FOD Fatty Oxidation Disorder | Communication Network

"All In This Together"

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The ***FOD COMMUNICATION NETWORK Newsletter*** was created and is currently edited by
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Any questions or comments should be directed to them.

From The Editor

The Gould family wishes all of you a healthy New Year and we hope your holidays were safe and not too hectic (not being hectic may be too much to expect, eh?). On a serious note, we do have some families who went through their first holiday season without their child ~ Dan, the boys and I wanted you to know that our thoughts and prayers were with you and your families.

Our winter issue is again information packed with family stories, resources and a book review. Sigma-Tau Pharmaceuticals, Inc. has also provided a pamphlet (*in 2000, no longer available) in your packet on Metabolic Disorders and the role of Carnitine that you can share with your families and medical professionals. I have also described in an article the major differences between Carnitor®, which Sigma-Tau markets, and the health food store/nutritional supplement carnitine. We are also fortunate to provide an article by Dr. Holmes Morton (*not able to print online, given to families in their Family Packet, however) sharing his personal and professional experiences with families coping with various metabolic diseases.

RED DOT ALERT The FOD Family Support Group is under a Red Dot Alert! Don't panic, it's nothing serious, but it is IMPORTANT! If your newsletter has a red dot on the front, it means that **I have not received your completed and signed Family Questionnaire**. If you just want to be on our MAILING LIST ONLY, please send me a

note saying that ~ otherwise **if you send the Questionnaire back I can list you on our Family List**. Either way it will let me know that you want to continue to receive the newsletter. So **if you don't see your name on the Family List and you want to be there, return the info ASAP**. If you cannot find your questionnaire, don't worry, just follow the format on the Family List with your name, address, phone, fax, E-mail, and your child's name and age and what disorder they have as well as any unaffected children's names. Also add any other info you feel important (i.e. mother had HELLP Syndrome with LCHAD child, child has seizures and takes medicines, testing labs used, Drs. consulted). Be sure to sign it and send it to me (DLG) by April 1, 1998. Also if you have had a change of address or phone number, etc. let me know. Be sure to state whether you are a family or a professional. We don't want you to miss out on receiving all this important information because we are '**ALL IN THIS TOGETHER.'**

Take care…
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Letters to the Editor

(Letters/Articles from Professionals/Researchers are ALWAYS welcome too)

Dear Deb: Just a little note to update you on our family's status. Brook is an LCHAD carrier like David and I are. She is doing well and is a happy two-year-old. Ravyn is doing well and is a three-year-old with a very strong attitude. Maybe the red hair has something to do with that.

Ravyn was diagnosed with LCHAD at the age of 8 months and has been hospitalized only once since then because she had the stomach flu and her intake of food was poor. There are times when she has a cold or the flu that we are really stressed, but we take it one hour at a time. We just try to make sure that she drinks fluids at constant intervals.

Ravyn is on a low fat diet, 12 grams per day and she does well with eating. She is in the 95th percentile for her weight and height and is a joy to all who meet her. Her doctor describes her as a vivacious redhead with an attitude. She eats lots of fruits and vegetables and has a 2:00 a.m. feeding during the night where she drinks a package of carnation instant breakfast mixed with a little warm water and skim milk. I feel comfortable with this night feeding and she does not go more than 6 or 7 hours without eating. Ravyn also takes MCT (Medium Chain Triglyceride) oil everyday. This gives her some of the fat that she can digest.

Ravyn goes to see an eye doctor once a year, to check for Retinitis Pigmentosa. To date, she shows no sign of this disorder. She also sees a heart specialist who is really the person we rely on most to help us raise Ravyn in the best way possible.

She will ask me if she can have specific food or if there is fat in it, which is amazing to me. She seems to know what she needs to do to survive and is a very strong little girl.

When we lost our daughter, Megan, at the age of 5months, we thought we would not have any more children. Then when Ravyn was born six weeks early with me having an extreme case of toxemia called **HELLP Syndrome** (which has been shown to be connected to carrying an LCHAD baby), we thought she would be an only child. Three months later we were pregnant with Brook and very scared because of all we had just gone through. When Ravyn was diagnosed, we were 4½months away from delivering Brook. Brook was tested for LCHAD at birth. She is a carrier and when she is ready to marry, her husband will have to be tested before they decide to have children.

Through it all, we have pulled together as a family and done the best that we can. We are very proud to have two beautiful little girls that make our family complete.
Love,
David, Amy, Brook and Ravyn Deshais
North Conway, NH

Dear Deb and Dan: Thank you for all your inspiring stories in your newsletter. Our youngest son, Michael, was diagnosed with MCAD when he was seven months old. He is doing extremely well and had his first birthday on August 7th. I spoke to you back in May after receiving your address and phone number from our pediatrician. Thereafter, we received all your past newsletters and more extensive information, regarding the disorder itself, than we had previously received from our doctors. I have sent in our registration and a brief story about what happened to Michael, regarding his first, and hopefully only, episode. Thank you for all your hard work and dedication. You have been an inspiration to many of us.

Thank you again and God Bless,
Eric and Kristi Mellema
Kennewick, WA

Dear Deb: Thanks for another wonderful newsletter. As for an **update on the DHA study** that Jane and three other children are involved in, I have sent you a one-page abstract of early results. The following is a short summary.

The **researchers at the Waisman Center and the University of Wisconsin Medical School stated that peripheral neuropathy and pigmentary retinopathy with vision loss are potential chronic complications of LCHAD.** They hypothesized that retinal DHA deficiency (an essential fatty acid) contributes to retinal dysfunction in LCHAD children (deficiency of DHA was found in one of the LCHAD children) and that DHA oral supplementation would stabilize or improve the eye abnormalities.

The abstract describes two LCHAD patients, but there are at least four children in the current study. **Preliminary results** after six months of DHA supplementation as a microencapsulated powder **indicated mild but significant improvement in visual acuity and it normalized plasma and erthocyte DHA in an LCHAD deficient child**.

Further study with more LCHAD patients over a longer period of time is necessary to evaluate the effects of DHA on their vision.

I also wanted to pass along the letter I sent out in regard to newborn screening. I copied some of the wording from your letter. I'll let you know what the state of Wisconsin decides! We are all doing well,

Jenny Carroll
Prairie du Sac, WI

Mellema family ~ MCAD

Michael is a very happy, energetic 10-month-old little boy. It is so hard to believe that we almost lost him at only 4-months-old. Michael has always been a very big eater. At only 8-weeks-old, he was eating 'mush' out of a bottle with the hole in the nipple cut out. He never seemed to be satisfied, his appetite anyway. The doctor said to continue feeding him at this rate, being that he obviously took it all in and needed it.

