

In this Issue

- From the Editor...1
- Letters to the Editor...2
- Family Stories...3
- Medical Update...8
- Q & A...9
- NBS Article...9
- Notes...10
- Love Messages...11
- Resources...13
- Kids Korner...14
- Reminders & Donations...15

From the Editor



The FOD Communication Network Newsletter was created by and is currently edited by Deb and Dan Gould, 805 Montrose Drive, Greensboro, NC 27410 (phone) 336-547-8682 <http://www.fodsupport.org> email: deb@fodsupport.org (AIM: fodgroup) Medical Advisor: Dr. Charles Roe; charlesr@baylorhealth.edu

The last few months have been busy preparing for the upcoming metabolic conference. As mentioned in our last issue, **Trish Mullaley of the National Coalition for PKU and Allied Disorders invited our Families and Professionals to their 2nd Metabolic Conference that will be held on October 3-5, 2002 at the Orange Convention Center in Orlando.** This is a joint Conference with Exceptional Parent's World Congress on Disabilities. **The registration fee of \$50 (through the Coalition) per person will allow you to attend both conferences.** The **Registration Form is on the back page of this issue**, as well as on our website. We will **NEED FOD VOLUNTEERS** to ask businesses to donate products for our 'goodie bags' so contact me (Deb) if you are interested. For the last Conference, we had @ 25 FOD attendees so we expect that to double or triple for this Conference! See the information below for further details. Make sure to make your reservations early!

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As mentioned in previous newsletters, mailing our printed newsletter depends on available funding. Unfortunately, because of the extremely high postage rates for overseas, all of our Families and Professionals outside of the US will need to access our newsletter online. We will try, however, to continue to mail out the Family and Professional Updates so networking can continue. **There is still a possibility that we will be going completely online and discontinue the printed issue 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 the next printed update will be.

Thank you to Dr Arnold Strauss for sharing an update on his interesting research at Vanderbilt University. We also planned another Professional article for this issue, but due to unexpected circumstances, that article will be printed in our January 2003 issue.

Thank you also to all of 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, etc.)** to share their experiences. We're also always looking for more lowfat recipes, poems, and pictures.

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. Additionally, THANK YOU to all the Professionals (researchers, dieticians, counselors etc.) who returned the **'Professional Questionnaire for FOD Referral Purposes.'** If you haven't already please **complete this one-page questionnaire on our website (Online Forms)** so we can update our files, **even if you are already listed on the printed Professional List.**

We are still in need of recipes for the **FOD Recipe Book** so please read Sharon's note in this issue so she can compile all your great recipes!

NBS Advocacy issues are getting GREAT exposure with everyone's continued efforts to make their states, hospitals, medical practices etc., aware of the NEED for expanding Newborn Screening in order to SAVE LIVES! Take a stand and get out there and share your stories, no matter which FOD (or Organic Acidemia, etc.) your Family deals with in order to SHOW that...

'We Are All in This Together!'

Take care...

DLG



Letters to the Editor

Dear Deb: We are trying to decide whether to go to the October Metabolic Conference in Orlando. Why would it be beneficial for us to attend and who are the speakers and topics for the FOD session? B.G. (MCAD Family)

•••The 2 greatest benefits of attending such a great conference is the chance to talk with other FOD Families face-to-face, as well as to not only gain valuable information from our FOD speakers but to have access to over 160 sessions offered by the World Congress on Disabilities (WCD). Their speakers will be covering MANY issues that are relevant to our Families (i.e. school performance, dealing with ADHD, your legal rights, managing care for a child with challenges etc.) over the course of 3-4 days. Even though our breakout day is just on that Thursday (October 3rd), you will have access to the WCD seminars and exhibits October 2-6. Read more below...

National Coalition for PKU & Allied Disorders Conference October 3-5, Orlando, FL

The FOD Family Support Group has once again been invited to participate in a Metabolic Conference ~ this year's conference is **jointly organized by the National Coalition for PKU & Allied Disorders (877-996-2723 www.pku-allieddisorders.org) and the World Congress on Disabilities and Exceptional Parent**. It will be held **October 3-5, 2002** at the Orange County Convention Center in Orlando, Florida (childcare will be provided through the WCD using trained professionals, at the Convention Center ~ details are still being worked out, but some information is on the Registration Form). There will be a reception Wednesday evening, October 2, from 7-10pm at the hotel for those attending the Conference.

October 3rd will be an all-day breakout session (lunch not included) for each Metabolic Support Group invited by the National Coalition (PKU, FOD, OA, MSUD, HCU, Tyr). Each Group will have several speakers throughout the day that will discuss issues related to their specific disorder.

On the 4th and 5th, the Coalition and WCD have planned Newborn Screening sessions that should be exciting and very informative. **The full WCD schedule is on our website.**

Additionally, for the \$50.00 registration fee, **families will also have the opportunity to attend some of the over 160 seminars and exhibits at the WCD on October 2-5**. Many of the topics will be very relevant to dealing with our disorders. There will also be free time to visit (and play at!) the local attractions, such as Disney World! **We will have shuttle service from the hotel to the conference center, however families will need to rent a car if they choose to visit some of the local attractions.** Comfort Suites does offer free transportation to some sites (not Disney though) so please check their link on our site for further details.

Our **FOD speakers** so far include **Dr Charles Roe, Dr Mark Korson, Lynne Wolfe** (Pediatric Nurse Practitioner), **Cris Trahms** (Registered Dietician), and **Dr Susan Winter**. Our day will be full of GREAT information. Dr Roe will not only speak on his current research but also spend time answering any questions families have been anxious to ask. Dr Korson's presentation is titled 'Fatty acid Oxidation Disorders and the Physiology of Fasting' and Lynne Wolfe will be speaking on 'How to give and get the Information and Resources needed to help your Child.' Cris Trahms will offer 'Proactive Parenting and Self-Management Skills' and Dr Susan Winter will discuss 'Carnitine Treatment for FODs.' **We will not be audio/videotaping because of costs, so be sure to bring your own recorders if you want to tape.**

It will be **important to register through the NATIONAL COALITION (and not the WCD) in order to get the special \$50.00 conference registration rate.**

Hotel information for National Coalition attendees:

Comfort Suites of Orlando
9350 Turkey Lake Road
Orlando, FL 32819
Phone: 407-351-5050

Hotel Reservations should be made through Expo Travel at 800-829-2281. Room rate is \$70.00 per room and state that you are with the National Coalition/World Congress on Disabilities Conference.



