

FOD

**Fatty Oxidation Disorder
Communication Network**



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Volume 8 Issue 2

The *FOD COMMUNICATION NETWORK Newsletter* was created and is currently edited by Deb and Dan Gould ~ 805 Montrose Drive, Greensboro, NC 27410 (336) 547-8682
Any questions or comments should be directed to them.

From The Editor

We hope all of you are keeping as cool as possible. Grab a glass of water or ice tea, put your feet up for a bit, and learn more about our FOD families. Since we have received so many Family stories, we decided to make this a Family issue. We were not able to put them all in this issue, so if you don't see your story, it will be in our January 1999 newsletter.

Families: If you do NOT see your name on the Family List, it's because I did not receive your Family Questionnaire. **Please** return the questionnaire. If you have lost the questionnaire, send a signed and dated letter with all the important information, as shown on the Family List. Otherwise, your family will remain unlisted on the Family List.

Thank you to all the families that contributed their creative ideas for our logo. **Our special thanks to Dell and Melanie Ruff for creating our new logo that we felt best symbolized the essence of our mission and goals** (*see our current website for acknowledgement of their contribution). The broken chain link represents the 'chain' disorders (all other FODs as well) and that even though an enzyme 'link' may be missing, we are '**ALL IN THIS TOGETHER**' to support each other! We hope you like our new look!

Since many of our families use non-prescriptive nutritional supplements, we have provided information on the nutritional content of a few of the familiar ones that families have mentioned to me over the years (*unable to reprint on this site but families receive it in their new Family Packet). Jeff Schmidt, our Webmaster (*1996-2000), also shares his personal experience with a supplement his entire family uses. Exercise Principles to be aware of for FOD families is offered by Cindy Duncan, a Physical Therapist who has worked with some FOD children in California. Additionally, Dr. Scaglia, a Genetics Fellow at Emory University School of Medicine (*in 2000, in Houston, TX), shares his experience with a child's rare presentation of Primary Carnitine Deficiency.

Just one announcement: Be aware that Sigma-Tau's liquid Carnitor® is now CLEAR. Yes it is the real thing ~ your pharmacist did not make a mistake! I hope you enjoy our summer issue and many thanks to those that have contributed articles, as well as monetary donations both of which help our children and future children. Your efforts are greatly appreciated!

Take care...

Deb and Dan Gould, Co-Editors

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Letters to the Editor

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

Dear Deb: First off I'd like to apologize for taking so long to return this form. Things had just started to settle down from a long terrifying summer when three weeks ago everything started up again. Ryan has been in the hospital three times in less than three weeks (hooked up to an IV) and we have made four trips to the emergency room. I'm happy to say that since his almost tragic first episode everyone tends to be on the cautious side and things are always handled quickly and efficiently. We're lucky to have some very good doctors who are working with Ryan.

I can't tell you enough how much we appreciated all the newsletters and information you sent. It's very eerie how familiar many of the stories sound to our own episode with Ryan. It's comforting to know we're not alone in what we're going through. I have already contacted a few people whose names and numbers I got from the information you sent. Dr. Roe was especially informative to talk to ~ what a nice man! If there is anything we can do, please let me know.

I've read in some of the articles that there is the possibility of Retinitis Pigmentosa associated with one of the disorders (*LCHAD). I'm a teacher for visually impaired and blind children and would be happy to answer any questions I can as far as my experience in working with children who have RR Thank you again for all you've done.

Sincerely,

Joni Smith

Jacksonville Beach, FL

Howard Family ~ MCAD

Our MCAD story started on 5 October 1996, when the evening before, our eldest daughter Kayla became ill with a vomiting illness. It was the first time that she had ever been vomiting, which is unusual for a five-year-old. She had been hospitalized in the past with asthma and whenever she was ill with any of the usual childhood viruses, she did seem to go very lethargic quickly. As I was always worried about dehydration, I had always given gastric mixtures or sweet drinks when she was ill. This time as she was vomiting and older, I thought she would be better sticking just to water.

The next day I was due to work and she was asleep in my bed. As I was getting ready for work my mother, who was babysitting, came to talk to her. By this stage she had stopped vomiting so I thought she was on the mend. Mum could not get through to her and I could hear the concern in her voice. When we spoke to her, she just was not there. The old saying "the lights are on but no one is home" is the only way I could describe how it was to look at her. I thought she had a virus that had caused some sort of brain damage.

I took her to our local GP and he advised us to take her to the children's hospital. The drive there was the worst 20 minutes of my life. Fortunately most of the morning traffic had gone, but I felt I was in my own little bubble of horror. It was a lovely spring day and on the radio I could hear all the happy morning cheer. The rest of the world was going about its usual business and I had "lost" my precious daughter. I could only image that the Kayla I had was gone and I was now left with a new mentally disabled child. I knew my way to the emergency department as I had been there on late night asthma visits. This time during the day I got the last car park right in front of a day care center. Again I was struck by the unfairness of it all.

Here in Australia we have a public hospital system that seems to be having a few problems lately. However, the Princess Margaret Children's hospital was just wonderful. I was rushed straight through and when I put her on the bed, medical staff seemed to come from everywhere. It reminded me of an episode of ER. People were everywhere poking and prodding. They were concerned that she was not responding to anything. I could not believe this was happening and I will never forget the scene of her lying there on the bed. I had not taken my handbag when I rushed out of the house. All I had was a fifty-cent coin for a phone call that I had found in the car and my car keys.

One of the things the medical staff was doing was to place her on an IV drip. As a result she slowly came back to life amazing us all. She sat up in bed and asked for a vegemite (popular Australian spread) sandwich and a can of Fanta. She was kept in the hospital for a few days and **a few tests were done, one for MCAD. When that came back positive our other daughter also tested positive.** That did surprise us as she was never inclined to become as lethargic as Kayla when ill.

The hardest thing to cope with was that this was a condition that we had never heard of and could not find any information on. Eventually a friend found the support group via the Internet. I thank you all for starting the group and providing information and stories about your experiences as it does help to come to terms with it. We have been living with it now for over two years and Kayla has only been hospitalized once since. Knowing that, staying away from fatty foods during illness, and only eating carbohydrates has made a huge difference. I have found rice cakes to be the magical cure when vomiting strikes. My greatest concern is for the teenage years when dieting is a major past time for girls. I consider us to be very lucky that neither of the girls had vomiting illness early in their lives. My heart goes out to all those who have lost a child to MCAD or similar. For 20 minutes on 5/10/96, I thought I had lost Kayla.

Kerri and Brent Howard
Perth, Western Australia

Thackrah Family ~ SCAD

We are Ernest and Tammy Thackrah. Our son's name is Ryan Alexander. At about 10-months-old, our local pediatrician began to worry about Ryan's eating habits and lack of weight gain. We were sent to Albany Medical Center in NY; which is only about 45 minutes from home. Upon arrival, a series of tests were done under the assumption of "failure to thrive." After a few visits and no results, Ryan was admitted for about a week for further study. Still nothing was found and we went on about our business.

