FOD Communication Network

(Fatty Oxidation Disorders)

'All In This Together'

July 1996 **Volume 6 Issue 2**

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

From The Editor

The summer heat is upon us and I hope all of you are staying as cool as possible. This issue of our newsletter will not be different as far as the format is concerned, but it is different in the way it has come to you. Because of various reasons, I am trying to utilize the expertise of our FOD families more. Instead of trying to put this together by myself, I have enlisted the help of several of our Families.

I want to personally thank all of you who have sent in your stories or comments. They really personalize our newsletter and other families connect with what you're saying. Please keep them coming! A special thank you to Judy Farrell for typing up all the information and formatting a great looking newsletter and to Lisa and Jeff Schmidt for doing the mailing labels for us. They are also responsible for getting us a Web page. They do a great job of updating it and taking new family information and questions. If any of you have any ideas as to enhance our newsletter, please let us know.

One of the ways we might be able to distinguish ourselves from other Support Groups, would be with a Logo. We are asking for your help. If any of you have **ideas for a Logo**, please draw them and **send them to us by December 1996.** Then we can print them in the January 1997 issue and ask for all of you to vote on the one that best exemplifies what we stand for. You can use drawings, phrases or whatever you think **brings out the essence of the FOD Family Support Group ~ that 'We Are All In This Together' for the total well-being of our children and our families.** Please send all ideas/articles by December 10, 1996.

Deb and Dan Gould, Co-Editors
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Letters to the Editor

Dear Deb: Dianna and I are so happy and excited to see you on the Internet. I was recently saying to Dianna that it would be wonderful if something like that would happen. It is so neat to see FOD here. I sent you a registration form email, but only so you would have our email address. We received our FOD letter today and that is how I

found the address for you here. As usual it's a great newsletter. We are always happy to receive it, and appreciate your hard work and DEDICATION to this letter.

As you know, Dr. Roe has moved to Texas, Baylor University, and is only 15 minutes from our home. I called him when he first arrived and volunteered our family to participate in any way he would like for us to. I kind of feel like the Deb Gould of Texas! But seriously, someone needs to be available to speak with and offer pointers to families who are just finding out that their child(ren) have MCAD. You helped us very much on our visit to North Carolina in '92 and I would like to do the same for families here since we are so close to the University.

Kathryn is doing very well, despite several small colds and minor infections. She has not had an episode in two years and God willing she never will again.

We enjoy the letters still, and are always happy to hear from our extended families at FOD.

Randall and Dianna Burns
Euless, Texas

Dear Deb and Dan: Thank you for the time and effort you have spent setting up the MCAD network. I'm very grateful that you have expanded your network to include all Fatty Acid Oxidation Disorders. This is certainly a large commitment on your part. In doing so, you are helping many families who have been desperate to connect with others.

I can remember how frightened and alone John and I felt after we were given the diagnosis that of LCHAD for our daughter, Jane, in November of '93. Dr. William Treem, the physician who diagnosed our daughter, was located in CT, hundreds of miles from our WI residence. None of the doctors who were caring for Jane at the time had ever heard of LCHAD deficiency, and had no idea what a diagnosis of LCHAD meant.

Our fear was compounded due to Jane's complications from her prematurity and the loss of her sister, Sarah, a year prior to this, from what now was suspected to be LCHAD. My attempts to locate an LCHAD family through the MUMs and NORD National Database, was unsuccessful. I was very thankful that a parent of one of Dr. Treem's patients, agreed to talk to us. This parent helped us through some difficult times during Jane's infancy, and continues to keep us updated on his daughter's progress.

Thanks to your commitment, parents of LCHAD children will now have easy access to other families in similar situations.

Sincerely,
Jenny Carroll
Prairie du Sac, WI

Dear Deb: Received the January 1996 FOD Communication Network newsletter. It's great and I love reading it and hearing about other people's situations. Although the stories are sad, it helps to be able to relate your feelings to what other people are feeling. It's wonderful to read about the success stories as well. I also hope you will continue using the medical updates. They help a lot. As a matter of fact, I just sent a letter to Dr. Kahler to ask some questions about the carnitine and the dosage Dustin is getting.

We are all doing fine. Dustin has not had any symptoms of MCAD for over 8 years now. He just turned 9 in November. I wanted to get this letter to you so you could see that we have a new address and phone number. I didn't want to miss an issue of the newsletter! We bought a new house in October and moved in the first weekend of December. The kids love it! They have a park right next-door and a huge backyard of their own. They recently got a new puppy too! As you can see there has been a lot going on! Aside from all that, I am still going to school full-time and will graduate, finally, in August of this year. Hope all is well with you and your family. Let me know if there is anything else I can do to help!

Sincerely,
Lisa Cecil
Evansville, IN

In the Nick of Time

When my husband Jim and I found out I was pregnant, we really never gave it a second thought about having another child. We already had a beautiful 3-year-old daughter. Stephanie was healthy and happy, so we thought it would be good for her to have a sister or brother.

After a normal and uncomplicated 40-week pregnancy, our son was born. Weighing in at 8lbs 1oz, he was a beautiful and healthy baby ~ at least we thought.

It all began on June 13th, 1994 although we did not know this at the time. Jim and I happened to go into my son's room to do something, when Jim looked at the baby and called to me. Well the sight was very scary. We thought our 5-week-old son was dead. He was so white! When I picked him up, he woke up and seemed fine. When I called the doctor, she had me take him to get a complete blood count at the lab. The results were normal, but his color never really came back. From then on he was a very pale baby.