Family Stories - *Nickolas Vukelich's Story, MCAD*

Hello my name is Marjorie Vukelich, I am writing to tell you about my son Nickolas Elijah Vukelich. We Live in Surrey, B.C, Canada. My son, Nickolas, was born September 11th, 2001 at 9:57pm, weighed 6lbs 12.8 ounces and was 21 inches long.

When Nicky was born he was a normal healthy baby boy. Two days after his birth we got to take our beautiful baby boy home. Nickolas had a feeding at 11:30 that morning (I was breastfeeding). About an hour after we got home he was due for another feeding, but he didn't want to eat. My mom and mother-in-law told me not to worry about it. So I put him in his crib and I lay down with him. I didn't sleep though. It was like **I knew there was something wrong.**

I got up and decided to try and wake him so that he would eat. I thought changing his diaper would do it. He still was not eating, so I phoned the hospital where he was born. They told me to take some breast milk and formula and mix it together and try to feed him by bottle and if that didn't work then call them back in 4 hours. Well 5 minutes later he was turning yellowish and his eyes were starting to cross. I got scared and called them right back. They told me not to go to the hospital but to take him to a clinic. I decided to take him to the emergency. **About 6 hours after bringing my son home** my father in-law and mother were rushing Nicky and I to the Surrey Memorial hospital. **He stopped breathing** on the way down there, but I was spanking him and he let out a small cry and was breathing.

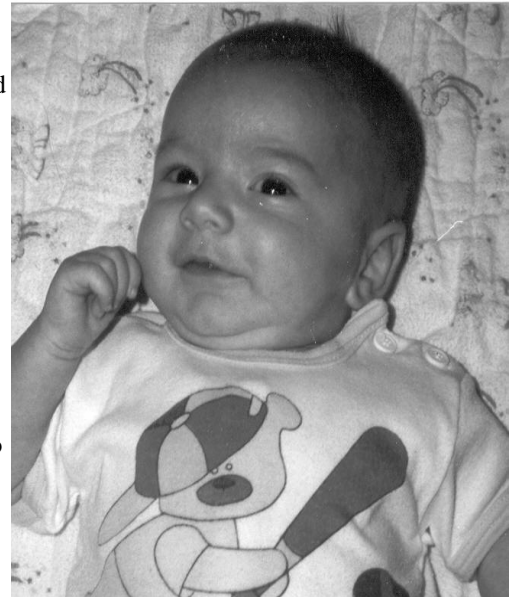
When we got to the hospital I rushed inside with Nicky. They took him from my hands and rushed him to the back. When they got him to the back, he stopped breathing and went into cardiac arrest. Nickolas was down for about 35 minutes when my husband got to the hospital. About 10 or 15 minutes after my husband arrived, **we were sitting watching the doctors working on our son and that is when they told us that our Nicky was gone. They stopped working on him at that point and I broke down.** A few minutes later the doctors and nurses were rushing around again. My husband and I asked what was going on. **Our son's heart had started to beat again on its own!** They told us then that they were going to transfer him to Children's Hospital in Vancouver, B.C.

When my husband and I got to Children's Hospital, the doctor that was on duty told us that if Nicky made it (he didn't think that Nicky would make it through the night) he would have major brain damage because he was down for 45 minutes. He did make it through the night, but for 2 days his eyes were fixed and dilated so we made arrangements to have him baptized on Saturday morning. **After he was baptized Nicky got better and better every day.** They did lots of tests on his brain because they kept showing abnormal results. **On September 20th my son was diagnosed with MCAD.** Nicky was in the ICU at Children's Hospital until September 22nd when he was well enough to be taken off the breathing tube and transferred. That was a Saturday and on Monday, September 23rd, **he had an MRI on his brain and we were ecstatic when the test showed nothing abnormal.**

Nicky was in the Children's Hospital for a total of 3½ weeks and was able to come home on October 6th, 2001. **I know we have a long road ahead of us, but that is okay because my baby boy is still with us. I thank God every day for the miracle he has given us.**

Nicky has been taking Levocarnitine since he was diagnosed with MCAD on September 20th (only 9 days old) and is a very healthy 5-month-old baby boy today.

Marjorie and Walter Vukelich
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Pharmaceutical Update

Sigma-Tau Pharmaceuticals, Inc. (makers of Carnitor® ~ www.sigmatau.com)
New Fax: 301-948-2049

If your **Physician** needs more information about L-carnitine (Carnitor®), dosages, or other questions, please have him/her **contact Sigma-Tau at 1-800-447-0169** 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.**



Family Stories - Andrew & Alexander's Story, LCHAD



We were happy together...my husband, myself, and our then 18-month-old son, Al. So happy that I decided that I wanted to have another baby to add to our happiness...another baby to share all the love our little family had to give. After an extremely rough pregnancy, Andrew was born exactly two weeks early, just like his brother. The moment we laid eyes on him, we were in love. Andy was the cutest little fellow, with long legs and hands just like his daddy's.

We loved and enjoyed our little bundle of joy very much and Al was especially attentive of his baby brother. But Andy did certain things that were very puzzling. He threw up (vomited) a lot, and hated being put on his back, to be changed or to be placed in his crib. Only when in our bed (between my husband and I) would he go to sleep. So there he was most every night, cuddled up safe and sound between mom and dad...until one particular night, when he was sixteen-months-old.

Earlier that day he didn't eat well, and had been unusually sleepy, with no interest in playing etc. His behavior was strange enough to me that I called his pediatrician and made an appointment for the following morning. He settled into bed with us that night (unbeknownst to me that it would be his last). He awoke at about 4am when he heard his dad getting ready for work. I awoke too, just in time to see him climb off the end of the bed and head towards the bedroom door. He stumbled, and his dad walked in at that moment and picked him up. He carried Andy back out to the living room and sat with him on the sofa. I got up too and went to see if Andy was okay. My husband and I both noticed that Andy was 'moaning.' This was very strange. We asked Andy to show us where he was hurting and he pointed to his chest. We decided immediately to take Andy to emergency.

The hospital staff did all kinds of tests on Andy, and everything came back negative, we were told. Until shortly thereafter, one particular doctor upon examining Andy, turned to us and said, **"You have a very sick baby."** And he then made arrangements for Andy to be transferred to another hospital. While informing us of this, **Andy went into 'cardiac arrest,' and two nurses lifted me out of the room, as I screamed Andy's name and he responded, yelling, "Mama, Mama."** No one could get Andy's dad out of the room. He stayed with him the whole time.

They wouldn't allow us to go in the ambulance, so we followed as close as we could. When we got there, we learned he was in PICU and we would have to wait about two hours before we could see him. My husband and I have no medical background between us, and so were quite shocked to see our precious son totally covered in tubes.

