FOD Communication Network

(Fatty Oxidation Disorders)

‘All In This Together’

January 1997 **Volume 7 Issue 1**

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

Happy New Year everyone! We hope all of you had a healthy and safe holiday season. With every New Year our FOD Network is expanding with both families and professionals. Now that we have our WEB page, more and more people are becoming informed of our Family support services and educational medical information. If you have access to the Internet be sure to stop by www.cinternet.net/FOD (*in 2000, our web page is now www.fodsupport.org and Mary Lingle, MCAD parent, is webmaster) and see what a great job Jeff Schmidt has done on keeping the page updated and informative. Thanks, Jeff, for all of your hard work.

With our increasing numbers, there must be SOME creative people out there to **help us create a LOGO!** In our summer issue, I requested your input and ideas for a logo ~ to this date, we have a few ideas drawn and sent in. So now that the holidays are over, all of you can concentrate on getting your creative minds to come up with a great logo! Once we have several, I can print them in the next issue and have you possibly vote for the one that best represents the FOD Family Support Group.

I am also **asking for help from our professionals** (researchers, physicians, nurses, counselors, nutritionists, speech therapists and all other professionals) involved in the direct or indirect care of any FOD child/adult and family. **We are trying to expand our knowledge about the less known FODs such as CPT, HMG, GAII and SCAD, as well as provide updates on the more researched deficiencies such as MCAD and LCHAD.** Any information about your current research or your experience working with these families would be greatly appreciated. Articles explaining (in layperson's terms!) what the disorder is and how it is treated, special programs (such as the one highlighted in our Family Story by Joanne Bregman), or ideas to help families and these children to better cope with the challenges of having a genetic metabolic disorder would be so very helpful for our families as well as for their own treatment teams working with their child.

We truly are **IN THIS TOGETHER** and it would help to unify our group even more if we included these types of articles, especially for the families that are trying to cope with so little information to begin with, because their disorder isn't researched as much as say MCAD.

Gaining more information on these even more rare disorders would not only be educational, it might **give us all that sense of belonging to something bigger than ourselves ~ which we all know is vital to healthy coping.** We also know for sure that **WE ARE NOT ALONE out there!**

We may have to work hard at getting information and effective treatment for our child at times, but people do care and there are **many out there working toward the same goal ~ Identifying these children earlier and providing effective treatments so that our children will have the greatest chance at a healthier life** (*in 2000, see www.tylerforlife.com for information about Newborn screening of FODs and other metabolic disorders and what your state tests for ~ also look on our web page under Newborn Screening).

So when you have a few moments in your busy schedules, which I know is difficult to find, write to us by May 1st and tell us how FODs have impacted your personal or professional life. Don't worry about it not looking like it has been written by a professional ~ write from what you know in your mind and your heart and it will be just fine!!

Deb and Dan Gould, Co-Editors
fodgroup@aol.com
336-547-8682

Letters to the Editor

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

Dear Deb: Thank you for sending the FOD Network new member Family Packet. I was very moved by all of the family stories and would like to send Jordan's story (VLCAD) in the future. Once again I realized how very lucky we are that Jordan made it through the first year and a half of life before her diagnosis. After living with this for almost two years, I feel like I have a handle on the ramifications of the disease when Jordan becomes ill. She has been hospitalized several times since her diagnosis, and like the parents who wrote one of the stories in the newsletter we also have an emergency protocol letter that we have found to be very helpful in dealing with doctors in the emergency room. Our letter even has a statement that reads 'Jordan's parents are the best judges of when she is beginning to deteriorate metabolically.' Her doctor, Dr. Richard Kelley of the Kennedy Kreiger Institute in Baltimore, has truly been a lifesaver. He is always available to answer any question and has gone out of his way to monitor Jordan's condition.

What I am most interested in learning from other families is how they cope with the day-to-day effects of the disease. For example, just last week I went on a field trip to a farm with Jordan's pre-school class. While she had a really good time, we had to leave much earlier than the rest of the class because she simply could not continue to walk and I ended up having to carry her back to the car. I wonder (and worry) about what will happen when she goes off to school all day. And of course, there is the stress we all feel

when our children get even the most minor illness. I know a lot of her playmates' parents cannot understand why I freak out when I hear that Jordan may have been exposed to a stomach bug!

As I mentioned on the phone, **Jordan also has severe multiple food allergies**. Preparing her meals is definitely a challenge for me, so **I am very interested in any dietary information.** I belong to the Food Allergy Network, which is a support group similar to the FOD Network. They have been wonderful in addressing those types of practical and emotional issues. I learned from them **how important a family network is**. Again, thank you for sending the information. I hope to be able to contribute to the newsletter in the future.

Sincerely,
Dawn Daugherty
Ellicott City, MD
Dawn39@home.com

Dear Deb: As you are probably aware, I have been trying since June of '95 to get Jane started on DHA (the Omega 3 fatty acid). I am hoping that this fatty acid will prevent retinitis pigmentosa and neuropathy in Jane and other children affected by LCHAD. It is hypothesized that children with an LCHAD deficiency are unable to efficiently process DHA from linolenic acid ~ resulting in a DHA deficiency.

After considerable effort on Melanie Gillingham's, MS, RD, part Jane was started on DHA capsules in May of '96. She remained on these capsules until a purified DHA source became available in June. After one month of supplementation on the DHA capsules, plasma DHA levels increased to greater than DHA adult control levels. It is uncertain at this time if Jane's DHA dose will be increased. Our clinic is still awaiting test results on RBC (red blood cells) and an evaluation of plasma and RBC during the supplementation of the purified DHA source.

Two other LCHAD children have also started supplementation of the purified DHA powder, which is easily mixed into the formula. ERG (Electroretinogram) and VEP (Visual Evoked Potentials) will be repeated in 6 months of normalization of DHA in the RBCs. The physicians hope to determine at this time if there is any benefit to this treatment.

There was considerable delay in starting this treatment since it was set up as a study and needed approval from the UW's Human Subjects Committee. An agreement also had to be reached between the UW and Martek Corporation, the pharmaceutical company that manufactures DHA.

DHA is receiving considerable media attention. It plays an important role in everyone's health. There is considerable interest in adding DHA to infant formulas and providing DHA supplementation to heart patients.

