed at home, preferably when there will be little distraction.

Participation in this research is entirely voluntary. You are under no obligation to complete the questionnaire once you have started. At any time you may withdraw from completing or submitting the questionnaire. If some questions are too difficult, they may be skipped. While a completed questionnaire is of most benefit to the researcher, any information gained is beneficial.

The submission of your questionnaire implies that your consent is given for the researcher to use the information you have supplied. Please note, that this study may be published in a scholarly journal and any specific identifying information will be removed or changed (such as your child's age or disability, etc.) Please remember that you are free to discontinue participation in the project at any time.

Any questions you may have regarding this project can be directed to either the researcher, Aaron Allen, or the supervisor, Prof. Barry Fallon of the School of Psychology (03) 9953 3205.

Should you wish to seek professional help as a result of if your participation in this research has raised issues for you and you wish to obtain professional support, please feel free to contact Dr Terry Bowles, senior lecturer and clinical psychologist at ACU, Melbourne (ph: 9953 3117). Alternatively you may wish to contact Parent Line (Counselling, information and referral service for parents) on 13 22 89.

***This study has been approved by the Human Research Ethics Committee at Australian Catholic University. In the event that you have any complaint or concern about the way you have been treated during the study, or if you have any query that the Student Researcher and Staff Supervisor have not been able to satisfy, you may write to:***

Chair, Human Research Ethics Committee

C/o Research Services

Australian Catholic University

Locked Bag 4115

FITZROY VIC 3065

Tel: 03 9953 3157 Fax: 03 9953 3315

***Any complaint will be treated in confidence and fully investigated fully. The participant will be informed of the outcome.***

Thank you very much for your support and cooperation. It is greatly appreciated.

# The 'Silver Linings' of FODs



All too often we are reminded of the difficulties associated with FODs. Hopefully this list will help us remember the 'Silver Linings' to these disorders as well ~

- ♥ We are eating healthier, therefore our minds and bodies are functioning better.
- ♥ Siblings of our FOD kids grow up to be compassionate, undiscriminating, empathetic human beings.
- ♥ We have never had to wait in emergency for longer than 10 minutes.
- ♥ I realize the importance of Child Health Research.
- ♥ I'm aware of different foods and their benefits.
- ♥ I know that at birth my child was screened for 300 different conditions (most parents with "normal" kids have no idea what the heel prick was even for!).
- ♥ I appreciate every second with my son, knowing that we could have so easily lost him.
- ♥ After his crisis the other week, I don't think I've ever been so happy to see and hear him getting into mischief – Noise is fantastic!
- ♥ Nothing is taken for granted.
- ♥ Sometimes when my kids are being extremely loud or messy, I start to scold them but then think about how much of a blessing it is to have them here to make that mess or be that loud.
- ♥ MCAD has made me more appreciative of our (family) time together.
- ♥ I don't worry about his dirty clothes unlike my friends – go ahead jump in that puddle, play in the dirt, be a kid.
- ♥ My kids can eat freezer pops whenever they want.
- ♥ I accept that things are beyond my control.
- ♥ I don't judge other people's parenting cause I know you have to do what works for your family.
- ♥ I read and ask questions about everything.
- ♥ I use the MCAD to scare the girls off trying drugs and binge drinking. It also gives them an "out" if they were ever in the situation from peer pressure over these issues.
- ♥ I've found wonderful friends and support thru the FOD list.
- ♥ If a car rides my bumper now, (instead of gestures) I move to the side because you never know – they could be on their way to the hospital.

## What is *your* 'Silver Lining?'

Compiled by Kim ~ please send your 'Silver Linings' to Kim at [garethsmommy@yahoo.com](mailto:garethsmommy@yahoo.com) to be included in our next newsletter



## NBS Update

**FOD website:** Be sure to visit our 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!

**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](mailto: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.**

♥♥♥ It just amazes me (here's another Editorial from Deb!) that our Families have to FIGHT to get formula (as well as other services – PT, OT, speech therapy, etc) covered for their affected child/adult. Many insurance companies are real quick to cover diabetic supplies and testing for individuals, many of whom develop diabetes (type 2) all because of their poor food choices, being overweight/obese, and having other factors – many of which are CHOICES – but they won't cover **LIFE SAVING FORMULAS** for infants, children and adults that have NO CHOICE in having their disorder! Where's the logic, compassion and COMMON SENSE in that? And some companies think that at age 6 (when formula coverage is often cut off) the child will magically become cured and won't need formula anymore?! Yet they will cover a lifetime of diabetic supplies?!

Something has to CHANGE – and one thing that SHOULD change is calling these formulas (and other products that are often 'prescribed' by Drs for the child/adult's metabolic cocktail) food supplements – they are really **MEDICALLY NECESSARY FORMULAS/FOOD/VITAMINS/ENZYMES ~ for our Families they are called LIFE ~ without them their loved one wouldn't be here!** ♥♥♥



## Pharmaceutical Update

An L-carnitine (generic form) supplement was approved for distribution by the FDA a few years ago. This **generic form (as well as the brand name Carnitor®) needs a Prescription from the Dr.** Please also note that Carnitor® and the generic form of L-carnitine are **NOT** the same as the over-the-counter carnitine supplements often bought at health food stores ~ those products are **NOT** regulated or approved by the FDA to be used for metabolic disorders (read the article on <http://www.fodsupport.org/pharmaceuticals.htm>). The term 'generic form of a drug' should **NOT** be used interchangeably with the term 'over-the-counter supplement.'