We had so many questions and as **we turned to the doctors with the word "WHY?"** literally written on our faces, they proceeded immediately to tell us that Andy's heart was enlarged and his other organ's were failing too. They wanted us to sign papers for a heart transplant, and informed us that his chance for survival was very slim. I immediately assured the doctor that my Andy would beat all odds. Then the machine in the room informed everyone in there that **Andy was in 'cardiac arrest' again.** Once again, my husband and I were shoved from the room, into the passageway. I only remember spinning, crying, and falling to the floor in a heap, blinded by my own tears...not knowing what had gone wrong with my beautiful baby boy. **The doctors came out to inform us that Andy did not make it.**

My husband did not know how he was going to explain to Al that his baby brother was not coming home. How could we explain to Al that his best friend, his playmate (Al was Batman and Andy was Robin), the baby he helped to feed and change, the baby brother he loved so much was never coming home again...

No words can describe how hard it was to say 'goodbye' to my son and to leave the hospital that night without him, still not knowing why or what had happened. For days and weeks I waited, for someone to come to the door, and say, "It was all a cruel, evil joke and we brought your baby back." I was in much more 'shock' than I realized and my heart, literally, ached for months.

We were led to believe that Andy must've died from some sort of deadly germ. And in my own mind, I always felt that couldn't be true. Not the way I took care of Andy, a germ could never have gotten passed me.

But, **nearly two years later** (after much pleading from my husband and son, Al, to have another baby) **I gave birth to a very healthy and beautiful baby girl.** Once again, big brother, Al, was very attentive, and proud of his little sister. But, we still could not stop thinking about Andy, all the time, every day. When our daughter, Analee, was one-year-old, I was pregnant once again.

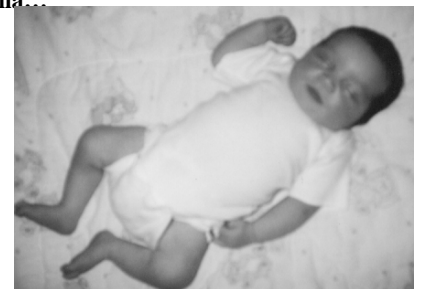
Our fourth child, Alexander, was born in the same month as Andy, December. He was a handsome little man, with a very healthy weight. We were filled with so much joy, and felt this baby was such a gift from God. And then **after only two weeks at home, Alexander suddenly turned blue in my arms one night.** This time I was allowed to travel in the ambulance with my baby. We went to the same hospital that Andy went to. And after barely surviving five days there, Alex was transferred to another hospital by helicopter so that he could be treated with an ECMO machine. During this time he was diagnosed with 'LCHAD.' Alex did well on the ECMO, but **after two months of fighting for his life there, at the hospital, he died from pneumonia...**

We learned thereafter, through investigation, that Andy had the same thing that Alex had ~ LCHAD. So we grieved for Alex, whom I call our hero and our little soldier, for fighting so hard to live. And we grieved again for Andy, upon learning for the first time, that LCHAD took his life too.

It has been an extremely rough road, and my love and devotion now go to my two remaining children, who have been true heroes as well, through all of this.

Our love and friendship to all the FOD Families,

Arleen and Albert Phang
Ontario, CA
Ajama1@att.net





Family Stories - *Rachel Pendley's Story, GA2*



Rachel was born on June 21, 2002, and after having three boys, we were thrilled. **She was perfectly healthy.** The only thing out of the ordinary was that her blood sugar was low when they first checked it after birth, so they had me nurse her right away. They rechecked and it was still low, so they had me give her some formula. They probably checked her blood sugar 4 or 5 times that first hour after birth. When I questioned why, I was told that sometimes when babies go through the stress of labor, it causes low blood sugar. I didn't think much of it then, but now I'm sure that it was because of the FOD. I was never informed of any other low blood sugars, so I assume that any other tests were fine.

The next three weeks passed without event. At her 2 week check up she got a glowing report. Then when Rachel was 3 weeks old, she refused to eat all night. It was the first time that she cried and I couldn't figure out why. She cried from midnight till 1am before I got her to go to sleep. Throughout the night she woke up every 2 or 3 hours but wouldn't eat. She was up just long enough to cry herself back to sleep. At 8 am I called the doctor because I feared that she could be dehydrating. The doctor said to wait a couple of hours and try to feed her again, but I figured that if she didn't eat all night a couple of hours wasn't going to make a difference. I knew something was wrong. I thought maybe an ear infection or virus. I asked if I could just bring her in. I got a 10 am appointment.

When the doctor examined her, she said that her heart was beating fast and her breathing was fast (I found out later that her heart was beating so fast that the doctor couldn't count it). She said that it could be pneumonia or some other infection.

She wanted me to take her right to the hospital, but I had my other 3 children with me. So I asked if it was OK to take them to a neighbor's house first. They said that was fine, but that Rachel needed to stay with them at the doctors. That was my first clue that something was very wrong. I took the boys to the neighbors, and when I returned to pick her up, the doctor said to take her directly to the hospital because she was having trouble breathing. That scared me and I kept making sure she was breathing all the way there. I called my husband and he met me at the hospital.

When we got there, we went to admitting and went through the normal slow procedure. When we got to the pediatric treatment room, they started an IV. She got very upset, and started crying hard. **The next thing we knew she was turning blue.** The nurses administered oxygen, and within minutes she was being rushed to ICU. **They got her stabilized, but her heart rate was in the 260's.** They did an EKG and an echocardiogram. We were told that there were structural abnormalities in her heart. They couldn't tell us anything else till the cardiologist arrived. The intensivist then said that they needed to insert a central line. It took a while to insert. She was pretty much out of it at this point. She had so many needles and lines coming out of her, I didn't know what to think. I just stood there watching and crying. **At this point the nurses called the hospital chaplain and asked if there was anyone that they could call to be with us. I thought that they were preparing us because they thought that Rachel was going to die.**

Finally the pediatric cardiologist arrived. He said that she had two holes in her heart, but that was not his biggest concern. Her heart rate was still in the 260's and 270's. He tried a number of things to get her heart rate down. First he put ice on her face, then medicine in her IV, but nothing worked. **The last resort was the heart paddles.** By this time our Pastor had arrived, and some friends from church. The doctor tried the paddles the first time, and they didn't work. At this point we left the room and went to the waiting room to update our friends on Rachel's condition, so that they could pray. While in the waiting room, our Pastor led us all in a word of prayer. When we got back to her room, her heart rate had come down. While we were gone, the doctor had doubled and then tripled the voltage. **The third time worked! She was out of immediate danger, but her breathing was still very fast and labored.** By this time, it was 7 or 8 in the evening.

