From the Editor

Thanks to a very generous donation from an Illinois church, we are fortunate to bring this printed issue to you! However, as I mentioned in our January issue, there is still a possibility that we will be going strictly online due to increasing copying and mailing costs — but for now please enjoy all the important information and stories we have for you in this issue. PLEASE SAVE the Family and Professional Lists because we don’t know when we will have another update. We also hope all of our moms and dads had great Days back in May and June — we were thinking about ALL of you!

The May 4 and 5 Metabolic Conference in Ohio was a HUGE success! Since I was unable to attend I want to personally THANK Teresa Cornette (LCHAD mom) for being our FOD Representative as well as Kathy Stagni, Organic Acidemia Executive Director, for helping to organize Friday’s all day FOD session and for coordinating speakers and childcare for us. I also want to thank Trish Mullaley of the National Coalition for giving us the opportunity to participate and PerkinElmer for their generous donation that helped us with Conference expenses. Families gained a great deal from hearing Drs Roe, Cook, and Singh speak on various FOD treatment issues, as well as Dr Capehart on Special Ed issues and Mr Valenzano from Exceptional Parent magazine. Parents emailed several comments about the Conference and overall they were very positive (see below and page 14). Being our 1st conference we learned a few things that we can build on and make better for the next one. Trish Mullaley of the National Coalition for PKU and Allied Disorders is hoping to organize another conference to take place possibly in Oct 2002 in Minnesota so mark your calendars!

Thank you very much to Dr Susan Winter for sharing her knowledge about the supplementation of L-carnitine when dealing with various FODs and to Dr Charles Roe for sharing information about his latest research study with a new nutritional supplement for all of the FODs (except MCAD). He spoke on this topic at the Conference and several families were very interested and encouraged by the positive results for families already in the study. Professionals ~ PLEASE let me know if you’d like to share your knowledge and expertise. We can always use more information and research articles or ongoing FOD studies on our website as well.

Once again, several Families have shared their joy, as well as their grief, by telling their ‘story.’ We welcome ALL of your stories and we will try to either print them in the newsletter or place them on the Family Stories or Newborn Screening page on our site. Our site has gotten a lot of exposure since July 2, 2000 when our graphic website ‘premiered.’ We have crossed the 17,000 mark and still climbing ~ averaging @ 350-450 ‘hits’ per week! Keep getting the word out about FODs and Newborn Screening ~ more states are getting on board with expanded screening but there is still LOTS of work to be done!

One way that we can promote a discussion on expanded NBS is by wearing your very own FOD Family Support Group T-shirt! However, because of costs and other details, instead of ‘selling’ t-shirts, we are possibly going to offer iron-on transfers for our Logo and the NBS popup picture (as seen on our website) that you can iron onto your own t-shirt. If we can find a company that can produce those transfers we will place an order form on our website (‘Online Forms’) ~ so keep an eye out for it! Proudly wearing your T-shirt would definitely SHOW others that...

‘We Are All in This Together’!

Take care... DLG

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Letters to the Editor

Dear Deb: I just wanted to thank all the people responsible for planning and organizing the recent conference in Ohio. It was helpful and informative. I especially enjoyed the Friday FOD breakout sessions. Dr. Roe is incredible and his knowledge of FODs is so awesome. Yet, he is very sincere, genuine, and answers questions without getting so bogged down in medical terms that we parents don't understand. Dr. Cook was a joy to hear. He is an enthusiastic public speaker and obviously loves his job. He relayed some very valuable information regarding neurological effects associated with FODs. I was also very impressed with Mr. Joe Valenzano of Exceptional Parent. This organization has published useful information regarding universal newborn screening (in conjunction with Sigma-Tau) that can be used with advocating expanded NBS in our home states and the nation. I hope all 3 of these individuals will be invited to the next conference. I would like to extend a special thanks to the sponsors, contributors, and exhibitors that made the conference possible. Being able to attend and meet so many people working for common goals and sharing our related stories is something I will never forget.

Robin Haygood, Mississippi
Mom to Ben (2/19/98 ~ 8/8/2000) MCAD, postmortem diagnosis
rlbhaygood@hotmail.com

Dear Deb: I would like to thank everyone who organized the 1st conference for FOD Families and Professionals (and other disorders). A special thank you to Trish Mullaley, Teresa Cornette, and to you. Also, I would like to thank all of the professionals who gave of their time to speak with us. It was a real honor meeting Dr. Roe in person and listening to his lecture on the treatment of FODs. I gained valuable information from all the speakers ~ Dr. Singh, Dr. Roe, Dr Capehart, Dr. Cook, and Joe Valenzano. Everyone had the opportunity to have questions answered and share information with Dr. Roe, Dr. Cook and parents, during a group discussion. Many of us skipped the Saturday afternoon session and talked one on one with them. Dr. Cook and Dr. Roe also took the time to examine my daughter and look over her lab work. What an experience. I wish everyone could have attended.

Jenny Carroll
Prairie du Sac, WI

Welcome to new babies!

Rebekah (unaffected), daughter of Sharon and Tyler Fisher, and sister to Isabelle (LCHAD) on January 12, 2001

Samantha Mae (unaffected), daughter of Lori and Jeff Michaud, and sister to Jordan (unclassified FOD) and Amanda (unaffected) on April 2, 2001
Isabelle was born in July 1998, just four days short of our first wedding anniversary. I was ecstatic. I had the little girl I had always dreamed of. She was beautiful, as all babies are. I tried to breastfeed exclusively but failed in my attempts. I would find out later that the hospital had given Isa, as we call her, both bottled sugar water and formula because of low blood sugar. We were never told and went home thinking we had a perfectly healthy baby.

At Isa's two-week check-up she had failed to gain weight. The doctor told me to supplement with formula. We did and although she seemed to throw up more than she swallowed, she very slowly put on weight. When we asked the doctor about her slow weight gain he just told us that since she was still on the "chart" she was fine. We asked about her constant vomiting and were told that she probably had reflux. We asked about her episodes when she would shake after waking from sleep before she would eat. He said we were probably just over reacting.

Our doctor, tired of what he called our needless worry, did refer us to see a pediatrician since he was a general practitioner. At seven-months-old, we were told by the pediatrician that our daughter was failing to gain weight adequately because I was not feeding her properly. Frustrated I talked to a friend's mom who told me to take her to the emergency room at an Omaha hospital and tell them we wanted some answers.

Our answers came in the form of a gastrointestinal specialist who told us that Isa had reflux. They put her on a very expensive formula and said see you in six months. At that time they also discovered that Isa had C-Dificile, an intestinal infection caused by being on antibiotics in the past. We assumed that was our answer to all our questions and went on with our lives. We tried not to worry because we had what we thought was our answer.

Shortly before Easter of 1999, Isa began vomiting. Not that vomiting was abnormal for her but we just couldn't seem to get her to stop. I took her to the emergency room and they gave her a suppository and sent her home. Although they did run blood tests they failed to test her blood sugar at that time. The next day she was still vomiting intermittently so we took her to the doctor. Since it was our doctor's day off we saw another doctor who told us that she wasn't dehydrated enough yet to merit a hospital stay. He said to take her home and watch her for the rest of the day. If she wasn't better by 4pm we were to call and he would put her in the hospital to be dehydrated using IV's. We waited anxiously for 4 to roll around and when we called him, he hesitated but then finally agreed to admit her. When we got to the hospital admissions the doctor's office had not yet called them. We were probably in the admit area for over thirty minutes before they were finally able to get a hold of the doctor and get admit orders. Finally she was in the hospital and they would make her better, or so I thought.