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

## Nutritional Update



### Mead Johnson's Helping Hand Program

Mead Johnson has a heritage of providing infant nutrition to babies with special needs, which is why we are proud to offer the Mead Johnson Helping Hand for Special Kids Program™. Mead Johnson believes it is important for infants and children to receive formulas they need for good growth and development, regardless of the families' financial status. Our program allows the child's physician to, in partnership with Mead Johnson, extend a helping hand to families who need a specialty formula or a metabolic formula but cannot afford it. Over the last 15 years, Mead Johnson has assisted over 5,500 families with the Helping Hand Program.

The Helping Hand Program is coordinated by the child's physician, who works with the local Mead Johnson representatives to determine eligibility.

Our baby boy, Nooa, who was due to be born in November, died the 1<sup>st</sup> of August in utero. I gave birth to him on August 7, 2007. They could not yet tell why he died, but he most likely had CPT I as his brothers, Joonatan, 6 years and Matias, 4 years do.

Maikku Sarvas  
[maikku.sarvas@boksi.fi](mailto:maikku.sarvas@boksi.fi)  
 Finland

## Condolences...

Kathy Maybee called me (Deb) on Saturday Jan 5, 2008 and told me of her 23-yr-old son's death the day before. Colin was diagnosed with MCAD after his 1<sup>st</sup> episode as a toddler and lived with challenging disabilities his entire life.

A combination of factors led to a crisis and his unexpected death.

Please keep the Maybee Family in your prayers.



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

## Special Article: **Munchausen Syndrome By Proxy (MSBP)**

by ~ Alisa Minkin  
[alisaminkin@yahoo.com](mailto:alisaminkin@yahoo.com)

Munchausen Syndrome is named after the Baron von Munchausen, an 18<sup>th</sup> century soldier known for his wild, improbable tales of his exploits. Patients with this syndrome fabricate a wide range of illnesses which lead to multiple unnecessary lab tests, hospitalizations and surgery. Munchausen Syndrome by Proxy (MBP) was first described by a British pediatrician, Roy Meadow, in 1977. He reported cases of children whose illnesses were fabricated by their parents. The term “by proxy” is used because these parents are believed to be projecting their own psychological needs onto their children. However, the actual motivation is unclear both in Munchausen syndrome and in MBP.

Basically, MBP is a form of child abuse. The caregiver is almost always the mother, according to the MBP experts. The MBP caregiver harms the child by causing unnecessary tests, procedures, hospitalizations, and even surgery. Parents have partially suffocated their children to simulate apnea, have poisoned them with various substances, and have caused infections by injecting them with their own blood or urine.

These children suffer greatly as a result of this abuse. Many have permanent damage, and some even die. Thus, doctors and other medical professionals have to be suspicious of this disorder, as they must be for all forms of child abuse.

MBP has been considered a rare form of abuse. However, there are a number of professionals who specialize in this disorder. They believe that it is not so rare. They have increased awareness of MBP and encourage health care professionals to suspect it.

The problem is that it is often very hard to tell if a parent is fabricating a child’s illness, or not. Medical textbooks have lists of warning signs for the “MBP perpetrator”.

**Unfortunately, these “warning signs” are simply not reliable indicators of MBP. They overlap tremendously with those of normal parents of children with chronic illnesses, especially children with unusual and/or undiagnosed conditions.**

A table in a recent article in *Contemporary Pediatrics* (modified from an article by Dr. Meadow) (Malatack et al, *Contemporary Pediatrics*, Vol 23 No 6) lists 8 warning signs for MBP:

- The child has a “persistent or recurrent” illness. This is typical for chronically ill children, too.
- The child appears too healthy to have the described symptoms. Children with metabolic disorders often appear completely well in between episodes.
- The symptoms are so unusual that the doctor says he has “never seen a case like it before.” Metabolic disorders such as fatty acid oxidation disorders and mitochondrial disorders are very rare, and may elude diagnosis for years.
- The child is symptom-free when away from the mother. If the disorder is episodic, it may not recur often enough to be seen when the child is separated from the mother.
- Mother is “excessively attentive” and insists on staying with the child. Mothers of chronically ill children, especially those with rare disorders, are the most knowledgeable about their children’s conditions, and must be strong advocates for their children at all times. No one can care as much about our children as we do!
- Mother appears “less worried” than the medical professionals. Parents of children with chronic illnesses cope in many different ways. Some intellectualize, some shut down emotionally, some are depressed, and some are just numb. All of these coping techniques may make a parent appear “inappropriately calm.”
- The child has “polymicrobial sepsis” without underlying immune suppression or severe abdominal illness - is unusual and is thus more of a red flag for MBP.
- One or more siblings have an “unexplained illness.” Fatty acid oxidation and related disorders are genetic, and thus recur in the family.

So, of the 8 “warning signs” for MBP, only one is specific for MBP. The other 7 describe children with chronic illnesses, especially metabolic ones, just as well. A compilation of MBP “warning signs” and comments by parents of chronically ill children is available at the end of this article.

Health care workers are mandated reporters of suspected child abuse. They have the responsibility to report all suspected abuse, including MBP. **Some parents have been falsely accused of this disorder. These parents face a double nightmare. They have ill children who may not be properly treated, and they also are under suspicion for harming their own children!** [The FOD Group is not immune to these FALSE accusations - Deb has spoken to at least 5-7 in the last few years!]

Margaret Talbot wrote about some of these falsely accused mothers in her New Yorker article (August 9, 2004), entitled The Bad Mother. This article is available online at [http://www.newamerica.net/publications/articles/2004/the\\_bad\\_mother](http://www.newamerica.net/publications/articles/2004/the_bad_mother).