On the other matter, I received a letter from Dr. Arnold Strauss, Professor of Peds and Molecular Biology and pharmacology at Washington University at St. Louis Children's Hospital (*in 2000, now at Vanderbilt). He has played a large role in advancing the research of LCHAD. He is considering performing some testing on heart metabolism in patients with LCHAD and other Beta Oxidation disorders. He is interested in knowing if parents would be interested in bringing their children to St. Louis for this kind of study. Please contact me if interested and I will notify him.

Jenny Carroll
Prairie du Sac, WI

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'MORE ON DHA (docosahexaenoic acid) and ARA (arachidonic acid)'
from Frank A. Oski, M.D.

Dear Dr. Wolff (*in 2000, researcher at University of Wisconsin, Waisman Center, conducting a DHA study with LCHAD): Having recently stepped down as Chairman of Pediatrics at the Johns Hopkins University School of Medicine, I have decided to devote time **making the public and pediatric community aware of the importance of certain fatty acids in infant nutrition. Getting the word out is critical to the health and well being of our children.**

The FDA is reviewing the nutritional needs of infants in order to recommend how they should be reflected in the level of nutrients in term infant formulas.

The Infant Formula Act directs the FDA to ensure the safety and nutritional quality of infant formulas. The FDA's review will determine the course of infant nutrition in the United States for years to come. The last revision in nutrient specifications occurred in 1985.

Of the issues likely to come before the FDA, the inclusion of **two fatty acids ~ DHA (docosahexaenoic acid) and ARA (arachidonic acid)** ~ is supported by strong scientific evidence. **They are the most prevalent long chain fatty acids in human breast milk. DHA is essential for brain and eye development and ARA is associated with immune function and infant growth.** Applying the principle that infant formulas should match as closely as possible the functional composition of human breast milk. DHA and ARA are two nutrients that should be required in all infant formulas.

Delaying the inclusion of DHA and ARA in formulas comes with a significant cost to babies. Forgive me for illustrating incalculable quality of life issues with limited conventional cognitive test standards, but **studies indicate that for every year of delay, more than two million formula-fed full-term babies born annually in the US may experience a 5-9 IQ point disadvantage to breastfed full-term babies (the difference is even greater for low birth weight infants). Other studies suggest impaired visual development and future behavior consequences as a result of this deficiency.** Meanwhile, DHA is already in some European and Asian infant formulas.

We have all the evidence we need to support inclusion. DHA and ARA are natural components in human breast milk, they are safe and available, and clinical data verify their importance when added at levels found in breast milk. **An expert committee convened by the World Health Organization has concluded:**

•DHA is important for brain development and breast milk is a good source of this fatty acid.

•The fatty acid composition of infant formulas should correspond to the amount and proportion of fatty acids contained in breast milk.

•DHA and ARA should be included if at all possible in infant formulas for both pre-term and full-term infants.

Other scientific and clinical bodies have come to similar conclusions.

Because of increasing public awareness, you should be armed with some facts about DHA and ARA for your patients' inquiries. Therefore, I have enclosed a fact sheet.

Warmly,
Frank A. Oski, M.D.
PO Box 23857
Baltimore, MD 21203-5857

DHA and ARA Facts

Fact l: ***A WHO (World Health Organization) committee recommends including DHA and ARA in formula.*** An expert committee convened by the WHO has recommended that all pre-term and term infant formulas contain DHA and ARA at levels found in human breast milk. The British Nutrition Foundation and the European Society of Pediatric Gastroenterology and Nutrition have made similar recommendations. DHA and ARA are already in some European and Asian formulas.

Fact 2: ***DHA and ARA are the most abundant structural fats in the brain and DHA is the most abundant structural fat in the retina.*** Brain tissue is about 60% lipid (structural fat, not adipose fat), about 25% of that is DHA and about 15% is ARA. DHA also comprises about 60% of the rod outer segments of the retina of the eye. Brain and other nervous tissues are unique in this high DHA and ARA content.

Fact 3: ***DHA and ARA are in breast milk.*** DHA and ARA are important components of breast milk. US infant formulas do not currently contain DHA and ARA. I urge mothers to breast feed as long as possible to ensure that their babies get an adequate supply. I also urge mothers to review their diets to ensure that their breast milk contains enough DHA. Dietary trends indicate that DHA intake in the US has declined by about 50% over the last 50 years.

Fact 4: ***DHA is essential for brain and eye development.*** The rate of brain growth in the perinatal period is so rapid that the baby's capacity to synthesize DHA from an essential fatty acid precursor present in formula is insufficient to keep up with the demand by the growing brain and nervous system. Infants should obtain DHA from their diets. Studies have shown that unless DHA is provided to formula-fed infants, their brain DHA levels are significantly lower than those in breastfed babies.

Fact 5: ***DHA is correlated with improved mental and visual function in infants.*** ***S***tudies show that children who were breastfed perform better on cognitive function tests later in life (by 5-9 IQ points) than those who were formula-fed even after taking into account all confounding factors associated with developmental test performance (e.g. socio-economic status, IQ of parents, etc.) A greater developmental disparity has been established for low-weight pre-term infants born without the benefit or the maternal delivery of DHA during the last trimester. They experience deficits of up to 20 IQ points compared to term infants and are at greater risk for behavioral problems. Evidence points to DHA as the reason.

Fact 6: ***Low DHA levels are associated with behavior problems in children.*** Specific behavioral (Attention Deficit Hyperactivity Disorder or ADHD) and learning problems have been shown to correlate significantly with low DHA levels. Research is under way to determine whether there is a connection.

Fact 7: ***ARA is correlated with infant growth and may be associated with immune function stimulation.*** To maintain serum ARA levels in formula-fed infants, the WHO committee recommended the addition of ARA to formulas at levels found in human breast milk.

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Dear Deb and Dan: The newsletter is definitely on the up and up! It looks great! It's been a while since I have updated. I have just completed 81 letters to New York State's finest Assemblymen/women and people of the Senate ~ what fun! But someone has to do it. Back in April of 1994, OAA put an article in the newsletter about the amendment of NY State's Insurance Law that had passed the assembly but not the senate in the last session 1995-1996, February. The amendment just seems to be being passed to different desks among the senators. So this means we start all over next session 1996-1997, February. Enclosed are copies of the amendment (Remember this is what we want to re-introduce).