Once we got to the room the nurses checked us in, gave Isa a hospital gown and left. Lab came about an hour later and took blood. We would only find out later that they once again failed to test her blood sugar. About two hours later the nurses came back and gave us a bottle of watered down Pedialyte to feed her. Finally at 5am the next morning they decided that she was ready for an IV. Because she was too dehydrated by that time it took them over 22 attempts to get the IV in. When they finally had it in it was in her ankle and they wedged her foot to a board to keep her ankle straight. She was very lethargic by that time and mainly just slept in mine, or my husband's arms. She stayed at that hospital until Thursday. I mentioned to the nurse that I thought that although she was able to keep some formula down she still seemed awful sick. The nurse agreed and called the doctor who I talked to on the phone. He told me that I was over reacting and that she was fine to go home. So, they sent her home even after she threw up on the nurse on the way out the door.

By the next morning she was so weak and barely able to suck on a bottle. I talked to our doctor's nurse and she told me, "don't worry so much, these things just take time." At noon I talked to the doctor who repeated the same message. At 4pm my husband called them and was told that we were probably stressing her out, since she was better in the hospital then she was at home. The nurse and doctor both recommended that we bring her to the hospital and let the nurses care for her for the night so we could go home and get some sleep. Of course I couldn't leave my baby so I kept her at home. By the next morning my beautiful little girl was unable to move on her own. She just lay wherever you put her. My husband and I knew that there was something seriously wrong so we put her in the car and drove the three hours to the hospital.

When we got there, they rushed her right in and did lab before we even saw a doctor. When they checked her blood sugar they found it to be 36 and within minutes her emergency room was flooded with nurses trying to get an IV in. We remained in the hospital for five days where they continually flooded her with glucose. By the end of the five days she was herself again. We thought that our fight was over. Only later did we realize how lucky we were she didn't die at that time.

Continued on page 4
Family Stories - Isabelle, LCHAD (cont’d)

After this episode we went back to our normal lives. I didn't switch doctors at that time because I thought that maybe now he would finally listen to me, which he did for the first 6 months or so. The only thing he didn't listen to me about was her blood sugar. I asked him about it having gone so low and he told me that it was normal for a sick child to have a low blood sugar. We were gullible enough that we listened. The only problem was that Isa's problems still continued. We kept going to our GI doctor at the hospital who told us that she was allergic to milk so we took her off all milk products. When this didn't seem to solve the problems I spoke with the doctor again and told him I wanted answers. He agreed to admit her to the hospital for some tests. Since she was scheduled to have her second set of ear tubes put in and her adenoids taken out the next week he set it up to follow that.

I was so excited because the GI doctor had told us that she wouldn't go home until they had an answer. We were finally going to learn what was wrong with our beautiful little girl. After Isa's surgery she was very ill. Although they didn't test it I am sure that her blood sugar was probably pretty low from not eating all day. Once we finally got some food in her she finally started to perk up. The GI doctor that had set up the hospital stay transferred us over to the other GI doctor. He ran GI tests for 1 day and then came to talk to us. All her tests were normal so she should go home. I had thought we would get answers. But he told us that there was nothing wrong with her and since our insurance didn't want to pay for a hospital stay after an adnoidectomy we should go home. I cried all night. I was so frustrated that no one seemed to care. I thought maybe he was right and it was all in my head. Maybe I had that psychiatric illness where you put illnesses on your children. I didn't know what to do. The one good thing was that while I was being questioned I mentioned the low blood sugar and the shakiness that she would get after sleeping. We were referred over to an endocrinologist.

About two weeks after that hospital stay, Isa woke up unable to stay awake. I had a glucometer at home so I checked her sugar and it was 32. I called the endocrinologist who told us to give her juice and honey. We did and her sugar went up to 235. We were at a loss. A few days later Isa, who had been suffering from diarrhea, had really high sugars in the 200s. When I called the doctor she told me to get to Omaha right away. She had a fatty acid oxidation defect. We have learned that she had diabetes but also glad that we finally had the answer we had so desperately been searching for. When they rechecked her blood sugar in the hospital it had gone down to 100. So, the diagnosis was wrong. Our endocrinologist contacted a metabolic specialist who suggested that she be tested for MCAD. She was dismissed a couple of days later and we waited for the results.

The results came back, negative. The test that they had done had specifically tested for MCAD and not for any other FODs. So we were once again without our answer. We decided to forget it and go on with life as normal. We kept her glucometer with us at all times to test her just in case we thought that she needed it. It was in August that we were coming back from vacation in Chicago ~ Isa became very ill and started throwing up almost overnight. I tested her sugar and it was 40. I tried our usual treatments but they failed so I called her endocrinologist who told me to get her to the hospital immediately. When we got to the hospital, I told them that she had hypoglycemia and hyperglycemia both but not diabetes. They tested her sugar again and it was 91. I thought that I was going crazy. They decided to wait on putting an IV in since her sugar was normal. About an hour later her sugar dropped so low that she couldn’t wake up so they finally put in an IV of glucose. She became better almost immediately.

After this emergency trip I called our endocrinologist who said that they better do a fasting study. When we did the study she was fine for the first hours. After about 13 hours of being without food her sugar dropped to the low 40s. They gave her an injection to trigger her body to release its stored sugar. It didn’t work and her blood sugar went down into the 20s. She couldn't stay awake on her own. The nurse had us pulling her ear lobe, slapping her, yelling at her, even shaking a tambourine in her face to keep her awake. It was one of the scariest moments of my life. Finally they gave her an IV glucose solution and her blood sugar went up over 300. During the day they had done a skin biopsy. We left the office feeling shaken but grateful that someone else had finally seen that I wasn’t making this all up.

About 2 weeks after her fasting study the results from her biopsy came back. She had a fatty acid oxidation defect. We have since learned that it is LCHAD. As I look back at all the times that she had been troubled with I see that they can be directly related to her LCHAD. I am grateful to finally know what made my baby so sick. I feel a little more in control. I have also learned not to question myself. Isa still has low blood sugars on occasion but she is doing much better. She is finally putting on weight at a steady rate. As we look back we realize that there is no logical reason why she isn’t dead or suffering from severe brain damage. We look at her every day and remind ourselves that she is truly a miracle from God!

I know now that other families aren't as lucky as we are. I know now that other families have lost their beautiful children because no one would believe them. My advice is simply don't give up. Be persistent. And never, ever let a doctor or anyone tell you that you are over reacting. Always, always trust your instincts!

Sharon Fisher, mom to Isabelle, age 2 (LCHAD)
Hastings, NE
tyandsharon@hotmail.com
Our oldest daughter, Jennifer, married Bill on June 4, 1994. On July 17, 1996 our first grandchild was born — Austin Christopher…big blue eyes, small weight, but healthy. Just before his 1st birthday he developed allergies and asthma. By this time I was already giving him sugar treats (juices, popsicles, suckers, etc). I always had a treat for him and saw him almost daily.

On November 18, 1999, Alyssa Jenna-Ann was born — a beautiful baby with red hair and big blue eyes, very healthy. On July 19, 2000, Jennifer and the kids spent the night with us. Austin woke the next morning with a temp and an earache. Later that day he was put on an antibiotic. During the late night, Bill woke with vomiting and diarrhea and by early morning, I too had it. A bit later so did my husband.