All child abuse, including MBP, is horrifying and must be prevented. Children must be protected from harm. However, false allegations of MBP are also traumatic, both for the parents and for the children. Parents of chronically ill children are the experts on their own children. They need professionals who will respect and support them, not be suspicious of them.

**The bottom line is that, as parents of children with rare disorders, we are at risk of a false accusation of MBP. The MBP profile, unfortunately describes...us.**

(cont'd on page 13)



## MSBP...cont'd

What should we do? I can't give you a list of ways to avoid being falsely accused. Hopefully, over time, medical professionals will know more about MBP, and how to avoid mistaken accusations. In the meantime, we all have to be our children's best advocates, as always.

**Advocacy is a topic for another article, but here are some basic suggestions.**

1. Always keep copies of all of your child's medical records in a binder. Bring it with you to each doctor visit.
2. Have your protocol letter, if you have one, with you at all times. Even if your child does not yet have a definitive diagnosis, it may be possible to have a protocol letter written by your child's metabolic specialist.
3. It is important, although not always possible, to stay calm when advocating for your child. Bring someone with you, if you need help!
4. Talk to other parents with similar children. Support groups, like the FOD Group, are amazing resources!
5. Keep learning as much as you can about your child's disorder.
6. Assemble a team of professionals. You will be the head of this team. You will need professionals who will listen to you and respect you as the team leader, the ultimate expert in your child.
7. Never ever give up! Remember that we are always here for you at FODsupport.org – **'We are all in this together.'** **No matter how hard it gets, you are not alone!**

### Sources:

1. **The Bad Mother** by Margaret Talbot, New America Foundation. The New Yorker, August 9, 2004.
2. **Munchausen By Proxy Defined** by Herbert Schreier, M.D. *Pediatrics* vol.110 No.5 November 2002, pp.985-988
3. **Beyond Munchausen Syndrome By Proxy: Identification and treatment of Child Abuse in a Medical** Setting. John Stirling Jr. M.D. and the committee on Child Abuse and Neglect, *Pediatrics* Vol 119 No.5 May 2007, pp.1026-1030
4. **Taking on the Parent to Save a Child**, J. Jeffery Matalck, M.D. et. al. *Contemporary Pediatrics* Vol 23 No 6 pp. 50-63
5. **The Munchausen Syndrome by Proxy Perpetrator Profile or Warning Signs**  
Author(s) unknown [another metabolic support group sent Deb that information]  
Source: See below info and on <http://www.msbp.com/>

• • •

### The Munchausen Syndrome by Proxy Perpetrator Profile or Warning Signs (quite different from diagnostic signs)

[Reactions from parents of chronically ill children appear in blue]

The following profile list is compiled from several profiles available on the internet, including the FBI list.  
**Note how illogical and contradictory they can be.**

- Primary caregiver, most often mother [99% of those accused are female]. This describes 50% of the population and most caregivers. You can't profile on such a common characteristic. Fathers are often very involved in caregiving, if you ask.
- Educated, middle to upper class. Why would this be a bad thing? So why are more accusations against poor mothers? This group is more likely to appropriately consider doctors to be their hired consultants.
- A highly attentive parent who is reluctant to leave her child's side and who herself seems to require constant attention. This is entirely typical and appropriate for the parent of a sick child. Often they have to play the squeaky wheel. Children should NEVER be left alone in a hospital. Hospital personnel EXPECT parents to stay overnight and help care for the child. An overwhelmed and confused parent needs and deserves reassurance.
- Friendly with medical staff and highly supportive and encouraging of staff. Totally appropriate in this decade. Interestingly, many MSBP accusations are filed the day after the patient sues for malpractice.
- Some medical background, most often nursing. Most parents of sick children end up with an amazing level of medical knowledge. Nurses are more likely to be vocal advocates because they realize medicine is an inexact science.
- Takes child to multiple physicians, moves frequently or transfers to another facility. Seeking experts is completely normal and appropriate for the parent of a child with a difficult or undiagnosed condition. Many disease groups have documented an average of 6-10 physicians missing the diagnosis. Not all those missed diseases are rare! (celiac) Families move due to job changes more frequently than in the past. Insurance changes can necessitate a change in physicians.
- Refuses to accept changes in diagnosis or lack of diagnosis. If an adult was in pain or feels terrible and told there is no reason for it, they would refuse to accept this. Why should parents accept the lack of a diagnosis?
- Demands specific medical procedures or medications. In this day and age, it is quite common and appropriate for patients to research tests and treatments and request them. Pew Charitable Trust has research papers documenting this.
- A parent who appears to be unusually calm in the face of serious difficulties. Different parents have different coping styles and this should not be held against them. Project Delivery of Chronic Care sends medical residents to visit homebound, profoundly disabled children. The residents are usually completely astonished at how well and calmly many parents cope with situations that most people would consider intolerable.

