

FOD

Support

fatty oxidation disorder communication network



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Welcome our New Medical Advisory Board - pg 2
Tax ID # 83-0471342 (501c 3 nonprofit tax-exempt status is pending)



From the Editor

Well, it took 16 years but as of Jan 1, 2007 **we are now officially a non-profit Group!** I had been 'holding off' all these years because the process can be daunting and there's a lot of paperwork and cost. Fortunately, I have enlisted the help of an accountant to file our tax-exempt papers so **hopefully later this year we should be a 501c3 non-profit ~ which means all of your donations will be tax-deductible retroactive to Jan 1, 2007. Our Tax ID# is 83-0471342. We can begin to accept donations** (but keep in mind **our tax-exempt status is pending**) so we will update our website with a Donation page where you can donate via PayPal (or mail a check to me made out to 'FOD Family Support Group') ~ there will be options to donate for the General FOD Fund (which will cover day-to-day costs), a Clinical Trust Fund (to raise funds to help clinically train new Drs/nutritionists etc in the field of metabolism and genetics), and a Research Trust Fund (to raise funds for FOD research) ~ all of these options can be given in honor or memory of a loved one. When you donate this year, you will receive a THANK YOU letter of acknowledgment for your donation. Again, **once our tax-exempt status is complete, your donation will definitely be tax deductible for 2007. Our Group's official main fundraiser every year** will be a Letter mailed out to everyone on our Mailing

List ~ the **'2007 Annual Giving Letter'** will be mailed some time in the next few months. With nonprofit status, comes extra bills for insurance, accounting help, postage, etc ~ **we hope you will be as generous as possible ~ since we are an ALL Volunteer Group no one has a salary ~ every cent raised helps our Families around the world!**

Recently, Kathy Stagni (OAA Director) and I had discussions with the staff at the United Mitochondrial Disease Foundation (www.umdf.org) as far as possibly piggybacking with them at their 2008 Conference in Indianapolis. They are able to offer so many more topics (many of which overlap with FODs) and speakers than we could ever assemble, as well as access to MANY medical professionals. Kathy and I may visit their headquarters and/or attend their 2007 conference in San Diego to see if it would be a good fit for our Families. We will let you know more when we start the actual planning process for the 2008 conference.

We still have some FOD yellow/blue Awareness Tshirts and Bracelets available so please let me know if you'd like to purchase them. The Bracelets can be bought on our website, but for now you will have to contact me about the tshirts (all adult unisex small to 2 xlarge). Bracelets are \$3 a piece plus postage and tshirts are \$10 a piece plus postage. Soon we will offer more product choices through cafepress.com. When you purchase a product through them we will receive a donation. We will have tshirts, hats, mugs, and several other products with our logo on them.

Thank you to all that answered the Research Survey on FOD Carriers ~ the Drs at Mayo are reviewing the surveys and will let us know the findings in the near future.

Thank you also to our Families that shared their struggles and challenges with us in this issue by way of their stories. We welcome ALL of your stories and pictures and we will try to either print them in the newsletter or place them on the *Family Stories*, *Newborn Screening*, or *Love Messages* page on our site. We would especially like to encourage families dealing with some of the less common FODs (i.e. HMG, Carnitine Acylcarnitine Translocase, TFP, CPT 1&2 etc.) to share their experiences. We're also always looking for more low fat recipes, poems, and pictures.

We also would like to hear from our Professionals ~ we always welcome new Medical, Research, Nutritional, Counseling, etc articles. Whether you're a Family or a Professional, we are all striving to create awareness, education, screening and diagnosis, clinical treatment, and research ~ by sharing your story or your expertise...

'We Are All in This Together!'

Take care... DLG



Letter from the Editor

FOD Email List 'Etiquette Rules'

[Although this issue has been resolved, I felt it was important for everyone in the Group, especially those that haven't joined the Email List yet, to read the information below]

Recently, we had some difficulty with members posting content over our privately owned and monitored Email List that was inappropriate for the diverse population that we serve. Unfortunately, the 'etiquette rules' on our 'Join Our Email List' page on the website, as well as the email that is sent to all new members, was either not read or ignored.

After several posts about the issue, I posted a message stating members could either abide by the rules, email those members individually off-List that have similar beliefs, form their own List, or kindly remove themselves from our List. To avoid another situation like this and for those that would like to continue to network with other FOD Families PLEASE be sure to read the information on our site as well the reminders below.

•Our Private List is open to FOD Families (and family members) and professionals working with FOD Families.

•Our List is for emotional and practical support for FODs only. And that includes a variety of issues such as school challenges, developmental delays, dealing with other medical problems that are intertwined with the FOD, living with the death of a child, etc. This List is not for seeking medical advice however ~ that can ONLY be attained by consulting with your own medical professionals. That sounds like common sense, but at times, some don't follow this 'etiquette rule.'

•Additionally, messages are sent worldwide to over 400 members. We have a very diverse group of members as far as ethnic background, religious beliefs, political beliefs, etc ~ and that is to be respected. However, this Private List is for FOD related issues ONLY and is NOT a faith-based public religious or political forum. There are other internet Lists for such a purpose. Please keep that in mind when posting your FOD concern or question.

We have had many members over the years post requests for prayers for their Families or have shared briefly in their Family Stories how God/Higher Power has helped them through these challenges ~ and they have done that with respect for others and the rules of this List. They have not gone over the line as far as excessive religious content. However, some have crossed that line at times and by doing so disrespected the rules of this List, as well as the diversity in ethnic background, religious beliefs, etc of the 400+ members on our current List. As commented to me (via private emails) by some of our members, if someone wanted to post a message debating abortion, satanic worship or about their anti-American views ~ do you think I would allow those topics to continue on our List? **I think not.** There are other PUBLIC forums for those types of messages ~ but our PRIVATE List is NOT that forum.

I hope the List 'rules' are fully understood and will not hinder anyone's desire to network with other FOD Families around the world. Thank you for staying focused on FOD issues and posting in a mature and considerate manner.

DLG

Deb Lee Gould, Director

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FOD Family Support Group Board of Directors

Deb Lee Gould, MEd, Director and President

Dan Gould, Treasurer

Mary Lingle, Secretary

FOD Medical Advisory Board



Dr Charles Roe, Dr Mark Korson, Dr Gerald Vockley, Dr Stephen Kahler, Dr Arnold Strauss,
Dr Barb Marriage, Dr James Gibson, Dr Gary Siskin,
Dr Andrew Morris (UK), [waiting on 1 Clinician acceptance], and Dr Janice Fletcher (Australia)



Family Stories

Rebecca's Happy Story ~ MCAD

Rebecca was born on April 2, 2005, but this story begins well before that. The fact that Rebecca was tested and that her MCAD was detected is, to us, truly a miracle. At some point during my wife's pregnancy, an article in the *Wall Street Journal* happened to catch my eye. The piece explained that all states test for the three "most common" (e.g., PKU) of the known rare genetic disorders, but only a handful test for the full battery of the 30 or so conditions, and the test to run them all (through Tandem Mass Spectrometry) is simple and very inexpensive. Having no knowledge of any such disorders on either side of the family, but figuring, "it can't hurt," I contacted one of the test providers (Baylor Health Care System Institute of Metabolic Disease) and ordered the \$25 test kit. The kit arrived in the mail, and got shuffled in with the baby stuff, almost to be forgotten.

As Rebecca's birth neared, my wife experienced some complications that caused her to be hospitalized on and off the two weeks prior to delivery. Things got quite hectic during that time, and during one of my trips between the house and the hospital, I remembered the test kit and initially couldn't find it. Something kept bugging me, though, and I eventually located it and brought it to the hospital. But that was only half the battle. The hospital's staff and in-house pediatrician refused to draw the blood for the test! In most cases, I think my wife and I would have given up on having this test run, but something compelled us to keep trying. So, at Rebecca's first office visit, we asked her pediatrician to run the test, and thankfully, he agreed. We dropped the completed kit in the mail, assuming we would never think about it again.

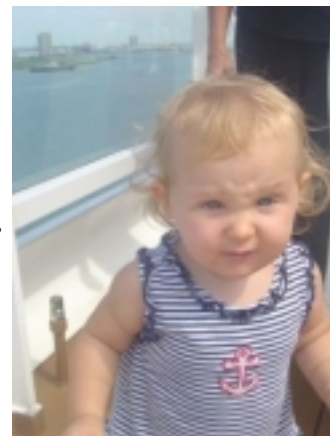
A few days later, my wife received a call from the pediatrician. He said the test came back positive for MCAD. The FOD Family Support Group was one of the first resources we were referred to, and has been a trusted knowledge-sharing base ever since. After the initial shock and fear wore off and as we became more educated (through the Group and Rebecca's geneticist), we began to accept and understand MCAD and realized how blessed and lucky we were to have learned about this when we did.