He had always been extremely constipated. Around March 4, we took Michael off all solid foods and substituted prune/water and alternate formula bottles for one day to help ease his constipation. By 9:00 am March 5, Michael was completely lethargic. I called 911, who in turn raced Michael to the nearest hospital. When we arrived at the hospital, there was a chaplain waiting in the emergency room for us. Luckily, Michael was still conscious. His blood sugar was at 16 (normal blood sugar 60-120). He had intravenous tubes in his forearm with glucose in them. Michael immediately became alert and started crying. His blood sugar went back to normal and he was in the hospital for 4 days under observation without further episodes.

A month later we saw the genetic specialist at the U of W who, after many blood samples, diagnosed Michael with MCAD. Michael is now on carnitine twice a day and you'd never know anything was wrong or is wrong with him. We are thankful for the quick reactions of the hospital and our doctors. We pray every day that we never have to go through this again. We welcome any suggestions on diets for a child of this age. At this point, he's still on fruit and vegetable baby foods. But how do you feed a child beyond the baby food stage? Thank you for all the wonderful information you sent to us. It is nice to read about other families dealing with this condition, knowing that we're not the only ones. Thanks again,

The Mellema Family
Eric, Kristi, Jacob, Brittney and Michael
Kennewick, WA

"The most beautiful things in the world
cannot be seen or touched,
but only felt by the heart"

Helen Keller

Bingham family ~ SCAD

Being a Registered Nurse on a high-risk obstetrics unit, I was used to helping families that had babies with life-threatening or chronic conditions, but I never thought we would be in their shoes, on the receiving end of a diagnosis of our child having a chronic disease with no cure. Even though Lindsay, now 3 years 8 months old, has done beautifully since starting her treatment. I am reminded everyday of how vulnerable she is. On some level, I feel very lucky too. Of course I wish that Lindsay had been born without a serious genetic disease, but I've also come to understand that her condition has given our family an extraordinary appreciation for the sweetness of everyday life. We also believe Lindsay was sent to us in order to help other babies be diagnosed and spared from these disorders through newborn screening and testing for the Fatty Acid Oxidation Disorders before they leave the hospital.

When Lindsay was born after an uncomplicated pregnancy and delivery, we were thrilled to have been blessed with a little girl (we have an unaffected 8-year-old son, Ryan). Lindsay was a perfect baby who albeit was unusually quiet but would drink a 'gallon' of breast milk a day. My concern began when she seemed uninterested in bouncing up and down on our laps, rolling over, crawling or creeping etc. Our pediatrician (who we saw) told us she just "maybe a little slower as second children sometimes are." At every check-up I voiced my concerns over her not mastering certain developmental milestones but because her weight gain and growth seemed average, I was told not to worry. By the time Lindsay was 15 months old she would sit quietly and play with her toys but could not bear her own weight, crawl, pull herself up, or cruise the furniture or take her first steps as many other one-year-olds do. Finally, our pediatrician agreed to do hip and leg x-rays, which were negative, and a referral to a neurologist was made. We met the neurologist two weeks later, after a half-hour of observation and a few tests we were told that Lindsay probably had a degenerative neuromuscular disease, a form of Muscular Dystrophy (SMA) and would only live to young adulthood (if it was the less severe form).

Our hearts broke for our beautiful strawberry-blond baby daughter and the stunted life we imagined she'd face. We felt sorry for ourselves too, loaded down by the constant dread of what the future might bring. The only things that kept us going those days were Lindsay's constant demands for food, medicine, therapies, play and attention, and the insistence of her 5-year-old brother that we "come and play."

Fortunately we soon discovered that some of our grief was misplaced as we were referred to a different pediatrician, Dr. Steve Koslov. Lindsay was scheduled for invasive testing to confirm the dreaded diagnosis of SMA. She also had an MRI that showed Lindsay had a birth defect in her spinal cord, which was also causing muscle delays, and a echocardio-gram of her heart showed a small hole defect in one of the walls of her heart (which is

now closing). She then, within a two-week time frame, had a bout with flu and chicken pox. Following those incidences she had a Grand Mal Seizure at home. Dr. Koslov ran a spectrum of blood and urine tests. He had a suspicion that Lindsay might have a metabolic disorder that was causing all of her various problems.

We were referred to Dr. Jon Wolff, at the UW-Madison Waisman Center, who is a pediatric biochemical specialist. More blood work, urine tests and skin biopsies were done which were sent to some of the foremost research facilities such as Baylor University, Duke University and Mayo Clinic. The correct diagnosis for Lindsay was SCAD, or Short Chain Acyl-CoA Dehydrogenase deficiency. SCAD is an inherited inborn genetic metabolic defect of metabolism which in turn is present since birth that prevents Lindsay's cells from breaking down fat into needed energy. This causes a toxic build up of fatty acids to accumulate in her system causing a myriad of problems such as low-muscle tone, lethargy, recurring infections as well as other possible developmental delays.

When the initial fog of the diagnosis lifted we were thrown into a crash course on these disorders. With the guidance of the Waisman Center Clinic's nutritionists, counselors, as well as Dr. Wolff and Dr. Koslov, we went through extensive fact finding in how to care for our daughter. I combed the hospital libraries and did Medline searches, as well as made dozens of phone calls to different organizations that specialize in rare genetic disorders. Lindsay's dad Greg, a computer-programmer/consultant went online to see what he could find on the Internet about info, treatment, and which Universities were involved in research. We even found a support group/newsletter by parents of children with these Fatty Acid Oxidation disorders that contained info treatment and support and even recipes! We have now filled a small file cabinet with articles, information, newsletters and Lindsay's doctor reports.

Each night for months we would literally drop into bed like dish rags, wrung out with exhaustion and anxiety. All this vigilance has taken its toll on our marriage. Greg and I were told that parents of chronically ill children frequently separate, and after a year of marital counseling, we too have become one of those statistics. But as strong as the pressures are against us, we both remain determined to be as involved and vested in both our children's lives as possible.