Michael is 8-years-old now and is starting the third grade. He is growing like a weed. Gabriella is 15-months and has just started walking. She loves foods of all kinds and naps and sleeps just like her dear old dad. I almost forgot just how easy it is to take care of a 'non-special needs' child.

Joseph is going to be 4-years-old this November fifth. He is in pre-K class at a nursery school. He has personal moods daily, but loves school in general. He is due to go back to his specialist next month. We will most likely be changing his diet around because of his weight gain. Joseph is 50 lbs now and 40 inches in height He looks like a linebacker in football, but without the padding under his clothes.

All and all things are fine here and I hope they stay that way! Hope all is well with you and your family. I will definitely keep you posted of things to come with NY State's Insurance Laws and with Joseph's progress.

Enclosed is the bill waiting to be passed in the NY Senate, as well as an article in the OA newsletter about how families can lobby to get the insurance laws in their state changed if their company does not cover metabolic foods or formulas.

Heather Marsella
Port St. Lucie, FL (formerly of NY)
HMars46542@aol.com

BILL # s ASSEMBL Y 4445-A
SENATE 5931

TITLE OF BILL
An Act to amend the Insurance Law, in relation to making insurance coverage for certain enteral formulas applicable to insurance policies and contracts and to repeal certain provisions of the Insurance Law relating to insurance coverage for certain nutritional supplements.

PURPOSE OR GENERAL IDEA OF BILL
This bill would require that every health insurance policy or contract which provides coverage for prescription drugs include coverage for the cost of enteral formulas for which a physician has issued a written order and which are medically necessary for the treatment of certain diseases and medical conditions. It would also require coverage of food products modified to be low protein necessary for the treatment of inherited diseases of amino acids and organic acids not to exceed $2,500 annually per insured individual.

SUMMARY OF SPECIFIC PROVISIONS
This bill amends Insurance Law §32I6(I), §3221(k) and §4303(u) to require all policies providing prescription coverage to provide coverage of enteral formulas, and in some cases food products, for which a physician has issued a written order and which are medically necessary for the treatment of malabsorption caused by Crohn's Disease, ulcerative colitis, gastroesophageal reflux, gastrointestinal motility, chronic intestinal pseudo-obstruction, and inherited diseases of amino acids and organic acids.

JUSTIFICATION
In 1993, Chapter 380 was enacted to require that health insurance policies providing prescription coverage include coverage of nutritional formulas required for the treatment of four hereditary metabolic disorders, including PKU. In addition to the disorders specified in the original legislation, there are numerous other diseases and medical conditions which require the use of enteral formulas and food products which are modified to be low in protein. These items, although technically nonprescription, are only available by physician order. They are crucial components of the diets of those afflicted with such disorders, which if left untreated, cause severe mental retardation or chronic physical disability.

This bill, which is based on a Massachusetts' statute, seeks to broaden the scope of disorders for which coverage is required and to repeal an exemption in the 1993 legislation which denied coverage in contracts of persons employed in more than one state or whose contract benefit structure was the subject of collective bargaining affecting persons employed in more than one state.

PRIOR LEGISLATIVE HISTORY
New bill.

FISCAL IMPACT
None to state and local government. The impact to insurance carriers is unknown.

EFFECTIVE DATE
This act shall take effect on the sixtieth day after which it shall have become a law and shall apply to all policies and contracts which cover persons employed in more than one state or the benefit structure of which was the subject of collective bargaining affecting persons who are employed in more than one state beginning on and after such date.

'Lobbying Guidelines for Insurance Benefits'
(from Food For Thought PKU Conference)
OAA Newsletter August 1996

Insurance coverage of metabolic foods and formula varies tremendously from state to state as can be seen from the attached table. States that have been successful in obtaining mandatory coverage for products used in the treatment of inborn errors of metabolism (IEM) have accomplished their goals through strong lobbying efforts. Dan Huber, a parent from Maryland, has some suggestions that have helped make their lobbying successful.

First, organize interested families together. Information can be gathered and disseminated quicker if more parties are Involved and the more people involved the easier it will be to stay ahead of the insurance lobbyists.

Second, find a Sponsor for your bill. Obtain from your state a Legislative Reference Guide or a General Assembly Roster (both of which are free). These contain a listing of members along with biographies and committees specific to each member. Use this listing to target your lobbying efforts at those members who have been in favor of similar healthcare legislation. Also obtain a Legislative District Map which identities the specific district structure of your state. Use this to match as many families with as many legislators as possible. Each family should contact their district and provide information regarding their specific inborn error of metabolism, the costs associated with food and formula, and the possible outcome and associated costs without treatment. It is suggested that a fact sheet could be developed so that each legislator is receiving the same information and so conflicting statements are not made. After providing them with the information, ask them (they most likely will not volunteer) if they would consider sponsoring a bill for formula/food coverage.

Prior to the committee hearings, have families call or write to their representatives (that did not help sponsor the bill) to make them aware of the bill and ask for their support. Ask families to report back as this allows those testifying at the hearings to know what concerns are out there and answer them in their time slot. If possible, get as many professionals to endorse the legislation by either testifying at the hearings or writing a letter of endorsement.

On the day of the hearing, have a variety of people testifying (e.g., professionals, parents, children on diet). Parents all saying the same thing can be annoying to committee members. Be concise and stay within your allotted time period. If possible, try and secure a brief meeting with the committee chairperson to discuss the case personally.

There are usually a few days after the hearing before the committee votes. Use this time to call or fax committee members and thank them for their time and remind them of the points that were reviewed at the hearing.

Once the committee has voted favorably and forwards the bill to the full legislative branch, you need to start over again and have families contact (by phone or mail) their respective representatives and senators to notify them of the bill and what it represents. Remember, organization and family involvement are the keys to success! Good Luck!!