(cont'd on page 14)

## MSBP...cont'd

- A parent who is depressed or overwhelmed. Again, a different coping style or a temporary stage. Most parents of chronically ill children get depressed at some point. Most are chronically overwhelmed. Getting help for the depression is a positive step and should NEVER be used against the parent. Often a parent will realize they are depressed and overwhelmed but be unable to take the time away from the child to care for their own health. Many fantasize about walking away. Remember the phrase, "It only takes a single child to raze a village."
- A parent who is angry and demanding. Again, a different coping style/ personality style and sometimes appropriate or necessary to get the child help. Many parents get little sleep due to their child's illness. Women in particular may still be accused of being hysterical. In the old days, the favorite treatment for some childhood illnesses was Valium for the mother.
- Marital problems, distant spouse. One spouse may spend extra time at work due to financial stress or may have to stay home with siblings. Marital stress is common even with colic. With a chronic or mystery disease, if doctors disagree on treatments, so will the parents. Many fathers leave due to the chronic illness or death of a child. This should not be held against the remaining spouse who needs additional support. Spouses may naturally and subconsciously fall into roles that don't fit your paradigm, yet they may be perfectly functional in a dysfunctional situation. Parents may take turns falling apart or keeping it together – an unwritten rule prevents them both from coming unglued at the same time.
- A parent who dramatizes small crises or seems to have new crises continually. As a way of getting your attention? Because life with a sick child IS full of crises? To laugh instead of crying? Is their Pissing and Moaning Quotient really that high or do they have many legitimate things to complain about? Parents of sick children get sick themselves easier, lose their keys and have minor traffic accidents more because they operate on overload every minute of every day. Complaining or talking about their stress is a good thing, but we no longer encourage parents to do it with their child's doctors.
- Welcomes tests, even if painful. Knowing is almost always preferable to not knowing, even with cancer or fatal diseases.
- Leaves out portions of medical history. Long, complicated histories need to be summarized. Dead ends or leads the parent doesn't put stock in may get left off.
- Child's symptoms don't fit known diseases. Medicine is full of mysteries and many people with rare diseases see dozens of doctors who don't recognize the pattern.
- A child who has one or more medical problems that do not respond to treatment or that follow an unusual course that is persistent, puzzling and unexplained. INDEPENDENT medical experts who have a flair for medical mysteries should review the ENTIRE medical record AND see the child with their own eyes AND be allowed to talk freely to mom about the medical history and her theories.
- Physical or laboratory findings that are highly unusual, discrepant with history, or physically or clinically impossible. Children with metabolic diseases have 'impossible' lab results. Lab work should be carefully repeated and any odd results thoroughly researched before any action is taken. Video cameras should be used with EEGs and apnea monitors. Toxicology results can be due to a chemically similar substance (epicac and benadryl look the same on chromatography). A toxicology expert should be consulted..
- Child has multiple hospitalizations. Common in chronic illness.
- Child's symptoms improve when away from mother. Some diseases get better on their own or have a course that waxes and wanes unpredictably. A change in diet may fortuitously improve the symptoms in an allergy or metabolic situation. The change in symptoms is valid only if mother has trained the observer to watch for subtle changes. Children with rare diseases have become much sicker and even died when away from the mother. The CINA attorney should see the child and talk to the temporary caregivers frequently. Temporary caregivers MUST have the full medical information from the parents.
- A family history of similar parental or sibling illness, unexplained sibling illness/death. Many illnesses are genetic. Relatives may live for decades with mild symptoms. Patient associations should be consulted for possible genetic connections that are not yet published. For deaths many years ago, parents should be asked if they have a theory about the cause of death. A retrospective look at unexplained deaths is needed. Parents should be allowed to provide witnesses.

[Please note: These comments can be copied, reposted and shared ~ these are not copyrighted. *The above article is WHY we NEED more clinically trained Drs knowledgeable in metabolism – so that disorders like FODs will be more recognized and parents won't have to endure LIFE-CHANGING FALSE ACCUSATIONS of MSBP!! DLG*]

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### 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 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 homepage for the donation box). Once we raise enough Funds we will be able to offer grants to Clinical Training institutions.

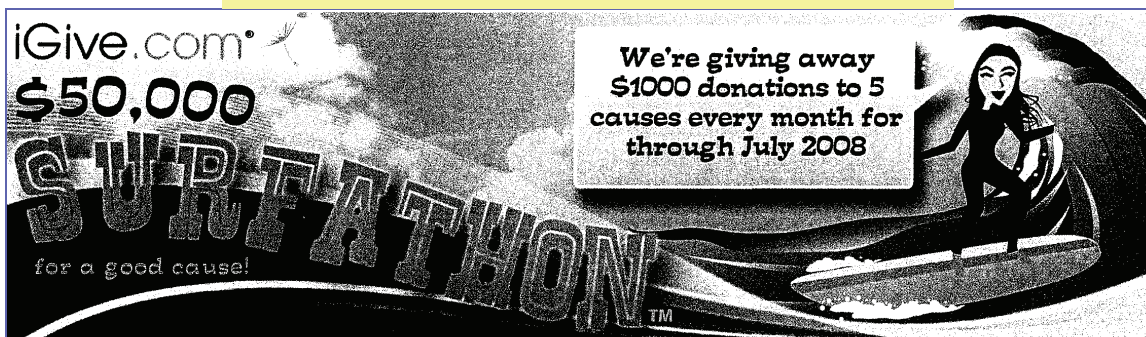
**We NEED your help NOW and in the FUTURE  
so our children will thrive and grow into adulthood with the best of ongoing care!**

## 'Fundraising' Information

Now that we are a 501c3 tax-exempt nonprofit, all of your personal donations, as well as those from your individual project efforts at raising FOD/Newborn Screening awareness are tax deductible! If you would like to plan your own project for FOD Awareness please fill out the **Family Awareness Project Form** on our homepage to help guide you in planning for the project.

Some of the projects that Families have planned, have included a percentage of profits from selling products from Pampered Chef, Tupperware, iGive, and PartyLite Gifts. Keep up the GREAT work ~ all for the benefit of our Families!

**Below is a GREAT way to Raise Funds for the FOD General Fund ~ Shop iGive!**



Surf Online Stores. Tell Your Friends. Win \$1,000 for Your Favorite Cause!