By 10 or 11 pm everyone left, but I stayed with her and slept in the hospital. I was just falling asleep about 1 am, when they came in and said that they were going to put her on the ventilator. After that they wanted to start an arterial line. A doctor from the peds floor came in to see what was going on and ended up staying most of the night. **He told me that Rachel probably had some sort of metabolic problem, because she should have been much better by then.** They took a lot of blood to do tests. They called the intensivist to come in the middle of the night. They worked on her for hours, taking things from the crash cart. It was so scary. I called a friend and talked to her from about 2 to 3 am. She helped calm me down. It was 4 am and they were going to try one more time to get an arterial line in her. I was totally exhausted and finally went to sleep. They never got an arterial line in her even though they tried two more times over the next couple of days. Instead the doctor put in another central line.

Friday morning, I woke up and she was stabilized. It was so sad to look at her. She had so many IV's, monitor wires, ventilator tubes and a catheter coming from her. **I counted every line including all the tubing for the ventilator, and there were nineteen.** They kept her pretty well sedated while she was on the ventilator. It was so sad to see her cry, because her mouth looked like it was screaming, but no sound came out. **It made me cry every time I saw her "silent cry."**

That morning about 11 am, the geneticist, Dr. Asamoah, came to see her, and talked to me. He asked about everything that had happened, and took a family history. He suspected that she had a metabolic disease, and tried to explain what that was to me, but I was so exhausted and overwhelmed. I could not believe all that had transpired over the last 24 hours. She went from slightly dehydrated to critical condition in 24 hours. They also gave her a blood transfusion because her iron was low, from having so much blood drawn.

Over the next few days she gradually got better with some steps backward. On Saturday, they tried feeding her my breast milk through an NG tube, but her acid level went up so they switched to Pregestimil on the geneticist's recommendation. Within a few days they started supplementing the Pregestimil with Moducal to help keep her blood sugar up. They checked her blood sugar every 3 hours from that point on. Monday morning, they took her off the ventilator and she did fine. **I was finally able to hold her!** Over the next week, they slowly weaned her off the glucose IV.

A week later, she was transferred to the regular peds floor. The geneticist came to see her again, and to explain again about metabolic diseases. This was the first time I learned that her low blood sugar was related to her metabolic problem. I had hoped to have a firm diagnosis by now, but not all of the tests had come back. **He said that she probably had a disease where she wasn't able to break down long chain fats.**



Family Stories - *Katie & Elizabeth's Story, Unclassified FOD*

Katie and Elizabeth had caught a tummy bug ~ their first at 4½ years and 18 months old. Both were unwell when Elizabeth was admitted to hospital with an enlarged liver, which the examining doctor discovered. After a week in hospital on a drip, and having undergone loads of blood tests, she was discharged and we were none the wiser. During this time, I had to make the decision as to whether or not I would travel to Brussels on business the following week. The thought that Elizabeth may go downhill again bothered me and I decided to pass this role over to a colleague. Little did I think that Katie would be so ill within such a short time.

Katie appeared to have gotten over the bug, though it had taken several days. I recall my mother's words ~ "How do we know that Katie's liver isn't enlarged too?" It turned out, subsequently, that she was quite correct in this assumption. Katie started being sick again. She wasn't eating and I gave her sugary drinks. I became very concerned and took her to the surgery where she was examined by a locum, who told us to carry on as we were.

That evening Katie seemed very poorly. **I had a conversation with a young doctor at our surgery, who did not want to come and see her at home. "That will cost an hour extra of my time," he said. I was horrified at his attitude.** I spoke to Healthcall later and had to wait until my husband's return from work so we could take Katie to the emergency surgery premises a few miles away. It was a dreadful evening, pouring with rain and not the night to be taking a little child out, who it turned out was so unwell. The doctor gave Katie a cursory look over and told us to keep rehydrating her. We took her home and put her to bed.

At midnight, when we were all asleep, the doctor we had seen at around 8 pm called to see how Katie was. I checked Katie who was sound asleep and spent the next couple of hours lying awake, concerned at the doctor's now apparent concern. She admitted she had been concerned when she sent us home. At around 5:30 am, Katie became delirious, repeating a telephone number from a child's television programme. Then the dreadful rasping breathing started. **I couldn't believe my child could be so ill.** My husband and I had put the baby monitor in Katie's room that night, as we were concerned. For no apparent reason, all the lights on the monitor went red and it started to make a buzzing noise, something that had never happened before. I immediately made the decision to call an ambulance. They told us to put her on the floor and put the phone to her so they could hear her breathing.

I picked up my mobile phone and rang our friend, Mike, who is a doctor. The first time the call did not go through. The phone indicated 'battery low.' In desperation, I tried again and amazingly the call went through and our friend arrived within just a few minutes to see Katie on the floor. My father, whom we called, also came and I will never forget his face as he looked down in disbelief at his beloved granddaughter.

The ambulance crew came in and then took Katie out on a stretcher. I turned to Mike for reassurance that Katie would be all right. He said that **she was a very ill little girl.** We went into the ambulance and began the journey to Colchester hospital, 18 miles away. Mike sat in the front and called on ahead to the hospital, something that saved vital time at the other end. When we arrived at the hospital, a team of about 12 doctors and nurses were waiting for us. **By the time Katie reached the hospital, she had no measurable blood pressure.** I understand Mike thought we might lose Katie and that if we didn't she was likely to suffer brain damage. Whilst we were on the way to hospital, **people had started praying for this little girl and I believe that these prayers and those that went on for the next week or so were answered in an amazing way.**

Injections. Resuscitation. Incredibly after a few minutes, Katie started to speak and asked, "When can I go home?"

Katie was transferred from A&E to intensive care. When my parents-in-law came over, Katie said: "Is that my grandad?" After a few hours, I was able to hold her. During this time, my parents and sister arrived with clothes and supplies for us all. Later on, a kind nurse came up from the children's ward and said that she would be looking after Katie when she was ready to come down to that ward. However, Katie's breathing was causing a great deal of concern and after a while a decision was taken to put her on a ventilator. She had pneumonia. The hospital, however, cannot keep children on a ventilator for more than a few hours and it was necessary for her to be transferred to another hospital. Fortunately, a bed was available at the world-renowned Addenbrooke's Hospital in Cambridge. A doctor and nurse arrived and started to put the various life support systems on to Katie. They said it would be too dangerous for her to undertake the one-and-a-half hour journey until she was stabilised. After another three hours, she was taken by ambulance to Addenbrooke's. My husband, Richard, and I travelled by car and went straight to the Paediatric Intensive Care Unit (PICU) to see Katie.

