FOD Support
fatty oxidation disorder communication network
FOD™ All in This Together™
Fatty Oxidation Disorders Family Support Group

In this Issue

The FOD Communication Network Newsletter was created by and is currently edited by Deb and Dan Gould,
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From the Editor

Even though I publicly thanked Dr Roe and the Institute of Metabolic Disease, Baylor HealthCare System for hosting and being a major sponsor for our FOD/OAA National Metabolic Conference, I wanted to acknowledge them again in our newsletter so ALL would see! Thank you to ALL of our Sponsors and Vendors (posted on our site, right sidebar). The **FOD Family Support Group** had a wonderful turnout (FOD 55, OAA 50 members) for our 2006 Conference in Dallas, June 23-24 in conjunction with the **Organic Acidemia Association** (www.oaanews.org). Thank you to Kathy Stagni, Director of the OAA, for being such a GREAT partner in planning for this year's event ~ our first by ourselves! Thank you also to all of our speakers: Drs Roe, Marriage, Sloan, Gibson, Rhead, Siskin, Kahler and Therrell and (adult MCAD) Rodney Porter for helping with the Professional/Adult FOD Panel. We learned A LOT and were able to network with other Families ~ and some even had time to 'play' at Gilley's!

All of our Speakers' talks (in PDF) will be on our website, right sidebar SOON! We will also have a Gallery of Pictures available ~ those that could not attend will see what they missed and maybe plan for our NEXT Conference in 2 years **IF** we can find a major sponsor, like the Institute was for us this year!

I also want to thank Eileen Shank (MCAD mom, mgeshank@comcast.net) for helping us negotiate rates/food etc at the Adam's Mark Hotel ~ that was a HUGE task and we greatly appreciated Eileen's expertise! Thank you, Kelly Madej (VLCAD parent, yadmad@sbcglobal.net) for sharing your beautifully made awareness bracelets with her daughter Kayla (VLCAD teen) ~ half of her proceeds were donated to the FOD Group! Kelly also made Emergency Care Notebooks for our Families and shared the extras with OAA members. It's a nice organizing tool for keeping track of Dr visits, business cards, protocols etc.

As part of each FOD registrant's registration fee, he/she received an FOD T-shirt. Because of popular demand (and because we ordered extras) we are offering the opportunity to have your very own!

Wearing your FOD T-shirt will also create Awareness of our Group, the various Disorders, and our Advocacy efforts for Expanded Newborn Screening, Follow-up Treatment, Formula Legislation, and Educating and Encouraging New Drs to Practice Metabolism/Genetics. ~ so wear it proudly! For now, I am taking orders via email and once we make our final move to MI we will put a PayPal credit card link on our website. Each Yellow Adult Unisex 50/50 Hanes t-shirt (size small to 2x large) with our royal blue logo on the left side is $10.00. Postage will vary depending on the number and weight of shirts and where they will be mailed. Please email me your order at deb@fodsupport.org and then I will let you know the postage so you can mail me a NON-tax deductible check (US funds). We will be in NC until AUGUST 15th and then we will be at our MI address (see newsletter letterhead for that address).

I have made some new Brochures and Business Cards with our new address and if any Professionals would like some, please email me and I would be glad to mail you some for your office/clinic.

Make sure to read about a Short-Term Research Survey on FOD Carriers ~ it will only be available online until Sept 2006. The info is in this issue and on our Medical Information page on the website.

Thank you 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, SCHAD, Carnitine Acylcarnitine Translocase, 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 (in pdf form). **Whether you're a Family or a Professional, we are all striving to create awareness, education, screening and diagnosis, clinical treatment, and research ~ by sharing your story or your expertise…**

'We Are All in This Together!'

Take care… DLG

Letter from the Editor

Imparting 'wisdom' in the midst of blatant arrogance!

This past winter, my 20-yr-old son, Kevin (MCAD, diagnosed at birth), had one of the most horrendous experiences in his life. Even though there were positive things (Kevin survived!) that came out of this story it was and is very disheartening to learn that after dealing with MCAD for 20 years, we still run in to a few professionals that THINK they know better than my son and what his Emergency Protocol from his FOD Specialist states!

Being the 1st state to mandate expanded NBS, you would think that health professionals in NC would have some idea of the disorders that are mandated. We were both totally amazed that we are STILL running into arrogance, ignorance, and patriarchal behavior on the part of some medical professionals ~ ALL at the expense of my son's health! To say the least, we did file a medical complaint with the State Medical Board in March (however, we are still waiting on the results).

To make a long story short, Kevin came home from college to have his wisdom teeth removed. As you all know, having surgery is a stress on a person with an FOD and special precautions MUST be taken. So pre-surgery, we discussed his Protocol with his surgeon and anesthesiologist – also giving each Kevin's written protocol. The surgeon 'GOT IT' (meaning he understood) but the other Dr DIDN'T ~ BIG TIME! We told both that the 10% dextrose IV MUST BE USED BEFORE, DURING, and AFTER SURGERY in order to keep his blood glucose levels above 100 to avoid a metabolic crisis.

Again, to make this short, even as Kevin was being wheeled into the operating room he INSISTED that he was supposed to have the 10% dextrose and NOT 5% ~ the Dr (handling the anesthesia and IVs) told him that 5% should be "sufficient for this situation." It was our conclusion that this Dr was basing his decision on what diabetics have used during surgery ~ MCAD IS NOT DIABETES! This Dr had NEVER treated someone with MCAD and totally dismissed Kevin, who IS an adult, as well as his MCAD Specialist's Protocol (which we have used for 20 years!).