It's easy - just visit online stores through iGive.com. More visits by you and your fellow supporters mean more chances for your cause to win a \$1000 donation! No purchase necessary - it's totally free.

- \* The more stores you visit through iGive.com, the more chances for your favorite cause to win a \$1,000 donation! (Up to 10 entries per person per day)
- \* Each visit to a different iGive.com store counts as an entry in this sweepstakes. (Same-store visits in the same month equal one entry)
- \* Get your friends involved for more chances to win!

## Ready to Surf for a Good Cause?



Ten months, 50 winning causes, with a total of \$50,000 in free donations.

Here's how it works:

Join iGive.com for free and visit up to 10 different online stores every day. Each of those visits counts as an entry in this sweepstakes. Every month, iGive.com will award \$1,000 each to 5 winning causes! Over 680 online stores participate in the iGive.com program, so there's something for everyone! This sweepstakes is valid 10/1/07 - 7/31/08. If you're already an iGive.com member, you can participate too!

For example:

Let's say you visit 10 different stores through iGive.com today, and 9 of your friends each visit 10 stores too. That's 100 entries for your favorite cause in just one day! Keep it up by visiting different stores through iGive.com, every day for the rest of the month. Be sure to tell your friends to do the same - more visits mean more chances to win a \$1,000 donation!

For complete rules and info, visit:

**www.Surfathon.com**

What's iGive.com?

In case you were wondering, iGive.com is an online shopping mall where up to 26% of each purchase at over 680 participating stores is donated to your favorite cause. For a limited time, we'll even add a bonus \$5 donation when you make your first purchase within 45 days of joining. Pretty cool, huh? Our free service was established in 1997 with the goal of changing online shopping for good. Learn more at: www.iGive.com

## Rally Your Team!

Get more people surfing for more chances to win \$1000 for your cause. Tell a friend!

Information is subject to change. Visit www.iGive.com for current details. © iGive.com Holdings, LLC

# Love Messages



Please remember these families in your thoughts and prayers throughout the year

Joan and Tim Aalberts  
Luke - Birth June 7, 1994 Death May 1, 1995

Sandy and Howie Aitken  
Kristopher - Birth Dec 22, 1997 Death Dec 29, 1997

Christy Axsom  
Kagan - Birth July 7, 2003 Death Jan 28, 2005

Jeanne and Mark Barilla  
Michael - Birth Feb 2, 1990 Death Nov 25, 1990

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

Delane and Althea Becker  
Warren - Birth June 9, 1987 Death Feb 4, 1990

Sue and Jim Berneski  
Michael - Birth Dec 28, 1992 Death Jan 3, 1993

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

Jacque and Mike Bradford  
Eric - Birth Aug 22, 1990 Death Aug 26, 1990

Cynthia Brown  
Miranda - Birth Death April 3, 2004

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

Barry and Julie Bryson  
Skyler - Born November 25, 1989 Death Aug 25, 1990

Carolien Grootaert - Callens  
Liese - March 2, 1988 Death Aug 25, 1990

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

Claudia and Atonio de Carmo  
Bruna - Birth July 22, 2003 Death Oct 31, 2004

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

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

Mark and Diane Casey  
Matthew - Birth Apr 15, 1974 Death Jan 13, 1975  
Jennifer - Birth Oct 19, 1975 Death Nov 13, 1979  
Lori - Birth Aug 31, 1980 Death July 1, 1984

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

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

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

Sandy and Jon Cooper  
Noah - Birth Oct 5, 1997 Death June 30, 1998

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

David and Amy Deshais  
Megan - Birth Feb 11, 1991 Death July 7, 1991

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

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

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

Lance and Dawn Goldsmith  
Joel - Birth Feb 15, 1990 Death Nov 16, 1990

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

Shelly and William Grabow  
Caleb - Birth Sept 14, 2001 Death Sept 27, 2001  
Noah - Birth Nov 18, 2003 Death March 23, 2004