Submitted to Organic Acidemia Association newsletter by:

Joyce Wong, MS, RD
Lipid and Metabolic Nutritionist
Regional Metabolic Center
Kaiser Permanente Medical Center
Oakland, CA 94611-5693
Printed August 1996

STATE LAWS THAT REQUIRE INSURANCE COVERAGE FOR DIETS

State	Formula	Foods	Disorders	Limitations
Alaska	yes	no	PKU	no
Connecticut	yes	yes	PKU, IEM	infants, children, pregnant women only
Florida	yes	yes	PKU, AA, OA	age 24, $2500 for food
(only available with special rider and increased premium on insurance)				
Maine	yes	yes	PKU, IEM	$3000 for food
Maryland	yes	yes	PKU, IMD	no
Massachusetts	yes	yes	PKU, AA, OA	$2500 for food
Minnesota	yes	yes	PKU	no
Montana	yes	no	PKU	no
New Hampshire	yes	yes	PKU, AA, OA	$1800 for food
New York	yes	no	PKU, MSUD, Gal, HSU	no
South Dakota	yes	no	PKU	no
Tennessee	yes	no	PKU	no
Texas	yes	no	PKU, 'Heritable Diseases'	no
Washington	yes	no	PKU	no

(OAA News August 1996)

Maya's Story ~ GA II

Maya is now 23-months-old. She is adorable, responsive, social, and we love her more each day. Many days, however, we hate the disorder and the fact that it makes her work so hard to accomplish what should otherwise be simple tasks. After many months of searching and battling parts of the medical community, we finally received a **diagnosis of ETF or Electron Transfer Flavoprotein Dehydrogenase Deficiency (MADD or GA2).**

Fortunately, Maya has been classified as having a mild variant of this disorder, which we have been told is quite rare. Unfortunately, we have no literature that describes her or other families with this diagnosis to correspond with. She is severely developmentally delayed, but with lots of help, continues to make progress.

Maya has two older siblings and when she was 4-months-old, I told her doctor that she felt mushy and unlike the other two. I was told not to worry and that she was still young. At six months when she hadn't rolled over, couldn't lift her head for any sustained period of time, continually fisted her hands beside her head, and had only gained two ounces over a two month period, I was told it could be CP. The first neurologist ordered an MRI, thyroid, renal and kidney screens. All were normal. We were told to take her home, watch her and that she would eventually show some development. Upon the advice of a developmental pediatrician we began intervention in the form of PT, OT, and speech/cognition therapy. We are extremely fortunate to have eventually found High

Hopes here in Nashville where Maya receives her services and recently began attending preschool.

Four months later, we sought the advice of another neurologist. This time a metabolic screen was ordered. It showed mild elevations of various organic acids. We were referred to Dr. Summar at Vanderbilt University who diagnosed her with Flavoprotein Dehydrogenase Deficiency. The diagnosis has been confirmed with a fibroblast. Maya now takes riboflavin and carnitine daily. We have **riboflavin oral suspension** made for us since a liquid application is easier for us to use. If anyone needs this **I can provide the pharmacy name here in Nashville.** It has made life much easier for us. She is responding well, her tone has improved, and her organic acids have been normal since beginning the carnitine and riboflavin.

Maya has improved quite a bit but remains significantly delayed. We are currently struggling with extreme eating difficulties that began this past January. Maya switched to all table foods on January 1 and ate with enjoyment and little difficulty even though she would not feed herself. After two weeks she developed another ear infection and completely refused all foods except liquids. We were forced ultimately to switch her to a high calorie liquid supplement that we still use for a reliable calorie source.

The side benefit from this was that she began to grow with the infusion of very high calories. She refused all solid foods for almost eight weeks. During this time we were told by all of her doctors that keeping her on a liquid diet was okay. With much perseverance we have been able to get her to take solid foods again, although she only mouths them and refuses to swallow any. She will be going into the Kennedy Kreiger Institute (Johns Hopkins) Pediatric Feeding Disorders Program as an inpatient in September.

Maya's therapists are all very good and very supportive of us and Maya. We would very much like to become part of your Network and perhaps even find a family with a similar diagnosis. I look forward to receiving the next newsletter and thank you for your good work.

Very Truly Yours,
Joanne Bregman
Nashville, TN

Follow-up letter from Joanne Bregman ~ Maya

Enclosed are the program materials from the Feeding and Swallowing Disorders Program at the Kennedy Kreiger Institute in Baltimore. Our experience at KKI was exceptional. A little history first about Maya's feeding problems.

Maya has always had difficulty with weight gain and growth in general. She was never an enthusiastic eater and would rarely if ever initiate a meal or snack. She rarely cried to eat even as a newborn. She was also very orally defensive which made feeding from a spoon

a bit tricky. By the time she was 15-months-old we did have a few foods she would eat pretty reliably, but they were mostly soft, not too chunky foods. We kept her on formula as a beverage for the extra calories.

When Maya was approximately 16-months-old, we decided to try her on table foods since she was showing a real disinterest in baby foods. Surprisingly and much to our delight she accepted these foods readily and actually opened her mouth to be fed! Her favorite foods seemed to be cheese tortellini and bananas. While she was not actually chewing her food, she was managing to suck and munch and swallow the food. After two weeks of good eating, she became sick with a bilateral ear infection. Immediately, all eating stopped. She would now only accept formula from a bottle.

Not knowing what to do and having no guidance from her doctors, we followed her lead and went back to a formula based diet. One nutritionist did suggest switching her to Kindercal (like Pediasure) since it is nutritionally complete and very high in calories. While she was not eating solid foods, the side benefit was that she began to gain some weight because of the daily infusion of at least 1000 calories. We then took her to see a feeding specialist at Vanderbilt ~ no help.

We slowly began to work back to solid foods beginning with the very first baby applesauce and yogurt. These two foods and the formula remained her diet for quite some time and this was without opening her mouth, but sipping the food off the spoon. We thought surely this would improve, but it actually got worse. Maya developed more aversive behaviors around eating and became increasingly selective about foods.

Even though her doctors all assured us children remain on these liquid diets for very long periods of time and do well, we were convinced that eating solid foods was a better course for her and for us. Her speech therapist also was concerned that she should get back to eating solid foods and swallowing. We noticed that she was now developing a gag as well.

In late July we accidentally heard about the feeding program at KKI. We were scheduled to be just several hours away in August, so we scheduled an evaluation for that time. Unlike the systems here in Nashville, KKI utilizes an interdisciplinary team approach (my dream come true). Maya was evaluated by an OT, behavioral psychologist, pediatric GI specialist, and a metabolic specialist. They conferenced while I was there and presented a proposed plan for her. We arranged to return in September.

While the typical length of their program ranges from four to eight weeks, we had only one week, for a number or reasons. The primary reasons had to do with having two other young children at home and the fact that our insurance company denied us coverage for the program. (This decision is now being reconsidered). Our goal for that week was to begin a feeding protocol to result in a good swallow study. The study was done on the fourth day and we were relieved to learn that swallowing presented no problems.