As Ryan turned approximately one, our pediatrician was still concerned about Ryan's lack of weight gain and growth. The idea of visiting Boston's Children's Hospital was brought to our attention and we proceeded to make an appointment. Upon arrival, many doctors, metabolic, neurologists and dieticians had visited Ryan while once again he was admitted for tests. Doctor Talley Sagie, under the direction of his now acting physician, Dr. Fran Dougherty, proceeded to test at the genetic level. Tests were sent world wide including Denmark and Italy as well as many universities in the US. After a period of trips to the hospital and a few admissions and tests such as skin and muscle biopsies, as well as countless blood work, and a feeding tube placement, **the doctors gave Ryan a diagnosis. SCAD was the name, and at the time he was only one of "twelve" cases diagnosed in the world.** Needless to say we were a little worried as to what was going to happen next.

Ryan had the feeding tube placed and since then has grown to about 23 pounds, up from 10 pounds when he was diagnosed. Still many tests have been taken, including ones of our own. Ryan's disorder so far has affected his muscle tone for which he receives physical therapy 2 to 3 times a week. At age three, he still doesn't walk or talk much, but let me tell you he sure gets around on his butt!!!

By the looks of Ryan, you couldn't tell he has a problem other than he is well below the 5th percentile on the growth chart. He is very active and even-tempered and is by no means a walk in the park. On our recent visit to Boston, Dr. Dougherty has clarified a few questions that we have been wondering about. However, it has complicated things a little more. Reason being, Ryan's tests have been somewhat inconclusive. Bottom line is they are not sure of some discrepancies in the tests. They are even leaning towards a more rare diagnosis that they have no cases of (*in 2000, we do have several families with an 'unclassified FOD' diagnosis, in that the Drs have yet to place a name on it possibly because they have not seen enough cases).

So, once again we start from the beginning. My intentions for writing are to get responses from other families with SCAD and their histories. Please feel free to print anything related to this article.

Ernest and Tammy Thackrah
Johnstown, NY

Henson Family ~ MCAD

On November 7, 1997, my mom kept Shane while I worked. He had been sick, running a fever and wouldn't eat or drink, so we carried him to the doctor. He said Shane had a viral infection. Shane has tubes in his ears so we were afraid he had another ear infection ~ they have not seemed to help much since we put them in. The only thing was he heard us better.

We took him home and the only thing we could get him to eat or drink was a few French fries and diet Mountain Dew. We didn't want him to dehydrate so since he took the diet Mountain Dew we gave him a lot. He had dehydrated as an infant about 6 months old (we thought). Now we believe it was the same thing we experienced November 8, 1997. I woke up and Shane was moaning and sleeping. I thought that he must have the flu so I let him sleep. He was shaking so I covered him only he wasn't shaking he was actually having seizures. I tried to wake him to give him some Pedialyte and he was like spaghetti. I got scared and called my Mom. She came over and we put him in the car and took him to the hospital.

When we got there they took him in and began to work on him. They asked us all sorts of questions. They said he was having seizures. He cried out. They said his sugar blood count was 8. They began fluids of glucose. They wanted to fly Shane to National Children's Hospital in Washington D.C., but couldn't because it was raining. So they sent him by ambulance. I rode in front. I couldn't believe this was happening to Shane. He was in a coma for 2½ weeks. They told us he had brain damage and would be retarded. It has been 2½ months and Shane is in a rehabilitation hospital in Maryland. **We know Shane has got along way to go. He can see and hear us and knows us. With rehabilitation and God's help I believe Shane will walk and talk. He may be slow. I thank God everyday for letting us keep Shane. I know it was his grace that kept Shane alive November 8th and I give him all the glory.** Thank you so much for the MCAD information you sent me. As I read the stories, I cried and thanked God Shane was alive. If you know anyone who has a story like mine I would like to know. We are not sure if they will be giving Shane a feeding tube. I am sorry I took so long to send these back. I will update you on his condition.

Jeannie Henson
Lexington Park, MD

Hughes Family ~ VLCAD

Thank you so much for sending all the valuable information in the FOD Newsletters via my sister-in-law, Donna Clark. Thank goodness we discovered your organization because without this we would know absolutely nothing about the condition that took our precious daughter's life eight months ago.

Claire was a talented, intelligent and very healthy ten-year-old who loved life cramming it with all the things she enjoyed ~ school, netball, competitive swimming, piano lessons, choir and dancing. She never sat still (and neither did we as we juggled all these activities with those of our two younger children, Cameron now 8 and Elizabeth aged 4). Claire's health had never given us any cause for concern. From the moment she was born she loved her food. She was breastfed for 2 years and was always a "good eater." She encountered all the usual childhood illnesses of chicken pox, regular bouts of tonsillitis, the occasional bout of vomiting etc., but always made a complete recovery.

However, in late May 1997, the entire family, one by one, was hit by a dreadful flu-like virus, which seemed to have attacked everyone we spoke to. Claire managed to fight it off for longer than most but finally succumbed, around June 7th. I immediately took her to the local emergency doctor (hoping the initial sore throat was as far as it would progress if treated quickly). She was prescribed some antibiotics but the doctor indicated that the virus would just have to run its course, as it did with each of us. So, for the next five days Claire felt lethargic, her whole body ached and her appetite waned. On the fifth day she started to improve so rapidly that she actually felt well enough to perform in the final performance of a large-scale "schools spectacular" concert (for which she had spent months rehearsing), dancing in 3 items, much to the delight of her family, teachers, and friends.

Claire continued to improve over the weekend, playing in the park with her friends and visiting family friends. However, on Monday afternoon (16th June) she began feeling quite ill again so I took her to our family doctor on Tuesday morning. She checked Claire thoroughly and felt that she was having a relapse of the virus or had maybe contracted yet another virus. She recommended fluids and rest but indicated that she'd like to see Claire if there was no improvement over the next couple of days. On Wednesday, Claire had some vomiting and was aching all over. By Thursday this hadn't improved and she had a high temperature so we returned to the doctor who then found Claire had an ear infection and prescribed an antibiotic (which she didn't take because of vomiting), panadol suppositories and fluids. By the next morning her temperature had returned to normal, the vomiting subsided and she actually ate some toast for breakfast. However, by the evening she was getting a sharp pain in her stomach that was eased by a warm bath.

Following a restless night (drinking lots of water) she awoke feeling and looking worse. Her breathing was becoming labored and soon she began vomiting again. She begged me not to take her back to the doctor claiming she just wanted to stay in bed and rest (the fact that I didn't INSIST at this point is an agonizing regret I will carry forever). Although she was vomiting on and off, she was taking in lots of fluids enough I thought, to replace what she was losing. At about 6pm, she decided to get up and lay on the lounge to watch some TV. When she walked, she was unsteady on her feet. Then, when she returned to bed an hour later, she yelled at me to "go and get my mother!" This really frightened me, even though she immediately realized her error. I then insisted we go to the hospital and she agreed, saying she felt too frightened to go to sleep.