The next day Alyssa started vomiting, but by evening she had kept down 2 bottles of pedialyte. She had her bath, played, and went to bed normally. In the morning Jennifer and Austin went into her room to get her up, but she was in a comatose state. They rushed her to the hospital, but she died 20 minutes later ~ July 22, 2000. It was so hard to hold her lifeless body and tell her goodbye.

For six months we thought she died from SUDS (Sudden Unexplained Death), then the autopsy report came back ~ MCAD. Jennifer, Bill and Austin were immediately tested. Through Austin’s urine test it was confirmed that he too had MCAD. We are still waiting for the results for Jennifer and Bill.

A genetic doctor from London, Ontario came to Windsor and spoke with Jennifer and Bill ~ the information given to them came from the FOD website (www.fodsupport.org). I am so grateful for this site and to those who share their stories. The doctors are very unaware of this disorder and unable to answer our questions, but to read the stories of those that survive are very encouraging and uplifting…and to the little angels that don’t make it, it’s up to us to spread their message.

Alyssa is now on L-carnitine 4 times a day and the doctors in London are keeping a close eye on him. In fact, they want to see him the end of April in London. They say that the sugar treats I gave him helped get him this far with no incidents.

Jennifer became pregnant in October and is due in July 2001. The baby will have to remain in the hospital until the results are back. We pray for a miracle that the baby will be okay. For Alyssa, she is always in our thoughts and prayers, and someday when Austin is older, he will know just how special Alyssa really was.

Dorene and Ron Bellaire, grandparents
(Jennifer and Bill Boucher, parents of Alyssa and Austin)
Tecumseh, Ontario Canada
Nananana49@aol.com

NBS Update
For the latest information on activities to promote expanding Newborn Screening in the US ~ go to the Tyler For Life Foundation website at www.tylerforlife.com. They also have many opportunities for you to become involved as a volunteer in the NBS advocacy effort. There is MUCH to be done so any and all help would be appreciated!

FOD Family Questionnaire
If you do NOT see your name on the Family List it is because I (Deb) never received the FOD Family Questionnaire that I sent in the Family Packet when you first registered with us. If you would like to be listed for networking purposes, please go to ‘Online Forms’ on our website (www.fodsupport.org) and print out the Questionnaire. Then SIGN it and DATE it so I have your permission to list you. Please mail it to me via the regular mail so we can list you in the next List Update.
Four and a half years ago, we adopted a beautiful baby boy. After 6 miscarriages and 11 years of waiting, we were ready to be parents. James joined our family at 6 weeks of age. We were delighted. We didn't complain about the fussiness and the vomiting or spitting up. After all, don't all babies do that?

As the weeks and months passed, I noticed that sometimes James' color would be pale, and he had tremors in his hands. These symptoms, along with the vomiting were sporadic, so the pediatrician said, "Let's wait and watch." Everything looked normal at his well baby visits. Looking back, James was a very fussy "pukey" baby. At the time, I just thought that some babies were like that.

The months went on and James was developing normally, despite the episodes of pallor, tremors, irritability and vomiting. After about age 2, James was able to talk and tell us of frequent belly pains. His symptoms were starting to form a pattern. The episodes now only occurred first thing in the morning. Every holiday, vacation, illness or exciting event would trigger an episode. The episodes were now occurring about every 2 to 4 weeks. His pediatrician thought he might have "cyclic vomiting syndrome."

By now he was about 3 years old and things were not any better. He was taking Zantac, which did seem to help the belly pain a little, but the episodes kept occurring. The pediatrician ordered blood work to be checked during his next episode. His blood sugar was 52. The pediatrician spoke to a pediatric endocrinologist who suggested additional lab work during his next episode. Meanwhile, I borrowed a glucometer to watch the sugars myself. Through trial and error, I found that cake gel icing was the only thing that would bring his sugar up without causing him to vomit.

The next episode was a bad one. His sugar was only 30 and he was barely responsive. We rushed him to the hospital, giving him cake gel icing along the way. He had lab work done and spent several hours in the ER getting IV dextrose. It took several months to get an appointment with the pediatric endocrinologist. The hypoglycemic episodes continued, each one causing great stress and anxiety. I was afraid to sleep at night for fear that my baby would be dead in the morning. We tried 1am juice, but terrible temper tantrums ensued. We figured he was burning more calories screaming and fighting than he was taking in.

After waiting several more months for a growth hormone stimulation test and a brain MRI, James was diagnosed (incorrectly), with growth hormone deficiency and possible cortisol deficiency. We gave James daily injections of growth hormone and thought things would get better. (He took injections for 6 months.) The episodes continued. His sugar was still dropping into the 30's. These were always bad days where he was lethargic for much of the day. He was lucky if he wasn't vomiting. The pediatric endocrinologist added Cortef medication. The steroid made him hyper and his behavior was terrible. (He stayed on Cortef for 3 months.) Of course, he didn't get better.

The worry, fear, frustration and desperation grew. James had more episodes and spent another day in the ER. This time, he was sent to a different ER, because the pediatrician on-call "didn't know how to handle him." After IV dextrose he was better and came home. James asked if he was going to die. I knew that something else was still wrong. Just as I was about to ask for a second opinion, his pediatric endocrinologist suggested James be evaluated by Dr. Stanley at Children's Hospital of Philadelphia, PA.

James was admitted to the hospital for 5 days of evaluation in January 2001. He was always healthy during his regular checkups, but he had his typical hypoglycemic episode while in the hospital. I FINALLY felt as if someone was taking this seriously. The doctors seemed determined to help James. I felt an indescribable wave of relief that someone was really going to help. James had 2 fasting studies done and a few other tests.

At his follow up appointment in March 2001, James was diagnosed with an FOD. We, as parents, have declined a skin biopsy at this time, because James has been through so much...maybe someday. James also sees a pediatric gastroenterologist for gastric reflux, increased stomach acid and chronic belly pain. He is taking Prilosec with some relief.

Here we are, 4½ years later, and we finally have an answer. I'm sleeping at night now, but still cautious. James takes his cornstarch every night and has white grape juice at 4am (without the tantrum). He has been symptom free for 2 months. He has had 2 ear infections without an episode.

There have been 100+ days in his short life that James was vomiting, lethargic and hypoglycemic. Hopefully there won't be many more. I am very thankful to Dr Stanley and his staff for diagnosing our son and giving us peace of mind. I am also very thankful to Deb and the whole FOD group for your understanding, information and support. I pray for God's help and support for all of our families and physicians.

Denise and Paul Fegley
Carlisle, PA
Family Stories - Kaitlyn, Canadian MCAD

Kaitlyn was born May 1, 1995. She was a very healthy, beautiful baby girl. When she was 2½, I went back to work and she went to day care. Kaitlyn was in daycare for about a year and half, full time. Since she was in daycare, she had all the flu's and colds that everyone else had. It seemed to me that she was always sick.

One Friday afternoon in early June 1999, when I picked her up, she said she wasn't feeling well. I figured as usual, she was coming down with the flu. We went home and had our supper. After supper, Kaitlyn started to vomit. She lied down and went to sleep. When she woke up she vomited again. This continued throughout the night. She couldn't even keep down a few tablespoons of water. In the morning I became very worried, as this was definitely not normal for Kaitlyn. Usually when she was sick she would vomit and be fine a few minutes later. This time all she wanted to do was sleep.