Maya worked with a team of two feeding therapists using a strict behavior modification approach since it was the belief of the evaluation team that this was the primary problem. Luck was on our side because Maya took to the program very early on. While we had some backsliding, once she figured out the reward system, we learned that she was able to open her mouth, accept and swallow a variety of solid foods and beverages.

I can't say enough wonderful things about the staff in the behavioral psychology department where the program operates from. In addition to their expertise and breadth of knowledge, they were continually supportive of me. Believe it or not, before I left, I was trained in Maya's feeding protocol and sent home with a training tape, written materials and home and pager phone numbers. KKI therapists have since called us to check up on our progress**.**

And progress has been the word. Maya gained 1pound within 15 days of returning home. Her weight gain has slowed some, but she continues to make wonderful strides in her eating. We have been able to reduce the frequency of 'rewards' within a meal and have increased both her volume of food at a meal and the textures of the foods. She has begun to learn how to chew, swallows well without any gag and is completely off the bottle. We have reduced her intake of the nutritional beverage by half and continue to use it only to help get in some extra calories. She continues to eat a wide variety of foods. It is a pleasure to feed her now and she actually initiates meals and snacks by very clearly letting us know she wants to eat!

Most importantly for me and my husband is the elimination of the stress we used to have surrounding her feeding problems. This is not to say, however, that it is easy. It requires consistency and I go to her school every day to feed her lunch. We are not at the point to have trained someone else in her protocol. But it is all worth it!

Of course the frustration is that this program could have just as easily passed us by. I have made sure to deliver a set of program materials to each of the physicians who follow Maya. We are trying to bring the KKI folks to Vanderbilt for grand rounds and to Maya's school for a parent forum that we will open to the community. I understand that Johns Hopkins will pay their expenses. If there is any additional information you would like to have, please let me know.

Sincerely,
Joanne Bregman
Nashville, TN

Patient Population at Kennedy Kreiger Institute

The program cares for children from birth to age 21, throughout the world, who have behavioral or medical feeding problems such as extreme food selectivity or refusal, inappropriate mealtime behaviors, skill deficits such as swallowing or self feeding, or vomiting.

Medical diagnoses include:
AUTISM
CEREBRAL PALSY
CYSTIC FIBROSIS
DYSPHAGIA
FAILURE TO THRIVE
FOOD ALLERGY
GASTROESOPHAGEAL REFLUX
GASTROINTESTINAL PAIN
GENETIC DISORDERS
METABOLIC DISORDERS
OBESITY AND WEIGHT MANAGEMENT
ORAL MOTOR DYSFUNCTION
PREMATURITY
REACTIVE AIRWAY DISEASE
SHORT BOWEL SYNDROME

Cost Benefits:
The comprehensive, effective design of the Pediatric Feeding Disorders program results in shorter average inpatient stays ~ 52 days compared to 171 days in other programs. In addition, the majority of children once dependent on supplemental feedings are discharged independent of tube feedings, or dependent for less than 25 percent of nutritional or fluid intake. These outcomes eliminate or significantly reduce the costs of tube maintenance, supply, formula, and nursing.

Feeding Disorders…
• affect 1 in every 4 infants and children and up to 80% of children with developmental disabilities.
• may be behavioral or medical in origin, or a combination of both.
• can be characterized by tube-feed dependence, swallowing disorder, or dysphagia, extreme food selectivity or refusal, obesity, or mealtime tantrums and aggression.

The Pediatric Feeding Disorders Program…
• is an innovative, comprehensive, and cost-efficient program using practical and effective treatments.
• serves individuals from birth through adult-hood and their families.
• combines **gastroenterology** and **behavioral psychology.**
• provides a continuum of care comprising **Inpatient, Day Treatment,** and **Outpatient** programs, and a multidisciplinary team including nursing, nutrition, occupational therapy, and social work.

Kennedy Krieger Institute
707 North Broadway Baltimore, Maryland 21205
410-550-9455 800-873-3377 (fax) 410-550-9459

Sydney and Amber ~ MCAD

On the morning of May 20, 1996, my husband and I took our daughter, Sydney, into the clinic. Both of our daughters had flu-like symptoms over the weekend, so just as a precaution we wanted our 7-month-old checked over because when they are that little it's hard to tell.

The doctor looked Sydney over and told us that it was just the flu and that in 24 hours she would be fine. He also looked at Amber since we were there and she had been sick also. Although she was doing much better, he said that he was sure that both Amber and Sydney had the same bug. If only we had known then what we know now!

The four of us went home at 10:00 a.m. We spent the day together and just tried to get both kids back on track and feeling good. Around 3 p.m. Sydney seemed to be getting more and more lethargic. I phoned the clinic and spoke with a nurse who basically told me to quit over-reacting ~ it was just the flu! Needless to say my husband picked Sydney up around 4:30 p.m. because we had decided that the clinic was not taking us serious enough and we were bringing her in. However, at that time Sydney looked up into her daddy's eyes and then stopped breathing. I phoned 911 and Gary immediately started CPR. When the paramedics arrived they told Gary that he was doing such a good job at CPR so he should keep administering it while they got set up. I was told to keep Amber calm and distracted. I had no idea what was going on.

The paramedics decided to transport Sydney to the hospital. At that point we told Gary to go with Sydney and Amber and I would meet him there. I packed a bag for Amber of clothes and juice thinking we were going to be there for the night. My mother went straight to the emergency room to be with Gary and Sydney. My dad came to pick Amber and myself up and take us to the hospital. The policeman that was at our house would not let me leave unless we had a ride because I was so hysterical.

Unfortunately, Sydney was declared dead at 6:08 p.m. The hospital staff said they had done everything they could. No words can describe what we were feeling. Of course we couldn't believe that this was really happening, but it was! It was quite sometime before Gary and I were ready to leave Sydney. But finally we had no choice. So we took Amber home without her little sister. I remember thinking this was the hardest thing I had to do.

If only I had known that this was just the beginning of tough things to come. When we arrived home, it was such an empty feeling looking at the spot where the paramedics had worked on our precious Sydney, but to no avail. Luckily for Gary and myself, my parents were there and were able to start making phone calls, and my sister and her husband were there to watch Amber because Gary and I were in such a shock that we were barely able to function.