The doctors at the hospital x-rayed her chest and found pneumonia on her right lung. She was dehydrated and her sugar level was very low. They immediately began a glucose drip. After about an hour, someone felt her abdomen and Claire suddenly yelled in pain. Soon, specialists began arriving and feeling her tummy. They took us aside, explaining that her liver was very enlarged. They arranged for Claire's immediate transfer by helicopter to the New Camperdown Children's Hospital in Sydney (2 hours by road from Newcastle). I traveled with Claire and Neil was going to bring the children down by car early the next morning.

One hour after arriving in Sydney, while I was waiting to be taken to Claire, a nurse came into the waiting room looking very worried. She held my hand, paused for a moment and as my heart pounded with anguish she told that my little girl was "gravely ill." She then took a deep breath and said, "We don't think Claire is going to make it." The feelings that followed are indescribable. My little girl was in acute liver failure. For the next 24 hours our brave little girl defied all expectations and managed to cling to life. The only hope we were given was a liver transplant (a nationwide donor search had begun) and a 'miracle.'

Claire had been in a coma since her arrival at Sydney and by 8am was on maximum life support. As I looked at my precious child lying there, barely recognizable because of the bruising and swelling, unconscious, I knew in my heart that her poor body would never be able to tolerate such major surgery and that time was running out, yet I was unable to give up hope. I stroked her beautiful dark, wavy hair and told her how much I loved her. I kissed her soft delicate hands and begged her not to die.

At 3am on June 23, 1997 (our Elizabeth's 4th birthday) my little girl's courageous heart could fight no longer. We stood by as the nurses frantically did all they could to help her. All the medical knowledge and equipment had failed her. I feel I had failed her also. I will never know a more helpless feeling. Our world had been torn apart. **We stayed with our precious girl for 7 hours ~ no machines, no tubes, no staff ~ just our family spending our last moments as 'the five of us'...our last moments with this adorable child, a wonderful daughter and sister.** We were so numb, so exhausted and so shocked that grasping reality was virtually impossible.

Over the following days and weeks, while still trying to come to terms with this catastrophe, we waited and wondered. Why? What could have brought about this horrific end to our little girl's life? What could we have done to prevent it? **The questions were endless. The doctors tried to prepare us for the possibility that an answer may never come.**

However, after 4 months of 'doing all that was humanly possible' to **find an answer, it finally came.** Large deposits of fat had accumulated in Claire's liver, kidneys and heart and the subsequent tests (in Adelaide, SA) indicated a **fatty acid oxidation disorder.** This answer brought with it so many mixed feelings and so many more questions. **How could this energetic and healthy 10-year-old child have had a potentially fatal underlying condition all her life without it being detected?** Why weren't there any signs earlier? The news that this is a genetic condition was even harder to grasp. The fact

that we, albeit unknowingly, had passed this condition on to our daughter and possibly to our younger children has taken a great deal of coming to terms with.

Trying to acquire some information about this condition was virtually impossible until, to our relief, my sister-in-law discovered your web site. This is ALL the information we have been able to locate. Cameron and Elizabeth have had skin biopsies and urine samples taken which, with Claire's samples, have been sent to France for testing (collected in December). Meanwhile we wait anxiously. We were told the results should be available March or April 1998. **We have been told Claire had VLCAD** and we have no information about this particular disorder. We would be eternally grateful for ANY information or contacts you could supply regarding VLCAD. Even if the results indicate that Cameron and Elizabeth are unaffected (*on March 16, received news that Cameron and Elizabeth's tests were normal!). We naturally feel a great need to gain an insight and better understanding of this condition. Thank you for your time and help and the wonderful and important service you provide.

Gratefully yours,
Meredith Hughes
Wallsend, NSW, Australia

A HUG The Universal Rx

No moving parts, no batteries
No monthly payments and no fees;
Inflation proof, non-taxable
In fact, it's quite relaxable;

It can't be stolen, won't pollute,
One size fits all, do not dilute.
It uses less energy,
But yields results enormously.

Relieves your tension and your stress,
Invigorate your happiness;
Combats depression, makes you beam,
And elevates your self-esteem!

Your circulation it corrects
Without unpleasant side effects.
It is, I think the perfect drug;
May I prescribe, my friend... The hug!
(And of course, fully returnable!)

Source Unknown (if you know please let me know!)

Hanson Family ~ MCAD

Thank you so much for sending me the newsletter packet so quickly and I apologize for taking so long to get back to you. The newsletters are amazing and so many of the stories sound so familiar. I checked the box on the questionnaire that I would send you my story, so here it goes...

Nicholas woke up Tuesday morning (1/31/97) very congested, coughing terribly. I took him to the doctor the following day and was told he had a bilateral ear infection and bronchitis. The doctor could not believe he was in such good spirits considering how sick he was. Anyway we took him home and gave him his medication. He seemed like a regular sick kid from then until Friday morning, this is when it began. He woke up Friday morning at 5:30am as he usually did. However he did not want to take his bottle. Since he was sick I let him go back to sleep. When he did not get up by 7-7:30 (even though I had the vacuum on) I went in to get him. I tried giving him a bottle again, but he would not take it. He was so limp, just opening and closing his eyes. I called the Doctor and told her I was bringing him to the emergency room. They took us in right away and put Nicholas and myself in a room alone. This I could not understand.

When someone finally came in, I just said "Look at him. This is not normal." Another Doctor came in and took him immediately. The next time I saw him, he was intubated, hooked up to an IV and being transferred by ambulance to the hospital's other site where the pediatric ICU was located. Once we arrived, I was told that we brought Nicholas in just in the nick of time. They then told me he was going to be fine, that his chest was very congested from pneumonia and he was having a hard time breathing. Never once did they mention to me that his blood sugar was 38.

The Doctors told me he would be home by Sunday. Well, Sunday came and other problems began to arise (heart speeding up and then slowing down, kidneys failing). I remember them telling me "This just happened, but he is stable now." Monday morning the cardiologist was checking Nicholas' heart again, when (thank God) he noticed that his liver was enlarged. This prompted the doctors to run liver tests. The next thing I knew the North Shore University Hospitals transport team was bringing Nicholas to Long Island.

We arrived at NSLJH at around 2:00am Tuesday morning and had our MCAD diagnosis by Thursday morning. Slowly but surely after six days in a coma, Nicholas began to wake up. He spent one more week in ICU and was ready to go home!!

I am so grateful to the wonderful Doctors and caring staff at North Shore and to God for giving them the wisdom, knowledge and compassion needed to save my Nicholas. Since his homecoming on February 13, he has been hospitalized twice. In May he suffered from a stomach virus and in July (the day after his glorious first birthday) he had roseola. Now at fourteen months, he is doing wonderful. He is walking, trying to talk and getting into EVERYTHING!