First thing Saturday morning when our family doctor’s office opened, I took her to the clinic. She advised that Kaitlyn had the stomach flu, but if she continued to vomit to bring her to the hospital as she was concerned about dehydration.

Early that afternoon, I brought her to the Children’s Hospital in St. John's, NF. Right away, they started an IV and did lots and lots of blood work. She wasn't responding to me or to the doctors by now. She was lifeless. It was really scary as the doctors kept asking me if she might have taken some depression medicine or may have drank cleaners as there were toxins showing up in her blood work. I knew this was IMPOSSIBLE. She was in emergency for approximately 18 hours, when she finally started to come around. She woke up finally, but was still very sleepy and hardly enough energy to walk, but the doctors let us go home. When at home, the same thing happened again, she would vomit and lie down. After another couple of hours like this, I had to bring her to hospital again. I knew this was serious, this was not Kaitlyn - she is a very active little girl.

After being in emergency for another 24 hours, they finally admitted her on Monday morning. It wasn't until Tuesday afternoon that she started to wake up (she basically slept form Friday evening until Tuesday afternoon). While in hospital they did lots of blood work, ultrasounds, and liver tests. She was feeling a lot better and by Friday, we went home. Still not knowing what was wrong.

It wasn't until October 1999, that they diagnosed her with MCAD. The doctors here are still quite new to MCAD. Kaitlyn is only the second known case in our whole province of Newfoundland. She has been on Carnitor® since October 1999, and is doing very well. She hasn't been sick since June of 1999, except for a cold here and there. I haven't worked since this all happened, but now that Kaitlyn is in Kindergarten and doing well, I feel confident enough to return to work.

Kaitlyn is an only child. Her dad passed away in Oct 1996 of a massive heart attack when she was only 18 months old. Therefore finding out about this support group has been wonderful, as I felt so alone in coping with this before. It is so nice and comforting to sit and read all the letters and find out about everyone else’s experiences, and knowing that others are doing very well with this disorder. As for those of you who haven't been so fortunate, and have lost someone with an FOD, my heart goes out to you.

Take care and thanks again for all the valuable information I received.

Diane Hilliard
Kaitlyn Hilliard (born May 1, 1995) MCAD
New Foundland, Canada
dhilliard@roadrunner.nf.net
I am writing to you today to share my story with you regarding my son Jonathan's pre-diagnosis of an Unclassified FOD (we are still in the process of specifying which disorder). It was Tuesday, December 19, 2000. The day started out like any other day in our house. I had just finished dressing my 8-year old twins for school when I scooped up my then 20-month-old son, Jonathan, from my bed where he lay sleeping (he had always been a "terrible" sleeper so he always ended up in bed with me). We went downstairs and I placed Jonathan on his back on the couch while I prepared the twins for school. While they were eating breakfast, I checked on Jonathan. I said "Good Morning" and got no response. I looked closer...his eyes were wide open but he was not moving and his face was a blue and yellowish color.

I immediately picked him up and his little body immediately went limp in my arms. I called 911 and then, thinking he might be choking, tried to scoop out his throat with my finger. He then clenched down so hard that I could not remove my finger from his mouth. I know it was probably only minutes, but it seemed like an eternity until the paramedics arrived. During this time my daughter was screaming "He's Dead" and I tried to reassure her he was going to be fine, when I honestly did not know if that was true.

My son asked me what he could do, and I told him to take his sister and go in the corner and pray very hard...that was all we could do. When the first paramedic arrived I ran out to the driveway to meet him. He immediately intubated Jonathan and brought him inside. Then two more ambulances arrived and hovered over my baby on my kitchen floor. They were getting no response. They could not find a vein to run an IV, so they had to puncture the bone marrow in his little leg to run the line. I thank God every day that they were trained to do that procedure. After calling my husband (who was at work an hour away) and my parents, I then left my other two children in the care of volunteer firemen until my father arrived.

Jonathan had a stomach virus the day before which gave him severe diarrhea. Although, from past experience, I "knew" that as long as he was drinking fluids (including pedialyte), had wet diapers and was crying tears that he was not dehydrated, I was still planning to take him to the pediatrician once I had gotten the twins off to school. Well, as you now know, I never got that opportunity. We ended up in the emergency room instead. Upon arriving at the hospital, I was met by my mother and my parish priest (whom I had called, but through various prayer lines was already aware of what was going on and had already been praying for Jonathan at the morning mass). My husband then arrived, only to see a team of doctors hovered over Jonathan and then he saw our priest. He did not know what to think ~ he broke down. I wanted to reassure him everything was all right, but again, I didn't know for sure.

About 45 minutes passed until we were able to see Jonathan. He was very weak, but he was alive. He turned to us and said "dad." We both started crying. Upon admission to the hospital, we still had no answers, except that Jonathan had been in a hypoglycemic coma. We had been told of a possible carnitine deficiency and were referred to a genetics specialist. When Jonathan was released it was two weeks until we saw the specialist.

I have to say the one thing I was always sure of was how to care for my children...now all of that confidence was gone. I did not want to be left alone with Jonathan for fear that this would happen again without warning. Well, on the first visit with the specialist, he told us he believed he possibly had LCHAD and wanted to run a series of tests. He had us start giving him cornstarch that very same night. I was still so confused. Upon reading a Good Housekeeping article about newborn screening, I was so angry to learn that Jonathan could have been tested for FODs at birth.

Continued on page 9

**FOD Mom writes book!**

*FOD and Me* by Sharon Fisher (LCHAD mom ~ see Isabelle’s Story in this issue) is a book that describes FODs in very easy to understand "kid" language. This book was written as an attempt to help my own FOD daughter to better explain herself to other children. The colorful photo illustrations are fun to look at. While all FOD kids are unique, this book gives a generalized picture of what any FOD child lives with. The book also includes a page on using a glucometer. Recommended for children ages 9 and under but could be read by children of any age. If you are interested in purchasing my book ($18.00 for book and postage), contact me at tyandsharon@hotmail.com.
Family Stories - Jonathan, Unclassified FOD (cont’d)

I immediately called my brother, David Cappiello, a Connecticut State Senator, and asked him to propose legislation regarding newborn screening. He did. The bill just passed through the Public Health Committee unanimously and is now going on to the next phase. I am so excited that I, along with my brother, may be able to spare someone the pain and trauma that my family has had to endure these past few months. My twins still have nightmares.

In hindsight, a lot of things in Jonathan's first year of life make sense. He was delivered by emergency C-section two and a half weeks early because every time I had a contraction, his heart rate dropped dramatically. I was insatiable ~ he was always hungry. He months (I nursed him until 18 months). Everyone instinct ~ Thank God for that. He knew what he

Then at one year he was tested for sleep apnea. He then got a virus that caused him to give up any solids he had begun eating and thrashing about in pain in between. The doctors could not figure out what was wrong, even with a series of blood tests.

I still get angry thinking about what he had numerous blood tests, an EEG, an echocardiogram awaiting the results of the biopsy, but the specialist is certain it is an FOD. We are still awaiting the results of the biopsy, but the specialist is certain it is an FOD.

I believe that Jonathan was saved for a reason. That reason is to get a law passed in Connecticut to have all babies screened at birth. God used us as a facilitator. I pray His plan works.