Over the next few days things just kept getting harder, doing things like picking out a casket, marker, etc. for our infant daughter who was just a few days prior ~ a bright and

happy baby. With the support of our family and friends we made it through the wake and funeral.

Three weeks had passed and we hadn't heard anything, so I called the medical examiner. I spoke with the doctor who had completed the autopsy. After listening to him offer his condolences, and telling what a beautiful and healthy daughter we had, he informed me that his autopsy revealed nothing and he was 99% sure it was SIDS. I told him that I did not believe that SIDS was the cause and that I still had a 2-year-old to be concerned about. I had seen Amber sick and had some major concerns about the similarities. He said he would do some more checking and let me know.

A week passes and I had not heard anything so I phoned again. He gave me the same song and dance. I told him I still did not buy the SIDS story so he should run a few more tests or do more research and if nothing showed up then SIDS it would be.

Another week passed and I heard nothing. So once again, I phoned them. I was told that the doctor was on vacation. I was then transferred to another medical examiner. I explained the situation to her, told her that SIDS was a category for unexplained deaths and that didn't feel right so maybe there was something else they could do. She told me about Sydney's blood sugar and although that was probably because she had the flu, she would pursue that path to reassure us about Amber. Another week passed so I phoned again, and was told still nothing. The next week I checked again, still nothing, however, they were checking into a rare metabolic disorder that might be a possibility, although they strongly felt it was SIDS. The test was pending for the next three weeks. **Finally I got a call from them stating that Sydmo (as she was called around the house) had died from MCAD Deficiency.**

We had no idea what this deficiency was except that it was genetic, so immediately raised flags about our daughter, Amber. After all that we had been through and dealt with we were still being treated as over paranoid parents, and told we will test Amber to put your mind at ease, but there is only a 1 in 4 chance so don't be concerned.

Finally we were referred to the University of Minnesota to see Dr. Susan Berry who is a specialist. All I could think was, "Oh wonderful. Another doctor or even better yet a specialist to tell us that we are just nervous parents." Only to my surprise after meeting with her and her staff, I felt comfortable. We told her of the concerns we had regarding the similarities with Amber and Sydney during illnesses. We explained that the first time Amber was sick was after she was 15-months-old and that they had all been pretty mild illnesses up until January 1996, when Amber became quite lethargic during a flu-like illness.

They were going to do DNA tests and it would take 3-4 weeks for the results. Based on what we told Dr. Berry regarding Amber she became quite concerned as well, and she did a urine screening. She told us this would not be 100% but it would help her decide which way the diagnosis was leaning.

The next day Dr. Berry phoned me to tell me that based upon the results of the urine screening she was very concerned about Amber and she asked that we come back the following day to meet with her and her staff. Of course, we said no problem someone was actually taking us serious now. We showed up the next day as requested and the next bomb was dropped. **Dr. Berry was so concerned she had the lab work around the clock and she had the results phoned in that Amber had MCAD.** After spending the day at the University of Minnesota trying to understand what this means for Amber, we went home exhausted and **feeling more than ever that life just isn't fair ~What had we done that our children deserved this fate?**

After talking about it immensely, **we decided that Sydmo was and still is truly an angel.** Although we miss Sydney so much and still love her as we do Amber, and would do anything to have her back with us we know that can't happen. So **we have decided to conquer MCAD Deficiency and keep Amber healthy.** We have now started the carnitine and the low fat high carbohydrate diet along with using cornstarch. Amber has had a few illnesses and we are all on pins and needles the whole time. But we also know that we have support from our family, friends, and also wonderful medical support from the U of M.

Unfortunately, we found out about MCAD to late to help Sydmo and for that we are very sad and heartbroken. But we know now that we can do so much to help Amber grow up. This has been very difficult for her as well. She lost her little sister and best friend. Our hope for Amber is that she doesn't lose anything else ~like her health!

Our thoughts and prayers go out to all of the families that are connected somehow with a Fatty Oxidation Disorder. We wish you all the strength and courage to get through it. We will keep you all updated with Amber's health. Thanks to all or you for being my sounding board. We wish you all happy and healthy times!

Anne Stitt
Bloomington, MN

Questions and Answers

[Please Note: This question and answer column is designed to answer questions, both medical and practical, on FODs and their treatment. Answers to questions are solicited from those who have had firsthand experience dealing with an FOD. These include physicians, parents of FOD children and children/adult FODers themselves. It is our hope to provide general guidelines in responding to questions posed as opposed to specific foolproof solutions. Additionally, it is especially important to note that our Medical Advisor, Dr. Charles Roe, formerly of Duke University Medical School and now Medical Director of the Institute of Metabolic Disease at Baylor in Dallas, has read and approved responses to all medical questions. However, because of the individual nature of each case, it is always important to discuss these guidelines with your physician before making any changes.]

Question: My son had a few hospitalizations and he gets upset at times. Is there anything we can do to help him relax?

Answer: Being in the hospital can be a stressful thing for anyone, but it is even more stressful for children. Music can help decrease the fear and stress associated with being in the hospital. Many music therapists are employed in hospitals, and they have used many different activities to help distract their patients, provide enjoyment and decrease stress.

If your child is admitted to the hospital, find out if there is a music therapist there. If not, there are many activities and songs that you can do with your child to help them relax. First of all, try to make the environment as familiar as possible. If your child has a favorite toy or stuffed animal make sure to bring it. If you sing songs or lullabies to your child at home, it is okay to sing to them in the hospital as well. Perhaps some nurses will even sing to the children. Sing a song such as 'If You're Happy and You Know It' but change the words to match how they are feeling (i.e., If you're angry and you know it stomp your feet or if you're sad and you know it say boo hoo). This will help the child identify his/her feelings and be able to express them. Singing songs also provides a welcome distraction.

If you want to do something fun, get the child to write a song with you about being in the hospital or the feelings attached to being in the hospital. For example, use the song 'Whistle a Happy Tune' from the "King and I." This song begins with 'When ever I feel afraid I...' Let your child fill in what he/she does when he/she is afraid. This will teach them coping skills and allow them to discuss their feelings and fears appropriately. Songs can also be made up to teach children about the hospital and about the things that are going to happen to him/her there. Whistles and blowing bubbles can be used with children to help increase their breath support as well as to provide some enjoyment.