Everyone at the hospital was wonderful. They made a dreadfully worrying time as stress-free as possible and there was peace in what was otherwise turmoil. We were given accommodation in the hospital grounds for the duration of our stay.

Katie was stable after her first night and Richard and I felt encouraged by this. That morning, we were asked to go to the consultant's room, where there were a number of doctors and nurses. We thought this must be a normal event for PICU admissions. The consultant spoke kindly, but frankly, to us. They did not yet know the nature of Katie's problem, but she was presenting in an encephalitic way. She was acidotic. **She had a 50/50 chance of pulling through. If she did, she could well have brain damage. To say our world felt as if it was falling apart would be an understatement. We were stunned.**

That afternoon, Richard and I felt an amazing sense of peace...we were aware of God's presence with us. A good friend from nearby came in to see us and we all prayed about the situation. **We were supported throughout this time by our family and friends and their prayers, as well as from people we did not know.** I remember walking back to PICU and being met by a nurse who said he had some bad news. He told me my dear grandmother (who had been ill) had passed away. Everything seemed to be happening at once.

The next few days continued to bring its highs and lows. At one point, Katie's hands went very tense and we were asked if there was any muscle problem in the family, which there wasn't. Thankfully, the remedy was to give her some calcium, which sorted this out. Many tests were performed on Katie. Once or twice, she was taken off the ventilator and then had to go back on it, but eventually she was taken off it, and we had to wait until she regained consciousness to see how she would be. I have never been so pleased to receive a call in the early hours as I was on this occasion. Katie had woken up and was asking for mummy. I rushed over to the ward and was so relieved to see our little girl conscious – looking very hollow-eyed, but nevertheless 'with it.'



Katie & Elizabeth's Story, Unclassified FOD ... cont'd

The next day we were on the children's ward. **The doctors wondered if Katie had an LCHAD problem, or possibly a fructose intolerance.** She was placed on a very low fat/no fructose diet, which we followed on our discharge from the hospital. Reading labels on food became a way of life for a while, as did the frequent blood/sugar prick tests. The LCHAD test was negative and we were referred to Great Ormond Street Hospital in London for further tests under Professor Clayton.

Both daughters were tested. They were put on a fast. After 12-15 hours, Katie particularly was wilting and started to go delirious and the fast was stopped. It turned out that neither Katie nor Elizabeth produced ketones. **A few weeks later they had skin biopsies, which showed a fatty acid oxidation problem, but the precise nature was still unclear.** All we knew was that their livers were not producing an enzyme to convert fat into sugar at times of stress. However, at least we now knew what to do if either girl could not eat or if their metabolism was altered by a high temperature. They have a high carbohydrate drink, and if they have a tummy bug and can't tolerate anything, they have IV dextrose until they are better.

Recently, Richard, Katie, Elizabeth and I have had blood tests. Research is being undertaken and **it looks as if they are getting close to being able to define the precise nature of the girls' problem** by sequencing the gene. It seems the **problem could be with HMG - Co-A syntase enzyme**. At the time of writing, we are waiting to hear more.

There is such a fine line between life and death and we realize how fortunate we are in not losing Katie back in March 1999. Having linked up with the FOD Network, who we are very grateful, we understand how many people have suddenly lost children because of an FOD disorder.

Helen & Richard Whybrew
Essex, England

Katie, Unclassified FOD, age 7

Elizabeth, Unclassified FOD, age 4

helen@whybrew.freemove.co.uk



Family Stories - *Catalina Arias's Story, LCHAD*

Hola. Espero que estén bien. Yo perdí el contacto por un tiempo, debido a problemas de fuerza mayor. Quiero agradecerle por la información que enviaste y que me llegó el pasado mes. Mi hija Catalina está muy bien. Ella está atendándose cada 6 meses en el Departamento de Medicina Genética de la Universidad Católica. Los doctores están bien contentos con su progreso. Aquí la tengo a mi lado como un mosquito revoltoso, junto con mi esposa. Todos estamos muy alegres.

Catalina nació el 7 de mayo de 1999 en Concepción 8ª Región, Chile. Su desarrollo fue normal hasta el 1 de Noviembre de 2000, cuando entró en una etapa de deterioro que en un principio pensábamos que se trataba de una enfermedad común. La llevamos a un pediatra, el cual pensó que se Catalina tenía un resfriado, y nos fuimos a casa. Al día siguiente, Catalina entró en coma. La llevamos de urgencia a la Clínica Francesa, donde los primeros exámenes que se le practicaron revelaron una deficiencia de azúcar en la sangre. Se le colocó suero de glucosa, el cual tuvieron que cambiar porque los niveles se le dispararon hacia arriba y no despertaba. Pasamos por varios doctores y una infinidad de exámenes, los cuales decían que estaba todo bien.

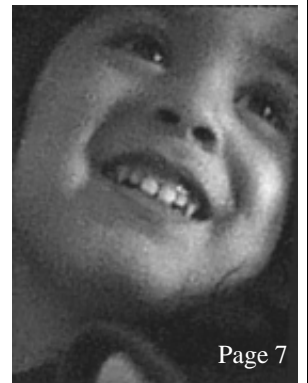
Al final, por sugerencia de su pediatra, nos visitó una geneticista de apellido Selman. La examinó, palpándola con sus manos y nos dijo que su hígado estaba recrecido, cosa que podría deberse a una enfermedad metabólica. Esto sólo podría confirmarse mediante un examen específico que se lleva a cabo en la Clínica Mayo de E.U. Nosotros procedimos a hacerlo. La geneticista también nos recomendó usar l-carnitina, la cual se comenzó a administrar inmediatamente. Llevábamos unos diez días de espera e incertidumbre, pero cuando la carnitina entró en su organismo Catalina despertó de su sueño. Al tercer día del tratamiento dejó la ICU, y en un corto tiempo nos la llevamos a casa. Más tarde, llegaron los resultados de la clínica Mayo confirmando el diagnóstico de la doctora Selman.

El diagnóstico es de L-Chad en estudio, por que la condición no se comporta típicamente. La verdad es que yo apenas sabría definirlo, pero los antecedentes están ahí, en la Clínica Mayo.

Te estoy enviando algunas fotos recientes de Catalina.

Manuel Arias Peñaloza elosoblanco@123mail.cl

Calle larga # 128 santa clara Bulnes 8región Chile





Catalina Arias's Story ...English translation

translated by: Meg Super - mrgt31@yahoo.com

Hello. I hope that you are all doing all right. I lost contact with you for a while due to major problems. I'd like to thank you for the complete information you sent me (Family Packet) that I received last month. My daughter Catalina is doing very well. She is being evaluated every 6 months in the Catholic University's Genetic Medicine Department. The doctors are very happy with her progress. Here she is, by my side, bugging like a mischievous mosquito, along with my wife. We are all very happy.