Pamela J. Sweeney ~ mother of Jonathan
Newtown, CT
Sweeney257@aol.com

Family Stories - Ben, MCAD

On February 19, 1998, Ben entered our life. He was a beautiful full term baby boy and our third child. Ben received the minimum state-mandated newborn screenings after he was born and was thought to be healthy. During routine well-baby check-ups, Ben was thought to be a typical child. He was growing and developing normally. During his brief 2 ½ years of life, Ben had learned to swim, to identify landmarks on the way to his grandparents’ house, to distinguish among the vehicles his various grandparents drove, to drive his own little Power Wheels Ford Pick-Up Truck, to pick out his Daddy’s backhoe key among a cluster of other keys, and had become fully potty-trained. He seemed so normal, so healthy. Little did our family realize that a “silent killer” was present in our Ben.

On Monday, August 7, 2000, Ben became ill with vomiting. He had no other symptoms such as fever or diarrhea. He had been sick with vomiting before, so we treated him by forcing fluids and small amounts of food to prevent dehydration. Vince and I stayed up with Ben until 10:30 while continuing to give him drinks.

Continued on page 10
Family Stories - Ben, MCAD (cont’d)

He slept on a pallet beside our bed that night. At 1:30 am the next morning, I awoke to find Ben opening and closing his eyes, but non-responsive to our commands. Suddenly, Ben stopped breathing and his heart stopped beating. I began CPR immediately on our living room floor while whispering what I feared might be my last words to my son. Vince was on the phone frantically searching for advice and help from 911 while beating his fist into the floor and begging for Ben to come back. Ben didn’t come back. He was transported to the local hospital by helicopter where attempts were made to revive him. No one was successful. Our apparently healthy son was dead within 12 hours of showing symptoms of illness.

Doctors and state health officials speculated about the cause of Ben’s death for almost a month. The list of misdiagnoses included: sepsis, meningitis, mosquito-borne encephalitis, and Reye’s Syndrome. About a month after Ben’s autopsy, we learned the real cause of death, a disorder we had never heard of before, MCAD.

Adding to our devastation, about a week after Ben’s MCAD diagnosis, we learned that his disorder could have been detected at birth or any other time before his fatal crisis with a $25 blood test. With this simple, inexpensive screening, doctors would have been able to diagnose Ben’s “silent” disorder. With an early diagnosis, a treatment plan would have been devised and Ben’s prognosis for a normal, healthy life would have been excellent. One doctor told us that with early detection of the MCAD disorder that Ben would most surely be alive.

Since Ben’s death, we have been very busy promoting expanded newborn screenings. We have written local pediatricians and obstetricians/gynecologists several times. We have written our legislators. Two local state representatives wrote a bill to require that doctors at least inform parents of these additional tests that are not required by law so that parents will have a choice to test their children, a choice we never had.

The bill was titled, “Ben’s Bill” and it was signed by the governor into law during a special ceremonial signing on Monday, April 16. Although our lives will never be the same because losing Ben was so unnecessary and unacceptable, we are proud of Ben’s impact on the future of children’s health in our state. We will continue our efforts to mandate CNBS in our state so that our children will have the best chance for a healthy life and parents will not have to endure such immense pain.

Vince & Robin Haygood
Parents of Ben (2/19/98 – 8/8/2000) MCAD, postmortem diagnosis
Lori (age 8) unaffected
Leslie (age 6) unaffected
662-844-3974
10298 Hwy 9 North
Belden, Mississippi 38826
rlbhaygood@hotmail.com

HOPE…in the eyes of a parent

inspired by and in memory of Ryan

There is ALWAYS hope…it just may not be or look like we feel and think it SHOULD be!

Many of my articles are fueled by my conversations with parents, just as the ‘Light in the Darkness’ article was (on our site, Coping and Healing page) – where a professional wasn’t going to tell a new FOD Family about our Group because she felt our newsletter was ‘too depressing’ for the family to read. In other words, this professional was basically telling this family that it’s HOPELESS to find any kind of ‘good’ support out there because there isn’t any at this time! She was making decisions for this family ASSUMING they wouldn’t want to read about LIFE and REALITY and all because it was too depressing for HER! Of course, there’s support – it just doesn’t ‘fit’ what others perceive as supportive – which to them may mean, “Let’s not talk about death.” Trying to protect families FROM reality as well as DENYING them their right to decide for themselves what is supportive is WRONG.

Continued on page 11
Just as wrong is when someone tells a family that, “It’s no big deal, the treatment is very simple. We have this all under control. No need to over-react” What that does is dismiss or minimize the seriousness of the disorder, possibly leading families into denial or thinking that they REALLY don’t have to be concerned. You may think that doesn’t happen – but it has and it does.

Hearing that message from a medical authority, on another subconscious level, also seems to magically ‘absolve’ parents/grandparents for having passed on a defective gene. That may sound like a bunch of psychobabble but let me tell you, I’ve spoken to enough families over the last 11 years to hear ‘guilt’ even when the words aren’t actually spoken!

None of us wants to think that we are responsible for our child’s disorder. Of course, when you put things in context and realize that NO ONE knows for sure which genes will be passed on and in which combination, it’s totally unrealistic to think we’re responsible for knowing that we are carriers (since diagnosis is often AFTER newborn screening, an episode or a death and BEFORE we know we’re carriers!) or even when we DO know, we need to remember that there is MORE of a chance that EACH child WON’T have a disorder (75%) versus having it (25%).

Waiting for some outside entity to tell us it’s no big deal or to absolve us of guilt or fear is NOT what HOPE is about. However, dealing with those issues of guilt and fear/stress (discussed in other Coping and Healing articles on our website) is a highly PERSONAL PROCESS that takes time and a lot of internal work and it CAN impact how you view hope for the future.

Sometimes that can be done by yourself, but in some cases it may help to talk to a counseling professional if they are causing concerns in your life. This is getting away from my main point but in a strange sort of way, this type of message almost skew hope at the other end of the continuum – implying there’s hope for your child and future children, because “It’s no big deal!”

There’s hope all right…it’s just NOT because it’s “No big deal!”

When a family hears a diagnosis of a rare disorder, the initial hope may be for a cure. However, as more information is gained and realizing that there is no cure, that hope may be readjusted to being able to treat effectively. And depending on the situation, that hope may need further ‘readjustment’ as time goes by and experiences change.

But what happens to hope when you hear that your child is going to die because there is no effective treatment so “Just go home and enjoy your child while you can.” Statements like this have been made to some of our families – talk about blasting all hope (according to the ‘normal’ definition/use of the word) for this family into the stratosphere! That professional or any person for that matter may be stating a ‘cold fact’ based on what few cases have been seen of a very severe form of an FOD, but HOW that ‘fact’ of inevitable death is conveyed has a HUGE IMPACT on how a family perceives hope!

Having experienced various transformations of hope myself (when we were given Kevin’s MCAD diagnosis I/we IMMEDIATELY thought he was going to die suddenly as Kristen had, until we gained more information), I try to compassionately convey to parents that have just been given that heart-wrenching prognosis that hope can be perceived in different ways...for not only the benefit of their child, but for their own present and future coping and dealing with their child’s (or other loved ones) condition, as well as death, whenever that may be.

Parents often feel so helpless and hopeless when they hear a prognosis like that ~ especially when it’s given in such a detached and many times unemotional way. Parents have told me that they feel as if the doctors and others have “given up” on the child and family. Now, before you jump all over me about Drs sometimes being detached and cold, I realize that SOME may present that way to really ‘protect’ themselves from feeling too much and getting attached ~ if they get too attached they might not be able to do the kind of work they do. I understand that thinking – however, that still doesn’t mean that the content of a devastating message can’t be given in a more compassionate and caring way. ‘Bedside manner’ DOES make a difference!