Deb and Dan, I am truly sorry for the loss of your daughter and could never imagine how you feel. But your strength to move forward and help others is a gift that will always be appreciated. I will keep the whole MCAD family in my thoughts. Thanks again,

Michele Hanson
Staten Island, NY

PS. Deb, I just wanted to let you know that I also received my MS in education and Advanced Certificate in Guidance and Counseling (right before Nicholas was born). I hope you will not be too disappointed when I tell you that all my coping strategies, ability to think rationally and theory upon theory on how to handle life's challenges flew out the window...

Dougherty Family ~ VLCAD (Initially diagnosed as LCAD)

Our first and only child, Jordan Elizabeth, was born on September 15, 1992. She weighed 8lbs 9oz and except for some episodes of severe colic was a happy, healthy infant. She had no major illnesses until she was 17 months old. She came down with what we thought was simple stomach flu. She couldn't eat and by evening she was becoming increasingly lethargic.

As first time parents we really didn't know that her behavior was out of the ordinary. My husband and I took turns sleeping with her as she was extremely irritable and restless. Around 3 am she had what we later found out to be a seizure ~ all I knew was that my daughter had just stopped breathing! We called 911 and after what seemed like hours the paramedics arrived and took her to the hospital. She had a second seizure at the hospital where it was discovered that her blood glucose had dropped to below 20. They stabilized her and transferred her to another hospital where we spent the next 6 days in intensive care while the doctors tried to determine what had happened.

Luckily one of the interns noticed abnormalities in her urine tests and sent the results to the Kennedy Krieger Institute, part of Johns Hopkins. A metabolic specialist, Dr. Richard Kelley, came to the hospital and told us that the results were virtually diagnostic for **LCAD Deficiency**, a fact later confirmed through further testing (***however, with more sensitive testing now available, LCADs are often being re-diagnosed as VLCAD.** **For the rest of this article, VLCAD will replace originally written LCAD).**

As I am sure all of you fellow parents can relate, we had no clue that such a disease even existed and no idea what to do next. We had only been home a short time when Jordan started vomiting daily. At first her doctors thought it was related to the VLCAD, but as more time went by they couldn't determine what was causing it. To make a long story short, she ended up being admitted to Johns Hopkins for 3 weeks for eosinophilic gastritis, a condition where the outlet of her stomach had completely closed off. She had also deteriorated metabolically from not receiving enough calories. Jordan was diagnosed with food allergies at 1 year. Somehow the initial episode of illness had accelerated her food allergies to the point where she had become allergic to almost all foods.

At first she could only tolerate a special formula and we gradually reintroduced her to food. She lost many of the allergies but remains severely allergic to peanuts, all dairy, eggs and beef. Jordan has required several other hospitalizations, the last when she was 2½. We do find that it gets easier to avoid hospitalization the older she gets, but it does require much begging and constant effort (like feeding apple juice around the clock). She receives daily supplements of carnitine and MCT oil and she is on a low fat diet, which for me isn't difficult given all of her dietary restrictions. We have been fortunate that so far Jordan has not exhibited any heart or liver problems as can sometimes occur with VLCAD. She does have reduced muscle tone, particularly in her upper body. Her gross motor skills are somewhat delayed and we still have to take a stroller anywhere that requires a lot of walking. Her fine motor skills are way behind those of her peers and she has speech problems as well.

We had her evaluated and they don't quite know what to make of Jordan. Her cognitive skills and intellectual abilities are average or above average yet in many ways she seems much younger than her peers. We don't really know what effect the seizures may have had. There could be some developmental delays and problems with attention related to the seizures, but at this point we don't know how it will affect her in school. **It does upset me that had we known about the VLCAD from birth we would not be dealing with this at all right now!**

After reading over what I have written so far it struck me that when I think of Jordan I really don't think of all of the things I wrote about. She is the happiest child I have ever seen. She gets such pleasure out of the simplest things in life that it really helps me to keep my perspective. While I've had many hurdles to overcome in terms of her physical health, from a behavioral standpoint she is a parent's dream (friends are jealous of me). She even wants to be a doctor when she grows up.

After reading about what other families have had to endure I do truly feel blessed that she's here. Luckily we are very happy with her specialist and the help we have received in managing Jordan's VLCAD from a medical standpoint. Still, I would very much like to hear from other parents about day-to-day concerns. How do you keep your child eating when he or she is sick? Does anyone else have concerns about school? I am really concerned about making sure all of Jordan's needs are met. I would be more than happy to share my experiences with anyone newly coping with a diagnosis. It really helps to talk to someone who's been there.

Dawn Dougherty, dawn39@home.com
Boston, MA (*in 2000, Ellicott, MD)

Aalberts Family ~ MCAD

Thanks so much for the packet of information that we received, we will be busy looking through all the information that you sent. After reading a few of the stories, I felt that I needed to share our story and how our lives were changed forever.

Our second son, Luke Timothy, was born on June 7, 1994. He was healthy and strong. Our 2½-year-old son, Tyler, welcomed him excitedly. Luke was an absolutely "almost perfect baby." Keep him fed and let him have his naps, and he was full of smiles all the time.

On Sunday, April 30, Luke woke up from his afternoon nap and started vomiting. He did not have a fever or any other flu-like symptoms. He could not keep anything down, but it didn't seem to bother him at first, he was still playing and smiling. To be on the safe side I went to the store and bought some pedialyte, but he could not keep that down either. At about 8pm, I started getting a little worried, so I called the doctor's exchange and told the pediatrician on call what was going on. He said that Luke probably had the flu and to just watch him, keep trying to give him pedialyte and to call the office in the morning. So, I hung up the phone and put Luke to bed, because he was so tired from vomiting and he had just been given more pedialyte. I checked on him before I went to bed and my husband checked on him before leaving for his night shift job ~ he was sleeping peacefully.

Tyler and I got up just after 7am the next morning. Right away I headed to Luke's room because I wanted to see how he was. I found him, lying on his stomach. I picked him up and he was stiff, blue and cold. I called 911 and started CPR right away, but I knew something was wrong. Two sheriff deputies came to our house right away and took over, but a few minutes later they came out and said there was nothing they could do ~ our son, Luke Timothy, died on May 1, 1995, at the age of 10 months and 23 days.

The Medical Examiner that came to our house said that it was probably SIDS, but the autopsy would show more. After they got all the tests back, our pediatrician called and asked our permission to send all the tests to a bigger hospital in Grand Rapids, because she was not satisfied with the results, but she did not want to say what the results were until they looked at them at Butterworth in Grand Rapids.

Five months after Luke had died, we finally sat down with our doctor and she said that Luke had died from a SIDS reaction to pneumonia. Even though he had no signs of pneumonia before he died. That was the best she could do and she admitted that things didn't add up, but there were no definite answers. We came to accept that we were not going to find all the answers. By this time, I was pregnant. So we decided to have genetic counseling, but they did not recommend any testing because it was SIDS.

On April 20, 1996, 11½ months after Luke had died, I gave birth to a daughter, Jayme Nicole. We were so happy but yet it was bittersweet because we still missed Luke so very much. She was healthy and grew like a weed.