Catalina was born on May 7, 1999 in Concepcion 8^a Region, Chile. Her development was pretty normal until November 1, 2000, when she entered a phase of deterioration that at first was thought to be a common cold. We took her to a pediatrician, who thought all Catalina had was the flu, and then we went home. The following day, Catalina entered a coma. We took her urgently to the French Clinic, where the first exams that were practiced on her revealed a blood sugar deficiency. She was placed on a dextrose serum, which quickly had to be changed because her blood sugar levels skyrocketed and she did not wake up. We went through various doctors and an array of exams, all of which said everything appeared to be ok with her.

Finally, her pediatrician suggested we consult a geneticist, Dr Selman. She examined Catalina, feeling her abdomen with her hands and told us that Catalina's liver was bad, and that it could be due to a metabolic condition. She explained this could only be confirmed through a specific exam that could be done at the Mayo Clinic, in the USA. We proceeded to travel and follow her instructions. The geneticist also recommended us to use L-carnitine, which began to be administered immediately. We then waited for ten days with feelings of uncertainty, and then when the carnitine entered her body Catalina woke up conscious again. She left the ICU at the third day. After a short while we were able to take her home. Later, the results of the clinical tests from the Mayo Clinic arrived confirming Dr. Selman's prognosis.

The diagnosis is of L-Chad in study, because the condition does not behave typically. The truth is that I barely would know how to define it, but her medical history is there, at the Mayo Clinic. I am sending you some recent pictures of Catalina.



Medical Update

Our laboratory (at Vanderbilt) continues to examine many aspects of fatty acid oxidation proteins and genes, both in patients with fatty acid oxidation disorders and in mice in whom several FAO enzymes have been deleted. **Three projects are summarized below.**

First, in conjunction with state laboratories responsible for newborn screening using tandem mass spectrometry, **we have searched for mutations in medium chain acyl-CoA dehydrogenase (MCAD), trifunctional protein subunits (TFP and LCHAD deficiency), and very long chain-acyl-CoA dehydrogenase (VLCAD).** The results from the Massachusetts/New England initial two-year experience (Zytkovicz et al., *Clinical Chemistry* 47:945-55, 2001) and previous data from Pennsylvania and North Carolina (Andresen et al., *American Journal of Human Genetics* 68:1408, 2001) clearly show that the **screening methodology is effective and efficient in finding newborns with MCAD deficiency.** However, **some heterozygotes may also be detected by screening.** The incidence of MCAD deficiency is about 1:15,000 newborns. **The mutation studies show that mutations other than A985G, the common MCAD mutation discovered 10 years ago, occur more frequently than previously suspected (about 30% of alleles).** In short-term follow-up, treatment with frequent feedings and vigilance is effective in preventing metabolic crises and death. The numbers of TFP, LCHAD, and VLCAD patients picked up by screening seems to be insufficient to conclude much about the effectiveness of screening for these disorders yet.

Second, we have generated mice with deletions of the TFP and VLCAD genes. Because these animals have no expression of TFP or VLCAD protein, **the mice are similar genetically to only the most severe of human mutations.** VLCAD deficient mice appear normal after birth and survive well. However, when stressed by fasting and/or exposure to the cold, the deficient mice rapidly develop low glucose and/or low body temperature and die. Later in life, VLCAD deficient animals become fatter than normal mice and develop heart rhythm problems. Because we can study these animals in detail to determine how they have adapted to loss of VLCAD and as to how they respond to various stresses, drugs (such as carnitine), and differences in diet, **we believe that we may find some important data that may prove relevant to children with VLCAD deficiency.** The TFP deficient mice have a more severe problem, and most die spontaneously and suddenly shortly after birth because of breathing difficulties and low blood sugar (Ibdah et al, *Journal of Clinical Investigation* 107:1403-1409, 2001). This is similar to severe and complete TFP deficiency that occurs very rarely in babies. **These animals are NOT similar to LCHAD deficiency. Again, we hope to study these animals in detail to better understand how fatty acid oxidation defects cause illness in children.**

Third, we have now found 15 families worldwide with complete TFP deficiency. Three types of presentation occur: (1) infants with severe heart problems and metabolic crisis who have all died; (2) toddlers with hypoglycemia and metabolic crises who may recover and do well; and (3) older children or adolescents who have episodes of muscle pain and weakness with stress but who are mostly healthy. **These results emphasize that some TFP mutations are fairly mild and that children, even with complete TFP deficiency, can survive well.** That is, **there is great variability in clinical status of TFP deficiency, as in other FAO.**

Thus, we continue to learn novel and exciting things about FAO disorders, both in people and in mice.

Arnold W. Strauss, M.D.
James C. Overall Professor and Chair
Room AA-0216 Medical Center North
Vanderbilt University
Nashville, TN 37232
615-322-3377 (Office phone)
615-322-2678 (Lab phone)
arnold.strauss@vanderbilt.edu



question & ANSWER



Question: Can you please address elevated ammonia issues and FODs? From my reading, I believe that once a child is symptomatic from elevated ammonia levels (i.e. vomiting), it must be treated. If it is not treated, it may get worse and lead to more problems like lethargy, coma and death

Answer: Ammonia is a normal chemical in our bodies from the breakdown of proteins. It can come from the proteins we eat or from the breakdown of our muscles and other body proteins that occur normally every day. Most Ammonia is broken down further in the Liver into Urea, which leaves our bodies in our urine. Ammonia levels can rise when the Liver is not able to work correctly from an infection, or a metabolic disorder affecting the enzyme function of the Liver. The Liver can be affected by many Metabolic disorders. "Reye-like" Syndromes have been associated with children who have undiagnosed Metabolic disorders, especially FODs. It is believed that high Ammonia levels can contribute to the lethargy we often see when children are diagnosed with Reye's Syndrome. Ammonia levels can become very high and cause severe problems, including coma and death, especially when the children are in an unrecognized metabolic crisis. There is a very complete list of the metabolic disorders that have been associated with "Reye-Like" Syndromes, and how undiagnosed metabolic Disorders and true Reye-Syndrome differ on the FOD Website under Medical Information. Ammonia is measured in a blood test. It is a technically finicky test requiring fast, non-tourniquet drawing, sometimes arterial, rather than venous blood, it must be put in ice immediately, and run in a very short period of time or the results can be falsely elevated. It is affected by when your last meal was eaten, how well the Liver is working etc. For children with FODs this would not be a routine test, but it would be considered if your child were very ill and lethargic.