We have come very far from those awful first months. Even though our days are still filled with medications, special diets and physical therapy, Lindsay is now a healthy preschooler and enrolled in preschool, gymnastics and ballet, and although she goes to doctors more than other kids do, medical care does not define her life. She has not been to the hospital, because of illness, since her diagnosis and since we have found Lindsay's 'recipe' for health, care has become routine. That's not to say it's easy. Like other serious chronic diseases, SCAD requires constant vigilance. Lindsay cannot digest high amounts of fat so she is on a low fat diet of 24 to 37 grams per day. She also must take an amino acid supplement called Carnitor® liquid, 1teaspoon 4 times daily, to help her body take up the fat and eliminate it before it builds up its toxic byproducts. She also takes an awful tasting vitamin B-complex, twice a day; to boost her metabolism, as well as a teaspoon of

cornstarch mixed in skim milk before nap and bedtime, to help prevent her blood sugars from becoming too low. In addition to the restricted fat in her diet she must also eat a high amount of carbohydrates to help maintain normal weight gain. Luckily pasta is her favorite and it's low fat and high in carbohydrates too. Every week to help maintain her muscle tone in large muscles, she receives Physical therapy through the Early Childhood program in her school district. She is also receiving occupational therapy to improve her fine-motor hand skills and some speech therapy.

In retrospect, shortly after beginning the carnitine liquid, multi-vitamins, low fat/high carbohydrate diet, and therapies, Lindsay's development took off. She began pulling up and cruising and walking 2 weeks after starting the regime. We knew we had found the 'recipe' for her success. Even her lab values became more normal. Now at 3 years 8 months old, Lindsay can do things most every other 3 to 4-year-old can. She walks, runs, skips, goes up and down stairs, and recently started riding a two-wheeler with training wheels. She is very bright for her age and is talking up a storm. She even recently has mastered potty training!

We have discovered that having a child with an illness doesn't mean giving up on the idea of a healthy childhood. So since she has learned to walk we are encouraging physical activity such as swimming, gymnastics and playing at the park with her brother and other children. Lindsay doesn't realize all this play is really therapy and we forget most of the time too. We are encouraging our children, to above all, love life. SCAD has changed our lives but we are working hard to make Lindsay's disease as small apart of her life as possible. We resist the impulse to treat Lindsay differently then her big brother, in areas such as discipline, that are not health related, and the low fat diet is a heart-healthy one for all of us!

If we want Lindsay's horizons to be unlimited, we have to define her as a normal child not as a 'patient.' Our family will always live with the burden of chronic illness, but that burden we have realized is not impossible to bear. We hope and pray that through cost effective newborn screening that can be done before babies leave the hospital someday, parents will be spared the agonizing months of waiting and wondering about the well-being of their child as we did. Meanwhile, we will rejoice in our exuberant, beautiful children who are filled with great love.

Kathy Bingham
Madison, WI

Greg Bingham
Madison, WI

To All concerned: Please help us to pass State Legislation so that Wisconsin can be on the cutting edge of this important, life-saving newborn screening test. Your support could save many children's lives like our beautiful daughter Lindsay's! The testing is out there, the treatment very simple and the results/outcomes are phenomenal if found early enough before damage is done! Thank you, The Bingham Family

Maxwell family ~ MCAD

My name is Deanne Maxwell. I recently lost a child on February 15, 1997 to MCAD. My child, Brandon, was 4-months-old. Brandon was in the hospital a month prior to his death. He had been admitted for a high temperature. The doctors were not sure of the cause for his high temp of 102.7° but they had done a urine culture that came back positive for infection. They felt he had a possible UTI and pneumonia, however they had done several tests to confirm this diagnosis. The renal ultrasound that was done to confirm UTI was negative, one doctor stated she had seen traces of pneumonia according to his chest x-ray and two other doctors said they did not see this. They had also done a blood culture and a spinal tap to find the cause of the positive urine culture and high temperature.

Treatment during the 3-day hospital stay was antibiotics per IV. Brandon's temp had subsequently declined during his hospital stay. The day of his discharge, the doctor who discharged him said he "probably had a bacterial infection." The doctor prescribed Augmentin at the time of his discharge. After he was discharged he had no recurrence of his high temperature.

Brandon very seldom cried and when he did it was for short periods. He slept a lot, but what infant doesn't. He ate very well ~ he weighed 16.8lbs at 4-months-old. Brandon never showed any signs of chronic illness. He had learned to laugh out and scoot by moving his arms and legs. He was always smiling even at people he didn't know. He was a very happy baby. **I never knew about MCAD until my child, Brandon died from this disease.** I was shocked to know that there was such a disease existing that has a treatment. I have worked for an ambulance service for eleven years and never heard of MCAD. I can't believe that I had to lose my child to learn about such a disease that has a treatment. If only the hospital would have known to do a blood screen for Brandon while or before he was hospitalized, he would probably be here today smiling at me.

I also have another child. **Tyler is 3-yrs-old.** He was tested for MCAD after we had found out that his brother had died from this disease. He too was **also affected with MCAD. His brother had to die to save his life.** Tyler has been taking Carnitor® for 10 days now. He was also admitted into the hospital when he was a baby at the age of 2-months-old. His symptoms were somewhat different than Brandon's. Tyler had a high temperature, would not drink his bottle, and was slightly coherent. He too was tested for spinal meningitis and they ran urine and blood cultures, but could not find a cause. The doctor said he "probably had a bacterial infection." Tyler has not been in the hospital since then. He has had cold symptoms, double ear infection and would run a high temp every now and then with no apparent reason. Tyler is a very hyper, energetic child. He always has a way with words. I try to tell him that he has to take his medicine so he won't get sick. He tells me that I need to take mine too.

I don't know a lot about MCAD, but I do know that our doctors don't either. I always thought that doctors knew everything. What a way to find out that they don't!! Dr. Downes, a medical examiner, had made the connection of Brandon's fatty liver to MCAD. If he had not known about this, Tyler would not be here. When I was talking with Dr. Downes about this prior to Brandon's test results for MCAD, I asked him if this

could be tested the same as the PKU and he stated to me that it could be done with the PKU, but this screen for MCAD was not enforced. I could not understand how this was possible.

Thank you for your time and interest in MCAD. If it weren't for Dr. Roe, Dr. Downes, and people like you who really care about people, then I would have lost my other child, Tyler. I read an article by Cheryl Rosenberger about how **some physicians are not interested in information on MCAD** and I understand completely. **Tyler was taken to a pediatrician and he had no interest in MCAD. He wanted to know if I was going to use him for Tyler's primary pediatrician, so he would know whether or not to bother reading what information he had on MCAD, because doing this was going to take 4 hours of his time ~ I stated to him he had answered his own question! I felt as though he didn't care if it was possible for another child to come to him and have MCAD, so what made my child any different.**

Deanne and Jerry Maxwell
Mobile, AL

Berneski family ~ MCAD

My husband, Jim, and I brought our first baby home from the hospital on our third wedding anniversary. Michael Joseph weighed 8lbs 3oz. Our pediatrician commented that he was perfect and we agreed. Even though we brought Michael home less than 36 hours after his birth we felt ready to care for a newborn. We had taken a baby care class, a breastfeeding class, and an infant/child CPR course. But all of the knowledge that we had accumulated on babies did not prepare us for what happened next.