Music is a lot of fun, and it is easily used to distract the child from the pain or the fear associated with being in the hospital. Parents can also benefit from using music. While listening to music or singing, you will relax and this will provide a less stressful environment for both you and your child. If you as a parent are relaxed, it is more likely your child will also be relaxed. Being in the hospital can be stressful for children and parents alike, but you can try to make it less stressful and even provide a little fun by using music. Try it, what have you got to lose?! If you have any questions or have any specific needs, you would like me to address, please feel free to contact me.

Lisa M. Gallagher, MA, RMT-BC
Registered and Board Certified Music Therapist

Question: Can Carnitine Deficiency cause other diseases, such as Diabetes or Arthritis?

Answer: Carnitine Deficiency is not a specific disease entity. It is a secondary metabolic consequence. Thus it cannot be said that it 'causes' other medical conditions. It has been

shown to be a secondary concern with many of the FODs, as well as some other diseases such as Diabetes.

Question: I have heard about a test that helps to diagnose FODs called 'In Vitro Probe.' Can you tell me more about it?

Answer: See following article.

'IN VITRO PROBE OF THE FAT OXIDATION METABOLIC PATHWAY'

Dr. Charles Roe
Baylor University Medical Center
Institute of Metabolic Disease

Rationale: There are now many inherited defects of mitochondrial beta oxidation that are currently referred to as 'Fat Oxidation Defects.' The clinical presentation often is similar for several of these. For example, several may present as hypoglycemia, others with cardiomyopathy, and still others with hypotonia and developmental delay. This requires extensive testing by a variety of techniques, some of which only indicate the 'possibility of an inherited fat oxidation defect, and finally leads to the performance of isolated enzyme assays involving fibroblasts or tissue biopsies. The diagnosis can be delayed by request of the wrong enzyme assay when several defects with different enzyme deficiencies present clinically in a similar manner.

Method: The in vitro probe of the beta-oxidation pathway was developed to provide a rapid assessment that would be highly specific for the diagnosis. Fibroblasts must be grown in culture from a skin biopsy over several weeks. The cultures must be tested for the presence of mycoplasma, etc. When adequate cells are available in culture, they are incubated with stable isotope (non-radioactive) labeled long chain fatty acids, like palmitate or linoleate, along with L-Carnitine. This incubation requires 3 days. If an enzyme is missing in the pathway affecting the degradation of the long chain fatty acid, then the diagnostic intermediates appear in the culture medium as acylcarnitines and are detected and quantified by tandem mass spectrometry analysis. The in vitro probe of the pathway, by this method, allows the simultaneous recognition of enzyme deficiencies throughout the whole metabolic pathway. This is equivalent to performing individual enzyme assays for the whole pathway but at greatly reduced cost. When a Fat Oxidation disorder is suspected then this approach leads quickly to specific diagnosis regardless of the clinical presentation.

Diagnostic Applications: The in vitro probe of the mitochondrial fat oxidation pathway can readily recognize the following disorders in fibroblasts:

- Carnitine-AcylcarnitineTranslocase Deficiency
- Carnitine Palmitoyl Transferase II (CPT II) Deficiency
  (neonatal. Infantile, and adult onset forms)
- Very long chain Acyl-CoA dehydrogenase (VLCAD) deficiency
  (distinguishing between the hypoglycemic and cardiomyopathic phenotypes)
- L-3-hydroxy-Acyl-CoA (LCHAD) Deficiency

(all phenotypes)
- Trifunctional Protein Deficiency
  (Enoyl-CoA hydratase, LCHAD, Thiolase)
- Medium chain Acyl-CoA dehydrogenase (MCAD) Deficiency
  (all cases regardless of mutation)
- Dienoyl-CoA Reductase Deficiency
  (using linoleate as probe)
- Short-chain Acyl-CoA dehydrogenase (SCAD) Deficiency
- Electron Transfer Flavoprotein (ETF) Dehydrogenase Deficiency
  (Glutaric aciduria type II or Multiple Acyl-CoA dehydrogenase deficiency)

Advantages:

1. Prenatal diagnosis can be accomplished by this same technique using amniocytes in culture.
2. When a fat oxidation disorder is suspected based on abnormal urine organic acid analysis, the specific diagnosis can be verified without excessive testing using less specific diagnostic methods.
3. Cost effective (e.g. oxidation rate studies can cost up to $1600 and abnormal results only indicate the possibility of a problem in fat oxidation while the In Vitro Probe of the pathway gives the specific enzyme deficiency causing the inherited disorder for less than half that cost.)
4. Precursors to other metabolic pathways can also be examined for inherited disorders affecting, e.g., branched chain amino acids.

References:

1. Nada, MA, Rhead, WJ, Sprecher, H, Schulz, H, and Roe, CR. Evidence for intermediate channeling in mitochondrial b-oxidation. **J Bio Chem,** 270, 530-535, 1995.

2. Brown-Harrison, MC, Nada, MA, Sprecher, H, Vianey-Saban, C, Farquhar, J, Gilladoga, AC, and Roe, CR. Very-long-chain-acyl-CoA dehydrogenase deficiency: Successful treatment of acute cardiomyopathy. **Biochem Molec Med,** 58: 59-65, 1996.

3. Nada, MA, Vianey-Saban, C, Roe, CR, Ding, JH, Mathieu, M, Wappner, RA, Bialer, MG, McGlynn, JA, and Mandon, G. Prenatal Diagnosis of Mitochondrial Fatty Acid Oxidation Defects. **Prenat Diag:** 16: 117-124, 1996.

4. Nada, MA, Chace, DH, Sprecher, H, and Roe, CR. Investigation of beta-oxidation intermediates in normal and MCAD deficient human fibroblasts using tandem mass spectrometry. **Biochem Med Mol Bio**, 54: 59-66, 1995.

Recipes

Strawberry Shortcut
Prep Time: 15 minutes
1 package (13.6oz) fat free pound cake
3 cups strawberries, sliced, sweetened
1 tub (8oz) COOL WHIP FREE, Fat free Whipped Topping, thawed

CUT cake into 16 slices. Place 8 of the cake slices on individual dessert plates.
SPOON about 3 tablespoons of the strawberries over each cake slice. Top each with 1/4 cup whipped topping. Repeat layers, ending with whipped topping.
SERVE immediately. Makes 8 servings.
Nutrition Information Per Serving: 270 calories, 2 g fat, 0 mg cholesterol, 170 mg sodium, 64 g carbohydrates, 3 g dietary fiber, 3 g protein.