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

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

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

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

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

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

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



Nikki and Toby Hiatt

Reece - Birth Aug 1998 Death April 18, 1999

Pauline and Bill Hill

Rosemarie Rees - Birth Apr 15, 1976 Death Dec 23, 1999

Amy and Matthew Hoffman

Grace - Birth Jan 25, 2001 Death Oct 25, 2003

Brad and Kim Holmes

Brittany - Birth March 20, 1991 Death Feb 21, 1997

Debbie and Dave Houk

Lauren - Birth May 4, 1988 Death Dec 15, 1989

Robert and Dixie Howard

Cody - Birth July 30, 1987 Death Dec 26, 1992

Stephanie and Doug Huber

Jace - Birth March 8, 2000 Death Feb 14, 2001

Meredith and Neil Hughes

Claire - Birth Sept 1, 1986 Death June 23, 1997

Karen and Steve Imhoff

Michael - Birth July 25, 1991 Death July 8, 2002

Brian and Patricia Karhu

Patrick - Birth July 15, 1996 Death July 28, 1997

Vickie and Burnell Keller

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

Diane and Mickey Kennedy

Marie - Birth Dec 1, 1989 Death Oct 5, 1991

Andy and Temple Ketch

Nancey - Birth Feb 8, 1989 Death July 20, 1990

Robert Knoff

Teresa - Birth Nov 7, 1994 Death June 29, 1995

Sondra Koehn

Darcy - Birth Aug 10, 2000 Death March 19, 2002

Jamie and Tom Lazzaro

James - Birth Dec 8, 1996 Death Aug 13, 1997

Lisa and Pete Leonardi

Devin - Birth July 18, 1997 - Death July 19, 1997

Mary Lingle

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

Darlene and Larry Lopez

Marissa - Death Feb, 1999

Heather and Phillip Marsella

Toni Marie - Birth Oct 8, 1990 Death March 22, 1991

Ron and Paula Matthews

Daniel - Birth May 19, 1981 Death Jan 12, 1982

Randy and Misty McDonald

Jeremiah - Birth April 3, 1991 Death Dec 15, 1991

Christine and Mark McFarland

Erin - Birth Aug 26, 1988 Death Jan 21, 1989

Linelle and Matt Meadows

Cole - Birth Mar 21, 1999 Death Oct 18, 1999

Elvira Melendres

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

Lori and Jeff Michaud

Jordan - Birth Feb 19, 1997 Death March 21, 1998

Simone and Michael Miller

Michael Dylan - Birth Aug 24, 1991 Death Aug 24, 1991

Kristen and Ken Mitchell

Nolan - Birth Aug 8, 2004 Death May 16, 2005

Mike and Sheryl Mulhall

Justin - Birth April 22, 1990 Death April 22, 1990  
Nathaniel - Birth Aug 15, 1991 Death Aug 18, 1991

Verna Parker

Charles - Birth Oct 24, 1988 Death Oct 26, 1988

Diana and Kevin Patterson

Trevor - Birth Aug 30, 1997 Death Mar 4, 1998

Steve Bruski and Liz Pease

Caitlin - Birth July 10, 1989 Death May 10, 1996

Albert and Arleen Phang

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

Jennifer and Jason Pierson

Alexander - Birth June 1, 1995 Death June 3, 1995

Stephanie and Andrew Plaisted

Drew - Birth May 7, 1997 Death Dec 27, 2000

John and Sally Reichelder

Zachary - Birth March 24, 1997 Death March 27, 1997

Tanya and Pat Robitaille

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

Brian and Cheryl Rosenberger

Kylie Ann - Birth Feb 7, 1990 Death Feb 11, 1990

Janice and Steve Rowland

Josey - Birth Sept 30, 1996 Death Oct 28, 1998

Litzy Sanz de Solis and Jesus Solis Sanchez  
Jesus - Birth Sept, 14, 1996 Death March 16, 1998

Jackie Shears  
Timothy - Birth Oct 3, 1991 Death Oct 4, 1992

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

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

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

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

Anne and Gary Stitt  
Sydney - Birth Oct 13, 1995 Death May 20, 1996

Lisa and Doug Tennyson  
Sammy - Birth Aug 23, 2000 Death Dec 21, 2001

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

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

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

Darren and Karen Wade  
James - Birth Jan 15, 1996 Death Aug 31, 1996

Sirpa and Jay Waananen  
Nora - Birth Mar 29, 2001 Death Aug 9, 2001

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

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

Denise and James Westman  
Benjamin - Birth March 11, 1987 Death Dec 20, 1988  
Beau - Birth July 10, 1991 Death Feb 19, 1995

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

Karen and James Whiteside  
Caitlin - Birth Aug 12, 1996 Death Dec 19, 1996

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

Christi and Ronnie Williams  
Preston - Birth Mar 11, 2000 Death Mar 15, 2000

'For some life lasts a short while, but the memories it holds last forever.'

~ Laura Swenson

**Deb Lee Gould, MEd**  
**MCAD Parent and Grief Consultant**

**Home Office Phone: (517) 381-1940**  
**[deb@fodsupport.org](mailto:deb@fodsupport.org)**



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.

Please know that all emails or phone contact with me (Deb) will be confidential. In order for me to understand your situation please take the time to complete the Grief Intake Form are on our homepage. It can be sent to me online or mailed/faxed.

For information on my educational background and grief training experience, I have posted some links on our homepage and on the Coping and Healing page.

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





## Allergy Resources

**Cooking with Allergies: Gluten-free, Sugar-free Cooking: Over 200 Delicious Recipes to Help You Live a Healthier, Allergy-free Life**, by Susan O'Brien (Marlowe & Company 2006)

**Allergy-Free Cookbook** by Alice Sherwood (DK Publishing 2007)

**Cooking Free: 200 Flavorful Recipes for People with Food Allergies and Multiple Food Sensitivities** by Carol Fenster (Avery Publications, 2005)

**The Ultimate Food Allergy Cookbook: How to Cook with Ease for Food Allergies and Recover Good Health** by Nicolette M Dumke (Allergy Adapt, 2006)

**The Whole Food Allergy Cookbook: Two hundred Gourmet and Homestyle Recipes for the Food-Allergic Family** by Cybele Pascale (Vital Health Publishing, 2005)

**Websites:** [www.Aaaai.org](http://www.Aaaai.org) , [www.Aafa.org](http://www.Aafa.org) , [www.foodallergytalk.com](http://www.foodallergytalk.com) , [www.kidswithfoodallergies.org](http://www.kidswithfoodallergies.org) , [www.mayoclinic.com](http://www.mayoclinic.com)



The **Sibling Support Project** is pleased to announce that we are now scheduling workshops for 2008. Please share this announcement with families you know and training directors, conference planners, and coordinators of family services from appropriate agencies. Many agencies wisely value the families they serve and are committed to providing family-centered care and services. However, even the most family-friendly agencies often overlook brothers and sisters. Brothers and sisters are too important to ignore, if for only these reasons:

- Siblings will be in the lives of family members with special needs longer than *anyone*. Brothers and sisters will be there after parents are gone and special education services are a distant memory. If they are provided with support and information, they can help their sibs live dignified lives from childhood to their senior years.
- Throughout their lives, brothers and sisters share many of the concerns that parents of children with special needs experience, including isolation, a need for information, guilt, concerns about the future, and caregiving demands. Brothers and sisters also face issues that are uniquely theirs including resentment, peer issues, embarrassment, and pressure to achieve.
- No classmate in an inclusive classroom will have a greater impact on the social development of a child with a disability than brothers and sisters will. They will be their siblings' life-long "typically-developing role models."