Answered by: Lynne A. Wolfe, MS, PNP, BC

Importance of Expanded Newborn Screening!

Many of you know some of my family's story as far as MCAD NOT being diagnosed in time with our 21-mos-old daughter, Kristen, in 1985, as well as having it diagnosed at birth with Kevin (now 16 yrs old and thriving!), but **I just wanted to share with all of you of how VERY IMPORTANT expanding NBS screening is** (which ALL of you already know!) and how it has touched not only my immediate family but my extended families. We **NEEDED it back in 1985** but the screening test was still in its early development and information about MCAD and the other FODs (as well as some other metabolic disorders) was not really out there for the general public (many medical Drs didn't even know about it either – some still don't!).

Lives are changed forever when a diagnosis (or NO diagnosis/death) occurs and the experiences run the gamut of emotions and thoughts ~ from tragedy to joy to even the 'bizarre!' Screening may not have been available for us 18 years ago (in IL, our home) but it sure came through a few years ago for 2 of my nieces (in their late 20s) and 7 months ago for Dan's nephew and his wife who happen to live here in NC (where it's mandated to screen for those 30+ disorders ~ although NC still NEEDS to get onboard for some other disorders so it can become a comprehensive state!).

Anyway, a timeline of events may better explain what I mean:

July 21, 1985 ~ our daughter woke up vomiting (we were told it's just the flu, let her sleep) and 12 hrs later she was dead from what they INSISTED was Reye's Syndrome (we KNEW otherwise). Six months later when I was pregnant with Kevin, my sister's Pediatrician read about MCAD in a Pediatric journal and mailed us the article. We INSISTED that he be tested when he was born despite our Doctors still insisting Kristen's death was RS.

June 12, 1986 ~ Kevin was born and his blood/urine was sent to Dr Roe when he was still at Duke University (where the expanded NBS test with tandem mass spectrometry was 1st developed). Dr Roe called and said he tested positive for MCAD. We sent liver tissue from Kristen's autopsy and he confirmed she had it too (even though we already KNEW that!). If Kevin had not been diagnosed he most likely would have died at 6 months when he had his 1st illness. Our 3rd child, Brian, born in 1987, is a carrier.

After Kristen's death, my 5 siblings went to be carrier tested and 3 of 6 of us were carriers ~ my older brother had a mix up with testing and never got back to it so he didn't know if he was a carrier or not. He figured when his kids were old enough to have their own children they could be tested for carrier state.

Little did he/we know that when his 2 daughters were pregnant in 1998 or so they decided to be tested with Dr Roe at Baylor ~ they were NOT carriers though ~ **the test came back POSITIVE for MCAD! BOTH of them had it.** Both have had 2 healthy and unaffected children since their diagnosis. They (my nieces) have made some diet adjustments (and carnitine when sick or pregnant) and are doing well.

Now move to January 2002, when Dan's nephew and his wife had their first child. His nephew knew he was a carrier for MCAD so they were anxious to get the NBS test back to see if the baby had that.

Well, **the baby didn't have MCAD but she DID have 3-MCC, an Organic Acidemia! And if NC hadn't been screening for those 30+ disorders, she most likely would have gone undetected until a serious episode would have occurred or worse!** Dan's nephew was going to be seeing Governor Easley at a function and he told me he is for sure going to go up to him and tell him how **expanded NBS saved his daughter's life** and that he's thankful NC screens for these disorders!

Importance of Expanded Newborn Screening! ...cont'd

So now our families are not only connected through an FOD but an OA and the ONLY way we KNEW was through EXPANDED NBS! When ALL states finally realize that **expanding NBS SAVES LIVES**, I'm sure there will be more family experiences like our own. But it will **ONLY happen when there is UNIVERSAL screening**.

Although I favor more of a Regional testing approach rather than waiting for each state to buy their own spectrometers etc, the word IS getting out how this expanded NBS can benefit ALL our Families. Along with all the other NBS Advocacy efforts going on throughout the country, there was also a congressional hearing on June 14th that addressed the issue of making EVERY Family and Professional involved with newborns AWARE and EDUCATED about the expanded NBS tests NOW AVAILABLE. **Parents have a right to KNOW that there are Labs already doing this expanded testing for a small fee and if their state/hospital does not offer it yet then they can go through those specific Labs.**

It will take continued nationwide efforts to make that happen ~ and it will not be easy as all have found out so far, but the **GOAL is SAVING LIVES, and it most definitely is a goal to continue striving for!**

Deb Lee Gould, Director



Rachel Pendley's Story (GA2) ...cont'd

We went home on Wednesday. The cardiologist diagnosed her with Wolf-Parkinson-White syndrome, and 2 VSD's. She has not had any problems with her heart since her crises. I was so scared to bring her home. I had to check her blood sugar and feed her every three hours around the clock. She was not a good eater at the beginning, so I also had to learn how to place an NG tube. Thankfully, I never had to use it.

A week after we brought Rachel home from the hospital, we went to see Dr. Asamoah. He retook all the blood tests and took a skin sample for testing. He gave me a pamphlet of the FOD support group and once again explained everything to me. **The test results came back at the beginning of November, and showed that Rachel has Glutaric Acidemia Type II.**

Since then Rachel has done very well. She is now a good eater, and is in the 90th-95th percentile for height and weight. Developmentally she is exactly where she should be with motor skills and language. She has been hospitalized twice with the flu to get a glucose IV, but no major problems. She is on carnitine and riboflavin, and is on a low fat/low protein diet. I now check her blood sugar only once or twice a day. She is able to go 6 hours between feeds at night with cornstarch. **I know that a big reason she is doing so well is that it was caught fairly early.**

I thank the Lord every day for my little girl, and for all that He has helped her through. I am also thankful for a good geneticist. **Dr. Asamoah is very good at explaining things to me and taking time to answer my many questions. He takes her FOD very seriously and is very cautious in her care. I am also thankful for the FOD support group.** I have learned so much on the list and from all the information that Deb has sent me.

Jill and Brian Pendley
bjpendley5@juno.com



Notes

Deb's Updated Email Address

Please update your address book ~

Main address is deb@fodsupport.org

Backup address at fodgroup@triad.rr.com

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 you 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**

(see page 1 of this issue for address) so we can list you in the next List Update.