In fact, we believe that the early detection through the supplemental screening may have saved Rebecca's life. You see, she underwent two surgeries in the first 13 months of her life ~ the first at only two months of age. Local anesthesia was acceptable, but general was preferred – and seriously pushed – by the hospital. But because of our knowledge of the MCAD, my wife and I successfully fought against the use of general anesthesia (which, of course, would have required overnight fasting) for the first surgery. Had we not known about the MCAD (and followed fasting orders), we wonder if Rebecca would have made it through that surgery. For the second surgery, which required general anesthesia, we worked closely with the surgeon and anesthesiologist, who took all of the necessary precautions (most importantly giving her a D10 IV drip throughout the procedure to maintain her blood sugar). Again, we cannot bear to think of what could have happened had we not been armed with the knowledge of Rebecca's disorder.

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

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

Dave and Chylynn Bastian
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Family Stories

Katie's Story ~ LCHAD

If someone had told me on the morning of March 31 that I would give birth to my daughter that evening, I never would have believed it. I was just shy of seven months pregnant. My pregnancy was considered low risk and had been unremarkable so far. My husband and I had just finished our childbirth classes, taken early by coincidence. I was so committed to natural childbirth that I had seriously considered switching to a midwife.

In the days leading up to March 31, I hadn't been feeling great. I was getting over a 24-hour stomach bug, and just couldn't seem to find my old energy. There were small signs that something was wrong, but nothing that seemed significant. When I felt I had to call in sick to work for the third day that week, my obstetrician's back-up doctor (my OB was on vacation) asked me to come in for an outpatient non-stress test, just to put our minds at ease.



I came to the hospital at 1 pm, and was told the test should only take about 20 minutes. An hour later, I was still hooked up to the monitors. I was having mild contractions. But more concerning, my blood pressure was quite elevated. After an hour and a half, I was admitted to the Labor and Delivery ward. I was told not to worry; I was only being sent there because they had better equipment, and they just wanted to observe me a little longer.

In Labor and Delivery, my husband Alex joined me as I was hooked up to more monitors and blood work and other labs were done. After several hours, the obstetrician came in and explained very calmly that I was suffering from preeclampsia, possibly HELLP syndrome, and I needed to move to a labor and delivery suite to prepare for possible birth. I had read a lot about preeclampsia, so I knew what this meant. I didn't really believe that I would give birth that night, though we were told it was a possibility. As we were brought into the delivery room and I was hooked up to IVs and a drip of magnesium sulfate was started to prevent the seizures that can come from high blood pressure, I wondered how long I would have to stay in the hospital. Even as they were giving me steroid shots to help our daughter's lungs develop more quickly, I didn't believe I would give birth that night.

Alex left to grab a bite to eat and call my mother to let her know what was going on. My baby shower was scheduled for the next morning, and we knew she needed to cancel it. He told her what the doctors had told us. *Don't come. Everything is probably going to be okay. We'll call in the morning.* While he was gone, the pain that I'd been attributing to the discomfort of the monitors became excruciating. Within moments, our obstetrician was viewing the baby through a sonogram. Her words made everything else stop. *We need to do this right now.* My placenta had abrupted. The baby was bradycardic. My blood pressure was sky-rocketing. If we didn't do it right away, we could both die.

I panicked because Alex was still out and I was afraid he would come back and not know where I was. He walked in the door right at that moment. He was incredibly calm, smiling at me, reassuring me that everything would be alright, though he was just as terrified as I was to hear the doctors yelling, "31 weeker! STAT!" We were rushed to the OR in a crowd of nurses, doctors, and anesthesiologists. Alex couldn't enter the OR until he had changed into scrubs. In the end, he was never able to enter, because as soon as I was transferred to the operating table, I went into respiratory arrest. I did not lose consciousness, but I could not move, communicate, or breathe. They could not wait to start the operation, because the baby was in distress, so while the anesthesiologists worked to reestablish my breathing, the doctors completed the c-section. I heard them announce that the baby was fine before I was successfully intubated and the anesthesia finally kicked in.

Thus, our beautiful daughter, Kate Alexandra, came into the world at 11:53 pm, so very unexpectedly! Amazingly, her Apgar scores were 7/8. She weighed 3 lbs. 7 oz., and even so tiny, she was absolutely perfect and beautiful. Alex was able to accompany her up to the NICU while I was stabilized and he brought me back cell phone pictures of our little angel. I was only strong enough to make it to the NICU on my third day. Katie spent almost no time on oxygen, was IV fed for the first few days, and then they started an NG tube, feeding her a special high calorie formula. The doctors and nurses in the NICU were calling us miracles. Everything could have gone wrong, but they'd managed to save us both.

I left the hospital five days later, without Katie, which was terrible. But I knew I would be back the next day and the next. My milk was coming in, and I pumped day and night so Katie would have all the benefits of breast milk. Katie was very slow to learn to feed by bottle, and even slower by breast. She spit up frequently and gained weight very slowly. All of this was attributed to her prematurity. Every day I asked how she was doing and if there was anything I should know or be concerned about. Every day I was told that she was doing great. I never asked about her newborn screen. I knew about newborn screens. They were for inherited diseases. We didn't have any of those diseases in our family. It never even entered my mind to ask about it.

We were ecstatic when we were finally told Katie would be coming home on April 28, almost a month after she had been born. For the first time, as our discharge papers were being handed to us, we were told by a nurse, "Oh, and you know about her abnormal PKU, right?" No. We did not. The nurse told us it was absolutely nothing to worry about. Katie had been screened twice, and her first test had come back highly irregular, but the second test had been much closer to normal.

(cont'd page 5)

Katie...cont'd

She assured us that this happened very often with preemies. She gave us the number of a leading endocrinologist at another hospital and told us to set up a follow-up appointment, just to be on the safe side. We did not know then that the nurses all refer to the New York newborn screening as the "PKU" test. We assumed from this statement that Katie had screened positive for the disorder "PKU," phenylketonuria. We went home and looked the disorder up and felt certain she did not have it, as the symptoms are severe within days if left untreated, and Katie had not experienced any of those symptoms. Still, we called the endocrinologist several times, trying to set up the appointment.

Katie was home from the hospital for five days. During that time, under the guidance of our pediatrician and a lactation consultant, we tried to convert Katie from bottle-feeding to breastfeeding. She was not a good breast feeder. She screamed when she was hungry and offered a breast instead of a bottle, but eventually would start breastfeeding. It was terrible, and we felt that something just was not right, but we knew that breastfeeding was best for the baby. On her fifth day home from the hospital, Katie did not wake herself for her feeds. I fed her by bottle, since she wasn't awake enough to breastfeed, but she took very little. The first feed that she took little, we didn't worry much, thinking she would feed more at the next feed. But at the next feed, it was as if she had never seen a bottle before. I tried for an hour to get her to take 10 cc. We knew something was wrong. She felt very cool, so we took her temperature and were alarmed to see that it was 34.4 C (93.9F). As we were waiting for her doctor to call us back, we noticed that her breathing was very shallow. In fact, it seemed like she was forgetting to breathe unless we gave her a little shake, which would cause her to gasp. That was it. We jumped in the car and hurried to the children's hospital where our pediatrician was an attending, which was closer to home than the hospital where she was born. What should have taken 20 minutes took closer to 40, due to rush hour, and we just kept shaking her car seat so she would keep breathing.

In the ER they immediately put her under warming lights and her temperature started to rise, but we found out that things were much worse than we thought. She was bradycardic and her heart just couldn't keep seem to do its job. Her blood pressure was dangerously low. She presented as classic septic shock, so the doctors began looking for a septic infection. She spent ten days on a respirator in the PICU, sedated so she would not fight the respirator, swollen because they were running extra fluids into her to help her heart do its job. She had cardiomyopathy and was in liver failure.

The first days in the PICU were a barrage of consultations and exams with doctors from different departments within the hospital. Cardiology, Infectious Diseases, Neurology. When Katie was admitted to the PICU, we had given the doctors her discharge record from the hospital where she was born, and because I was still on maternity leave, I was able to stay nearly all the time at Katie's bedside and meet with every doctor who examined her. The doctors gave her an array of heavy-duty antibiotics to fight the infection and medications boost up her blood pressure. Cultures for different infections kept coming back negative.

I was always there for rounds, and came to understand all of the medications Katie was on. After the first few days, I began questioning decisions that were being made, such as keeping Katie off feeds with nothing but a glucose drip for several days on the chance that she might come off her respirator. I began to notice that a particular resident who was assigned to oversee Katie's care frequently made mistakes during rounds, reporting that Katie was receiving full feeds when she was receiving none, for example. Since the beginning, I had been asking if Katie's irregular newborn screen may have something to do with this, and I asked the hospital to consult with an endocrinologist, since we had been referred to an endocrinologist, but had never had the chance to see her. Katie's pediatrician, who was visiting every day, also felt there were some errors being made. In spite of my requests for a full explanation of her newborn screening, I was treated by the attending in charge of Katie's care as an annoying parent who asked too many questions. When Katie started improving, I accepted that the newborn screening probably had nothing to do with this illness. We were just so overjoyed to have Katie coming off the respirator and to see her central IV lines and arterial lines finally come out. We spent several days on the regular ward, teaching Katie to feed from bottle and breast again, working with a new lactation consultant, and left the hospital after 14 days confident that Katie would be okay. The day after discharge, we brought her in to the pediatrician's office for a last antibiotic shot. He was delighted with her. She seemed to be in wonderful condition. She was even breastfeeding at home.