On March 13, 1997, Jayme suddenly started vomiting in the afternoon after lunch. She became very tired and slept in my arms all afternoon, except when she had to vomit. In the evening when my husband, Tim, came home, I said "Do we need to be concerned?" He said "They are going to tell us the same as they did when Luke got sick, so let's just

wait until morning." I could not just put her to bed and let her be by herself. So, I slept on the floor and Jayme slept on the couch, where I could be with her.

The next morning about 5am, she woke me by the sounds she was making and they did not sound right. I sat her up and the sounds got louder and she acted like she could not see me or know where she was. I called Tim out of our bedroom. He could not believe or understand what was going on. She was breathing and her eyes were open, but she did not know us, nor would she stop the strange moaning. Tim called 911 and the paramedics came right away. They said she had some type of seizure. We got to the hospital here in Holland right way. We only live a couple of blocks from it. The doctors and nurses immediately started a bunch of tests. They checked her sugar level ~ it was 3! They right away hooked her up to IVs and did more tests and a CAT scan. The pediatrician on call finally came in and said that they were transferring Jayme to DeVos Children's Hospital in Grand Rapids because she was in very serious condition and they did not know what it was.

At DeVos, in the PICU unit, I told them what had happened to Luke. They ran more tests, but still no answers. In the late afternoon, we met a wonderful doctor, Michael Wood, a pediatric endocrinologist who said that **he was 100% sure that Jayme had MCAD and that Luke probably died from it too** ~ he just needed blood work sent to Duke Medical Center to confirm it. Jayme was 22 days old when this happened to her. About a month later, Duke asked our permission to test Luke's PKU newborn blood screen to see if Luke had MCAD also, and he did. **Two years after he died we finally had a definite answer.**

Jayme is now 21-months-old and is doing great. She has had only one episode of vomiting and had to be taken to the ER and put on an IV for a few hours. She now sees a biochemical and genetic specialist at the University of Michigan Medical Center, Dr. Jess Thoene, who we were referred to by Dr. Wood. He felt that Dr. Thoene knew more about MCAD and could help us more than he could.

That's our story. Thanks for listening. We are glad we finally found a support group who knows what we are going through and what we have been through. We wish you all a healthy year in 1998. And we will keep in touch.

Joan and Tim Aalberts
Holland, MI
Tyler - unaffected, Luke - deceased, Jayme - affected

Ruff Family ~ MCAD

Stomach virus...just what we needed with a seven-week-old baby in the house. Our oldest daughter, Callie (4½), had had it. Now our middle child, Anna (17 months), had it. We were concerned that baby Ben would be next.

From the start, Anna had always been our little eater. She had been through ear infections and bronchiolitis, but never missed a meal or a snack. We even let our child go to sleep with a bottle. Anna's bout with the stomach virus was different from Callie's bout. Anna seemed tired and slept most of the day. I called another mother with a child that had the virus. She said that her daughter had slept quite a bit, but was getting over it. We waited. That night, Dell stayed in the room with Anna. She was up off and on with vomiting and diarrhea. Ben and I were up with the usual feedings.

The next morning, Dell went to work. I was going to let all the little sleepyheads sleep. I decided, though, to check Anna's diaper. She moaned but did not put up the usual fuss over a diaper change. I called the doctor. We went straight to the emergency room (Arlington Medical Center, TX). Emergency Triage failed. We were told to wait. There had been a traffic accident. We sat with Anna while the others were called back for treatment. We decided we could not wait any longer. Anna was moaning and not responding to us. I took Anna up to a nurse who finally realized that we needed help immediately. Thank goodness for the blood sugar check. Anna's blood sugar was at 15. She immediately got a doctor and about three other emergency staff members. We were asked several times if there was any way that Anna could have taken an insulin pill. We told them "No!" several times. After dozens of tries, an IV was started in her hairline. After getting Anna stable enough to travel, she was transferred to Cook Children's Hospital in Fort Worth. Once again we were asked if Anna could have gotten into someone's insulin pills. They could not explain what was happening. Anna started doing better after a few days of glucose IVs. Tests were done. We came home.

A week later we received a call from our family doctor. A doctor at Baylor in Dallas had been contacted about Anna's test results. Dr. Charles Roe had an explanation for us. **Dell and I met with Dr. Roe and we were given information on MCAD.** Anna started taking carnitine. We keep an emergency sheet with us at all times. Anna has been back to the emergency room/hospital twice since her first episode. In both cases, the emergency sheet information was extremely necessary. The doctors initially treating her knew nothing of MCAD. She was treated in emergency and a knowledgeable doctor was called. We have been very fortunate. We have lived in areas where Anna can receive excellent care. We thank God for facilities like Cook Children's and Vanderbilt. We are also thankful for and to Dr. Charles Roe and others involved with research. We are grateful for our family doctor in Mansfield, TX. Dr. Caplan would see Anna on five minutes notice. He had a staff that educated themselves about MCAD. He also informed colleagues about MCAD. We are settling down in Franklin, IN. We have already become familiar with Vanderbilt Children's Hospital. As of this writing (September 25, 1997), Anna (3) has been home from the hospital for two days. Anna's siblings, Callie and Ben, are carriers for MCAD.

Dell and Melanie Ruff
Franklin, IN
mruff@flash.net

Pharmaceutical Update

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

Medical Research Study: Recruiting FOD Patients for Study

The Division of Cardiology in collaboration with the Division of Pediatric Cardiology of the College of Physicians and Surgeons of Columbia University at the Columbia-Presbyterian Medical Center in New York are recruiting patients for a federally funded study of heart blood flow and fatty acid metabolism using positron emission tomography (PET) scanning in patients with inherited or acquired cardiomyopathy (heart failure).

The aim of the study is to determine the prevalence and severity of abnormal fatty acid metabolism in patients with inherited or acquired heart failure in order to gain a better understanding of how heart metabolism is affected by these disorders. Our ultimate goal is to identify and treat such cardiomyopathies with pharmacologic therapy designed to correct the metabolic abnormalities. And ultimately, in those with inherited defects, with gene replacement therapy. Metabolic therapies are currently being treated in our experimental animal lab.

Under normal circumstances, fatty acids serve as the major source of energy for the heart. Some forms of inherited or familial cardiomyopathy are due to deficient or inactive enzymes involved in the metabolic pathways involving fatty acids. These abnormalities in fatty acid metabolism can lead to insufficient energy production and may also lead to heart failure because of the accumulation of certain metabolites of fatty acids in the heart muscle. PET scanning permits precise measurement of blood flow and metabolism in the heart using the administration of a small amount of radioactive fatty acids by vein. The whole procedure takes about 3 hours, but actual scan time is about 1 hour (three 20-minute scans). In subjects under 18 years of age, the amount of radioactivity administered is approximately equivalent to 1 year of background radioactivity and is considered by the FDA to be within the limits allowed for experimental procedures of the type. However, radiation risk is cumulative, so any additional radiation exposure should be carefully considered.