Professional Questionnaire for Referral Purposes

All Medical/Health Professionals: Please complete the Questionnaire on our website www.fodsupport.org under 'Online Forms' (even if you are already listed on our printed Professional List ~ this is an Update) **if you would like Families to know that you diagnose, clinically treat and/or do research with Children and/or Adults with Fatty Oxidation Disorders.**

Please return to Deb Lee Gould via email or regular mail.
deb@fodsupport.org or 805 Montrose Drive
Greensboro, NC 27410



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

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

Jacque and Mike Bradford

Eric - Birth Aug 22, 1990 Death Aug 26, 1990

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

Mark and Karen Carpenter

James - Birth May 7, 1985 Death Dec 6, 1986

Jenny and John Carroll

Sarah - Birth March 4, 1992 Death Sept 1, 1992

Mark and Diane Casey

Matthew - Birth Apr 15, 1974 Death Jan 13, 1975

Jennifer - Birth Oct 19, 1975 Death Nov 13, 1979

Lori - Birth Aug 31, 1980 Death July 1, 1984

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

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

Sandy and Jon Cooper

Noah - Birth Oct 5, 2001 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

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

Brandis Greichunos

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

Jeannette and Keith Guillory

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

Nicole and Chris Gulinello

Alec - Birth Feb 21, 2001 Death Aug 24, 2001

Michael and Nicole Gumiel

Michael - Born March 28, 1998 Death April 4, 1999

Carol and John Hall

Sarah - Birth June 8, 1998 Death July 30, 2000

Robin and Vince Haygood

Ben - Birth Feb 19, 1998 Death Aug 8, 2000

Ralph and Angie Hedrick

Chelsea - Birth Jan 11, 1995 Death Apr 3, 1996

Nikki and Toby Hiatt

Reece - Birth Aug 1998 Death April 18, 1999

Pauline and Bill Hill

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

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

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

Brian and Kim 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

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 Melendes
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

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

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

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

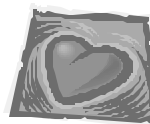
Richard and Amy Warner
Andrew - Birth May 1978 Death Nov 18, 1979
Scott - Birth May 1983 Death April 25, 1985

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 - Born June 14, 1993 Death June 17, 1993

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



*'The journey from grief to hope
does not happen simply, but it
happens if you will let your heart
ride along.'*

~ Sasha, from Wintersun

FOD Recipe Book

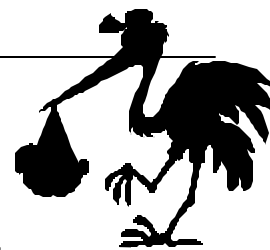


Sharon Fisher is **still compiling low-fat recipes for an FOD cookbook**, which will cost \$6.25 each plus shipping and handling. **Each book sold will help donate \$3.00** (non-tax deductible, however) **to the FOD Family Support Group** and will help us with copying and postage costs. We **still need more recipes as well as pictures of FOD kids**. Please **include the following with your picture or recipe: Name, Relationship to FOD person, Type of FOD, State or Country you are from**

If you do not wish to use your name etc., you can be anonymous contributor. Contact Sharon Fisher for more information ~ 402-463-5699 or tyandsharon@hotmail.com

Welcome to new babies!

- Michele (formerly M. Tubb) and Kevin Burgess are proud parents of Nadia, sister to Treyvon (LCHAD), who was born on Sept 26, 2001.
- Rosemary and Jim Luebrecht ~ Nicholas was born on Oct 10, 2001, and was 9lbs 1 oz. His sister, Jennifer (MCAD), loves having him here.
- Stacey and Paul Webber and brother Joseph (Unclassified FOD) announce the birth of Colby James on Nov 28, 2001, weighing in at 9lbs 12 oz and 22" long.
- Stephanie and Andrew Plaisted welcomed Lucas Patrick (brother of Drew, undiagnosed MCAD) into their lives on March 3, 2002. He was 7lbs 5 oz and 20" long at birth.
- Koryn Korissa Lafferty entered the world on March 27, 2002 at 6:02am. Proud parents are Cathy and Keith and sister, Carli (MCAD).



Resources

- **NBS and Formula Legislation Email Lists** ~ see the **National Coalition for PKU & Allied Disorders** at www.pku-allieddisorders.org ~ they provide Email Lists that **raise awareness for the need to EXPAND Newborn Screening in this country and discuss ways to promote that objective**, as well as a **List to advocate changes in Legislation for coverage of metabolic formulas**.
- **Driven to Distraction: Recognizing and coping with attention deficit disorder** by Edward M. Hallowell, M.D., and John J. Ratey, M.D.
- **Children's Hopes & Dreams-Wish Fulfillment Foundation** ~ Pen Pal program for all children 5 through 17 years with a chronic or life-threatening disorder, any disability, dealing with a loved one's illness, death or separation from the family. Call 973-361-7366 or email CHDFpenpal@juno.com.
- **Sensory Integration International** ~ <http://home.earthlink.net/~sensoryint> (310) 320-9986

Kids Korner



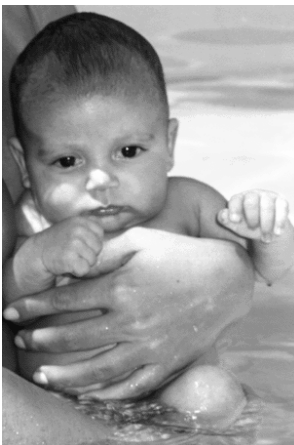
Floortje Jansens (MADD/GA2),
Belgium



Juan Fernandez (VLCAD),
Argentina



Koryn Korissa Lafferty —
parents Cathy and Keith



Arthur Barbosa (Undiagnosed),
Brazil



Kevin Gould (16, MCAD),
Exercise testing at Baylor



Candace Boyd (LCHAD)



Madeline Thorn (MCAD)



Alexis & Zach Kilburn (GA2)



Family & Professional Donations

Family Donations: Linda and Erik Kocher in honor of Audrey (MCAD), Dana and Dean Bretthauer in honor of Troy (CPT2), Stephanie and Andrew Plaisted in memory of Drew (MCAD), and Arlene and Albert Phang in memory of Andrew and Alexander (both LCHAD).

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

We greatly appreciate donations to help with postage and copying fees. **Checks can be made payable to FOD FAMILY SUPPORT GROUP.** Because we are not officially a non-profit organization, donations are not tax deductible at this time.



Thank you to Erika Wallace - erikawallace@hotmail.com (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.



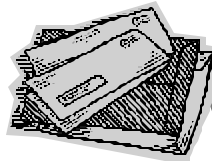
Reminders

Families - Please send **TYPED** stories by **December 1, 2002**. 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 **December 1, 2002**. Also, please return to Deb the **Professional Questionnaire** even if you are already listed on the printed Professional List.

"Our greatest glory is not in never failing, but in rising every time we fail."

~ Confucius ~



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