This situation is also a lesson in NOT GOING BY BLOOD SUGAR ALONE to determine state of metabolic crisis. Kevin's glucose was supposed to stay above 100 ~ he came out of surgery at @76 and he FELT LIKE HE WAS DYING physically (nausea, vomiting, total body aches, shaking, headache, etc) and emotionally! Of course, the 'normal' low blood sugar level is considered to be @50 ~ but I believe and I know many of you Families that have unfortunately been there too, KNOW those with FODs can't always go by that. Under stress, Kevin's protocol states in BOLD letters that he is to be maintained over 100 and he actually does better at 110-120.

Additionally, despite seeing how Kevin reacted to this surgery, they were NOT going to admit him ~ it took 3 CALLS to his specialist (out-of-state) to FINALLY get them to admit him to the ICU. And once he was put on the 10% dextrose IV for a day he 'turned around' and felt good enough to go home and finish recovering. To say he least he wanted to get out of there ASAP!

To our knowledge, Kevin survived this experience with no major complications ~ HE WAS LUCKY! Some of our kids and adults aren't! This also happens all too often in our ERs across the world ~ and we need to address that by continuing to EDUCATE, EDUCATE, EDUCATE!

This situation should NEVER have happened! Patients, no matter what their special circumstances may be, NEED to be assured that established written medical protocols will be followed and that something like this will NEVER happen again. We have a LONG way to go in educating Professionals about FODs ~ but it CAN be done!

[Please also be sure to read Dawn Lobell's (formerly Dougherty) article about educating medical students in the Medical Update section.]

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Family Stories

Stephen's Story ~ TFP

In Nov 2001 we were delighted to welcome a fourth child into our family. After three girls we finally had a boy. Prior to birth unusual things noted were an abnormal quad screen, indicating our child may have Down's syndrome. I also had very low amniotic fluid by the 12th week, and worked very hard to increase and maintain it. We chose to forgo amniocentesis because with only a 10% chance of problems, we felt we could deal with them at birth. Plus, it seemed a little risky due to the low amniotic fluid issues. Stephen's birth was difficult. He had a hard time turning his head to line up correctly, and pulse went down with hard pushing. Excellent doctors helped us ease him into the world. He appeared to be a healthy, full term, 9 lb 2 oz boy.

Stephen had a good apgar score but was very sleepy. Unlike our daughters, he seemed too tired to nurse in the initial hours. But everything seemed all right. Exhausted after laboring all night, I turned him over to the nurses so I could rest a little before facing the challenges of parenting. During the next 24 hours Stephen was still unable to eat much (now I recognize the lethargy) and had a low blood sugar of 24. Everyone wondered if I had gestational diabetes (I didn't), and passed this off to his being a large baby. Our excellent pediatrician ordered glucose/water. The lactation nurse wasn't too happy about that, and met with me to set up pumping and a supplemental nursing system (SNS) that would not take so much effort on Stephen's part.

In hindsight, both approaches were desperately needed and correct. I was to feed Stephen every 2 hours during the first 48 hours, pumping what little milk I had before milk coming in, supplementing with formula, nursing with the SNS, and snatching 20 minutes of sleep when I could. Nurses checked his blood sugar every few hours to make sure he was responding. It seemed to work, although I remember a panic stricken morning a day after returning home, feeling that Stephen was lethargic and therefore must be hypoglycemic again. I rushed back to the mother/baby unit and begged them to check one more time. Blood sugar was fine; my fears were eased. I pumped and nursed using the SNS for about a month until Stephen had enough strength to nurse on his own.

At the 2 weeks checkup the nurse commented that Stephen's tone seemed a little low in the neck area. He appeared to have torticollis. We chalked this off to the difficult birth and kept watching. Stephen was a high maintenance baby. He wanted to eat frequently and to be held and comforted most of the time. But his weight and height were absolutely normal. By about three months I was supplementing with rice cereal to help meet his growing appetite. He had more bowel movements than any child I've known, usually 5-7 daily, but did not appear to have diarrhea. He had a lot of projectile spitting but did not appear to be vomiting. He tired easily, and was a little delayed in gross motor skills. We explained away unusual things as those that would go away with time, and tried to not worry. After all, he was our fourth child; we were experienced parents of three girls who understood that we didn't have to stress about every little thing. We just tucked Stephen under our arm and hit the ground running every morning.

By about month five, concern was growing. Our pediatrician agreed to have him evaluated at the local Children's Therapy Center. They identified gross motor skill delays of unknown origin and did a few sessions of therapy. By 8 months he would quickly spit up all foods offered except baby rice cereal, sweet potatoes, and yams (all starchy complex carbs, interestingly enough.) I was just starting to supplement the cereal with Similac rather than breast milk. He was unable to suck from a bottle or any sippy cup that required any amount of oral-motor strength & coordination. He hated lying on his tummy, never rolled over, and although he could sit at approximately the right age, he could not get himself into a sitting position and required some support to stay there. Holding him was like holding a bag of potatoes. He never used his legs to help support himself. We hoped Stephen was just following his own timetable. We planned to start therapy in earnest when we returned from a family reunion/vacation.

We traveled 900 miles by car to a lake in the high desert (7000 ft. above our accustomed Seattle area home) for our vacation. Routines were interrupted, we were distracted, and while we were visiting with family Stephen seemed even less energetic than usual. It was hot and dry. We **all** felt a little limp. Just prior to our return trip home, both Stephen and I came down with a cold virus with fever. Five hundred miles from home Stephen began throwing up. We decided to keep going and be sick at home in our own beds. Three hours after throwing up, Stephen became very limp in his car seat. Concerned, I took him out and lay him on a pillow. He seemed very ill, began rolling his eyes back in his head, and twitching. We broke all the speed limits and headed for the closest emergency room, about 40 miles away.