Patients who are eligible for this study include those with inherited (familial) cardiomyopathy and their unaffected siblings (to determine whether perfusion and metabolism of the non-affected sibling's heart is normal), and patients with idiopathic cardiomyopathy (i.e. when no cause can be found for the heart failure) as well as their unaffected siblings (to determine whether abnormalities in heart perfusion or metabolism are normal in these children).

There is no cost to the patient for the actual test procedures. The patient's primary physician must provide a referral to Columbia-Presbyterian Medical Center for the scan.

For more information, you may contact: Dr. Daphne Hsu, Division of Pediatric Cardiology at (212) 305-6575, or Dr. Steven Bergmann, Division of Cardiology at (212) 305-7594. Patient scheduling is made through Melanie Phipps, RN, at (212) 305-0897.

Medical Update

‘Rare Case Presentation of Primary Carnitine Deficiency’

L-carnitine is a naturally occurring molecule that is essential in fat metabolism (breakdown) in humans. Carnitine is absorbed from the diet in red meat and dairy products. We can synthesize carnitine from the amino acids lysine and methionine, in the presence of different enzymes in the liver and kidneys. Roughly 75% comes from the diet and 25% comes from what our body produces. **Carnitine performs two very important functions in fat metabolism: 1) it is a carrier molecule that transports long chain fatty acids into cellular mitochondria (the cells' furnace) and 2) the shuttling outside the cell of "acyl" groups, chemicals that are toxic to the cell, where they can be safely excreted in the urine.**

Carnitine deficiencies are generally classified as either "primary" or "secondary." **Primary carnitine deficiency** is a genetically inherited disease that interferes with the uptake of carnitine into the cells and tissues. It is **caused by defective carnitine transport and it affects heart, skeletal muscle, kidney, intestinal cells, and skin fibroblasts.** **Secondary carnitine deficiency** can be **caused by a vast array of metabolic disorders in which carnitine is readily excreted in the urine bound to different metabolites or organic acids in which there is abnormal loss or over utilization of carnitine.** Carnitine depletion results in impaired oxidation (breakdown) of long chain fatty acids that our bodies use during fasting and starvation. Primary carnitine deficiency is associated with low blood and tissue carnitine concentrations.

There are **two forms of the primary deficiency** that have been described: **myopathic (related to muscle) and systemic (involving many tissues and organs).** The myopathic form is characterized by a progressive lipid (fat) storage myopathy beginning in either childhood or early adulthood. This leads to muscle weakness and recurrent episodes of myoglobinuria (muscle protein in the urine). Blood carnitine levels are generally within normal limits with skeletal muscle the only affected tissue. The systemic form of carnitine deficiency may present in early infancy with recurrent episodes of hepatic encephalopathy (coma due to liver failure with high blood ammonia). These episodes are accompanied by hypoglycemia (low blood sugar) and the inability of making ketone bodies (the breakdown products of fatty acids) that are essential for many organs during conditions associated with starvation or stress. Other symptoms may include hypotonia, failure to thrive, episodes of coma, gastrointestinal complaints, and anemia. Later in life systemic carnitine deficiency may cause heart myopathy (enlargement and failure of the heart muscle). The cardiomyopathy associated with this condition usually responds promptly to dietary carnitine supplementation.

The following case describes the presentation of one child with systemic carnitine deficiency. A son was born to healthy, unrelated parents. He did well while taking a regular infant formula until five weeks of age when he started vomiting and having abdominal pain. The attacks were thought due to a milk allergy. His formula was switched to a protein hydrolysate formula (Alimentum). He had several episodes of upper respiratory tract infections and then at eight months of age, during one of these episodes, he refused feeding, became very irritable and lethargic, and was admitted to a local hospital to rule out meningitis.

He was found to have an enlarged liver, low blood sugars, mild anemia, and an elevated ammonia with mildly elevated liver function tests, suggesting a diagnosis of Reye's Syndrome, a disorder associated with influenza virus and aspirin exposure. His electroencephalogram (brain wave study) was abnormal suggesting a diffuse disturbance of brain function. He responded positively to intravenous glucose and was discharged home on a reduced protein formula in view of the high blood ammonia level. Biochemical evaluation indicated the presence of dicarboxylic acids (undigested fats) in the urine.

A metabolic evaluation at nine months of age showed an infant with normal development and growth. Biochemical evaluation at that time indicated persistent elevated blood ammonia levels, with persistent dicarboxylic acids in the urine, which were ascribed to the presence of MCT oil (medium chain triglycerides) supplements in the formula. However, the dicarboxylic acids increased after discontinuation of MCT oil and the child continued to have continuous infections and hyperammonemia. At 10 months of age his plasma carnitine levels returned very low (close to zero), with basically normal urinary carnitine excretion, which would not be expected in view of his low plasma carnitine levels. Blood was obtained from this patient and an acylcarnitine profile performed was normal, ruling out secondary forms of carnitine deficiency.

Dietary carnitine supplements were started and increased to 100 mg/kg/day. These supplements normalized his enlarged liver, the elevated ammonia in plasma, the liver function tests, and the dicarboxylic acids in his urine. His parents noticed an improved activity level and a marked reduction in the frequency and severity of infections. Repeated carnitine determinations demonstrated normalization of plasma carnitine levels, with increased urinary carnitine excretion, suggesting a transport defect. At 21 months of age, a skin biopsy was performed and defective carnitine transport confirmed the diagnosis of primary carnitine deficiency. Currently at 4 years of age, his growth and development are normal, but he still requires high doses of dietary carnitine.

The presentation of this child was not typical in the sense that primary carnitine deficiency is not usually associated with the presence of dicarboxylic acids in the urine. This is most frequently an indicator of a carnitine deficiency secondary to a defect in the breakdown of fatty acids. Another factor that makes this presentation unusual was the persistence of high blood ammonia that is not frequently present in primary carnitine deficiency. While this is a rare disorder of fatty acid oxidation, we hope that it helps focus attention toward signs and symptoms less frequently associated with this condition.

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Resources

Guide for Parents: 5 separate booklets cover treatment, nutritional and medical guidelines, genetics and resources for MCAD, GA II, Isovaleric Acidemia, Carbamyl Phosphate Synthetase Deficiency and Ketone Utilization Disorders. They are available from: PacNoRGG, CDC, Clinical Services Building, 901 E. 18th Ave., Eugene, OR 97403-5254 541-346-2610 (fax) 541-346-2624 or kerry_silvey@ccmail.uoregon.edu

Great and Simple Gifts: Newsletter for people with disabilities and those who care for them. Written by Nancy Norwood (on our family list). Her daughter, Elizabeth, was diagnosed years ago with 'Reyes Syndrome' and experiences residual effects from a childhood episode. Contact Nancy at: 9727 Harrytown Rd., Mercersburg, PA 17236 717-328-9482 or gsgifts@cvn.net

Kidability: Mother of a child with cerebral palsy opened a store for infants and children with special needs. The store carries clothing, toys, utensils, shoes, a book collection, information on equipment, alternative treatments, and support groups. Contact Lisa Pawelkewic, 65 Park & Shop Plaza, Elk Grove, IL 60007 800-333-8087 or kidability@aol.com or www.kidability.com

Book Review ~

Why can't I eat that! Helping kids obey medical diets

Dr. John F. Taylor and R. Sharon Latta
R & E Publishers, 1996

Why can't I eat that! Helping kids obey medical diets written by Dr. John E. Taylor and Ms. R. Sharon Latta is a book that explores the psychological/emotional aspects of having a child with dietary restrictions because of a chronic medical condition, as well as practical behavioral and environmental tools for helping the child and family follow prescribed guidelines.