But it would not last. Again, on her fifth day at home, she stopped feeding. This time, we took her temperature right away and saw that it was low, though not so dangerously as the first time. We bundled her up in blankets warm from the dryer and took her temperature again. It was dropping fast. Again, we headed back to the ER.

This time we thought it was different. She wasn't having any breathing difficulties, in fact, she was breathing very fast. The triage nurse at the ER was less enthusiastic than we were. We were thrilled that her blood pressure was normal and her heart was not bradycardic. But the nurse knew that her fast breathing couldn't be maintained. Alex stayed with Katie while I went to register her, and when I returned I was shocked to learn that the doctors wanted to put her back on a respirator. The doctor explained to us that at the rate she was breathing, the muscles in her diaphragm would become exhausted and then she wouldn't be able to breathe at all. Following routine, one of the nurses did a heel stick to check Katie's glucose. It was 13. We were told that normal for an infant was from 60 to 120; that anything below 20 was when veins started collapsing and organs stopped functioning. We were ushered out of the room and the doctors did everything they could do to find a vein. Katie weighed only 5 pounds at this point, and she was still bruised from all of her sticks during her previous hospital visit. It took them an hour, an hour during which Alex and I sat waiting, running through everything we could have done wrong to cause this illness. We just couldn't believe that we were here again, and that Katie was so close to death.

(cont'd page 6)

Katie...cont'd

We were actually lucky that her glucose had gone so low, though it didn't seem so at the time. The low glucose had doctors talking about a metabolic issue before we had even left the ER. Suddenly everyone was interested again in those newborn screenings. Katie was admitted to the PICU late that night, and the next morning, she saw the hospital's genetic specialist for the first time. Seeing the results of her first two newborn screenings, coupled with her symptoms over the past month, he immediately suspected a fatty acid oxidation disorder. Blood and urine samples were taken and sent overnight to specialists at Baylor University, who analyzed the samples and had results for us within 48 hours. Finally, when Katie was almost 2 months old, we learned that she had LCHAD, an inherited inborn error of metabolism. With LCHAD, Katie is unable to process fats for energy, and the long chain fats in her diet (breast milk is very high in fat) had been accumulating in toxic levels in her body, infiltrating her heart and other organs and compromising their function. The day we received Katie's diagnosis is the same day that doctors started the labs which would help get Katie onto the heart transplant list, because in the interval since her first admit to the children's hospital, her cardiomyopathy had become much more severe. Her heart was barely functioning.

Once we had a diagnosis, however, everything began to turn around. Katie was taken off all lipids in her IV feeds, and was soon started on a formula mix made up primarily of medium chain fats, which Katie has no problem metabolizing. She was started on carnitine as well, which helped her body flush out all of the toxic long chain fats which were floating around in her system. We agreed with our metabolic doctor that Katie needed a g-tube, which would always allow us to get fluids and vital sugars into her if she was unable or unwilling to eat. Once Katie recovered from the surgery, we were able to finally bring her home.

The more we learned about the disorder, the more we understood how lucky we are that we did not lose Katie in either of her two metabolic crises. The difficult thing to come to terms with is that Katie need never have had the crises that brought her so close to death, not to mention her severe cardiomyopathy. New York State mandates screening for LCHAD for all newborns. If the hospital where she was born had simply followed up with a specialist, as her newborn screening indicated, or at the very least taught us to treat her as if she had LCHAD until it was ruled out completely, we would never have tried to breastfeed her or give her preemie formula or let her sleep up to four hours at a stretch – all things which made her sicker and sicker. We hope that in the future, doctors will be obliged not only to complete newborn screens, *but to clearly explain to parents any abnormalities*. If we had had more information, we would have been better able to advocate for our daughter's needs every step of the way.

Today, Katie is thriving. She's meeting all of her developmental milestones and is a happy, beautiful, 8-month-old. With treatment, her heart function has slowly improved, and her cardiomyopathy is almost completely resolved. Feeds will always be an issue for Katie, and we know that as she starts to move more and use more energy, she may face more hurdles in the future. For now, we are just enjoying each and every day and all of her little discoveries and achievements and delights.

Taryn and Alex Paladiy
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Deb's New Address and Grief Consultation Services

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Soon I will be offering (at no charge) additional grief consultation services to our Families, as well as to the public, that have experienced the death of a child or other loved ones and are having a difficult time living with this reality. These services will be offered via our website. In place of a fee, a donation to our FOD General Fund will be requested, but not required. All emails or phone contact will be confidential. I will post specific intake forms on the site in the next few months – probably on the 'Coping and Healing' page. To give you some information on my educational background and grief training experience, I have posted some links on our History and Mission page (right sidebar).



Family Stories

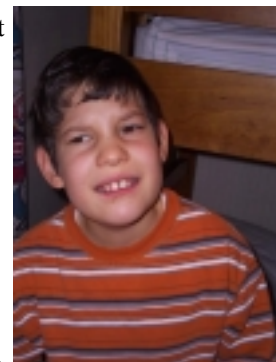
Austen's Story ~ GA2/MADD

I share the same story with many of you. The normal pregnancy, the c-section birth, the sight of that precious, little face and the feeling that finally, all was right with the world.

And then the shock.

My previous pregnancy, eight years ago, was difficult. I had conceived triplets through the in-vitro process, after trying for years to get pregnant. I lost a baby after my first attempt so I was off my feet for this whole pregnancy and hospitalized four weeks before their birth at thirty weeks. Although they were premies and had to stay in the NICU for five weeks before coming home, they had few problems once they were home and were all good nursers after they got the sucking reflex, which happens at about thirty two weeks of age. I nursed all three of them for the first six months and when they went onto solids my kids were great eaters!

On to the birth of my special Earth Angel, Austen James, which was 8 yrs later. I was surprised that he had no interest in breastfeeding and although the nurses said it was not an uncommon thing for a baby not to eat for the first few days, I remember being very concerned about his crying. He wailed like only a hungry baby could. When he was taken from my room so I could get some rest, I could hear his cries in the little nursery down the hall, louder than all the others. The second day was like the first. Now I was worried. The staff seemed indifferent. He still wouldn't eat, but he was clearly unhappy. That evening lying next to my bed in his little bassinet, his wailing forced me to get out of my bed to pick him up. The nurses were all busy and because it was a Friday there were lots of visitors and noise and rejoicing the birth of all the new babies. Once I got Austen settled in my arms and I was comfortable I tried once again to nurse him. Nothing. His crying turned to a sound that a little kitten would make, the light was low and I held him and tried to soothe my sweet little man. I don't know if I fell asleep or we both became one again and my breaths were his and finally he was at peace. Suddenly my dream turned into a nightmare. I stroked his head and it was cold. I called his name and he didn't move. I screamed at the top of my lungs for help and my baby didn't flinch. I recall screaming forever until the room was full of people and lights and the hallway was silent. Austen was a strange blue color. They took him away and I knew he was dead and I still kept screaming.



My writer's block is kicking in. This is where I always stop the story. I can't keep writing because I feel sick and clammy and the tears make it hard to see. I need to finish this story because maybe it could have a happy ending.

Austen was eventually revived. The nurses said he was without oxygen for twenty minutes. I think it was longer because no one came to my room to tell me anything and I was very hoarse. He was transported by ambulance to New England Medical Center where he was stabilized from the seizures, put under oxygen and once again I had a baby hooked up to wires and tubes, but there was no excitement this time. He had suffered serious brain damage and on the third day of his stay in the NICU, I was asked to sit down with the doctors who had been following him. The metabolic doctor who had been spending a lot of time with him, told me that he had a serious genetic defect. She called it Glutaric Acidemia type II or otherwise known as Multiple Acyl Co-A dehydrogenase Deficiency (MADD). She told me that it was a fatal disease and explained that he could not metabolize fats or proteins. She said that no other child born with this disease had lived for longer than six to eight months. She was patient with me when I cried. She said that she wanted to send a muscle fibroblast to a doctor in Iowa who would confirm the disease. She said that he could be brought home once he was taken off the tube feeding him through his nose and suck on his own. He should be given the best life possible in the next few months. It was best "not to resuscitate" should he stop breathing again, because of all the damage that he had already sustained. He was not to drink breast milk, too much fat and protein, so he needed a special formula.

Up to this point, I was in shock and depressed and felt very alone and defeated. But as I spent days with him watching as he came out of his long sleep and when he finally looked up at me and took formula from a bottle, something changed in my attitude. On the day we were told we could go home I became an angry, assertive woman, a person I had never been in my whole life. I demanded an apnea monitor to have at home in case he stopped breathing, I insisted that I would breast feed him and I didn't want the formula, (after all if he was to be given the best life in six quick months, shouldn't he be allowed to breast feed?).