I’m here to say that despite what the eventual and inevitable ‘outcome’ will be HOPE IS STILL POSSIBLE...yet in a different way. It’s not a matter of debating whether knowing ahead of time is ‘better or easier’ than a sudden death ~ that isn’t the point. The point is if you can work through your fear, anxiety, guilt, and other emotions of grief instead of focusing ONLY on the ‘inevitable outcome’ that was devastatingly placed before you, you can take each precious moment in the PRESENT and cherish it NOW, so those memories will be with you to help you in the FUTURE.

You can also try to make your child as comfortable as possible during this time ~ families have sometimes been ‘advised’ (directly and indirectly) from having certain procedures done (i.e. surgery) because “it won’t do any good” ~ but if it makes your child more comfortable instead of fighting for every ounce of energy or strength for days or weeks or years, than it WILL DO SOME GOOD! If you can embrace your circumstances and your child from THAT perspective, it opens you up for channeling some of your heartache in a more HOPEFUL way...and benefiting you and your child in the process. Hope CAN BE transforming for all involved!

Intellectually acknowledging that yes, a death may happen soon, LOOKS like all hope is gone…but it really isn’t. Saying that there’s absolutely NO hope is a false statement to me...there may be no hope for an absolute physical cure of some disease but that doesn’t mean that ALL hope in ALL realms is nonexistent!

When you perceive hope ‘wholistically’ you become more open to other meanings for yourself. By not just ‘staying up in your head,’ and experiencing what is happening with your mind, body, AND spirit ~ you will SEE how hope can be transformed from the darkest of darkness to a new kind of ‘lightness.’

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HOPE...in the eyes of a parent (cont’d)

It certainly may not look or feel that way the moment you hear a shattering prognosis, but over time, it IS possible if you BELIEVE it’s possible...I KNOW firsthand it’s possible!

Hope comes in many ‘colors’...I happen to be drawn to ‘yellow’ (as evident by our pamphlet, card, and ‘my rose’). For me, it brings me that light and strength when the ‘shadings’ of hope may not look so bright. Every time I see or think of a small yellow rose, memories of Kristen flood my being and in a strange sort of way I draw energy and HOPE from that. As odd as it may sound, THAT is what the true power of ‘mystery’ and spiritual connection is all about and it CAN have a transforming effect on the rest of your life...as well as your family’s life!

On that note...I’ll end this as I began ~ There is ALWAYS hope...it just may not be or look like we feel and think it SHOULD be!

Allow YOUR more enlightened vision of HOPE to transform your own lives...

Deb Lee Gould, Director
FOD Family Support Group
July 21, 2001
Kristen’s 16th ‘anniversary’

Medical Update

Carnitine Therapy for Fatty Acid Oxidation Defects
Susan C. Winter, MD
Medical Director, Medical Genetics/Metabolism
Valley Children’s Hospital, Madera, CA
winter2571@aol.com

Carnitine is a natural substance important to the transport of fat into the mitochondria where it is “burnt” for energy. Carnitine is also important in removing the biochemical “ashes” remaining after the fat is metabolized to energy. It does this by binding to the biochemical ashes and carries them out of the mitochondria and then out of the body as carnitine bound “ashes” (acylcarnitine derivatives) dissolved in the urine. Carnitine is eaten in the diet in red meats and dairy products, including breast milk, and is also made in the body from breaking down muscle protein and converting it to carnitine.

As with all natural substances, deficiency can occur. Carnitine deficiency is nearly always secondary to other problems and may often be due to more than one factor. In infants and small children with small muscle masses, carnitine deficiency can develop easily due to poor muscle protein supplies for synthesis. These small children are very dependent on dietary carnitine for their supply. If the diet is inadequate from generalized malnutrition, or due to a special formula not supplemented with carnitine or Total Parenteral Nutrition (TPN) that is unsupplemented, deficiency can develop within weeks. Children and adults with gastrointestinal malabsorption, such as those with cystic fibrosis or chronic diarrhea, can develop deficiency. Increased loss of carnitine from the blood or urine can occur with hemo- or peritoneal dialysis as it is a small chemical and comes out in the dialysis fluids. Carnitine deficiency is also seen in children with kidney disorders affecting the reabsorption of needed chemicals from the filtered urine, renal Fanconi syndrome. In children with genetic metabolic disorders affecting fat oxidation, carnitine deficiency occurs due to a massive excretion of carnitine in the urine bound to the unburnt “ashes” of fat metabolism. These unburnt fats attached to carnitine can be detected in the urine of these patients in high levels and this is the basis of the acylcarnitine derivative testing being used for newborn screening using the tandem MS-MS method.

Carnitine deficiency is associated with many symptoms. Since the deficiency is nearly always secondary to another disease process, the symptoms are often those of the primary disease plus additional problems that can be reversed with carnitine replacement therapy. Deficiency of carnitine results in decreased energy available to muscle and muscle weakness and low muscle tone. Growth of muscle, and thus weight gain, also requires energy and the child with carnitine deficiency usually has failure to thrive. Carnitine deficiency can affect the cardiac muscle and result in poor cardiac contractions (cardiomyopathy). Energy is important to brain function and abnormalities of brain function can be seen including convulsions, lethargy, irritability, and even coma.

Continued on page 13
Medical Update (cont’d)

These children are very susceptible to infections and with the frequent infections they often show signs of deterioration of mental and physical status. Liver function may worsen and liver failure may occur. In children with genetic metabolic diseases, carnitine deficiency can be life threatening due to the inability to excrete the unburnt “ashes” left over from incomplete fuel burning. These accumulating ashes are toxic and poison the individual. Without carnitine to take these toxins out, the individual may die or suffer irreversible damage.

Carnitine is available as a medication and is approved by the FDA for treating secondary deficiency due to metabolic diseases. In the USA, only one company, Sigma-Tau Pharmaceuticals, Inc., sells pharmaceutical grade L-carnitine (Carnitor®) that is available through prescription. Oral L-carnitine is available as a liquid with 100 milligrams of carnitine in each milliliter and as a tablet with 330 milligrams of carnitine per tablet. Intravenous L-carnitine is also available in vials each containing 1 gram in 5 milliliters of solution. Oral carnitine is poorly absorbed and only about ¼ of what is swallowed is taken into the body. The rest is excreted in the stool. This can result in diarrhea, stomach upsets and in about 5% of people, a very fishy odor caused by certain bacteria in the bowel of some people converting carnitine to trimethylamines. Intravenous carnitine is fully available for body use as it bypasses the bowel absorption problems and for this reason is the preferred route of administration in children in life threatening crisis. Doses of carnitine used are variable and range from 50 to 600 milligrams/kg/day with oral carnitine and 25 to 300 milligrams/Kg/day with IV carnitine. Higher doses are usually used in children and adults with serious metabolic disorders during times of metabolic stress and decompensations.

Complications of long term or short-term carnitine treatment reported have been few and not serious. The body odor due to trimethylamines can be treated by taking a low dose of an antibacterial substance such as metronidazole to kill off the bacteria making the trimethylamines. The gastrointestinal upset and diarrhea is often short lived and usually improves if the dose is lowered or given with food or more frequently. With IV carnitine, the medication may burn if infused too quickly and may cause reversible pain and irritation if it gets under the skin (interstitial).