The Sibling Support Project is the United States' only national project dedicated to the concerns of brothers and sisters of people with special health, developmental and mental health concerns. We specialize in providing lively, family-friendly, and highly-rated workshops on sibling (and father and grandparent!) issues to audiences of parents, service providers, university staff and students, and siblings of all ages.

We've conducted workshops on sibling issues in all 50 states, Canada, Ireland, Japan, Guatemala, New Zealand, and England and have helped establish over 200 replications of our award-winning Sibshop program in eight countries. Our books for families include *Sibshops*, *Views from Our Shoes*, *Living with a Brother or Sister with Special Needs*, and *Uncommon Fathers* and our new book for teen sibs, *The Sibling Slam Book*. And our work and publications have been featured in newspapers (*Washington Post*, *New York Times*), magazines (*Exceptional Parent*, *Sesame Street Parent*, *Reader's Digest*), professional publications (*JASH*, *Journal of Pediatric Psychology*, *The American Academy of Pediatrics News*), and television (*ABC News' 20/20*, *Nightline & World News Tonight* and *Brazelton on Parenting*) across the United States.

We'd welcome an opportunity to present at your agency or your next conference or training event. We'll show you how parents and providers can decrease siblings' concerns and increase their opportunities, how to create "sibling friendly" services, and even how to start your own Sibshop.

Addressing siblings' concerns benefits everyone: brothers, sisters, parents, agencies, taxpayers and especially the family member who has special needs. In many important ways, brothers and sisters ARE the future--and are too important to ignore.

If you would like to learn more about our workshops, seminars, and keynotes please call or contact us by email and we'd be happy to send you more information. Our schedule is beginning to fill up, but we still have openings.

Don Meyer, [donmeyer@siblingsupport.org](mailto:donmeyer@siblingsupport.org)

Director, Sibling Support Project, <http://www.siblingsupport.org/>

A Kindering Center program



## Recipes

### Angel food cake with Fruit and Cream Cheese

We made a fat-free angel food cake (Betty Crocker sells a mix - it has LOTS of sugar, but this is a birthday cake!), sliced it in half and filled it with fat-free vanilla pudding (from Jello) and sliced fresh bananas. Then we reassembled the halves and iced it with fat-free cream cheese icing (basically, fat-free cream cheese, a little skim milk, and a few tablespoons of confectionary sugar), and we mounded sliced strawberries on top. It was delicious! Even Katie, who had completely refused table food up to that point, dug right in! Enjoy!

Taryn [tpaladiy@gmail.com](mailto:tpaladiy@gmail.com)

Mom to Katie, 20 months, LCHAD, Queens, NY

(cont'd on page 20)

## Recipes...cont'd

### Sugar Cookies

I make these twice a month and my son who is three loves them:

- 1 cup melted butter (we use promise fat-free or parkay spray fat-free and pour it to measure)
- 2 cups of powdered sugar (if they are cut outs use powder, if not use granulated)
- 4 eggs (we use egg beaters since they are fat-free)
- 1 tsp of vanilla extract
- 1/2 tsp salt
- 4 tsp of baking soda
- 2 tbsp milk (we use skim so it is fat-free)

Put in the fridge for a least one hour so it is easy to roll. I normally make the dough the day before then roll out the next day. Make sure to cover it in the fridge.

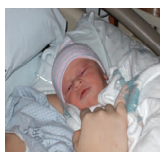
We also make icing for our cookies:

- 1 box powdered sugar
- 1/4 cup of butter (I will only use parkay because it won't clump, I use the fat-free spray and pour it to measure). The butter has to be melted all the way.
- 1 tsp vanilla then add milk 1 tsp at a time to desired thickness. It will get thicker as it sits, but you can always add milk.

Hope this works for you,  
Stephanie Smith, Indiana  
Brayden Smith, 3, MCAD

## Welcome to New Babies!

**Kory Joseph Lafferty** was born on Sept 21, 2007 at 4:41pm, weighed in at 8lbs 6 oz, and was 21½" long. Catherine and Keith and their other children, Karli (MCAD) and Koko are excited that he is here!



On November 23, 2007 at 6:50 pm Miriam and Christopher Staffen welcomed a beautiful 7 lbs 4 oz baby boy to the world. He was 18½" long. Connor Orian Staffen has blue eyes and a little brown hair.

Heli (adult GA2/MADD) and her husband, Markus, welcomed into the world a son, Timi, on July 20, 2007. His sister Milla is glad to have a baby brother! Timi weighed 3320 grams and was 51 centimeters long. Everything is ok with him! Also I am ok ~ having GA2/MADD didn't show any bad signs. I did have to have a c-section and ended up with an infection, however. Here are some pictures of Timi and Milla feeding him. So happy mother...  
Heli, 37, MADD/GA2, Finland



James and Melanie Shannon of New Albany, MS, welcomed Lilly Lauren Shannon into the world on November 27, 2007 at 11:49 pm. Lilly weighed 7 lbs 8 oz and was 19¾ inches long. Lilly has 2 brothers ~ Tucker (6 years old unaffected) & Thomas (undiagnosed MCAD, Mar 14, 2006 ~ Mar 16, 2006).