(cont'd page 8)



VLCAD Email Network

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

Austen...cont'd

He went home and I pumped and he learned how to nurse. I got in touch with the FOD Group and got a home computer (one of my smarter purchases!). Austen got bigger and gained weight and I became more determined not to let the diagnosis defeat us. We got the confirmation from the fibroblast that he had "2% of controls...as low as enzymes get." It was a mitochondrial disease and there was no cure except to continue with the carnitine and B2 supplements that were supposed to sustain him. I read Dr. Andrew Weil's book, "Spontaneous Healing" and was particularly affected by the chapter that addressed malfunctions in DNA. He says that it can be reversed through diet especially by ingesting natural enzymes. I changed my diet radically after going to see a naturopathic doctor who put me on a meat-free, dairy-free diet which included mostly raw fruits and vegetables (both Austen and myself still follow this diet). I didn't stop there. I sought out a Native American shaman, a Catholic priest who was a faith healer, a chiropractor...and a second opinion from another metabolic doctor.

From the first time I met Dr. Korson, I knew that we would be in good hands. He believed in treating Austen the individual, not the disease. His approach was much more hopeful and that is what I needed to keep going, especially since I was a single parent at this point. He marveled at his weight gain and cognitive abilities, although he was delayed, he seemed to be progressing. The one concern was that his head circumference had come to a halt. Dr. Korson prescribed CoQ10 and in the next few months after starting it, his little head started growing again, although he is still considered to be microcephalic. When we started with solid foods each meal was traumatic, because he would throw it up. I had to clean up the mess and start all over again, because I knew if he didn't eat we would end up in the ER. He came to recognize that he had no choice in this food business ~ he had to keep it down! I weaned him very gradually off of the barbiturates that he had to take for seizures and he has never had another one that I know of. Early on I recognized that Austen had a severe visual impairment and hooking up with Perkins School for the Blind got us involved with the infant toddler program, pre-school, and now the 'Lower School.' Social skills, PT, OT, sensory integration, mobility, music therapy, gym, arts, swimming and of course academics are only part of the total program. We have a skilled health care clinic on the grounds and we have been very lucky to live so close to the school and be part of this wonderful community.

Today, almost ten years after his birth, he is of normal height and weight, a handsome devil who is devoted to his older siblings, Nathan, Sasha and Taylor, and his loving stepfather, Joe. It has not been an easy road. We have had many bumps and starts. He stopped sleeping (night and day) at about age three. Several trips to the ER after vomiting bouts, severe sinusitis (now controlled with Periactin), incontinence still to this day, it hasn't been easy. He has many food allergies which have been hard to decipher since he can't really tell us 'where it hurts' and displays his discomfort through tantrums or negative behavior, although once we got the wheat, eggs, peanuts, etc. out of his diet we have seen much less confusion and better spirits. The change in diet and realizing that his behavior was on the autistic spectrum (and getting the diagnosis of asperger's syndrome), has afforded me with much more knowledge of how to help my son deal with this world that he doesn't really understand, and help others to understand his world.

I feel strongly that the choices I have made for my son have been the right ones, but I have been guided all along with this wonderful FOD community and without the experience from other parents I would not have made some of the connections that have made such a big difference in the quality of my son's life. Thank you, Mom, Maggie and Deb. I am feeling much better.

Gwen Abele

gwenabele@hotmail.com



Family Stories

Vayda's Story ~ Undiagnosed LCHAD, Canada

Vayda Irene Oliver [Porochnavy] was born Aug 6, 2006 in a Vancouver Hospital. She was 5 weeks early and weighed 5lbs1oz ~ perfectly healthy. Our bundle of joy came home 5 days later.

Then came the fatal quick onset of agitation, hypothermia, moaning turning into a purr, and unresponsiveness while driving to Kelowna. We were already speeding to the Merritt, BC hospital, arriving at approximately 10:20. She took her last gurgled breath running into the emergency department. The health care staff was right there at the entrance and the physician commenced CPR. All her formula came up from her last feed 3hrs and 20min ago. We all ran to this room and they actively hooked her up and intubated her. We watched her go from white to grey. She took 1 more little breath and listened to her heart beat go lower and lower not responding to the cardiac protocol medications. She died, announced at 11:05 Sept 2, 2006. All staff went silent and shocked to the disbelief of what occurred with no answers.

(cont'd page 9)

Vayda...cont'd

SIDS???

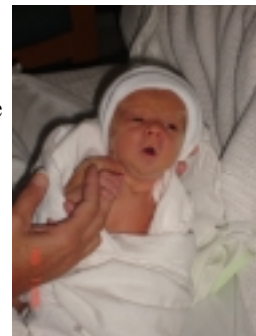
She was sent to Kamloops for an autopsy and found that she had a slightly enlarged heart and fatty liver but not bad enough to cause her death. So another pathologist took a look. We buried her here in Vancouver Sept 9, 2006. We received a call the very next day diagnosing Vayda with LCHAD.

I have never heard of this and it took some time to absorb. We now know she had the common subtype of LCHAD and it has been seen before. Which now concludes if all the Newborn screening blood testing would have been done with the rest of her blood work, this LCHAD would have been detected. She still would be alive, and treatment started.

LCHAD [Long-chain 3-hydroxyacyl-CoA Dehydrogenase Deficiency] is a condition in which the body cannot oxidize fatty acids because an enzyme is missing or not functioning correctly. Therefore fatty acids attack vital organs and leads usually to death. Treatment, if diagnosed at birth, is a low fat diet with a high-carbohydrate intake and avoid fasting.

We must include this Newborn screening blood test in every province.

Why does every province in Canada vary in blood screening? Newborns are dying because it varies with what type of screening is being done and where. Go online to www.savebabiescanada.org to see the list of provincial blood screening. The website also gives more family stories and literature documenting that there is evidence for the necessity to include this Newborn screening within Canada. It would change our results and newborns would survive. The cost is minute when it comes to the outcome and the life of a child ~ \$50 ~ please let's save our babies. Ours died unexpectedly and I do not wish this for any other family or baby to experience!

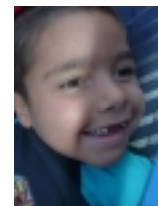


We miss our little angel... Vayda (nickname Betamax)
Brenda Porochnavy and Dave Oliver
[The hearts of All our FOD members go out to Vayda's Family. DLG]

♥ ♥ ♥

Condolences

Joe Cabrera Myram (SCAD, almost 7), son of Mandy Myram and Enrique Cabrera Falero of the UK died on Sept 14, 2006. Mandy, Enrique and daughter, Lara, 3 yrs old, will miss their son and brother greatly.



Tanya and Ashley Belew of TN sadly informed our Email Listmembers of the death of their daughter, **Haley Elizabeth** (LCHAD) on Dec 29, 2006.

Haley was 18-mos-old. Her sister, Allie, and Haley's parents would like to thank all in the FOD Group for their support.

Soon after hearing of Haley Belew's death, I was informed of the death of 1 yr-old **Skyler Rain Chance** (GA2/MADD), daughter of Samantha and Geronimo, sister to 14 yr-old Tabitha Lynn Jones, and grand daughter to Jo Ann Willard. Skyler was a 'light' to her family.
Skyler died on her 1st birthday ~ Dec 24, 2006.

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

♥ ♥ ♥

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

*We would also like to offer our condolences to
Dr Rebecca Wappner's Family ~
Dr Wappner clinically treated many of
our FOD children over the years*

Dr Rebecca Wappner

Dr. Rebecca Sue Wappner, 62 of Carmel, IN, died Wednesday, September 6, 2006 at home. Her death followed a six-month, brave and courageous battle with cancer. Rebecca was born in Mansfield, OH on February 25, 1944. She graduated Summa Cum Laude from Ohio University in 1966 with a B.S. in Zoology. While attending O.U. she held memberships in Phi Beta Kappa, Mortar Board, Phi Kappa Phi, Alpha Lambda Delta, Sigma Xi, and Iota Sigma Pi honoraries. Becky was also a member of Sigma Kappa sorority. Dr. Wappner received her M.D. degree in 1970 from The Ohio State University. She trained in Pediatrics at Children's Hospital in Columbus, OH prior to moving to Indianapolis. She was Professor of Pediatrics and of Medical and Molecular Genetics at Indiana University School of Medicine. She continued to work until shortly before her death as Staff Pediatrician and Director of Metabolism and Genetics, Department of Pediatrics, The James Whitcomb Riley Hospital for Children. She was also Director of the Pediatric Biochemical Genetics Laboratory, the Gaucher Treatment Center, and a consultant Pediatrician to Wishard Memorial Hospital. She was a Fellow in the American Academy of Pediatrics, and the American College of Medical Genetics. Dr. Wappner was a member of the American Society of Human Genetics, American Medical Association, American Medical Women's Association, Indianapolis Medical Society, Society for Inherited Metabolic Disease, the Society for the Study of Inborn Errors of Metabolism, and the International Society for Newborn Screening. She was the Indiana Project Director for the Detection and Management of Inborn Errors of Metabolism.

Her publications were numerous, including Biochemical Diagnosis of Genetic Diseases, Genetics in Primary Care & Clinical Medicine, Physician's Guide to the Laboratory Diagnosis of Metabolic Diseases, and numerous chapters in OSKI'S PEDIATRICS: PRINCIPLES AND PRACTICE. She was an active member of Soroptimist International.