Treatment of fatty acid oxidation defects with L-carnitine has been shown to be safe and, especially during the times of metabolic stress, life saving. Theoretical concerns regarding cardiac arrythmias in children with long chain fat metabolism defects have never been substantiated and no ill effects have been reported in this group of patients. Many children with long chain defects have been shown to reverse serious complications such as cardiomyopathy on carnitine therapy. In general, carnitine therapy has markedly improved the health and life style of children with fatty acid oxidation defects.

Research Study:

Treatment Protocol for Inherited Disorders of Fat Oxidation

Institute of Metabolic Disease
Baylor University Medical Center, Dallas, TX
Charles R. Roe, MD, Medical Director

Inherited defects of mitochondrial beta-oxidation are autosomal recessive disorders. These defects prevent adequate energy production from long-chain fatty acids. During illness or fasting, toxic fatty acids, or their intermediates from partial oxidation, accumulate in most organs. Attempts to treat the long-chain fat oxidation disorders with dietary medium chain triglycerides (MCT) have not been generally successful. Commercially available MCT oil, in the US, contains fatty acids that require Carnitine palmitoyltransferases I & II, Translocase, VLCAD, LCHAD, and Trifunctional protein activity for complete oxidation. Current research in our Institute has identified a fatty acid that does not require these enzymes for further oxidation and therefore appears to be very effective for the treatment of these mitochondrial disorders. Unfortunately, this novel fatty acid is contraindicated for the treatment of MCAD deficiency since MCAD is required for its oxidation.

The treatment protocol includes infants, children and adults (including pregnant women) who have documented deficiencies of mitochondrial fat oxidation. These disorders include all clinical phenotypes of Carnitine-Acylcarnitine Translocase (CATR), Carnitine Palmitoyltransferase I and II (CPT I, CPT II), Very Long Chain Acyl-CoA Dehydrogenase (VLCAD), L-3-Hydroxy-Acyl-CoA Dehydrogenase (LCHAD), Mitochondrial Trifunctional Protein (TFP), and Short Chain Acyl-CoA Dehydrogenase (SCAD). A diagnosis must be established and well documented before a patient can qualify for the protocol. In addition, each patient’s cultured skin cells must be completely investigated by the Institute of Metabolic Disease at Baylor (Dallas) to determine if the proposed intervention is potentially applicable. Each patient is admitted for up to 9 days for the initial treatment protocol. Chemical and metabolic monitoring as well as serial exercise and muscle strength testing and NMR spectroscopy, as indicated, will be utilized in the evaluation. The Institute will provide the dietary components for a period of 18 months (length of the protocol). During this interval, follow-up visits to Dallas are required at two, six, twelve, and 18 months.

For further information regarding expenses and insurance requirements contact Mrs. Karla Jerkins (FODRX@baylordallas.edu).
**Conference Comments**

*The conference was GREAT!* Thank you for all the work you did. The FOD sessions were very informative. It was good also seeing Dr. Roe again after five years. I have always been amazed at "teachers" pouring out the knowledge that they have reaped (usually from texts). This man wrote the texts! He is brilliant. Drs. Roe, Cook, and Singh helped us all to understand FODs better. I especially enjoyed learning about other FODs, not just about MCAD. Many of the questions were answered. Dr. Capelhart's presentation concerning Special Ed Laws was great. The information gained has helped me understand what others are going through. My cousin has a child (non-FOD) that is profoundly mentally retarded and developmentally delayed. She had been told that he would never walk and talk. School has been wonderful for him. He has been attending public school since he was three. At age seven, he is walking without a walker and can speak a little, but he understands a lot! Mr. Valenzano from EP (Exceptional Parent) is a great motivator. He has a vision for Universal Newborn Screening. His company has the resources. And this is only the FOD part of the conference. I will not go into the other sessions on Newborn Screening, but I will say that they were great. Are there any more T-shirts and can I buy one? They are good conversation starters. *Thanks again Teresa (and others who helped) for all your time and hard work!*

We gained so much information at the conference this past weekend. Dr. Capelhart was such a great help to us. His discussion on what schools really are obligated to provide for children made us sit up and take notice, since we haven’t been offered much, education wise, since he finished EI three years ago. We took G. for his regular 4-month check-up April 27th. Dr. Cohen drew more blood to test for Angelman’s Syndrome, another genetic disorder involving a deletion on chromosome 15. Dr. Cohen told us that children with metabolic disorders often have Angelman’s, also. Dr. Roe told us on Saturday that the symptoms also mimic metabolic disorder symptoms, too, so...unfortunately, now we sit and wait for a few weeks. From what I understand, it isn’t uncommon to be affected by both Angelman’s AND a metabolic disorder. If anyone has any information, or knows anyone affected by this, let me know. *For those of you that couldn’t make it to the conference, next time there is one, if at all possible, GO!* Being in Ohio, it was quite convenient for us, but it’s worth traveling for, too. We so enjoyed meeting so many of the people on the listserv.

I do have a bit to say regarding the FOD portion. The doctor panel was not quite what I expected. The doctors did not go over the oxidation process, autosomal interpretation, genetics, an overview of each disorder, and the new FODs being discovered, etc. I have been to metabolic conferences where parents are spared nothing when it comes to disorders/diseases that they are inquiring about. I enjoyed the other speakers, but I felt the Drs just scratched the surface of FAOD. Don’t misunderstand me, they are great doctors! You were terrific. It was nice meeting you (Teresa Cornette), Trish and the others. Good luck to you and your efforts.

What a conference! Spending time sharing and crying with those whose babies were not saved was most special to me...I will be happy to send the education info to anyone interested (great stuff), and also to answer questions (i.e. what to bring, how was it being there for 9 days etc) *if you have definitely committed to being in Dr Roe’s Treatment Protocol Study* since we are in the study already (Lisa Gibson, bgibson@austin.rr.com). Great meeting of those who were there!

I thought over all the conference was wonderful! The question and answer session with Dr. Roe and Dr. Cook was my favorite. I wish that could have been longer. As we went from table to table, the questions that others asked made me think of new questions I would have liked to have asked. Going around the room a second time would have been great. I was able to corner Dr. Roe after the session and did get my answers, but wonder if others had more to ask too. The whole day Friday with the FOD sessions was awesome. I got a lot out of it. I learned some things I am doing right such as my daughter’s diet, and some things that aren’t going so right such as my three older children still not having been tested for MCAD after H’s diagnosis last year (they are in the process now!). It was an incredible day. *Teresa, you did a great job running things. You kept things interesting. I liked how you made us stand up and introduce ourselves. It made me feel like we really were part of the same group. We were all there for the same reason. The best part of the conference for me was meeting the other parents. It was great hearing their stories and sharing mine. I can’t wait for the next one!*

The FOD break was GREAT! Finally, we were able to put faces, names, and email addresses together.