At the emergency room in LeGrande, Oregon, a team of nurses worked for a good 20-30 minutes to get an IV in. Finally a scalp IV was established. Examination and x-ray showed no ear infection, no lung problem. When permission was sought to do a spinal tap I remember thinking, is this really necessary? I was still in denial that something serious could actually be wrong. Spinal tap was negative. Blood glucose was not too bad at 58. Conclusions were that he was severely dehydrated and had high white counts due to unknown origin. IV rehydration with D5 and two IV doses of antibiotic perked Stephen up enough to convince everyone he could weather the trip home to Seattle and was to check in with his pediatrician the next day.

Stephen woke for his usual 5:30am nursing, and then slept on and on as I rushed around getting other kids dressed for their day. At 9:15am, as I was carrying him across the parking lot to the Dr's Office, I could feel him going limp once again. When I could not rouse Stephen in the waiting room the nursesrushed us back to a room. He began twitching again. The pediatrician happened to be familiar with liver disease and immediately recognized a very large and hard liver upon examination, 3 cm below the right coastal margin. (How could the other doctors have missed it?) He sent us immediately to Children's Hospital. Reality was beginning to set in.

TFP...cont'd

We tearfully told the story over and over to nurses, residents, fellows, and different doctors. More tests: CT scan, all kinds of blood tests. Things that caught attention were large liver, developmental delay, severe axial hypotonia, altered mental status, increased liver enzymes, bicarb of 17, and high lactate level of 8.8. Glucose was 60 at admission. More tests ordered: EEG, MRI, blood work-ups, urine organic acids. By the next morning Stephen had episodes of hypoglycemia, hypotension, and temperature instability. He was very puffy, extremities were cold; he was sent to ICU where he was warmed, received a blood transfusion and dopamine drip due to low blood pressures. We were petrified. EEG revealed slowing consistent with encephalopathy. EchoCardiogram appeared normal. Urine organic acids suggested long chain fatty acid metabolism defect. Acylcarnitine profile confirmed suspected LCHAD. The new words made our heads spin. My husband and I were ecstatic when told it was treatable. He began a low long-chain fatty acid diet of Portagen plus Polycose alternating with breast-feeding. Carnitine supplementation began.

Initially, things seemed to be going well, despite a femoral blood clot from a pic-line. But we were at the beginning of a roller coaster ride. Every day seemed like a week and a different ride.

Day 5: Stephen was having a hard time keeping things down, NG tube inserted; fever began again, more problems with vomiting. The tube was changed to ND.

Day 6: He was breathing increasingly faster and seemed hollow-eyed. It took two days of increasingly worse symptoms to convince the doctors that the normal LCHAD treatment was not going to be enough.

Day 8: Stephen was transferred to PICU once again and placed on beta blockers. We struggled to understand how bad things were.

Day 10: Stephen's right lung collapsed, filled with fluid. Emergency ventilation. Fever raging with pneumonia. Reality that we may lose Stephen hit like a brick wall.

Day 11: O2 needs exceeded what normal ventilation could provide; switched to high frequency ocillatory ventilation to avoid lung damage if possible. Things happening so fast.

Day 12: Left lung failing. Air leaking into the space between lungs and heart. Stephen is puffy and obviously uncomfortable.

Day 13: Emergency Care Conference called. The conference room filled with surgeons, genetics, neurology, cardiology, PICU attendings, nurses, counselor, and hospital ethics personnel. We felt the gravity of the meeting. We were given the facts (heart/lung failure) and the choice to either try ECMO, a type of heart-lung bypass involving surgery, or to discontinue all support and spend our final moments together in a quiet room. I ached to hold my son, and had been denied that privilege for four days. We did not want to prolong obvious suffering. We had one hour to decide. While my husband and I prayed and talked it over with each other, PICU prepared for either decision. Because brain functions were still intact, we could not let him go without giving him every chance. We said our goodbyes to him before clearing out of the room being transformed into a surgical unit. His skin was tight and swollen with air leaking into all tissues. Tiny tears trickled down the sides of Stephen's face, though he was sedated beyond awareness. We put Stephen in God's hands, with many prayers for the surgeons and caretakers. Every hour seems like a day; we hung onto life hour by hour.

Day 15: A pic-line removed due to swelling and probable blood clot, making both left arm and left leg off limits for lines.

Day 16: Good news of the day was that he was able tolerate a little more nutrition in the ND tube. Previously Portagen was diluted with Pedialyte 50/50, delivered at 5cc/hour. That's 1 teaspoon! Today he was up to 75/25 Portagen and 10cc/hr. He's been kept alive with hyperalimentation (IV food) minus the lipids (fats.)

Day 17: PICU attending tried something radical. Surfactant therapy, normally used in premies with underdeveloped lungs, not known to be especially helpful in 8-month olds. Within an hour Stephen's lungs were doubling the oxygen delivered and began re-inflating.

Day 18: Another dose of surfactant. Impressive response, as lungs expand to hold more air.

Day 21: OFF ECMO, back on oscillator. I was thrilled and terrified, knowing Stephen could never go back on ECMO.

Day 22: Put on regular ventilator.

Day 23: A setback. Stephen starts spiraling downward again, respiratory failure status and is put back on oscillator. We prepare for the worst and sign a DNR.

Day 24: I'm told this is the worst case/most stubborn case of pneumonia the PICU doctors have ever seen. Stephen cuts a new tooth, about the fourth one since admittance. He is teething like crazy in addition to all the insult to his body!

Day 28: Enough improvement to go back to regular ventilation. This time they eased him down to it in micro baby steps. Stephen is a fighter.