Dr. Taylor is a family psychologist and has written extensively on children and parenting and has worked with many children with special dietary needs. Ms. Latta offers information from her own personal experience of raising 4 children, each with dietary restrictions. She understands firsthand the adjustments that are necessary for the children, as well as those within the family system. She often shares her expertise by consulting

with professionals and speaks at schools, mental health groups, and parent support groups.

The **bottom line of this book**, in my opinion, is stated in this sentence: "**Your child must learn to be responsible for his (her) dietary choices**" (p.95). However, getting to that point as your child grows is easier said than done! This book does an excellent job of exploring all types of 'roads and potholes' that journey may encounter. The point that is stressed throughout the book is that working with dietary restrictions is not only the child's concern, but also a family issue. The child lives within a dynamic family situation and environment, and personalities, as well as the specific medical condition involved (and the cognitive/physical/emotional capabilities of the child), are going to pose different challenges for the child, the siblings, the parents, and others that come in contact with the child.

The authors discuss parent/child/family issues from an emotional level, as well as cognitive and behavioral perspectives. Understanding and accepting that all 3 interact and impact each other will assist families in their challenge of motivating their child to cooperate with the special dietary needs.

The first 2 sections describe how **it is necessary for parents to understand their OWN hearts (emotions) and minds** after learning of their child's medical and dietary needs. They are then more aware of how important it is **to model EFFECTIVE ways of working through 'hurdles'** that most likely will occur possibly on a day-to-day basis as their child grows and shares in more responsibility (if capable) for their diet and healthcare.

The last 2 sections discuss finding support inside and outside the family and suggestions of what to do when the diet routine is not followed, such as during holidays, hospitalizations, or when a child protests having to be on a restricted diet. They also discuss how siblings are affected by the diet and how they can be of help. Some of the suggestions and tools offered throughout this book may not fit your personal family situation. However, I am sure you will find many relevant suggestions "to open doors of communication and cooperation within your family" (p.xxii). **Communication is IMPERATIVE on a one-to-one basis, as well as within family dynamics and working with professionals.**

One of the authors' goals is "that this guidebook will become a family reference source, one to be employed often" (p.xxii). As far as MY situation is concerned, they have accomplished that goal!

Deb Lee Gould, Director

‘Physical Therapy: Principles of Exercise’

Activity and exercise are critical to our health and welfare. To remain well lubricated and functional, our joints must be taken through their ranges of motion. Our muscles need to be lengthened, so that they can contract, allowing and initiating movement and activity. For physical health at least, our bodies need to be challenged by exercise. During activities of daily living, where only short bouts of energy are required, the body's use of sugars and carbohydrates for fuel is sufficient. When the demand for energy is prolonged, as in certain types of exercise, the high rate of consumption of these sources leads to rapid depletion. In normal metabolism, the use of lipids, or fats, as a fuel source is effective, not only to spare the utilization of sugars (particularly glucose and glycogen), but also as an additional energy source during sustained activity (Brooks & Fahey, p. 138).

Sugars and carbohydrates do not require an oxidative process (breakdown using oxygen) in the change from food substance to available energy. Lipids, however, require a multi-step oxidation process to be converted into an energy source that the body can use (Brooks & Fahey; p. 67).

The goals of exercise are numerous: According to Wolff's Law, growing bone will adapt to forces placed on it, namely gravity and muscle pull. Exercise, then, affects the way the skeletal system develops. Activity is also important in preventing muscle atrophy related to disuse, and maintaining or improving muscle strength. Overall endurance, through a more efficient cardiovascular system, is enhanced by exercise as well as joint and muscle range of motion or excursion of movement. These are important in preventing stress related injuries. Finally, repetitive activity is important for refinement of skill or coordination (Kisner & Colby, pp. 10-16).

There are several important guidelines to remember when considering an exercise, activity or sport, as outlined by the American College of Sports Medicine. The exercise needs to be done on a regular basis, that is, no less than 3 times a week. Sessions should last from 15 to 60 minutes based on tolerance and fitness goals. The heart rate should be maintained at 60-90% of the individual's maximum.

Appropriate nutritional demands need to be met before, during (depending on the length of the activity) and after exercise. This is of particular importance for the fatty oxidation disorder population, since with exercise the sugar/carbohydrate stores will be more rapidly depleted. Consult with your doctor for specific recommendations regarding nutritional requirements for you or your child before beginning an exercise/sport routine.

Research that links exercise to improved health and well-being is plentiful. As health care providers, specialists and parents, our job is to find safe parameters in which our charges can be active through exercise and sports. This generally requires creativity and extra research on our part, but it is well worth the effort.

Cindy Duncan, PT, NDT Certified
Physical Therapy and Wellness Center, Inc.
Red Bluff, CA