Michael did not breastfeed well in the hospital. The nurses and doctors assured us that he was getting enough milk and that his breastfeeding would improve. At home Michael began to nurse more efficiently but never for more than a few minutes. He was wetting diapers but not after every feeding. He became fussy and he refused to eat or sleep. On the third night home his breathing became noisy and we thought he was getting a cold. A visiting nurse came to the house the next day. His temperature was unusually low and she suspected that he was having trouble regulating his body temperature. The pediatrician told us to bring him into the office later that day. As the nurse was leaving, Michael turned gray.

We took Michael to the emergency room. He was admitted and his condition quickly worsened. He was panting and his blood was very acidotic. Doctors regulated his body temperature and put him on bicarbonate and antibiotics. He began having seizures so he was transferred to St. Christopher's Hospital for Children in Philadelphia. Even there no one could tell us what was wrong. Michael went into cardiac arrest twice and the doctors revived him. We kept telling ourselves that the doctors would figure out what was wrong and then he would be okay. Twenty-four hours after Michael was admitted he went into cardiac arrest for the third time. We were asked to leave the hospital room. We sat in the waiting room until **the doctor came out and told us what we already knew ~ Michael**

had died. We just couldn't believe that this had happened to us. I had taken such good care of myself when I was pregnant and he looked like such a healthy baby when he was born.

The autopsy showed fat deposits on the brain, heart, and liver, which indicated a metabolic problem. **One month later we learned the disorder was called Medium Chain Acyl-CoA Dehydrogenase (MCAD).** For a baby to have MCAD both parents must be carriers of the defective gene. If they both are, then there is a one in four chance that their children will inherit the disease. Babies with MCAD are unable to break down their fat for energy when they run out of the glucose that we all get from food. In Michael's case, he was not getting enough breast milk in the first few days. A normal baby would have used its fat stores for energy but Michael could not. If MCAD is diagnosed early the treatment is simple ~ the baby should not go without eating for more than 8-10 hours. For breastfed MCAD babies, formula should be given to supplement breastfeeding for the first few days until the mother's milk comes in. MCAD babies are in a life-threatening situation when they are unable to keep food in their bodies due to fasting, vomiting, or diarrhea. In these cases the baby must be hospitalized and put on IV glucose until normal eating resumes.

Once the information on MCAD had sunk in I we decided to try to have another baby. Five months after Michael's death we were expecting again. At 12 weeks we went for genetic counseling to determine if prenatal testing was feasible. An ultrasound was performed to date the pregnancy. Much to our surprise we discovered that we were not expecting a baby ~ we were expecting two! It appeared that there was only one placenta meaning that the twins were identical. If they were, the MCAD diagnosis would be the same for both babies. Since prenatal testing was only experimental we decided against it.

Based on the information that we had we felt that we could manage the disease if they had it. And since there was only a one in four chance that they would we tried to think positive. One week before my due date I gave birth to 6lbs 5oz and 6lbs 4oz identical twin girls, Samantha and Marissa. They appeared perfectly healthy and were formula fed while we waited for the test results. **Three days after their birth we found out that they both had MCAD.** We decided not to breastfeed because we felt that the stress of caring for two MCAD babies would be enough when there was still so much we didn't know about the disease. We tried to learn everything we could about MCAD. We felt so isolated from friends and family. Everyone seemed to be having babies so easily. Why was this happening to us? We kept a logbook for the first few months. We wrote down when they ate and how much they ate. We were constantly worried about mixing them up and feeding one twice and not feeding the other. As they grew and we could see how normal they looked and acted we became more comfortable about dealing with the disease.

Although we must always be very careful that they eat regularly and have a snack before they go to bed at night, their development has been entirely normal. They have been hospitalized twice with gastrointestinal viruses. Both times they began vomiting and became very lethargic. Our doctors are well aware of the consequences of delaying

treatment so at the first sign of trouble the girls are admitted to the hospital and put on IV glucose. We learned that MCAD occurs in approximately 1 in every 10,000-20,000 pregnancies. **Although this is still rare, it is occurring more often than some diseases that are mandatory to test for at birth such as PKU**. It is estimated that MCAD may cause up to 3-5% of crib deaths and 10% of Reye's Syndrome cases. Approximately one fourth of the babies with MCAD die the very first time they are sick. If a child is diagnosed with MCAD after one or more serious episodes of MCAD-related illness there is a chance of various complications including motor skill delays, cerebral palsy and attention deficit disorder.

When the twins were 18 months old we were pleasantly surprised to find out that we were expecting again. Prenatal testing was available then but we opted against it since there was no other indication of a problem with the pregnancy. Patrick Michael was born on July 11, 1996. He weighed 8Ibs 12oz and he appeared perfectly healthy. **Unfortunately, the test for MCAD came back positive again.** By this time the girls were ready to start preschool. We were concerned that they would bring home a lot of illnesses to the baby so I decided to give breastfeeding another try. The first few weeks were very stressful but eventually Patrick and I got the hang of it and we eliminated formula completely. The treatment for MCAD is so simple. **Our hearts break knowing that had we found out in time, Michael could have lived a normal life. He is more than an angel to us ~ he is a hero. His death and diagnosis made it possible for his sisters and brother to lead healthy lives.** While they will always have to avoid prolonged fasting and may require occasional hospitalizations, their prognosis is excellent. We hope that someday all newborns will be tested for MCAD so that no one else will lose a baby to a disease that can be treated so easily. All of our love,

Sue and Jim Berneski
Warrington, PA

MCAD Hospital Experience

Newsletter looks great, Deb! Thank you for all that you do for the group. The newsletter arrived at a very opportune time for us. Alex has just returned home from his first hospitalization since his MCAD diagnosis over a year ago. He had a virus with vomiting and diarrhea. He maintained good blood sugar levels for the first 48 or so hours and then just when he looked like he was on the mend he started throwing up again and his sugars started dropping. When his sugars went from the 100s where they'd been running to 53 we called our pediatrician. We had been in the day before and he just gave us some ideas on feeding schedules and other options for liquids but told us to keep an eye on his sugars.

He knows our geneticist from working at Egleston during his residency so he is very knowledgeable on MCAD. Unfortunately when we called the pediatrician's after hours service we got another doctor in the practice. I told him that our doctor had specifically asked us to have him paged but the service obviously didn't follow our requests. After the pediatrician on call asked what MCAD stood for I knew we were in trouble. He then told

us to give him Gatorade (something our geneticist specifically said not to do, possibly due to Alex's young age), not to give him his formula (something our pediatrician had specifically said TO do in small quantities), and this is the kicker ~ he then told us to give him Gatorade until bedtime and then to put him down for the night and let him sleep and he'd probably be better in the morning. I knew that Alex's situation was not critical yet to hear such words coming out of a pediatrician's mouth really scared me.