Day 30: Stephen's 9-month birthday. We celebrated in party fashion, grateful for the opportunity to have Stephen up to that point. The best part of the day was the nurses let Val and I hold Stephen, ventilator tubes and all. As a team lifted him into our arms we both cried and cried. It had been three weeks since we had the privilege. Stephen was still sedated out of his mind, but he had less of the paralytic drug, and was "with it" enough to pull the hairs on Val's arm. Rather than restricting visitors to two in the room, the staff allowed our three girls to be there with us. Bless them! We rescinded the DNR.

Day 32: We were able to hold Stephen again. This time he looked us right in the eye and gave us the best smile possible with a piece of tape on his upper lip holding the respirator tube in place. He kicked his leg like he does when he is happy. It was a great experience! He looked very good and puffiness from retaining fluid is gone.

TFP...cont'd

Day 34: Finally off the ventilator! On less sedation and much more aware of his misery. It tugs on one's heart strings to see his discomfort. When he cries, no sound comes out because his throat is so sore. Hacking cough, which is a good thing, we are told.
Day 36: The last IV line was removed. He is taking full feeds through the ND tube.
Day 37: I can hardly believe this is the same kid. Stephen is able to sit with support, holding his head with own power. Able to clap, smile, flirt with the nurses. He really hates the nasal oxygen tube and feeding tube, and manages to hook his finger under it and pull at often as possible.
Day 39: Val was holding Stephen, but I was close by and we were both interacting with Stephen. Stephen reached up for my face so he could maul it with his hands, trying to pull my nose, ears, and hair off, and said MA! Val insists he really meant DA! But I know the truth. We were in heaven. It is the first time we have heard his voice in a month.

After approximately three more weeks of recovery, including g-tube placement, Stephen came home, thankfully without need for additional oxygen. Total hospital time: 9 weeks. Just prior to his release, we were informed that the gene sequencing report had officially changed Stephen's diagnosis to Trifunctional Protein Deficiency; he was deficient in LKAT enzyme in addition to LCHAD.

Stephen is now a handsome, bright, and rambunctious preschooler who will be five in November. He dreams of being an astronaut or a doctor, makes "deals" with us all the time to try and get what he wants, and teases his sisters mercilessly. He has more energy than all of us on most days. He has recovered completely from the heart and lung trauma and from most of the developmental delays.

Stephen still works a little to be understood when he speaks, but that does not stop him from speaking...rather, he just gets frustrated with the rest of us. He is slightly weak in the trunk, but that doesn't stop him from doing anything he really wants to do. And he has a little vision loss in one eye due to retinal damage, but he compensates beautifully, fooling even me until he failed a vision test at 4 years. He began reading phonetically when he was 4 years, 2 months old, earlier than even our girls.

He continues his low fat (10-15% long chain), high carb diet with Portagen, MCT oil supplementation, Carnitine and anti-oxidant vitamin therapy. He eats pretty normally, within the limits of his diet, and knows to ask if the food or treat is "Stephen friendly." At night we connect his g-tube to a pump to deliver a nighttime and middle of the night dose of formula, although at this point he can fast for up to 9 ½ hours with no ill effects at night.

With all the factors involved in a child's well being and ability to survive, it seems completely unfair for anyone to say that LCHAD ***OR*** Trifunctional Protein Deficiency (TFP) is not effectively treatable. Doctors do not truly know which child will respond to treatment until the situation has played out. How can Stephen have TFP and seem so normal at age 4 ½ when the data all suggests another outcome? It is because doctors, therapists, and parents gave him a chance by not giving up. It seems Stephen is one who truly does do well on the regimen. No one knew at the beginning, or even dared to hope. He has done as well or better than any LCHAD (generally considered less severe) child who has found effective treatment. We all worked and worked and worked during the first four years of his life to ride the roller coaster and begin the marathon. Our insurance company has paid around a half of a million dollars to support the effort. We had a good chance of ending up with a brain-damaged child, or no child at all, and we accepted that responsibility when we said "ECMO." But the reality is that Stephen is now a bright child with the same hopes and dreams of any child. He has a future full of opportunity.

We are unfortunate to live in a state that does not screen for all 29 American College of Medical Genetics (ACMG) recommended metabolic disorders (only 9.) But we are fortunate to live in an area with an excellent Children's Hospital staffed with experienced doctors. And we are hopeful that Washington State will soon move beyond the discussion stage and begin screening for LCHAD and TFP.

I would think the insurance companies would be BEGGING every state to do the $40 screen and prevent costly crisis and recovery. I would think the states themselves would recognize that the kids who have LCHAD and TFP are beginning to survive despite lack of screening, due to increased awareness and better ICU doctors. And that these children who survive likely WILL end up in an intensive care unit somewhere, with parents and doctors searching for answers as quickly as they can. Would the states that do not screen tell the doctors to quit saving these kids? I think not! Yet they somehow think it is better not to jump into screening disorders that they believe (according to existing data) are not treatable. Although our state seems hesitant to screen without a full infrastructure in place for the "what-ifs," the hospitals are committed to treating whoever comes in the door, regardless of ability to pay, and are committed to saving lives.

I took the time to write this story to offer proof that there are TREATABLE cases of TFP, and to suggest that the burden of decision whether or not each case of a metabolic disorder is treatable lies with the individual patient's doctor and parents, not in a board meeting. Does the state have an obligation to provide full local support if they screen? I would have been happy to just have a direction, a list of professionals who had experience, whether out of state or not. Every state can hardly be expected to immediately have professionals on hand with years of experience. I hope our story will find its way to any state debating the benefits of screening for LCHAD and TFP.