Dr. Wappner will be sorely missed by her family, staff, patients, their families, and everyone whose life she touched. She was an extremely caring physician who was very loved and respected. Becky will be missed for her wit, her crazy sense of humor, and her endless generosity. She exuberated an overwhelming love for her patients. Dr. Wappner was preceded in death by her father, William H. Wappner, and is survived by her mother, Helen E. Wappner; sister and brother-in-law, Diane and David Kracker; nephew and his wife, Stephen and Erika Risser. Burial services will be private. A Memorial Service and Celebration of Life will be held at The First Congregational Church, 640 Millsboro Rd, Mansfield, OH 44903 on Tuesday September 12 at 11 a.m., and at Riley Hospital for Children on Thursday, September 21 at 6:00 p.m. The family has asked that donations be made to Riley Children's Foundation Dept. of Metabolism Endowment, or to The Richland County Foundation for The Dr. Rebecca S. Wappner Memorial Scholarship Fund.



URGENT NEED for Medical Professionals

With more Families being identified with an inborn error of metabolism (through expanded newborn screening), **our Families will need ongoing Clinical Care from knowledgeable and caring professionals.** In addition to our Newborn Screening Advocacy, our Group is hoping to bring awareness to medical schools and other medical organizations and facilities the **need for educating and training new Professionals** (physicians, metabolic nutritionists etc) **in the field of Medical Genetics and Metabolism** to treat our children, as well as our FOD adults. **We NEED your help NOW** and in the **FUTURE so our children will thrive and grow into adulthood with the best of ongoing care!**

This will also be **one of our MAIN goals of our Fundraising efforts** ~ Besides raising funds for FOD Research, we would also like to raise funds to help Clinically Train new Medical Professionals. It may be awhile before we can offer a grant to an FOD Clinical or Research Center but it's exciting that we might be able to contribute to an effort that would benefit our FOD Families around the world!



Medical Update

Regional FOD Meeting Summary

I wanted to write sooner about the regional FOD meeting, but it has taken me quite some time to reflect and digest the day. I'll try to encapsulate the meeting, but I'm not qualified to speak specifically about what our speakers discussed. I encourage all to view the DVD of the morning session to get the specifics of what the speakers had to say.

Our guest lecturer was Dr. Arnold Strauss, M.D., professor at Vanderbilt University and director of the Vanderbilt University Children's Hospital. Dr. Strauss was gracious enough to fly the night before, and fly back later in the day.

The meeting actually began the night before at the "Meet the Speakers" reception. This presented a less formal introduction for us to meet, share stories and swap information. Food was plentiful thanks to the many volunteers who prepared low fat and fat free foods.

Dr. Strauss arrived a little behind schedule directly from the airport, whereon we collectively besieged him. After a moment to collect himself, he finally met all of the faces of children and families for whom he had been instrumental in the diagnosis of their FODs. There were lots of tears and lots of pictures. It was an emotional and happy meeting for many of us.

The emotion of the night before carried over to the Meeting on Wednesday as Dr. Strauss began his presentation by acknowledging those families that he'd had the opportunity to help. The presentation traced the history of the diagnoses of various FODs from the 1970's to the present day.

Fighting to speak above the clamor of the torrential rain, Dr. Strauss highlighted the work of many other scientists investigating FODs, and the personal tragedies that led to many of the early discoveries and diagnoses. He soberly recounted stories of parents and researchers who, without proper treatment protocols, made mistakes with devastating consequences.

Dr. Strauss' recurrent theme was the fight for greater funding and more research. He urged attendees to fight to expand newborn screening across the country, as well as urge congressional support for more expansive study. He discussed current research with VLCAD mice and the possibilities for new treatments that might arise from such expanded funding. One of the more shocking revelations was that the incidence of all FODs combined has lowered to approximately 1 in 5,000 births. That means that there are more of us out there than anyone thought.

Dr. Strauss' presentation was very personal. The emotion of the man behind the scientist kept shining through. He seemed really touched by the hopeful sentiments in the room. His passion for his work and for helping those with FODs was evident to all of us.

Dr. Strauss was joined on stage by Dr. Margretta Seashore, director of the genetics at Yale University and Yale New Haven Hospital and Liz Perrone, APRN, a pediatric nurse practitioner whose office is learning to deal with a growing population of FOD patients. The panel discussion was open to questions from the audience, and the room let loose. Parents and medical professionals in the audience quizzed the group on everything from nutritional supplements and schooling options to political action for expanded research.

The diversity of the FODs represented made the day even more enlightening. While VLCAD and MCAD families predominated, TFP, CPT-2 and LCHAD families were present and active participants. The panel discussion was so successful, it carried beyond its allotted time.

Participants broke for lunch, or even complimentary chair massage offered by volunteer massage therapists. Opportunities for walking on the beach were dashed, however, by the wet weather.

While the adults were busy, many of the children in attendance were down the hall in the children's room: a room staffed by retired pediatric nurses, teachers and moms with children with special needs. The children had toys, videos and books to keep them busy.

After lunch, the attendees heard a panel discussion by Dr. Seashore and the Yale genetics staff, on the difficulties of proper diagnosis and newborn screening. Dr. Seashore's soothing demeanor elucidated many comments from the attendees on the proper role of the geneticist in the diagnosis and prognosis stage. Many of us shared our stories and offered suggestions to the medical professionals as to how to address families in their most desperate hours.

The rest of the afternoon was devoted to an open forum for families and scientists alike on any topics. Most of the discussion centered on the difficulties of raising an FOD child. Those parents whose children had reached their teens gave invaluable advice on dealing with doctors, schools, family and friends, such as how to deal with the "he/she looks so healthy" problem.

The open forum also ran long, as the group continued sharing stories and hardships. When the day ended, we felt we could keep talking for hours more. We felt that we were saying goodbye to family. The next morning, I'd realized I still had so many questions based on what was learned that day.

For those of you who were there, I have some more mushy stuff (I apologize). A huge thanks must go out to those volunteers for making this happen. Our group, Team Ella, is not a bunch of professionals. We don't have experience in setting up and running meetings and yet, due to the hard work of so many people, we received a lot of positive feedback. I hope all who attended received something positive. We certainly did. Pat Grodski, Ella's Grandma, was a driving force to make this happen, not for any other reason but to connect with those around us who are struggling with the same conditions and issues. Her strength and determination made this meeting possible. We obviously can't thank Grandma enough.

(cont'd page 12)

Medical Update...cont'd

We have received copies of the DVD of the meeting from the videographer and some have been distributed. If you'd like your own copy, you can purchase a copy from the videographer directly. Please email Pat Grodski at Bam2400@aol.com and she'll get you arrange it with the videographer. Dr. Strauss, Dr. Seashore and the other participants were very gracious to let us tape them, so that others would be able to see their presentation(s). Being a lawyer, I have to ask that those who receive a copy not use the material in any way other than educational. The copyright is owned by the creators of the tape and the speakers, and the speakers would object to any other use.

At the end of the meeting, we received such positive feedback that we plan to hold another meeting. The suggestion was two years from now and, given the amount of effort that goes into this, I couldn't disagree. At some point we'd like to create a planning committee and invite anyone who'd wish to participate. Let us know if you'd like to be a part of the committee so we can include you when the time comes.

To all of you who were able to attend, thank you for making our meeting such a big success. To those who couldn't attend, we hope to meet you someday and share your stories too. One thing the meeting showed us is that we are not alone.

Alex & Lori

Dad & Mom to Ella (2 yrs-old, VLCAD)



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, fax or regular mail:
deb@fodsupport.org or
 US/Canada Fax: 866.290.5206 Overseas Fax: 313.432.5928
 2041 Tomahawk
 Okemos, MI 48864

Cook Book Suggestion

I just got a really good cookbook for kids. It's called *The mom's guide to meal makeovers* by Bissex and Weiss. It's definitely focused on low fat, healthy eating and is very kid friendly and EASY. It takes recipes that kids traditionally like and substitutes healthier, lower fat ingredients. I made some waffles with sweet potatoes in them ~ they were so easy and everyone loved them. I have not found one recipe in there that my kids didn't like! And they use ingredients you most likely have in your pantry/freezer.
<http://www.mealmakeovermoms.com>

Dianne
 Mom to Juliana, 5, undetermined metabolic disorder
 and Mateo, 2, unaffected
dirios@bu.edu



'Food' Books by Ellyn Satter

Child of Mine: Feeding with Love and Good Sense

How to Get Your Child to Eat (but not too much)



The **Sibling Support Project** is pleased to announce that we are now scheduling workshops for 2007. Please share this announcement with families you know and training directors, conference planners, and coordinators of family services from appropriate agencies. Many agencies wisely value the families they serve and are committed to providing family-centered care and services. However, even the most family-friendly agencies often overlook brothers and sisters. Brothers and sisters are too important to ignore, if for only these reasons:

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

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

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

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

Addressing siblings' concerns benefits everyone: brothers, sisters, parents, agencies, taxpayers and especially the family member who has special needs. In many important ways, brothers and sisters ARE the future--and are too important to ignore. If you would like to learn more about our workshops, seminars, and keynotes please call or contact us by email and we'd be happy to send you more information. Our schedule is beginning to fill up, but we still have openings.