I asked him to let our doctor know that we'd had this conversation. Only minutes after I hung up the phone our doctor called us and told us to take Alex to Egleston (where he had been diagnosed). By the time we got to the hospital his blood sugar was 37. What we thought would only be an overnight stay for some IV fluids turned into a 3-night stay. His sugars didn't respond as well as we hoped and he still had some problems keeping food down. But our wonderful geneticist insisted on getting us home on our third day there. Alex's sugars responded well and he was holding down food well enough for him to be home for Father's Day!

As scary as hospitals sometimes have the impression of being, it was comforting to be there when Alex's sugars were low. We have since spoken to our doctor about our experience with the pediatrician on call and he is going to address it to the entire practice. He had introduced Alex's case to the practice when we first entered the practice, but unfortunately for us someone wasn't paying attention. Needless to say, our doctor has given us his pager number and home number. It is also comforting to know that someone in the genetics department is also always on call.

Since then Alex has bounced back beautifully. He actually learned to put himself to sleep in a crib and to sleep the whole night there during the experience. Something that we are very grateful for! Not exactly the way we had in mind to get to that end. Thanks again for everything.

Erika Wallace
Atlanta, GA

Pharmaceutical Update

Sigma-Tau Pharmaceuticals, Inc., makers of Carnitor® can be reached at 800-447-0169 or on their web page www.sigmatau.com.

BE ON ALERT:
'Major Differences Between the Drug Carnitor® and the Health food Version of Carnitine'

Over the last several years I have spoken with several FOD families that were originally advised by their physicians, pharmacies or HMOs to substitute the health food version, or nutritional supplement of carnitine, for the FDA approved prescription drug product,

Carnitor®, sold by Sigma-Tau Pharmaceuticals, Inc. When I speak with FOD families, I try to impress upon them that there are **MAJOR DIFFERENCES between the regulatory requirements of these products,** and that **for the most part, today's standard treatment for many of the FODs (along with special dietary requirements and/or supplements) is the use of the drug Carnitor®, and NOT the health food version of carnitine.**

The prescription drug Carnitor® has gone through rigorous pre-clinical (animal) tests, as well as clinical trials which demonstrated that the product was SAFE and EFFECTIVE for PARTICULAR DISEASE STATES or CONDITIONS. Additionally, the manufacturer had to submit to the Food and Drug Administration (FDA) a complete chemistry, manufacturing, and controls section of the prescription drug product, as well as samples of the product. The FDA granted marketing approval to Sigma-Tau Pharmaceuticals, for the treatment of primary carnitine deficiency in 1986 and for secondary carnitine deficiency of genetic origin in 1992. Even though Carnitor® is commercially available, the manufacturer must continue to comply with additional regulatory requirements. If there is any change in the chemistry or manufacturing processes of the drug, any change in the labeling of the product, or any adverse experiences associated with the use of the drug, the FDA **MUST** be notified. Finally, the manufacturer of Carnitor® is required to comply with FDA's Current Good Manufacturing Practices (CGMP) regulations which set forth minimum methods, facilities, and controls used in the manufacturing, processing, and packing of Carnitor®.

On the other hand, **the manufacturers of the health food store or nutritional supplement of carnitine, DO NOT GO THROUGH SUCH RIGOROUS PRE-CLINICAL AND CLINICAL TESTING, NOR ARE THEY REQUIRED TO CONTINUALLY MEET SPECIFIC REGULATORY STANDARDS.** Although the manufacturers of the health food version of carnitine must comply with the FDA's CGMP regulation for FOODS, those requirements are MUCH LESS stringent than for the manufacturing and sale of prescription DRUGS like Carnitor®. Thus, **the manufacturers are PREVENTED BY LAW FROM MAKING THERAPEUTIC CLAIMS for their product because the EFFICACY (EFFECTIVENESS) FOR USE IN THE TREATMENT OF DISEASE HAS NOT BEEN ESTABLISHED.**

Additionally, despite the FDA's regulations for Foods, if the health food carnitine manufacturer's facility is located OUTSIDE the US (i.e. Japan and Switzerland), the FDA does not routinely inspect those facilities. Therefore, safety issues for the bulk form of carnitine are in question for these facilities. Our government checks the bulk carnitine for health food use at the U.S. border and has issued an **IMPORT ALERT WARNING on some mixtures of carnitine as UNSAFE. ONLY the L-carnitine form (Carnitor® contains ONLY L-carnitine) is naturally occurring and SAFE.** It should also be noted that the DL-carnitine, sold in health food stores as Vitamin B, competitively inhibits L- carnitine and can cause a deficiency as well as possible toxicity and myasthenia gravis type symptoms.

In a **study comparing the Pharmaceutical product of L-carnitine with 12 health food products claiming to contain L-carnitine, it was found that the disintegration rates of tablets and capsules were UNACCEPTABLY LONG for 7 of the 12 health food brands tested.** Individuals using most of these products would **receive LESS than 60% of the advertised amount of L-carnitine.**

The **Pharmaceutical product**, on the other hand, **MET ACCEPTABLE STANDARDS FOR BOTH DISINTEGRATION AND CONTENT.** The researchers stated that the **INCONSISTENT BEHAVIOR OF THE NON-PRESCRIPTION PRODUCTS** in the disintegration test **indicates LACK OF QUALITY CONTROL** in the manufacturing process.

FOD Families and Professionals **need to be aware of these MAJOR DIFFERENCES** because the **health food store and nutritional supplement version of carnitine is INAPPROPRIATELY BEING USED FOR THE TREATMENT OF METABOLIC DISEASES.** Thus, FOD individuals may be at high risk for possible complications if a metabolic crisis should occur.

WHY RISK THE SAFETY and THE LIVES OF OUR CHILDREN WHEN WE KNOW CARNITOR® IS A SAFE and EFFECTIVE DRUG PRODUCT ALREADY OUT THERE DOING WHAT IT'S DESIGNED TO DO ~ HELP OUR CHILDREN!