Diane (and Val) Nielsen
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LCHAD Email Network and New LCHAD website

Valerie Fulton (Adam, LCHAD, http://adamslchad.com) is email networking many of our LCHAD Families, just as Gina is doing with VLCAD.
If you'd like to become a part of her email network
contact Valerie at vallchadmom@yahoo.com

Family Stories Christopher's Story, CPT 1, UK

♥♥♥ *This heart-wrenching story is the reason Expanded Newborn Screening and EARLY Treatment are needed AROUND the world! DLG* ♥♥♥

Our son was born in 1991 and he became ill after forty hours. Before he went into a coma we noticed that he was jittery and informed the doctors who tested his blood sugars twice and both times were low. The doctors did nothing about it. Christopher became very ill and nearly died and was left with brain damage, but no answer as to why this happened. The doctors informed us that as Christopher grew up, he would not walk, feed himself or communicate ~ well he's done all of that!

He grew up to become a cheeky teenager who lives life to the fullest. However, a year ago he became ill over night and went into our local hospital. He was getting really sick and became very irate and seemed to be under physical stress. His last words to the doctors were an obscenity!

The doctors did not listen to us about moving him to a larger hospital on the first day of his illness. The next thing we knew he was dying in front of us. He had three seizures and his oxygen levels were going down and his lung collapsed.

He was transferred to another hospital and when we got there, they informed us that he would die if the swelling in his brain would not stop. He had ammonia levels of 644. These levels were not coming down and they had to filter his blood three times.

He was on a life support for 14 days. Then he just opened his eyes very slowly, but he did not move for another month. He was in a catabolic state. The Doctors informed us that he had a urea cycle defect, which was not true, and the only way we would find out would be to have a liver biopsy, which is also not true. It was done via a simple blood test. We found out about this test and informed the doctors. We felt as if we were doing their job!

For four months he was not getting any better and was going back into the same state. We were then transferred to a London hospital and within two weeks we knew that it was not a urea cycle defect. CPT1 was the diagnosed eight weeks later.

Our life had been changed forever more ~ we had lost a character that was full of life. We have had to battle every step of the way during his stay in hospital and we are still battling the system for him.

We have little faith in our doctors because they have not treated anyone with this condition. We give him cornflower at night before bed and maxijul drink during the day. He loses magnesium and we give him supplements for this. He also suffers from seizures. He has lost his mobility, feeding skills, continence and communication skills. We have three younger children and we are really afraid and worried that they might have the condition.

Are any of you a part of Dr Roe's C7 oil research in Dallas? We would need to fly to Dallas and stay for two weeks, but this will cost a lot and we are trying to see if any airline will help us with free tickets.

What sort of treatment is your child on? We would love to hear from you! We now know that we are not alone in this world ~ we are in the UK!

Kind regards and take care,
Adrian, Valeria, Christopher age 15, Alex age 6, Stephen age 4, and David
adrian@varney998.fsnet.co.uk

♥ ♥ ♥

Deb's NEW ADDRESS as of August 15th, 2006

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Medical Update

Educating Medical Students

My daughter Jordan (13, VLCAD) and I have participated in several lectures to medical students given by Jordan's metabolic specialist, Dr. Richard Kelley. I want to share with everyone what a wonderful experience it has been for both of us!

Dr. Kelley is the Director of the Clinical Mass Spectrometry Laboratory at the Kennedy Krieger Institute in Baltimore. He is also an Associate Professor of Pediatrics at the Johns Hopkins School of Medicine. Every year, he gives a lecture to first year medical students on the fatty acid oxidation process. We've attended the lecture several times over the past ten years (I've learned a lot, even though it's pretty technical and at times over my layperson's head!). Dr. Kelley explains the chemistry involved in fatty acid oxidation, and then talks about the various fatty acid oxidation defects – in other words, what can go wrong in the process.

After the lecture, he asks me to talk about what happened when Jordan had her metabolic crisis (she was diagnosed at 17 months after coming down with her first stomach flu). So I explained how Jordan had been sick with the flu. She had diarrhea but no fever, and seemed lethargic. In the middle of the night I noticed that she had "stopped breathing" so I called 911 and they rushed her to the hospital. At the time I had no idea that what she was experiencing was a hypoglycemic seizure. Dr. Kelley asks me to describe what happened to Jordan, and then relates what happened when Jordan was taken to the hospital. They started an IV immediately, and took blood. He tells them what her various blood tests showed. Her glucose level was 16 and her liver was enlarged – but they had no idea what was wrong with her. They ran some more tests, then she was transferred to another hospital where they took more blood and urine samples. She was in intensive care and she almost didn't make it through the first night. Dr. Kelley then explains to the students that several days later a resident noticed that there were no ketones present in Jordan's urine…a sign of a possible fatty acid oxidation defect. Thankfully the resident had trained with Dr. Kelley, and she sent Jordan's lab work to Kennedy Krieger. Dr. Kelley came to the hospital to tell me that he was pretty sure that she had VLCAD (later confirmed by a biopsy).

In the past, Dr. Kelley has invited another patient to participate in the lecture. "John" (not his real name) was diagnosed with MCAD after suffering a metabolic crisis similar to Jordan's. Unfortunately, John's parents didn't discover that anything was wrong until they went in to wake him up in the morning. He was in a coma, and as a result suffered severe brain damage. He couldn't walk or talk, and they had to put him in a long-term care facility. John's grandmother brought him to the lecture every year. Sadly, I recently learned that John died this year. Dr. Kelley (with John's family's blessing) included John in the lecture to point out the differences between an FOD patient who received treatment in time, and one who didn't. It underscores the importance of a proper diagnosis and treatment, and Dr. Kelley and I both use the lecture to stress the importance of newborn screening. It will be difficult to attend the lecture this year without John, but I understand that his grandmother will probably still come to tell his story.