Don Meyer
 Director, Sibling Support Project
 A Kindering Center program
 6512 23rd Ave NW, #213
 Seattle, WA 98117
 206-297-6368; fax 509-752-6789
 donmeyer@siblingsupport.org
 Sibling Support Project website: www.siblingsupport.org
 Sibling Support Project online training calendar: <http://plus.calendars.net/sibshop>
 Our brothers, Our sisters, Ourselves

Traveling with Children

This site gives information from TSA about traveling with children.

<http://www.tsa.gov/travelers/airtravel/children/index.shtm>

At the bottom of the previous site is a link to a page for people with special needs, and the link for people traveling with medications is below.

http://www.tsa.gov/travelers/airtravel/specialneeds/editorial_1059.shtm

I think these will answer most, if not all of your questions, and the TSA site should be the most up-to-date and official information you can get.

Rodney, MCAD, 40



Special Law Article



Litigation and the Child With a Metabolic Disorder

I have been actively handling cases involving kids with metabolic disorders for roughly seven years now, and I've found that parents of these children sometimes aren't sure how legal cases work in several important ways. That's not surprising, and it's not their fault. The legal system is confusing, and the law is not always the same depending on what state you live in. So let me take a shot at explaining some basics. I think it may be helpful to any parent whose child has an inborn error of metabolism and was injured.

First, let me tell you how I got involved in the "metabolic world." One of my law school friends, Dean Jerrehian, has a son, Matt, with PKU. In the 1990's, Dean lobbied hard for expanded newborn screening. Dean told me that Matt is an honors student – but that his success was only possible because Bob Guthrie fought to screen PKU kids in the 60's and 70's. Dean said he wanted to give back and fight for today's babies who could benefit from the next generation of screening.

Quickly, however, Dean became frustrated with bureaucratic delays. He became convinced that state governments and hospitals would not move faster to expand screening unless they were forced. Dean approached me with a newborn-screening case in Pennsylvania involving a family he knew and asked me to take it. I did, and our firm litigated it for over five years, all the way to the Pennsylvania Supreme Court.

Since that time, we have taken cases involving children with metabolic disorders in Pennsylvania and in other states like California, Colorado, Georgia, Illinois, New Hampshire, New Jersey, Texas, etc.

Two Types of Claims: (1) Screening and (2) Delay In Diagnosis and Treatment

There are two types of claims I see, and sometimes one case will have both claims.

The first claim type is a "screening case." This is where a child was not offered screening that is broad enough, or perhaps screening was performed, but it was done improperly.

We have brought several lawsuits against hospitals for not offering or disclosing supplemental newborn metabolic screening. Typically, a state will have mandated screening for between two and ten disorders, but will not offer supplemental screening. We have claimed successfully that, at a certain point, birth hospitals have a duty to offer or disclose expanded screening – even if their state does not mandate it.

Unfortunately, and this is important, in almost all such instances one cannot sue a state for failing to uphold its duty to timely add new disorders to the state's mandatory panel. The law is very clear on this.

So, typically, we are left with suing hospitals and pediatricians in instances where the hospitals/doctors knew about the screening, knew the state was delaying unreasonably, and still did nothing. These cases – to be successful – usually will involve children born after 2003, but each case is so fact dependent that it's hard to generalize. In Pennsylvania, for example, expanded screening has been around since the mid-90's, so earlier cases are viable here.

The other kind of screening case usually involves mistakes in screening. Examples: Blood is drawn too early, before feeding; a positive result is not reported; or the lab used the wrong cut-off to define a positive result. In these cases, if the mistake is made by a state laboratory, some states insulate or severely limit suits against government entities, but it still is important to have the case analyzed carefully.

For example, in Illinois, the state itself is insulated from suit but its employees are not. In a case there, where a lab worker failed to report a positive that resulted in brain damage to a child, the employee was sued individually because it was clear that the state would pay any judgment against its employees – even though it didn't have to. The settlement negotiated with the state in that matter provided money to pay for the child's large life-care and medical expenses, costs the parents could not afford.

The second claim type that I see is delay in diagnosis and treatment. This is very common in metabolic cases because doctors in the United States generally have poor training in recognizing inborn errors and sometimes believe that metabolic disease is not treatable.

By far the most common diagnostic error involves children brought to a hospital/doctor with a history of poor feeding and lethargy, frequently with spitting up or vomiting. If the child is not too sick, the parents (often first-time parents) will be told that they are "overreacting." On the other hand, if the child is critically ill, doctors will do a workup for infection and perhaps other potential problems but will not order simple screening tests to check for inborn errors until days later – after an infection is "ruled out."

The truth is, in a newborn who appears healthy at birth but deteriorates shortly after feeding, metabolic disease is just as common as infection. There is simply no reason to delay the workup for inborn errors. In these cases, days, often even hours, can mean the difference between an unaffected child and a child with special needs.

Another common scenario is the GA-1 child who is sent to a specialist because of a large head. Despite, a wildly abnormal head CT or MRI, the baby is diagnosed with "benign extra-axial fluid collections of infancy" or "external hydrocephalus" without any thought about an alternate diagnosis.

I also have seen several examples of children with urea cycle disorders who have not been promptly treated with dialysis and instead are given so-called "ammonia scavenger drugs" such as sodium benzoate or sodium phenylacetate, which are not generally effective when ammonia is high enough to cause neurological impairment.

Children with galactosemia often develop e-coli infections even before screening results are returned. Ironically, we see infection worked up *first* in cases of other misdiagnosed metabolic disorders, but galactosemia kids sometimes are treated for jaundice only – without any appreciation that they also have a life-threatening infection.

(cont'd page 15)

Special Law Article...cont'd

The Statute of Limitations

A statute of limitations is a deadline that courts impose on a claimant. The rule is, if you don't bring your case within a certain time, it is too stale, and it won't be permitted. For adults, most states impose a two-year statute of limitations, although it varies. There also is an exception in many states called "the discovery rule." In that instance, a state that has a two-year statute of limitations would permit a claim if made within two years of the date that malpractice is "discovered."

What parents need to know is that almost all states extend the statute of limitations dramatically for kids. In Pennsylvania, for example, a claim may be brought on behalf of a child until the child is 20 (i.e., 18 years of age, plus the two year statute of limitations). Courts don't want to penalize children if their parents, for whatever reason, don't bring a timely claim.

The exception is a case where a child dies. Even though it is a lawsuit about a child, courts consider that a parental claim and will apply the parental statute of limitations.

Retaliation

Many parents are afraid to investigate a claim because they are afraid that the medical system will retaliate against their child in some way, perhaps by denying treatment.

Although I understand this concern, and of course we can make no promises, our experience has been that this almost never happens. Particularly in the case of a child with special needs, most providers understand that a lawsuit is the only real chance parents have at getting enough money for their son or daughter to receive the very best care. Often our clients already have switched their child's care anyway. A move from the hospital or doctor whose omissions caused injury usually solves any potential problem.

Special Needs Trusts and Medical Assistance

I frequently hear concerns that any settlement in a case will disqualify a child for Medicaid and/or social security. By law, money that a child receives in a lawsuit must be put into trust, typically called a "special needs trust." The special needs trust is specifically designed not to disqualify a child from receiving medical assistance. We never have had a child's assistance status change as the result of receiving money through litigation.

These are some issues that come up in metabolic cases. I hope my short descriptions are helpful.

Charles P. Hehmeyer, Esquire
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Philadelphia, PA 19103
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Facsimile No.: 215 - 988 - 0618
E-mail: cphehmeyer@raynesmccarty.com



Pharmaceutical Update

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

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

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

Special Education Law

Dorene Philpot <http://www.dphilpotlaw.com/>

Disclaimer: Dorene Philpot is an attorney in Indiana, so any answers she gives will reflect Indiana law, which may differ from the laws in your state. Viewing the information on this web site is not to be considered in any way as a formation of an attorney-client relationship. This web site exists merely for educational purposes. If you require legal advice that pertains to your particular circumstances, please consult the legal professional of your choice.* [The FOD Group was given permission by Ms Philpot to reproduce this page from her website. She often uses these points in a powerpoint presentation to parents. DLG]*

Special Ed Law: TOP 10 TIPS FOR PARENTS

Tip #1. Take advantage of your right to receive an Independent Educational Evaluation.

When you request an IEE in writing, the school must do one of two things:

- A. Tell you yes, the school will pay for the independent evaluation.
- B. Tell you no and file for a due process hearing against you.

ONE OF YOUR BEST RIGHTS

In my humble opinion, being able to request an independent evaluation is one of your best rights under the law. Why?

1. You are a parent, not an educational program designer. Going to a professional and finding out what your child actually needs is the first step to good advocacy for your child.
2. You can use the results to convince the IEP participants to give your child the services that your evaluator is recommending.
Improve your odds, should you need DP
3. You can use the results to bolster your position if you end up in a hearing.
4. Ideas on choosing an evaluator: Geography - Subject area - Talking to other parents/professionals to get names of good evaluators.