Deb Lee Gould, Co-Editor

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Medical Update

North Carolina Newborn Screening Update: In our June 1997 issue, I included an example of a letter that I sent to various legislative and medical personnel in regard to getting FODs included in the state's routine newborn screening testing. You are welcome to use the information within the letter for your own letters. I am excited to say that the pilot program is working. Since implementing the program in mid-July 1997, three children have been diagnosed with MCAD ~ 3 children who otherwise may have gone undiagnosed, possibly experiencing severe illness and/or death. **Newborn screening saves lives! Please continue to pursue FOD newborn screening for your own state or region. Maybe someday our efforts will promote it being done routinely on a national basis! (*in 2000, NC is the only state that MANDATES testing of all newborns for 30+ disorders, it is no longer a pilot study ~ refer to www.tylerforlife.com to see what your state tests for).**

Deb Lee Gould, Director

'In Case Of Emergency!'
Reminder to parents or guardians

Parents ~ carry your protocol sheets with you in case of emergency. Also, before your child may have an episode it may be a good idea to go in and talk with physicians, ER personnel, and/or pediatric floor staff in order to help educate them on your child's emergency needs. Provide nursing staff and the doctor's office with copies of the protocol sheets.

Resources

Statewide Parent-To-Parent Organizations (provides parent matching within state)
Alabama: Parent-to-Parent Connection Network 800-846-3697
Alaska: Parent-to-Parent 907-790-2246
Arizona: Pilot Parents 800-237-3007 (602-242-4366)
Arkansas: Arc Parent-to-Parent 501-375-7770

California: PHP Family Resource Center 408-727-5775 www.php.com
California: Early On Program 800-515-BABY
Colorado: 800-284-025
Connecticut: Parent-to-Parent 860-667-5288
Delaware: Parent Information Center 302-366-0152
Florida: Florida Network on Disabilities 800-825-5736 (813-289-1122)
Georgia: Parent-to-Parent 770-451-5484
Idaho: Parents Reaching Out 208-769-1409
Illinois: CCAR Industries 217-348-0127
Indiana: IPIN 800-964-4746 (317-257-8683)
Iowa: Pilot Parents 800-952-4777 (515-576-5870)
Kansas: Parent-to-Parent 800-264-6343 (913-233-4777)
Kentucky: 800-525-SPIN (502-485-0035)
Louisiana: Parent-to-Parent 800-299-9511 X4268 (504-896-9268)
Maine: 800-870-SPIN
Maryland: Parent's Place 410-712-0900
Massachusetts: Fed. for Children w/Special Needs 800-331-0688
Michigan: Family Support Network 800-359-3722 (313-256-3684)
Minnesota: Pilot Parents 612-827-5641
Missouri: Parent-to-Parent 800-743-7634
Montana: Parent-to-Parent 800-222-PLUK
Nebraska: Parent-to-Parent 800-284-8520 (614-644-9165)
Nevada: Parent Network 800-216-7988 (702-784-4921)
New Hampshire: Parent-to-Parent 800-698-LINK (603-448-6393)
New Jersey: Family-to-Family of NJ 800-983-4800 (908-818-0779)
New Mexico: Parents Reaching Out 800-524-5176 (505-865-3700)
New York: Parent-to-Parent of New York State 800-305-8817
North Carolina: Family Support Network 800-852-0042 (919-966-2841)
North Dakota: Pathfinder Family Center 800-245-5840
Ohio: Family Outreach 419-596-3873
Oklahoma: 800-42-OASIS (405-271-6302)
Oregon: 541-885-7387
Pennsylvania: Parent-to-Parent 717-540-4722
Rhode Island: Parent Information Network 800-464-3399 (401-727-4144)
South Dakota: Parent-to-Parent, Inc 800-658-5411 (605-334-3119)
South Carolina: Parent-to-Parent 800-578-8750 (803-252-0914)
Tennessee: Parents Encouraging Parents 615-741-8530
Utah: Hope ~ A Parent-to-Parent Network 801-272-0493 (V/TTY)
Vermont: Parent-to-Parent 800-800-4005 (802-655-5290)
Virginia: Parent-to-Parent Statewide 800-210-5414 (804-282-4255)
Washington: Parent-to-Parent 800-821-5927(ID, WA, OR) (206-364-3814)
West Virginia: Parent-to-Parent 304-489-1951
Wisconsin: MUMS (& National Database) (414-336-5333)
Wyoming: Parent Information Center 800-660-9742 (307-684-2277)
(Reprinted from January 1997 MUMS newsletter)

University of Miami School of Medicine: Brain and tissue bank for developmental disorders

Hundreds of babies a year are diagnosed with devastating disorders of development for which there is little understanding. Chromosomal disorders, aminoacidopathies, hyperammonemias, neuromuscular disorders, developmental brain disorders, sudden infant death syndrome, unexplained mental retardation, autism and other childhood disorders are perplexing medical mysteries whose unsolved answers will only be found with continued and dedicated research. For this reason, the **Brain and Tissue Bank for Developmental Disorders funded by the National Institutes of Child Health and Human Development** with the expressed goal of advancing meaningful research. It serves the critical purpose of collecting, preserving and distributing human tissues to qualified scientific investigators dedicated to the improved understanding, care and treatment of developmental disorders.

By examining these tissues and comparing the unaffected with the affected, scientists may begin to unravel endless questions. And as answers unfold, so will deeper understanding, offering hope to the future lives of all afflicted children and their families.

The Brain and Tissue Bank for Developmental Disorders reaches out to individuals and organizations across the United States to encourage donor registration. For some, this may be difficult to consider in light of the emotional stress that they have already undergone. But for others, this commitment may offer a sense of purpose. It may offer comfort in knowing that the quest for knowledge and medical understanding will carry on.

The focus of this Bank is the research of childhood disorders; therefore, infant, child and young adult donors are most sought. However, anyone, regardless of age, is invited to donate, especially family members of individuals with disorders. **The Brain and Tissue Bank distributes tissue exclusively for research purposes. YOU MAY CALL 1-800-59-BRAIN from anywhere in the continental United States** to discuss any and all concerns relating to tissue donation. **Your call will be received in strict confidence**.
University of Miami School of Medicine, Department of Pathology (R-5)
PO Box 016960 Miami, FL 33101

Internet Grief and Remembrance Sites: Free web sites to create a memorial for your child or any loved one. Also lists excellent grief and healing resources and a chat room for coping with the death of a child. www.virtual-memorials.com and www.wbs.net.

Research Resource: Research programs pertaining to metabolic muscle disease: Dr. Georgirene Vladutiu, Director of the Robert Guthrie Biochemical Genetics Laboratory at Children's Hospital of Buffalo (NY) stated in a recent UMDF newsletter that their lab is working on identifying new mutations in the gene for Carnitine Palmitoyl Transferase (CPT) and developing novel detection methods for these mutations. The adult onset of CPT deficiency causes pain and stiffness when triggered by exercise, extremes in temperature, fasting, or anesthesia during surgery. CPT

patients can also experience a breakdown of muscle that can lead to kidney damage. The infantile form of CPT can affect many organ systems. The lab offers molecular (in blood) and biochemical (blood or muscle) testing for CPT disorders. Research is also working toward finding more cost-effective approaches to diagnosing muscle disease, as well as trying to identify high risk individuals for mitochondrial muscle disease.