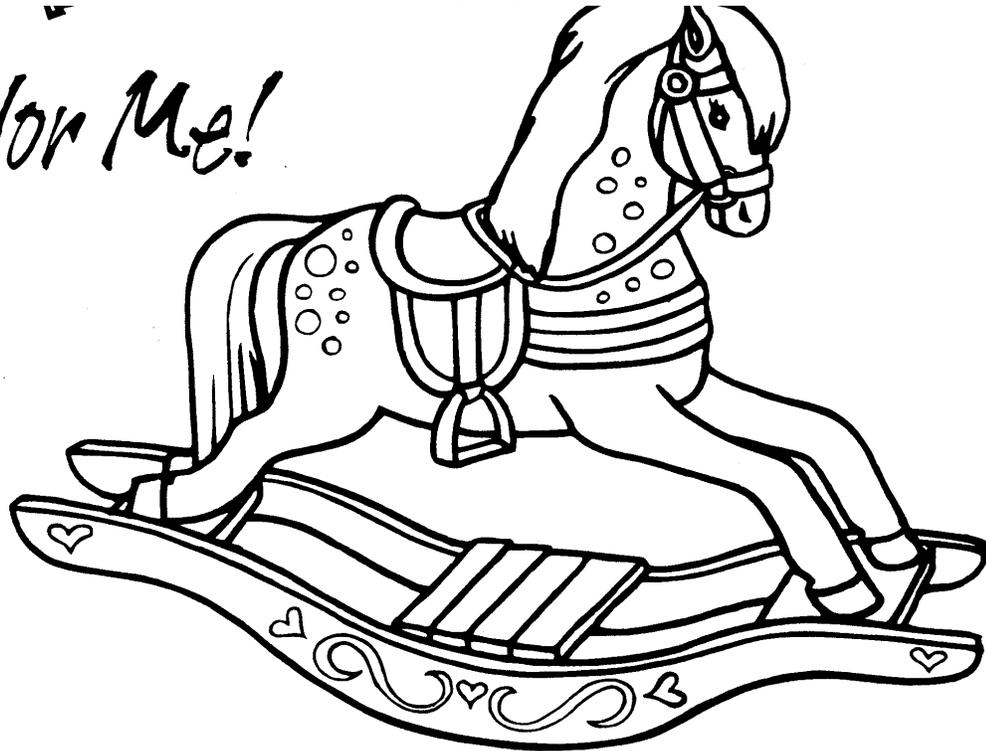
Love Messages

(Please see our most current online issue)

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

Kids Korner

— ✓
Color Me!



Attention Kids and Parents: Send us your photos, recipes, hints and helpful tips, funny quotes, logo ideas and comments, etc. and we will try to include them in future issues of the FOD newsletter!

Logo Idea



Currently we have adopted this logo to represent the FOD Family Support Group. The family that designed this logo said that it represents a 'break' in the chain of life for our families, much like the missing enzyme, but that we are still connected because we are 'All In This Together.'

If anyone has any thoughts about this logo or what kind of changes could be made to it, please drop us a line or send us your own sketches and ideas.

Nutritional Alternative to Medication ~ One Family's Experience Using Reliv International's Nutritional Products

About 4 years ago our daughter, Stacey, began to experience a seizure disorder. She was originally diagnosed as a "migraine baby" but has since been diagnosed with focal seizures of unknown origin and a carnitine deficiency, deemed to be secondary disorder. She has been on Phenobarbital, Tegritol, Lamictal, and currently Neurontin. None of these medications have been able to control her seizure activity to an acceptable level on their own. In addition to less than favorable results, she suffered from undesired side affects. The Phenobarb continued to deplete her already low levels of carnitine. The Tegritol made her cranky, groggy, and at times, near lethargic. The Lamictal affected her behavior such that she appeared to suffer from minor Attention Deficit Disorder-like symptoms. The Neurontin has not affected her behavior, but her metabolism. She has gained about a pound a month since she's been on it.

Our goal is to control Stacey's seizures 100% without the undesirable side affects. While that may not be possible, we are looking at all ways to accomplish this. Stacey's body chemistry doesn't work like a 'normal' person's does. She is unable to metabolize certain fatty acid chains. One thing we've tried to overcome this with is nutrition.

We heard about the Reliv nutritional products from one of our church pastors. His daughter suffered from chronic fatigue syndrome for more than 2 years. They had been to numerous doctors in Cincinnati, Cleveland, and Denver. None had been able to help her. After taking these products for about 6 months, she began to get her life back. We had also heard of a study using these products with ADD/ADHD kids. Some of the kids in the study were actually able to reduce or eliminate their dally doses of Ritalin.

We figured we had nothing to lose so we began to use these products with Stacey. What we've noticed is an increase in her endurance, strength, and overall energy levels. She is

more able to sleep through the nights, which has made us VERY happy! She would generally wake 3-4 times a night, and in turn, wake us. Now we ALL sleep better. Her seizure frequency has gone from 1 seizure every day to day-and-half, to one seizure every week-and-half to weeks.

These products are not just vitamins they are food formulated in proper, BALANCED nutrition. They contain vitamins, minerals, herbs, phytonutrients, and essential amino acids. Because they are food, actually food concentrate, they are perfectly safe. Anyone from 6 months to 100 years of age can take them. They are all natural. (***these statements are not necessarily the opinion of the FOD Family Support Group. Please be aware that supplements do not always go through rigorous testing/regulation as do FDA-approved products. Additionally, even though separate products may be termed 'natural' there still may be interactional effects depending on what other supplements and/or drugs you/your child may be taking. Be sure to discuss any supplements with your/your child's Dr before making any changes**).

All of the ingredients are on the FDA Generally-Accepted-As-Safe list. There are no warning labels on them. They are patented by the US government. The patent is for the formulation of ingredients, not the ingredients themselves. A lot of people ask how this is different from taking vitamins. It's like this...if you want to make a cake, you need several things: flour, eggs, salt, sugar, water, milk, etc. However, these ingredients won't make a cake unless they are mixed together in proper proportion to each other. The scientist who formulated these products studied the human body at the cell level to determine how each nutrient is used and what amount of each nutrient is optimal. The result is a formulation that works in a way that taking a vitamin supplement just can't.

While we still don't have Stacey controlled like we want, we have seen very positive results with these products, without any of the negative side effects. In fact, if she goes a single day without these products, we can see a noticeable change in behavior, decline in her energy level, and an increased rate of seizures. We continue to look at ways to balance medication with nutrition, in hopes of discontinuing medication altogether at some point in the future. We know this won't happen overnight, but we're committed to continue because the nutrition certainly isn't going to hurt.

Reliv makes no medical claims for any of its products and they won't cure anything. What they do is provide your body with what it needs so that it can take care of itself. The miracle is not what's in the can, it's what the human body can do when it's given what it needs. As an aside, our whole family takes these products on a daily basis and have all gotten good results ~ higher more consistent energy levels and fewer trips to the doctor's office are only a couple.

Please feel free to contact us should you have any questions or desire any additional information about these products.

Lisa and Jeff Schmidt
jschmidt@cinternet.net

Donations Received

The FOD Family Support Group would like to thank: Scott and Margaret Dozier, Howard and Shelley Singer, David Killey, and the National Reye's Syndrome Foundation of the United Kingdom for their generous donations. We greatly appreciate donations to help with postage and copying costs. Please be aware, however, that donations are not tax-deductible since we are not officially a non-profit group. Checks can be made out to: Deb Lee Gould. Please note on the check that it is for the FOD Family Support Group.

Reminders

Family stories and professional articles: Please submit by December 1, 1998 to be included in the next issue.

Please return **signed Family Questionnaire** or hand write your information as on the Family List in order to be listed on the Family List.

Newborn Screening: Families in several states are writing to their legislatures ~ Keep up the good work. Do Not Give Up!

Our **Medical Advisor, Dr. Charles Roe**, welcomes FOD families to directly consult with him. He is at the Institute of Metabolic Disease at Baylor in Dallas. Contact him at 214-820-4533 for information.

Pictures wanted: of your FOD child and/or family for our January 1999 Kids Korner. Pictures will not be returned.

Thanks again to Erika Wallace, Eric and Lori Schmid, and Jeff Schmidt for all your work on the mailing lists, the newsletter and the website!

July 1998

Volume 8 Issue 2

[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** ☐