Tip #2: Focus on goals and objectives in child's IEP.

Goals and objectives must be OBJECTIVE and MEASURABLE. If they are not objective and measurable, you have no way of knowing if your child is learning. Goals and objectives must be provided in all your child's areas of need (academic, behavioral, social, attention, anxiety, sensory, speech, etc.). You must receive reports on your child's progress (or lack thereof) at LEAST as often as typical children receive mid-terms and report cards. However, you can ask for them more often. Goals and objectives drive the rest of the IEP services and placement, not the other way around.

Tip #3: "Rinse and Repeat"

When you want better services but really don't want to file for a hearing, you can ask for 12 things, get a few, have another conference, add a few more, on and on. Generally speaking, people want to cooperate and reach a happy medium. So, the school usually will agree to give you a few of your requests.

Tip #4: Use the power of FBAs/BIPs

Functional behavioral assessments: Purpose is to get at what's triggering the behavior, assessing what the behaviors area and determining what the child is "getting out of" the behaviors. Behaviors are not just MISbehaviors.

What is an FBA?

An FBA involves the systematic collection and analysis of data over a period of time in many settings. It involves input from the school, from the parent and involves a scientific-like inquiry, not a simple filling out of a form.

WARNING: Garbage in, garbage out. If your FBA is insufficient, the Behavioral Intervention Plan devised from it will also be insufficient and, in fact, could even be harmful.

Behavioral Intervention Plans (BIPs)

A BIP is a PLAN for handling the behaviors, with the goal being to extinguish the maladaptive behaviors. It can be changed by the case conference/IEP team as needed. It's not set in stone.

What if it's not working?

When the behaviors continue to escalate over a period of time after the implementation of a new BIP, one of two things is occurring: EITHER the BIP is inappropriate OR the BIP is not being implemented appropriately. Period.

FBAs/BIPS crucial for kiddos with autism

If the school is incapable of performing an appropriate FBA and appropriate BIP, then outside professionals can and should be brought in to provide the expertise and "fresh eye" needed. This is something that the school must do at its own expense if the school is incapable.

(cont'd page 17)

Special Education Law cont'd

Tip #5: Entitlement to services to age 22

Schools try hard to get children out of their programs at age 18, even if the children are not ready. I believe that this is the primary reason that schools do NOT want to retain children and push for "social advancement."

A Word on Retention

Parents: If you are thinking that your child needs to be retained, this should be a huge, red flag to you that you need to analyze whether the school's programming is appropriate or not. If your child is not making adequate progress, it's possible that the reason is that the school's program is not appropriate. Retention won't fix this. The definition of insanity: "Doing the same thing over and over, hoping for a different result."

Keeping your child in services past 18

Lofty goals and objectives. Inability to pass high-stakes testing your state devises and implements.

Guardianships and POAs

Parents of children with disabilities often go to the civil court in their county and get a guardianship of their children upon their turning age 18. Advantage of a guardianship: It cannot be "undone" except by court order. Is less "attackable" than a POA because permission of the child is not required for a court to grant this. Guardianships help you retain decision-making power for your child's educational programming. POA validity can be questioned and they can be fairly easily undone.

Tip #6: High-stakes testing remediation

If your child is not passing your state's high-stakes testing, which is called the ISTEP in Indiana, your child is entitled by law to "remediation" of the deficiencies that led to the failure of your child to pass these exams. This can be a way to get intensive services during the summer, if your school is balky at giving Extended School Year (ESY) services.

Tip #7: Accommodations/Mods

Pay attention to these. Sometimes these are the KEY to keeping your child in a less-restrictive environment. Your independent evaluator can be a great source for recommendations on these.

Tip #8: Mechanisms for dispute resolution

Case conference. Facilitated case conference. Mediation. Complaint with state DOE. Due process (Filing doesn't mean you HAVE to go to a hearing, but it can be used as a way to let the school know how serious you are.) Settlement likelihood high.

Tip #9: Suspensions and expulsions

If your child is out of school for more than 10 days, if your child has special needs, he or she is supposed to receive services. The school doesn't get 10 days, then another 10 days, then another 10 days. The law says any part of a day in which your child is removed (for example, you are called to come get your child), that day counts as a day of suspension.

Incarceration

Even though a juvenile facility or jail is probably the worst place for your child to be, many of you will face a situation where the school calls the police on your child and has him/her hauled away. If the child's IEP is inappropriate or isn't being implemented or was never even identified in the first place, those can be used to make the criminal case go away. Consult with a criminal attorney if you run into this.

Incarcerated child's rights remain

A already identified special needs child who is incarcerated is STILL entitled to educational services and is still entitled to have his IEP implemented. When I take these types of cases, we name both the school and the correctional facilities as Defendants/Respondents and will let the hearing officer sort out who is responsible for educating the child. In my state at least, 100 percent of these cases that I've handled have settled.

Fighting the "Good Fight"

Parent training and education. The single best thing you can do to make sure your child receives good services.

A. Know your state laws. B. Know the federal laws. C. Connect with other parents.

Strong advocates system

If you are a parent of a child with a disability, find a good advocate to help you at case conferences. If the first advocate doesn't work for whatever reason, keep looking. Not all advocates are alike. Different personalities, negotiating skills levels, knowledge levels come into play.

Schools using courts system as BIPs

Luckily, the courts are getting wise to the schools' use of them as a way to attempt to skirt having the child around because the child is difficult to deal with and the school would rather get rid of him than teach him.

OTHER SOURCES FOR INFO

To see a redline comparison between IDEA 1997 AND IDEIA 2004, go to:

<http://www.copaa.net/pdf/IDEA97-04COMP.pdf> or <http://www.copaa.org/news/idean04.html> to download individual sections.

In addition, you can go to the National Association of State Directors of Special Education and see a side-by-side comparison at <http://www.doe.k12.ga.us/curriculum/exceptional/index.asp>.

[Also note that www.wrightslaw.com is another site that helps parents and advocates understand special ed law; www.parentadvocates.org may also offer some help in finding a special ed advocate in your state. DLG]

Love Messages

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

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

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

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

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

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

Tanya and Ashley Belew
Haley Elizabeth—Birth May 31, 2005 Death Dec 29, 2006

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

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

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

Cynthia Brown
Miranda - Birth Death April 3, 2004

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

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

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

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

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

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

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

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

Samantha and Geronimo Chance
Skyler Rain—Birth Dec 24, 2005 Death Dec 24, 2006

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

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
Noah - Birth Oct 5, 1997 Death June 30, 1998