Pharmaceutical Update

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

Medical Update

I recently spoke to Dr. Kenneth Pass, who is the Committee Chair of the Council of Regional Network for Genetic Services (CORN), which is sponsored by the federal government and addresses public health aspects of medical genetics. It helps to coordinate activities among other federally funded genetic networks and to implement programs of national significance. Standing committees address identified areas of concern within the discipline of genetics. I asked Dr. Pass **what we, as a National Support Group could do within our own states to advocate Newborn Screening for FODs and to have them included in the routine screening procedure. If we let our voices be heard, children across our country would not have to die because of lack of early diagnosis and treatment.**

Dr. Pass strongly suggested that we write letters to our State Commission of Health as well as to the State Assemblies. He stated that **3 criteria were required for new disorders to be included in the routine testing** and this info can be included in your letter. The following is my 'synopsis' and opinion about those criteria:

1). **The condition has to occur frequently enough** ~ PKU occurs 1/15,000-20,000 (may vary yearly and state-to-state) and some of the other disorders already tested in some states (i.e., Maple Syrup Urine Disease or Galactosemia) can occur less frequently,

such as 1/50,000. MCAD, for example, occurs between 1/10,000-20,000. So it fits the 1st criteria. Some of the other FODs are more rare but still important to be tested for using the same bloodspot!

2). **There has to be an established test to detect these disorders.** Many labs across the country now have the specialized equipment to test for many of the FODs! We have several listed on our professional list. Dr. Roe at Baylor, Dr. Kahler at Duke, Dr. Strauss at St. Louis, just to name a few. If you professionals would like our Network to be informed about your services, send me a synopsis of what you offer. Additionally, researchers can now detect some of the FODs with amniocytes. So there are tests out there. However**, because the equipment for this type of testing is so expensive, it may be more cost effective to promote Regional Testing Centers instead of state centers.** Mentioning that in your letter may be helpful.

3). **There has to be a treatment available for the disorder.** We fit that category also. Ideally, the assessment and treatment approach would be multidimensional ~ medical, physical, behavioral, cognitive, emotional, and possibly spiritual (if that's important to your family). The treatment for several of the FODs include a drug component (i.e., Carnitor®) with nutritional restrictions and/or suggestions (i.e., high carbohydrate/low fat or watch the protein. Even though the cost of testing for FODs may still be a bit higher (*in 2000, it's $25, see our web site for Labs that do NBS) than the already established newborn screening tests, Dr. Pass said having those 3 criteria has a higher priority than cost. **So if you want to help us push for newborn screening, write your letters highlighting those 3 criteria as well as your own personal connection with these metabolic disorders. Your input could possibly someday save a child's life!**

[Criteria info also from: Newborn Screening Committee, The "Council of Regional Networks for Genetic Services (CORN)." National Newborn Screening Report ~ 1992, Atlanta, December 1995]

Resources

1). **Provincial IODE Genetics Resource Center** provides info on genetic disorders for families and professionals in Canada. They are developing a WEB page that will offer listings of Genetic Clinics across Canada, genetic resources on the Internet, upcoming conferences and online version of Canadian Directory of Genetic Support Groups. Their page is www.lhsc.on.ca/programs/medgenet/htm .
The Resource Center's address is: Regional Genetics and Molecular Biology Program 800 Commission's Road E, London, Ontario N6C 2V5 519-685-8500

2). **The Parent's Helper** lists over 1,100 organizations dealing with health and family issues. It can be ordered by calling: 212-980-8230.

3). **Center for Medical Genetics** 1901 Research Boulevard, Suite 160, Rockville, MD 20850, 301-460-GENE Toll Free 888-448-9600 Fax 301-517-4999

Dr. Kenneth N. Rosenbaum has recently left Children's National Medical Center in Washington. D.C. He is presently the Director of the Center for Medical Genetics as well as the Medical Director of Pediatrics for Adventist Health Care Mid-Atlantic.

The Center for Medical Genetics is able to provide experienced care for children and adults with any type of genetic disorder. In addition, specialty clinics with emphasis on Down syndrome, Gaucher disease, neurofibromatosis, and skeletal dysplasia will be available. The Center will also provide genetic services through its prenatal center and its cancer genetics counseling program.

Submitted by: Carmella Sameso, MS
Genetic Counselor

Children's Hopes and Dreams Foundation has a FREE Worldwide Pen-Pal Program for Children with Chronic or Life-Threatening Diseases. 280 Route 46, Dover, NJ 07801, 201-361-7366

Love Messages

(Please see our most current online issue)

If there is a gift for us in exchange for all our losses, it is a new, constant state of cherishing.

Stephanie Ericsson
Companion Through the Darkness

Just as whole forests burn to the ground and eventually grow anew, just as spring follows winter, so it is nature's way that through it all, whatever we suffer, we can keep on growing.

Judy Tatelbaum
The Courage to Grieve

Kids Korner

Question: Why can't doctors get rid of the bad gene and replace it with a good one?
Kari Farrell, Menasha, WI

Answer: According to Dr. Roe, this is a possibility for the future and some FOD researchers are currently working on that but it is a very complex issue scientifically.

Because of that it will probably be several more years before it may ever be a possibility for Fatty Oxidation Disorders.

Donations Received

Even though our newsletter is provided through the generosity of Sigma-Tau Pharmaceuticals, Inc., we greatly appreciate family or professional donations. However, because we are not a non-profit organization, be aware that donations are not tax-deductible at this time. Thank You to: Karen and Dave Mallory for your generous donation to the FOD Family Support Group.

Reminders

• Thank You All for your holiday cards, pictures, and thoughts ~ they were greatly appreciated!

• A **HUGE thank you** to **Judy Farrell** for typing and formatting this issue for us, as well as to **Erika Wallace** for typing all the Mailing Labels and the Family/Professional Lists**. I couldn't do this without their help!**

• We'd like to see more LOGO ideas, favorite recipes and items for the Kids Korner like questions, comments, concerns, stories written by kids, pictures, even troubles related to diet or medication. Who knows, maybe another child has been there and can offer help.

Remember we're ALL IN THIS TOGETHER!

Any Professional/Researcher/or Parent that would like to add any new or further information on FODs we'd be very interested in hearing from you. We'd really appreciate your contributions. Thanks!

January 1997
Volume 7 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.]