I had my baby boy, John Richard, Sunday July 22, 2007 at 8:34am. He was a huge 8lbs 14 oz. We followed our protocol for feeding him and checking blood sugars and found out yesterday that he does not have MCAD!

We are so thrilled to have a healthy baby.

Heather and Marcus Harwood.

Maren, 22mos (MCAD) and John



# Kids Korner



Parker Hammon  
SCAD



Juan Fernandez, 13  
VLCAD  
with mom, Maria  
Martha and dad,  
Pablo  
Argentina



Shelly with  
Caden and Emily  
Grabow

sibling 'angels'  
Caleb and Noah  
both had TFP

Mary Flahive  
MCAD



Riley  
MCAD  
Perth Australia



Lacey  
3 years old  
MCAD  
[her mom, Chrissy,  
created the  
wonderful video  
montage!]





# Family & Professional Donations

**Family Donations:** The Zemeckis Charitable Foundation (Leslie and Robert) in honor of their sons, Zane (MCAD) and Rhys. They will be acknowledged as 'Gold Sponsors' at our 2008 National Metabolic Conference. Another FOD Family member anonymously donated a very generous amount to both the General Fund and Research Fund in memory of Meghan Grace Morton (undiagnosed MCAD), and they will also be 'Gold Sponsors' for the Conference.

Gerry Lee Hogan in memory of Kristen (undiag MCAD) and in honor of Kevin Gould (MCAD). Mary Thorson, in memory of her daughter, Wendy (TFP) and Mary B O'Neill in memory of Wendy. Susan Stewart Widmann, Donna and Robert Krenn, Dennis Dietrich, Steven Dietrich, Joe Wilson, Lynn and Ollie Trewartha, Frank Strand and 2 anonymous donors in honor of McKenna (MCAD) and Wade Widmann. Mrs Janet Wolcher, Mrs Alta Huber, Mr Philip Huber, and Maria and Craig Tuttle all in honor of Ryan A Tuttle (unclassified FOD) and in memory of Eleanor M Tuttle, Ryan's grammy. Mary and Hugo Holm in memory of their grandsons, Matthew Christerson and Matthew Bradford, for their birthdays. Holly and Keith Brown in memory of their son, Clyde (VLCAD) and also Sandra and Charles Green in memory of Clyde. Joyce Thompson. Patti Phears, in honor of grand daughter, Elora (still testing). Heather and Vincent Rose in honor of Dylan (MCAD) and Dominick. Anonymous donor in honor of Gareth DiPaolo (MCAD). Jewel DiPaolo in memory of Nick and Al DiPaolo. Maureen Pienta. Nicole Early. Taryn and Oleksiy Paladiy in honor of Kate. Doreen Henricks in memory of Lauren Elaine Young. Lisa Wondercheck. Cheryl Emory in loving memory of Colin Scott Maybee (MCAD). **Tshirts, Bracelets, Ribbons, FOD CafePress.com, GoodSearch browser, or iGive shopping:** BethAnn Folcher, Amy Little, Mary Thorson, Doris Ulosovich, Joan Seifert, Connie Higgs, Valerie Fulton, Philip White, Brenda Goodman, Joyce Thompson, Catherine Healy, Kristin McFeters, Nancy Hamm, Melissa Krafft, Velda Peterson, Debbie Ramirez, Angela Riley, Heather Harwood, Galdys Larson, Jeanne Kirk, Pat Grodski/Team Ella, Mika Shelfer, Phil Kirschenmann, Sheri Sandstrom, Kim DiPaolo, Krystena Richards, Joy Cohen, Tina Engelson, Beverly Isgett, Taryn Paladiy, Debbie Stacy, Holly Brown, Marilyn Colon, Debra Kettleson, Rebecca Sommer, Kelli Dietrich, Shannon Hurley, Nathalie Matthews, Wendy Barrett, Heather McAvoy, Joseph Pagano.

**Professional Donations:** Sigma-Tau Pharmaceuticals, Inc. (makers of Carnitor®); Random House Bertelsmann, as a corporate matching gift to the Tuttle Family's donation. Chuck Hehmeyer. We greatly appreciate donations to help with general daily costs, website fees, 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.**

## 2007 Financial Standing for the FOD Group

*[before our accountant has completed her report for 2007 tax forms]*

**FOD General Fund - \$30,529.24**  
**FOD Clinical Fund - \$ 1,592.42**  
**FOD Research Fund - \$3,106.06**  
**FOD Petty Cash Fund - \$ 89.04**

**Total Assets \$35,316.76**  
**Total Expenses/Conf \$11,800.90**

**[on 1/3/08 I transferred \$15,000 from an anonymous donor from our Gen Fund to the Research Fund]**

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. Once the Research and Clinical Funds reach a substantial amount, we will be able to offer grants to clinicians and researchers in the US.



Thank you to Erika Wallace - erikawallacepa@yahoo.com (Mailing Lists), Mary Lingle - Mcartwrite@aol.com (Web Page) and Brian Gould - gouldbr1@msu.edu (newsletter) for all your hard work. Special thanks to Sigma-Tau Pharmaceuticals, Inc. for their continued financial support.



## Reminders

**Families** - Please send **TYPED (preferably in word document)** stories by **July 10, 2008**. 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 **July 10, 2008**. 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.

**'You will find as you look back upon your life that the moments when you have truly lived are the moments when you have done things in the spirit of love.'**

~ Henry Drummond



## Communicate With Us

*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 **ADD** me to your mailing list  
 Family Professional (please circle one)  
 Name/Address or Address Correction (circle one)

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

---



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Please include ideas for future issues or your questions