Jordan had some very mild brain damage as a result of the seizures – she has ADHD and some additional problems with her executive functions, but otherwise she's fine and looks like any other 13 year old. She is in a regular education program in school and has been in good health. For the past few years, Jordan has answered questions from Dr. Kelley directly about what it's like to have VLCAD – how it affects her physically, and in school. We both talk about her diet, and about our protocol letter. Jordan's pretty good at answering in front of a full lecture hall! I think that it really makes her feel good to be the center of attention. The students ask her questions after the lecture – she knows that she is helping them to understand her disorder, which makes her feel really important. I know that it helps her self-esteem.

After the lecture we usually have several students come up to us with questions, and I always walk away feeling like I have contributed to the body of knowledge about FODs. I can imagine that these very students will one day be in an emergency room treating one of "our" kids, and it feels good to be able to "educate" a doctor! I believe that putting a human face to the dry lecture about chemistry really makes an impact, and I have had several students tell me that it really helped to have us there. Hopefully it will help everyone – it is a rewarding feeling. I would encourage anyone with the opportunity to participate in a program like this to do so.

Please contact me at dawnd39@comcast.net if you have any questions.

Dawn Lobell (formerly Dougherty), Ellicott City, MD

♥ ♥ ♥

VLCAD Email Network

Gina (Brett, VLCAD) has started an FOD subgroup E List for VLCAD families. If you are interested in **networking with other VLCAD families around the world please email Gina at** ginamjb@optonline.net or call her at (845) 928-9574.

Medical Update...cont'd

Research Survey: Fatty Acid Oxidation Family Questionnaire

This survey is intended to take a **comprehensive look at symptoms in patients (both children and adults) and their family members.** Some may be aware that Dr. Jamal Ibdah's mouse model of Trifunctional protein (TFP) deficiency revealed liver changes in the 'unaffected' carrier mice that resemble those observed in type II diabetes.

Furthermore, in a mouse model of carnitine deficiency Dr. Prem Shekhawat observed that some mice develop gastrointestinal findings resembling inflammatory bowel disease. As readers of the FOD List emails, we also noted the occasional reports of parents who experience symptoms that are supposedly unrelated to them being carriers of the FAO disorder their children are affected with. We hope that **this survey, if completed by as many individuals as possible, will help us to further our understanding of FAO disorders in affected patients and carriers with the ultimate goal to improve prevention and treatment.**

The first part of the questionnaire asks questions about the individual affected with a specific FAO disorder. We have then included questions about children of that individual (if applicable), their parents, siblings, grandparents, aunts & uncles, nieces & nephews, and cousins. We have provided ample space for those who have additional symptoms not listed as well as specific areas for those who may have been diagnosed with additional conditions.

I have included the survey below (it is also on the FOD website, yellow box on the right sidebar). You may forward this email (and/or the attached Word document) to the FOD Family Support Group mail list or others that you may feel would be interested. Questions may be forwarded to my email at merritt.lawrence@mayo.edu.

<<FAO Survey Invitation.doc>>

http://survey.venturecs.net/faodisorder.htm

This **survey will be available** for completion for the next 3 months (**through September 2006**)

Thank you very much for your interest and support of this survey,

J. Lawrence Merritt, II, M.D.
Dietrich Matern, M.D.
Mayo Clinic College of Medicine
Rochester, MN, USA
Tel (507) 538-1581

• • •

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!

Also take a look at our homepage where **Dr Brad Therrell's 2006 Conference presentation** slides will be posted soon. He did a wonderful job presenting the status of Expanded Newborn Screening around the world!

Nutrition Update

Be sure to check out our 2006 FOD/OAA National Metabolic Conference Speaker Presentations on our website's homepage. We have all of our Speakers' slides from their talks. As for Nutrition, Dr Barb Marriage, of Ross Metabolics, shared her expertise not only during her one-hour presentation, but also during a Professional/Adult FOD Q & A Panel at the end of our 1st day. Please refer to our homepage to learn more about 'Chewing the Fat on the Nutritional Management of FODs.'

MCT Oil was purchased by Novartis Medical Health, Inc from Mead Johnson & Company effective Feb 13, 2004. MCT Oil is a modular source of Medium Chain Triglycerides for patients unable to digest or absorb conventional fats. You should consult your Dr on the use of this product. Refer to **http://www.novartisnutrition.com/us/productDetail?id=593&source=summary** for further information.

Some of our Families have found an **alternate MCT oil** through Health & Sport. It is **100% MCT Oil** and is basically the same quality as the other Oil. It is less expensive (it costs about $17.00 for a 33.8 oz bottle). To order, refer to their website on the link **http://www.health-n-sport.com/energy/mct_gold_medium_chain_triglyceride_oil_1_liter_33_8_fl_oz.htm**

Recipe

Fruity Slush

1 frozen orange juice
1 frozen lemonade
1 10oz frozen strawberries
4 10oz maraschino cherries (if I had my druthers, I'd leave these out, but they are the favorite of others...so in order to get them frozen throughout and not all at the bottom, mix this and freeze a bit at a time.)
20 oz crushed pineapple
2 bananas, mashed
2 Cups sugar.

Mix and freeze ~ enjoy! This Fruity Slush is a real hit for sore throats.

Deb Porter, wife of Rodney, MCAD 40
debwolfwoman@yahoo.com

Questions & Answers

Q: Can someone post a conversion of glucose levels used in UK versus what is used in the USA?

A: To convert from mmol/L scale (Aussies, Brits and most of the rest of the world) to the mg/dL scale (Americans and Canadians) multiply the low (mmol/L) value by the conversion factor of 18 (actually it's 17.96875, for those of you who are more compulsive).
Or divide the American mg/dL by the same number to get the mmol/L.
So: 4 mmol/L is 72 mg/dl; 6 mmol/L is 108 mg/dL etc.
Note that this conversion factor is specific for glucose - you need a different factor for other chemicals.