Cyclic Vomiting Syndrome Association: Kathleen Adams, President
13180 Caroline Ct. Elm Grove, WI 53122; 414-784-6842; Fax: 414-821-5494
Email: kadams@post.its.mcw.edu www.beaker.iupui.edU/cvsa
CVS is an uncommon, unexplained disorder of children and some adults characterized by recurrent, prolonged attacks of severe nausea, vomiting and prostration with no apparent cause. The CVSA will hold its 2nd Scientific Symposium on April 23 & 24, 1998 for clinical and basic investigations. It will be centered on the physiology of vomiting, migraine mechanisms and how it is all related to CVS. Contact Kathleen for more info.

National Father's Network: Provides support and resources to over 3000 fathers/families of children with special needs and professionals working with them. Free. Contact: James May, National Father's Network, Kindering Center, 16120 NE Eighth St., Bellevue, WA 98008 206-747-4004.

Education Issues: Technical Assistance for Parent Programs (TAPP)
Training and information to parents of children with disabilities; informs parents about their children's rights under special education and other laws. TAPP Central Office: Federation For Children With Special Needs, 95 Berkeley St., Boston, MA 02116, 617-482-2915 Fax 617-695-2939 website: www.fcsn.org.

Exceptional Parent Magazine
June, July, August 1997
Excellent 3-part series of articles on Mitochondrial Metabolic disorders, of which FODs are included. Extremely informative!!

LOGO Idea and Inspiration ~ Jessica's Guardian Angel

Hi Deb: Thank you for the info you sent me. I haven't read it all, but what I have read makes me think my daughter does have a fatty oxidation disorder. I read that you were looking for a logo. I have enclosed something I did on my computer. It is just an idea. I am not an artist. So feel free to have someone redo it, if you like it.

Let me tell you what gave me the idea for this logo. When Jessica was 11-months-old, she almost died from the stomach flu. That was the beginning of this roller coaster ride for my family. Over the past 5 years she has been a typical child except for having to graze on food throughout the day. This past February I had an appointment for my adopted daughter at the Children's Hospital. She is very small and her doctor thought growth hormones might help her.

I have 5 children, 2 biological and 3 adopted, and needless to say, it is very difficult to get coverage for every child when I have a doctor's appointment for one of them. For this appointment I did find coverage for everyone and that doesn't happen very often.

A couple of days before the appointment my tooth broke and I had to reschedule the appointment because I had to go the oral surgeon. So when we got another appointment, I didn't have coverage for Jessica and had to take her with me. It just so happens that her doctor from 5 years ago was there in the next room. His name is Dr. Philp Gruppuso, and he is the Director of Pediatric Endocrinology and Metabolism at Hasbro Children's Hospital and also, Professor of Pediatrics at Brown University School of Medicine. What are the chances he would be right in the next room and offer to examine Jessica when we didn't have an appointment for her?

During his examination he discovered she had an enlarged liver and wanted to start her testing all over again. Now remember, she wasn't even supposed to be with me on the first appointment I had scheduled. He asked me to get all the family history I could and I told him this would be difficult because my mother's mother died at age 29 from a stroke. I called my mother and asked her if there was anyone I could call to start this process. She gave me the number of someone in California to call. I called this person and come to find out she is my mother's cousin. The strange thing about this story is my grandparent's siblings married each other (my grandfather's sister married my grandmother's brother) and so gene wise the history for my family is exactly the same as my mother's cousin because everyone from my grandparents back is the same family. And to make the story even stranger, my mother's other cousin has a daughter (who would be the equivalent of me) who has been tracing the family history for the last two years. Within two days I had all the death certificates of my family and all their history. Can you believe that? Even now when I think about it, it still blows my mind.

When Jessica was sick 5 years ago our doctor told us to calm down and that we were overly protective because of all the problems we had had with our son Nathan and his seizures. My husband Bill made up his mind to take her to the emergency room that day. If he hadn't she would have died.

I truly believe that Jessica's guardian angel is watching out for her and all of the other children who get through these episodes. It is divine intervention. In February a certain chain of events had to take place for Jessica to be with me that day and for us to run into Dr. Gruppuso. **God has a plan for her and my family. I envision Jessica with the wings of an angel wrapped around her and that is the inspiration for my drawing.**

I'm sorry this turned out to be such a long story, but I wanted to share it with you so you could understand my thoughts about the drawing. Good luck finding a logo. I know it is a tough process to decide.

Book Review ~

Special Children, Challenged Parents: The Struggles and Rewards of Raising a Child with a Disability

Robert A. Naseef, PhD
Birch Lane Press Book, 1997

"There are many lessons on this journey for connection and support as we are drawn together by our similarities, meeting through tears and laughter. It takes courage to acknowledge the hurt or grief and loneliness and to risk being hurt again. But that risk is necessary to get to the other side of sorrow. Whether we are related by chance or choice, we must learn to accept and honor our differences. When we do this, we can divide our sorrow, multiply our joys, and make connections to support us through a lifetime."
(p. 172)

I pulled this quote from the above book because I felt it really 'spoke' to many of our families, especially at the moment of hearing that our child/children had a genetic disease or when we experienced a parent's worst nightmare of having to bury one or more of our children. It really **embodies our Network's main themes of 'We are all in this together,' 'We are not alone,' and that 'People truly need people' for ongoing support.**

Over the summer I was introduced to this book via the Internet. The author, Dr. Robert Naseef, a psychologist specializing in helping families of children with special needs, was offering support groups like ours an opportunity to review his 'labor of love.' And I was truly glad that I took him up on his offer!

You see, Dr. Naseef intimately knows all about grieving the loss of a dream of a 'perfect' child. His book was inspired by his own personal experiences with his son, Tariq, who has autism. Some of you may say that this book may not relate to your own situation

because it's not the same disorder as FODs. If you believe that, then you'd be the one really missing out on a very powerful expression of one man's journey; individually and with his family (immediate and family-of-origin) and friends and coworkers, of learning to cope and live with a long-term disorder and coming to grips with the discrepancy between what he calls the 'imagined' and the 'real' child, as well as to learn how to accept and love Tariq for who he is ~ his son.