*We are all in this together.* Thank you to all that helped set up the FOD sessions and provided the huge, meatbooks and shirts. We look forward to seeing you all at the next conference!
Love Messages

Joan & Tim Aalberts

Sandy and Howie Aitken

Jeanne and Mark Barilla

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

Delane and Althea Becker

Sue and Jim Berneski

Jacque and Mike Bradford

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

Barry and Julie Bryson

Carolien Grootaert - Callens

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

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

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

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

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

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

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

David and Amy Deshaix

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

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

Lance and Dawn Goldsmith

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

Jeanette Guillory
Dominique - Birth Jan 21, 1997 Death Jan 23, 1997

Michael and Nicole Gumiela
Michael - Birth March 28, 1998 Death April 4, 1999

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

Robin and Vince Haywood
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

Brad and Kim Holmes

Continued on page 16
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

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

Brian and Kim Karhu

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

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

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

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

Jamie and Tom Lazzaro

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

Mary Lingle
Candice - Birth Feb 2, 1991 Death Nov 8, 1993

Darlene and Larry Lopez
Marissa Death Feb, 1999

Heather and Phillip Marsella

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

Randy and Misty McDonald

Christine and Mark McFarland

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

Elvira Melendes
Katherine - Birth March 6, 2000 Death May 3, 2000

Lori and Jeff Michaud

Simone and Michael Miller

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

Verna Parker

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

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

Brian and Cherryl Rosenberger

Janice and Steve Rowland

Litzy Sanz de Solis and Jesus Solis Sanchez

Jackie Shears

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

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

S. Elizabeth & G. Douglas Turman
Philip - Birth April 6, 1994 Death April 8, 1994
Grief is like a long valley, a winding valley
where any bend may reveal a totally new
landscape

~C.S. Lewis, A Grief Observed~
Kids Korner & Konference Pics

Jeanne Bailla
Matt & Megan (MCAD)
Cousin Danny (carrier)

Howard & Shelley Singer (Madison - unclassified)

Teresa Cornette
Dr. Roe

Dell & Melanie Ruff (Anna - MCAD)

Jenny Carroll
Megan & Jane (LCHAD)

Shoshannah Robbins (MCAD)

Jacque Bradford (Alex, MCAD)
Willadean Short (Tiesa, CPT2)
Tera Mize (TFL Pres.)
I recently read the book *Raising Cain: Protecting the Emotional Life of Boys* (NY: Ballantine Books, 1999, 2000) by Dan Kindlon, PhD and Michael Thompson, PhD. Even though most of what they shared I have either learned over the years (sometimes the hard way!) through raising my/our own 2 boys or through courses taken in graduate school, I felt their information was vital and could be useful in relation to issues that many of our families deal with (i.e. grief issues if a sibling dies from an FOD, anger at having to take special formulas or meds, not being able to participate in certain activities due to seizures etc) especially when dealing with boys/men. Not that these same issues don’t affect girls/women, but this particular book focuses on the inner life of boys and how we can nurture these inner workings and promote emotional growth instead of complicating it or contributing to a shutdown of emotions.

This book addresses the emotional needs of boys from the beginning of their life through boy/manhood. No matter how old or physically large a man is he often carries with him in varying degrees and intensities what he learned (and didn’t learn) in childhood from the messages he received (and perceived) from parents, teachers, coaches, peers and society as a whole. The authors share their experiences in talking with boys and men and their thoughts and insights on the price we ALL pay when those needs aren’t met and expressed in constructive ways. In societies/cultures that don’t actively promote healthy expression of feelings by males, professionals from many areas (medical, mental health, law enforcement etc) are seeing increases in substance abuse, violence, academic underachievement, suicide and accidents.

The findings in this book can help FOD Families in many ways, but it’s really a book that fits into LIFE in general. The emotional life of boys is much more expansive than just dealing with an FOD or FOD-related loss/grief issues. ALL aspects of life are touched by emotions – HOPEFULLY by understanding what boys need to be emotionally healthy and then by teaching/modeling constructive expression, we can raise more ‘emotionally literate’ children that grow into emotionally literate adults.

Unfortunately, we have what the authors call a ‘culture of cruelty’ in our own society that pigeon-holes boys into narrow roles and ways to behave or express emotions or masculinity and if you don’t fit that role (i.e. macho, physically strong, boys don’t cry etc) then you are considered less than male (and to many that means ‘sissy’) and often treated that way by other boys, men, and much of society.

We ALL need to be aware of the messages we send our boys, directly and indirectly, so they can feel good about themselves and have a healthy sense of self and not feel that they have to hide from others just because they don’t ‘fit in’ with what some call masculine. Masculinity (as well as femininity) comes in many ‘shapes and sizes’ and who is to say who has it and who doesn’t have it?

Some say that different media (i.e. TV, music, movies, videogames etc) don’t influence how boys (or anyone) feel, think, or behave, but from what these authors share about their experiences in working with troubled boys, that opinion, in MY opinion, is strongly put in doubt! The angry, belligerent, sexist, homophobic etc messages often heard and seen in today’s world stifle and discourage emotional growth and definitely don’t promote it ~ for ANYONE! Boxing a boy into a certain ‘role’ or way of being can cause more harm than good. Feeling isolated from their own selves as well as society, is what most likely exacerbates problems within families, communities, societies and the world.

Our challenge is to enhance our boys’ inner selves and lives – not to contribute to the toxic mentality that propels and perpetuates that ‘culture of cruelty’ upon our children.

Reading this book will most definitely give you as parents a greater awareness of how you can be that catalyst in your own sons’ lives, as well as any boy you come in contact with, so they will grow into the men they are meant to be.

Deb Lee Gould, MEd
Director, FOD Family Support Group
March 2001

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### Resources

- **When your child has a disability** by Dr Mark Batshaw  ISBN #1557664722
  Covers guidance on pediatric care, behavior, development, education, early intervention, legal rights, benefits and much more.
- **Call me Gene** at www.science2discover.com/book2.htm. This book explains genetics in a way that children can understand. It is a book for the general population. A more religious-based version is called *My name is Gene*.
- **Secrets of Fat-Free Cooking** by Sandra Woodruff. Avery Publishing Group.
- **Bowes & Church’s Food Values of Portions Commonly Used.** Nutritional values of all kinds of foods.
- **Taking Seizure Disorders to School** by Kim Gosselin. Geared toward children with seizure disorder and explains it in normal terms for children to understand. It is a wonderful book for young children to learn about their friends who suffer from seizures in their class. I (Lisa Cajuste) highly recommend it for anyone dealing with this issue as Ashley has MCAD and she will be starting school in the fall. Her MCAD is complicated by seizure activity. To order call or write (314) 861-1331 Publisher or (800) 801-0159, Jay Jo Books, LLC. PO Box 213 Valley Park, MO 63088-0213.
Family & Professional Donations

**Family Donations:** Chris and Anna Gatch and their church in honor of Madison DesLaurier (MCAD), Paul and Stacey Webber in honor of Joseph (Unclassified), Denise and Paul Fegley in honor of James (Unclassified), Gaynor and Shaun Lewis-Wilkes in honor of Niamh (LCHAD) and Jordan, and Liz and Frank Harnos in honor of Johnny (MCAD) and Steven (MCAD).

We greatly appreciate donations to help with copying, postage, and website fees. Checks can be made payable to DEB LEE GOULD. Please note in the check’s memo section that it is for the FOD Family Support Group. Also, please be aware that we are not a non-profit organization, so donations are not tax deductible at this time.

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**Thank You**

Thank you to Erika Wallace (Mailing Lists), Mary Lingle ~ Mcartwrite@aol.com (Web Page) and Brian Gould ~ BulaBri2000@hotmail.com (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.

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**Communicate with us**

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

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**Don’t ever stop loving**

Don’t ever stop believing
Don’t ever stop dreaming your dreams...

~Blue Mountain Cards~

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**Reminders**

Families: Please send TYPED stories by Dec 1, 2001. To be listed on the FAMILY LIST, 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 1, 2001.