David A H Whiteman, MD
[Note from Deb: Hopefully Dr W will be back in clinical practice in the Boston area SOON! DLG]

Q: How is the dose of carnitine determined?

A: The dose of carnitine in metabolic disorders varies widely, depending on the condition and the ability of the patient to use it. About 85% of the carnitine given by mouth is NOT absorbed, and that fraction is used by gut bacteria. They can produce trimethylamine (TMA), the fish-odor substance, so when we smell the fish odor we know we've passed the limit of what we should be giving by mouth. There are various ways to alter gut bacteria, to lessen the amount of TMA being made. Also, there are some people who have a genetically-determined limitation on their ability to deal with TMA--they can have the fish odor no matter what they eat.
For many conditions 100 mg/kg/d is quite adequate--those of us who use carnitine in patients with MCAD deficiency typically use this amount. PA often requires much more. Many of us will double the oral dose of carnitine during times of illness. There are some patients with GA II who get 800! It should be spaced out throughout the day as evenly as possible, as big surges in the blood level of carnitine will cause more of it to be lost in the urine. Patients with the carnitine transporter defect require a huge intake of carnitine to get enough into their tissues.
When carnitine is used intravenously we also use a wide range--25 to 100 mg/kg/d, but some patients have needed much more than that.
It takes a long time to fill someone up with carnitine, especially their muscles, once the tissue levels get low. Some things can improve quickly, but it may take many months, or even longer, before improvements are complete. Cardiomyopathy due to carnitine depletion can be improved rapidly, for example, but it will be a long time before recovery is complete.
As for adverse neurological effects, these have been rare in my experience--I'm not sure I've seen anything convincing, but some parents have said their child became "spacey" or had seizures. I've seen the opposite--seizures subside and behavior improves--in children who were given carnitine because of a low plasma level not due to a nameable problem.

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

Q & A cont'd

Q: Has there ever been any research on using cornstarch as a slow-releasing carbohydrate in FODs?

A: Using cornstarch has only ever been researched in Glycogen Storage diseases and has never been studied in FODs. The research was done when Dr Roe was at Duke and it has been duplicated by just a few others. ARGO brand cornstarch is the one highest in amylopectin and it seems to hang around in the GI tract 6-8 hours IF there is no insulin secreted. That means it must be given in a sugar-free, uncooked drink (sugar-free Koolaid, Cyrstal lite etc...Not juice, milk etc). The major side-effect of too much cornstarch is severe constipation so it should be concentrated no more than 2 TBS in 4 oz and some kids may need more liquid to keep from getting very constipated. In general, preventing prolonged periods of fasting and prompt management of illness protects against hypoglycemia in children with FODs. Rarely, do children with FODs have severe, persistent enough hypoglycemia to routinely need cornstarch.
Hope that helps,

Lynne
Metabolic NP
lawpnp@mac.com

Pharmaceutical Update

If your Physician needs more information about L-carnitine (Carnitor®), dosages, or has other questions, please have him/her contact Sigma-Tau Pharmaceuticals, Inc., and ask for the Medical Information Department or state that he/she has a question about carnitine. This service is available around the clock 7 days a week. The phone number is 1-800-447-0169.

Within the last 2-3 years, a new L-carnitine (generic drug form) supplement has been approved for distribution by the FDA. Click on http://www.fda.gov/cder/ob/default.htm and it will list Approved Drugs and Therapeutic Levels of Equivalents. Please note that the generic levocarnitine liquid, tablet , and injectable drugs (as well as Carnitor®) need a Prescription from the Dr.

Please also note that **the generic DRUG form of L-carnitine is NOT the same as the over-the-counter carnitine supplements** often bought at healthfood stores ~ those products are **NOT regulated or approved by the FDA to be used for metabolic disorders** (read the article on our Pharmaceutical page for further information). The term 'generic form of a drug' should NOT be used interchangeably with the term 'over-the-counter supplement.'

▪ (Washington, DC, May 25, 2006) - Genetic Alliance announced today that it has published ³Understanding Genetics: A Guide for Patients and Health Professionals² in collaboration with the District of Columbia Department of Health (DC DOH). This comprehensive manual provides a wealth of genetic education materials for patients and health professionals for Washington area community-based healthcare clinics. It is designed to help patients and health professionals understand the place of genetics in health care. The straightforward and intuitive guide covers basic genetic concepts, complemented with in-depth information about diagnosing genetic conditions, newborn screening, family-history collection, genetic counseling and genetic testing. A section on local information focuses on patient care, patient and provider education, and genetic services in the Washington, DC area. The 120-page manual is published in print and electronic formats and is being distributed by the DC DOH Washington area healthcare clinics.

³This Guide is another critical step forward in achieving higher genetic literacy rates for both patients and their providers by bridging a gap in access to basic genetics information,² said Sharon Terry, MA, President & CEO of Genetic Alliance who served as Executive Editor for the guide. ³Genetic Alliance has a vision of a world where individuals affected by genetic disorders have all the resources they need to live fully," Terry said. "Information is a huge part of this and we were excited to work with the Department of Health to create and disseminate quality information for patients and health professionals in Washington, DC.²

Over the past few decades, advances in genetics and genomics have revolutionized the way we think about health. While genetics has traditionally been associated with pregnancy, birth defects, and newborn screening, every disease is influenced to a greater or lesser degree by an individual¹s genetic make-up. Therefore, it is important to consider the impact of genetics for any condition diagnosed throughout a patient¹s lifetime and in any community throughout the world. ³We are pleased to announce the availability of this guide because of its tremendous value in its ability to translate genetic information, which at first may appear complex, to both the general public and healthcare providers,² said Dr. Gregg A. Pane, MD, Director, DC Department of Health.