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

Nikki and Toby Hiatt
Reece - Birth Aug 1998 Death April 18, 1999

Pauline and Bill Hill
Rosemarie Rees - Birth Apr 15, 1976 Death Dec 23, 1999

Amy and Mathew Hoffman
Grace - Birth Jan 25, 2001 Death Oct 25, 2003

Brad and Kim Holmes
Brittany - Birth March 20, 1991 Death Feb 21, 1997

Debbie and Dave Houk Lauren - Birth May 4, 1988 Death Dec 15, 1989	Mike and Sheryl Mulhall Justin - Birth April 22, 1990 Death April 22, 1990 Nathaniel - Birth Aug 15, 1991 Death Aug 18, 1991
Robert and Dixie Howard Cody - Birth July 30, 1987 Death Dec 26, 1992	Verna Parker Charles - Birth Oct 24, 1988 Death Oct 26, 1988
Stephanie and Doug Huber Jace - Birth March 8, 2000 Death Feb 14, 2001	Diana and Kevin Patterson Trevor - Birth Aug 30, 1997 Death Mar 4, 1998
Meredith and Neil Hughes Claire - Birth Sept 1, 1986 Death June 23, 1997	Steve Bruski and Liz Pease Caitlin - Birth July 10, 1989 Death May 10, 1996
Karen and Steve Imhoff Michael - Birth July 25, 1991 Death July 8, 2002	Albert and Arleen Phang Andrew - Birth Dec 7, 1989 Death April 17, 1991 Alexander - Birth Dec 3, 1994 Death Feb 8, 1995
Brian and Patricia Karhu Patrick - Birth July 15, 1996 Death July 28, 1997	Jennifer and Jason Pierson Alexander - Birth June 1, 1995 Death June 3, 1995
Vickie and Burnell Keller Paul - Birth Mar 31, 1993 Death Sept 20, 1993 Annie - Birth Nov 26, 1998 Death April 22, 1999	Stephanie and Andrew Plaisted Drew - Birth May 7, 1997 Death Dec 27, 2000
Diane and Mickey Kennedy Marie - Birth Dec 1, 1989 Death Oct 5, 1991	John and Sally Reichelder Zachary - Birth March 24, 1997 Death March 27, 1997
Andy and Temple Ketch Nancey - Birth Feb 8, 1989 Death July 20, 1990	Tanya and Pat Robitaille Richard - (stillborn) June 24, 1993 Rachel - Born August 13, 1995 Death December 29, 1995
Robert Knoff Teresa - Birth Nov 7, 1994 Death June 29, 1995	Brian and Cherryl Rosenberger Kylie Ann - Birth Feb 7, 1990 Death Feb 11, 1990
Sondra Koehn Darcy - Birth Aug 10, 2000 Death March 19, 2002	Janice and Steve Rowland Josey - Birth Sept 30, 1996 Death Oct 28, 1998
Jamie and Tom Lazzaro James - Birth Dec 8, 1996 Death Aug 13, 1997	Mandy Myram and Enrique Cabrera Falero Joe - Birth Jan 22, 2000 Death Sept 14, 2006
Lisa and Pete Leonardi Devin - Birth July 18, 1997 - Death July 19, 1997	Litzy Sanz de Solis and Jesus Solis Sanchez Jesus - Birth Sept, 14, 1996 Death March 16, 1998
Mary Lingle Candice - Birth Feb 21, 1991 Death Nov 8, 1993	Jackie Shears Timothy - Birth Oct 3, 1991 Death Oct 4, 1992
Darlene and Larry Lopez Marissa - Death Feb, 1999	Lisa and Scott Sleezer Emily - Birth March 5, 1998 Death June 18, 2001
Heather and Phillip Marsella Toni Marie - Birth Oct 8, 1990 Death March 22, 1991	Leah and Paul Sofranko Kyle - Birth Feb 7, 1988 Death Feb 5, 1989
Ron and Paula Matthews Daniel - Birth May 19, 1981 Death Jan 12, 1982	Rhonda and Matt Southard Trace - Birth May 2, 2000 Death Aug 26, 2000
Randy and Misty McDonald Jeremiah - Birth April 3, 1991 Death Dec 15, 1991	Janna Sowers Kelsie - Birth April 23, 1993 Death April 23, 1993
Christine and Mark McFarland Erin - Birth Aug 26, 1988 Death Jan 21, 1989	Anne and Gary Stitt Sydney - Birth Oct 13, 1995 Death May 20, 1996
Linelle and Matt Meadows Cole - Birth Mar 21, 1999 Death Oct 18, 1999	Lisa and Doug Tennyson Sammy - Birth Aug 23, 2000 Death Dec 21, 2001
Elvira Melendres Katherine - Birth Mar 6, 2000 Death May 3, 2000	Rick and Stephanie Thomas Trina - Birth July 1977 Death Jan 14, 1978
Lori and Jeff Michaud Jordan - Birth Feb 19, 1997 Death March 21, 1998	Mary Thorson Wendy - Birth Sept 20, 1987 Death Sept 10, 2005
Simone and Michael Miller Michael Dylan - Birth Aug 24, 1991 Death Aug 24, 1991	S. Elizabeth & G. Douglas Turman Philip - Birth April 6, 1994 Death April 8, 1994
Kristen and Ken Mitchell Nolan - Birth Aug 8, 2004 Death May 16, 2005	

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

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

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

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

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

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

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

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

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



*'Don't walk behind me...I may not lead.
Don't walk in front of me...
I may not follow.
Just walk beside me and be my friend.'*

~Albert Camus



Future FOD Fundraising

To get us started with Fundraising, we will be doing some of the following projects ~ as we learn more about non-profit fundraising procedures and regulations, we may try to offer a larger event. The information below was also included in one of the IRS tax forms required for tax-exempt status filing:

1. **Mail solicitations:** We will mail an 'Annual FOD Letter of Giving' to Family and Professional members on our Mailing List (@1200). There will also be a notice/form in our next newsletter for donations via personal check or online.
2. **Email solicitations:** We have over 425 members on our Email List and that is the only email solicitation we will do. We do **not** do mass public emailing.
3. **Personal solicitations:** Word of mouth will play a big role in spreading the word about our Mission. Families all over the world can speak about our Group and mention we accept donations. Deb will also personally write corporations soliciting donations.
4. **Foundation and Government grant solicitations:** One of our members is also a grant writer and has offered to donate her expertise in order to solicit funds for our various activities, such as copying and postage costs, phone calls, supplies, Conference costs, and possibly a special event.
5. **Phone solicitations:** We will **not** do phone solicitations.
6. **Accept donations on your website:** Our website tells the mission and history of our organization, personal Family experiences with FODs, and the services we provide. We will set up the website to allow donations to be submitted through the site. We will have a PayPal, Inc., link where individuals can donate to our **General Fund (for daily operations), Clinical Trust Fund, or the Research Trust Fund**. They can also mail us a check.
7. **Receive donations from another organization's website:** Many of our members have utilized shopping sites through iGive and Cafepress. We will have a link on our site for those services. They donate a certain percentage of what members buy to your organization.
8. **Awareness Bracelets and Tshirt Sales:** We will sell bracelets and tshirts on the website and all donations (after costs) will be designated for the **General Fund's day-to-day operations**.
9. **Other:** Families have offered to run their own fundraisers to raise funds for the Group. Some suggestions have been book sales, pampered chef and Tupperware proceeds, golf outings, walk/runs, to name a few. At this time, Families can sponsor their own fundraiser and donate their funds to the Group. However, only the FOD member will get the tax-deduction (when we receive tax-exempt status). Deb will also offer additional grief consultation services free of charge, and personally ask (via email or phone) for a donation.

Thank you to all that have donated over the years so that we may continue to provide our support and information to Families and interested professionals at no charge. Your funding helps to cover costs such as copying and postage, webpage fees, phone calls to new FOD Families (US and abroad), and Conference costs ~ none are used for administrative salaries.

THANK YOU from ALL of us!

Donations will be acknowledged in our newsletters, unless the donor requests that their donation be kept private.

Kids Korner



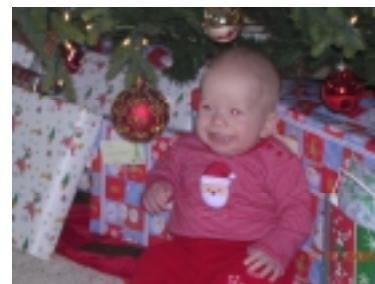
Abrish Somlai
(LCHAD)
Hungary



Sebastian Monk
(VLCAD)
Spain



Vayda (undiagnosed LCHAD,
Canada) and her parents,
Dave and Brenda
(story on page 8)



Greyson Fleming
(MCAD)



Blakley, Ava (MCAD)
and Maelyn Garrett



Family & Professional

Family Donations: I apologize if I miss anyone on this List for this issue ~ my laptop crashed before I could save my entire listing ~ please let me know if I left you out of the donations from July through December 2006. Hugo and Mary Holm in memory of their grandsons Eric Bradford (undiagnosed MCAD) and Matthew Christerson (VLCAD). Raymond and Virginia Forthofer, Louise Ramos, Pat and Alex Grodski, Rex and Cheryl Kennedy, Dorene Bellaire, Ed and Tamara Trevino, Darlene Carson, Brenda and Bruce Goodman, Kathy Stagni, Julie Giddens, Karin Cleary, Karen Underwood, Diane Nielsen, Anne McMeneny, Angela Morgan, Rachel Hall, Sandi Hershberger, Lisa and Gonzo Jaquez, Kristen and Peter Gruber, Jennifer Arveson, Maria Tuttle, for a special Hammon Family Gift. Thank you to all that have bought products from companies on the Internet that support the iGive program of donating a certain percentage to Groups like ours. For more info on the iGive program, visit <http://www.iGive.com/html/refer.cfm?causeid=24970>.

Professional Donations: Sigma-Tau Pharmaceuticals, Inc. (makers of Carnitor®) and Nutricia NA (makers of metabolic foods and infant formulas).

We greatly appreciate donations to help with postage and copying costs, website fees, conference costs, phone calls, and raising funds for FOD Clinical Training and FOD Research. **US Checks can be made payable to FOD FAMILY SUPPORT GROUP. We have filed for 501c3 nonprofit tax-exempt status ~ our status is pending. Once our status is complete your donation will be tax-deductible retroactive to Jan 1, 2007. Our Tax ID # is 83-0471342.**

Thank You

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

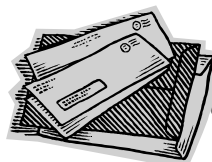
The views expressed in the FOD Communication Network Newsletter do not necessarily represent the views of our Advisors or all of our members. Before trying anything new with your child or yourself in regard to treatment, please discuss matters with your doctor or specialist.



Reminders

Families - Please send **TYPED (preferably in word document)** stories by **June 10, 2007**. To be listed on the FAMILY LIST (refer to our website, Online Forms), please return the SIGNED Family Questionnaire or hand-write your information as seen on the current Family List and sign and date it. Continue to spread the word about FODs and the need for screening ~ it will SAVE LIVES!

Professionals - Please let us know about your research and/or clinical work with FOD Families. Send articles by **June 10, 2007**. Also, please return to Deb the **Professional Questionnaire** even if you are already listed on the printed Professional List. Refer to our website, Online Forms.



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

'You gain strength, courage, and confidence by every experience in which you really stop to look fear in the face. You are able to say to yourself, "I have lived through this horror. I can take the next thing that comes along." You must do the thing you think you cannot do.'

~ Eleanor Roosevelt