He does an excellent job of interspersing his own fears and struggles and ongoing process of healing with cases from his research and clinical practice of working with families with a chronic illness or a disability. He gives workable parenting strategies for 'getting in tune' with your children and understanding their temperaments and why they behave the way they do, how to assist in changing behaviors, as well as creating an environment for promoting bonding and a positive relationship. Additionally, he also discusses coming to terms with your child's limitations, depending on the severity of the disorder. He recognizes that men and women, as well as children, will respond differently to what is going on within the family depending on their unique perspective and offers helpful strategies to understand how each person may express their feelings of grief, denial, anger, fear, anxiety, guilt, sorrow, and even joy, in a variety of ways.

He is very honest about how dealing with his son's autism has taken its toll on him personally and professionally ~ something I'm sure we can all relate to at some point in time in our own journeys. He discussed that it's a real challenge to redefine yourself as a parent when you learn your child has a disorder, as well as learning who your child is, and what your relationship with your child may be, depending on the type of disorder (will they be raised/cared for at home or is there a need for professional long-term intervention).

No matter what the severity, love can be a very strong connecting force even when it appears all hope is lost and that love possibly cannot be returned from your child because of a variety of reasons. Often with autism, children appear to be 'in another world' and as Dr. Naseef expresses, it is oftentimes extremely frustrating trying to reach them the way we as parents hope and desire to reach them. Yet, on a personal note, I strongly believe that on some level that we may not understand, that love is connecting. We may not see it outwardly but it's there. I imagine that challenge may be part of all our journeys ~ learning different ways of connecting with our child ~ all of our children ~ whether they have a disorder or not.

I highly recommend this book as a resource on facing the daily challenges of dealing with a chronic disorder. Dr. Naseef offers a variety of educational resources, as well as support organizations. Throughout his writings he stresses that connections and support are vital. We are not islands and by seeking medical, educational, emotional, physical and spiritual support we are not only helping ourselves and other parents we are ultimately helping our children and our families. On that point, I will end as I began ~ with a quote (p.153):

"A friend is one to whom one may pour out all the contents of one's heart, chaff and grain together, knowing that the gentlest of hands will take and sift it, keep what is worth keeping and with the breath of kindness blow the rest away."

Deb Lee Gould, Director

Love Messages

(Please see our most current online issue)

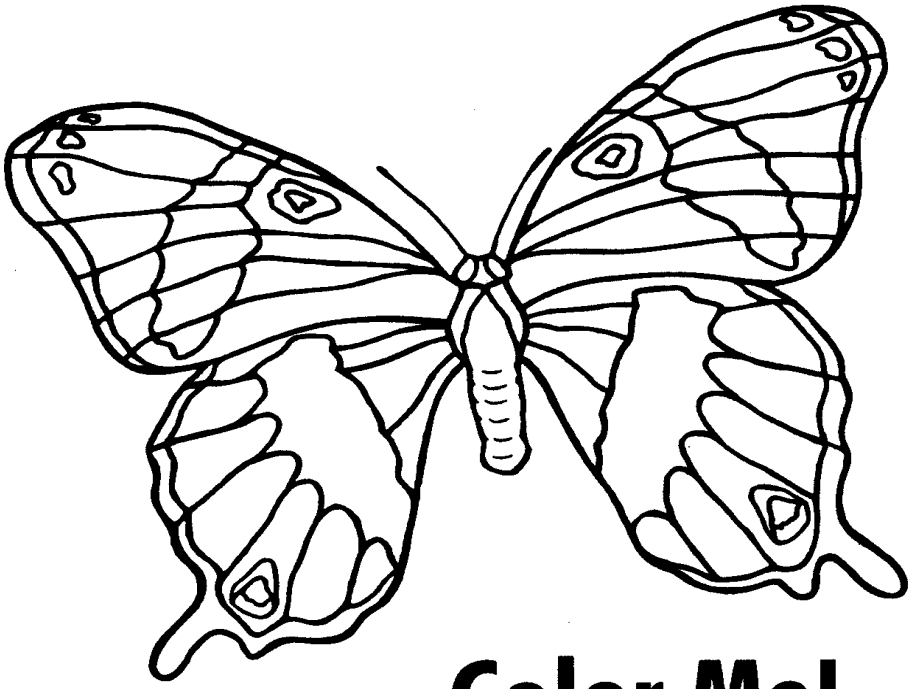
'We remember best what we love most'
from a Hallmark card

Kids Korner

Unscramble the words below. They are all foods that are high in carbohydrates:

eercla	sapat	crie	absne
skraccer	tsrufi	drbea	onpprco
sctrroa	cpishna	ecttuel	

(answers on last page)



Donations Received

The FOD Family Support Group would like to thank: Gloria Van Arsdale, Diane Rudzitis, Bill and Marie Lewis, and Karin Leonardi for their generous donations. We greatly appreciate donations to help with postage and copying costs. However, because we are not a non-profit organization, be aware that donations are not tax-deductible at this time. Checks can be made out to: Deb Lee Gould. Please note on the check that it is for the FOD Family Support Group.

Reminders

• **Families:** Continue to send your stories. They are informational and very inspiring. Pictures would be great too. Also **sign and return your Family Questionnaire.**

• **Book Reviews:** If you've read a helpful book that you think our Network should know about please share your opinion by writing a short review stating some main points and what you gained from reading it.

• **Kids Korner:** Any stories or questions out there from our older FOD kids? Let us know.

• **Education:** Continue to educate your families and as many professionals as you can about FODs, as well as advocating Newborn Screening for your state/region. We have to be Proactive ~ it will save lives!

• **Help!!!** I need help! Is anyone proficient with the bulk mail process? Since we don't have many families/professionals in the same city/state, the process is pretty complicated and time consuming if you don't know what you are doing ~ and I have no idea what I am doing as far as that is concerned! So if you have any ideas, let us know.

• **Logo Ideas:** Logo ideas needed ~ be creative. So let loose!

• **Thanks:** Thanks AGAIN to Eric and Lori Schmid and Erika Wallace for all your help.

ANSWERS to word scramble: cereal, pasta, rice, beans, crackers, fruits, bread, popcorn, carrots, spinach, lettuce

January 1998
Volume 8 Issue 1

[Please Note: Our Group began in 1991 as the MCAD Family Support Group ~ in 1996 we expanded to include all of the Fatty Oxidation Disorders (FODs). Please be sure to read the most current newsletters to get the most updated information on FOD diagnosis, Newborn screening, treatment recommendations, research, and names of FOD researchers/Labs.]

Medical Advisor for the FOD Family Support Group is Dr. Charles Roe, Institute of Metabolic Disease at Baylor in Dallas. Email is cr.roe@baylordallas.edu