³This guide is exceptional because it was written for community-based healthcare centers in the Washington, DC metro area, but at the same time, the guide presents basic genetics information that can be accessed by providers at all levels, working with patients from any community.² said Sharon Terry.

▪ Doris Rapp wrote a wonderful book called ***Is This Your Child?*** ~ it describes how allergies can affect behavior.

Welcome to New Babies!

Kendra and Sam Habeb welcomed their new baby at 9pm on Feb 21, 2006. He was 21" long and 7lb 4oz. His name is Nicholas Shine Habeb. Nathan (GA2/MADD) and sister, Abigail, love their new brother.

Shelly and William Grabow have a new baby girl ~ Emily Grace arrived on March 20, 2006 at 1:37pm and weighed 10lbs 5.7ozs. She has lots of hair and is beautiful! She was welcomed by big brother, Caden, and is lovingly and 'heavenly' being watched over by Caleb and Noah (both TFP).

Love Messages

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

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

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 Gumiela
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 Mathhew 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 Cherryl 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, 1987 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

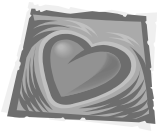
Denise and James Westman
Benjamin - Birth March 11, 1987 Death Dec 20, 1988
Beau - Birth July 10, 1991 Death Feb 19, 1995

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



"To love and be loved is to feel the sun from both sides."

~ David Viscott

Condolences

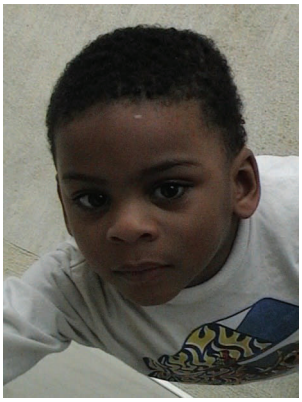
All of our FOD children will ALWAYS be with us in our hearts!

'DONATIONS'

'DONATIONS' ~ The **FOD Family Support Group is a family-based support group,** but we are **not** officially a non-profit organization at this time and **we do not actively solicit donations.** However, over the last several months, we have been asked by many of our family members how they can 'donate' to our Group (ie., for special gifts for our Families that are facing major life crises). We decided that the safest way to do that was to offer the PayPal option, in addition to the usual 'donation' by US check. It's important for us to tell you **if you choose to make a 'donation', it would not be tax-deductible.**

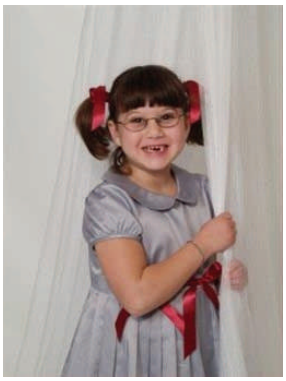
Thank you to all that have donated over the years so that we may continue to provide our support and information to Families and interested professionals at no charge. Your funding helps to cover copying and postage costs, webpage fees, phone calls to new FOD Families (US only at this time), and Conference costs ~ none are used for administrative salaries. **THANK YOU from ALL of us!**

Kids Korner



Lloyd B
(LCHAD)

Matias (CPT I) and brother,
Joonatan Sarvas, Finland



Ysabel J
(LCHAD)

Austen (GA2/MADD) and triplet siblings
Nathan, Sasha and Taylor Abele

Brett (VLCAD), Marcello (LCHAD),
and their nurse, Clare Kenny

Isabelle D
(MCAD)

Kayla M(VLCAD) and Rachel
G(VLCAD)

Family & Professional

Family Donations: Jill (SCAD) and Peter Fisch in honor of Matthew and Zachary (both SCAD) and Sara, ~ their donation helped us sponsor our 2006 Conference. Family of Wendy Thorson, Judy Posch, Garrett Barry, Marlan and Connie Johnson, Mr and Mrs Kim Brandner, Mr and Mrs James Evans, Mr and Mrs Rodney Porter, Nanette Gjesdahl, Mr and Mrs Dale Johnson, Mr and Mrs Lyle Krogstad, and Mr and Mrs John Sundvor in memory of Wendy Thorson (adult TFP). Gerry Lee Hogan in memory of her granddaughter, Kristen Marie Gould (undiagnosed MCAD) and in honor of her grandson, Kevin (MCAD, 20). Cindy and Kevin Wilt in honor of Zachary (MCAD). Thank you Kelly and Kayla (VLCAD) Madej for making your beautiful bracelets for the Conference, sharing part of the proceeds with our Group. Also thanks to all that bought the FOD Awareness bracelet and the FOD T-shirts.

Thank you to all that have bought products from companies on the Internet that support the iGive program of donating a certain percentage to Groups like ours. Please remember, however, that those **donations are NOT tax-deductible because we are not a nonprofit organization**. For more info on the iGive program, visit http://www.iGive.com/html/refer.cfm?causeid=24970.

Professional Donations: Sigma-Tau Pharmaceuticals, Inc. (makers of Carnitor®)

We greatly appreciate 'donations' to help with postage and copying costs, website fees, conference costs, and phone calls. **Checks can be made payable to FOD FAMILY SUPPORT GROUP**. Because we are not officially a non-profit organization, if you choose to donate, it is not tax deductible at this time.

Thank You

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.

Reminders

Families - Please send **TYPED (preferably in word document)** stories by **DEC 15, 2006** To be listed on the FAMILY LIST (refer to our website, Online Forms), please return the SIGNED Family Questionnaire or hand-write your information as seen on the current Family List and sign and date it. 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 **DEC 15, 2006**. 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.

'True independence and freedom can only exist in doing what's right.'

~ Brigham Young

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