Everything seemed fine, but then on June 27th, 1994 our lives changed forever. That morning the baby wasn't eating very well, so when Jim came home from work we decided to take him to the emergency room in case he was dehydrated. As Jim drove, I tried to keep the baby awake. When we arrived, Jim took the baby and started to walk while I got the diaper bag. As I turned around and saw Jim running I got scared so I ran after him. When I got to the ER, I noticed Jim was crying and realized something was seriously wrong. He told me the baby had stopped breathing in the parking lot. After getting him to breathe, the baby stopped again when Jim reached the ER door.

The nurse took him right away and it seemed like eternity before we saw anybody again. Everything that happened before we saw our son again is still blurry, but I remember waiting in this little room. Awhile later a woman social worker and a priest came in. We know the woman was trying to help, but with all her questions she really made me feel like it was my fault by smoking during my pregnancy. The priest was talking about having him baptized after he dies, but at that moment we could not handle the thought of him dying. Finally a doctor came in and said the baby's heart and liver were enlarged and most likely they would have to do heart surgery.

I don't remember how or why they decided not to operate, but I remember them saying we could see him. He was very critical. They were taking him to ICU when we first saw him. He was this little body with all these tubes stuck in his arms, legs, and head. They said he probably would not make it through the night. Thank God he did and after two long days and nights, he was finally stable enough to be moved to a private room, but we still did not know the reason why he was so sick.

We had talked to many doctors and they all had lots of theories and speculations. But nothing was definite. Then four days later we learned he had LCAD (*in 2000, many LCADs are being re-diagnosed as VLCAD). We didn't understand any of it, but by talking to many doctors we found out that this was not his first episode. The first incident was that day in his room where **he would have been just another SIDS case if we hadn't picked him up in the nick of time.** We also arrived at the hospital just in time or he would have died.

Four days later he was well enough to go home on an apnea monitor. He was doing very well on his special diet and had visiting nurses come see him twice a week. One month after his first hospitalization, he was readmitted with a heart rate of 310 and diagnosed with Supra Ventricular Tachycardia.

A nurse once told us **we really picked the right name for our son ~ his name is Nick.** As of today, he is a beautiful 22-month-old baby, who is developing well with his diet and regular checkups and has since out grown the SVT. We thank God everyday that he is still with us.

Deb and Dan, thank you so much for letting us share our story. Thank you for this newsletter, it has really helped us a lot. We would very much like to talk to other parents going through this. It makes it a lot easier when you talk to someone who knows what it is like. Thank you again.

Sincerely,
Jim and Christine Trafford
East Providence, RI

Adam Fulton, 5 years old ~ LCHAD Update

The story of Adam was published in the OAA and FOD newsletters in December 1993 and June 1995 respectively. When his story was first published, there was little research on LCHAD[1] survivors. Now in 1996 we know of several families around the world who have LCHAD children that have survived past early infancy. Many, like our son, are doing well. However, now that more LCHAD children are being quickly diagnosed and successfully treated, it is time to look at the potential long-term health problems caused by this rare genetic disorder.

Adam was metabolically stable from 7 months to 3 ½ years, suffering only from a bout with chicken pox, and a few colds and ear infections that required the usual treatments. He was fed a special formula by NG tube up to age 2. As he became stronger the NG tube was used only for nighttime feedings and when he was sick. At 2 the addition of cornstarch to his formula[2] eliminated the need for a nighttime feeding, and made the NG tube unnecessary. Except for his need for this special high carbohydrate formula and daily carnitine requirement, Adam was functioning and developing like a normal toddler. We had read in research papers about LCHAD children experiencing severe muscle pain, myoglobinuria[3] and retinal abnormalities. However, Adam seemed so healthy, and his metabolism was so well controlled that we thought he might be exempt from these serious complications.

In July 1994 we were enjoying a vacation at a family camp in the mountains when Adam's stable metabolic state came to an abrupt end. Several subtle factors combined to trigger a severe LCHAD episode. We were at high altitude (@6000 ft.), which made his body work harder to cope with exercise, dehydration, and keeping warm. He also had a slight cold or respiratory distress due to the dust, and was too excited to take naps.

In the afternoon of the second day of our vacation, after being in the swimming pool, Adam complained of muscle pain in his legs. Within an hour his legs hurt too much to walk. At dinnertime he vomited. We tried feeding him formula and fruit juice, but he felt so bad he didn't take very much. He slept fitfully during the night, whimpering due to severe muscle pain. By the next morning he was too weak to sit up, his breathing was labored, and his urine was dark brown. We rushed him to the local emergency room facility about 45 minutes away. By the time we got him there he was too weak to lift his head. Luckily **we had a letter with us from his metabolic doctor describing his treatment protocol.** He was **put on a high volume IV of 10% dextrose** to stabilize his metabolic condition and protect his kidneys from the myoglobinuria[3]. He was then transferred by ambulance to the local Kaiser hospital in Sacramento over 100 miles away where he remained for 8 days.

Adam was very weak after this episode. He couldn't walk for several days. We were devastated by this extreme and sudden set back in Adam's condition. Of course the fact that it happened in the middle of our vacation didn't help either. Another devastating

blow was yet to come. While Adam was in the hospital, his eyes were examined and it was discovered that he had the beginnings of abnormal retinal pigmentation.

Adam's illness in July 1994 was the most serious since his initial LCHAD presentation at 5 months. Since then he has been hospitalized for myoglobinuria in December 1994, February 1995, May 1995, and February 1996. We believe these later episodes were brought on by a combination of factors including mild viral infection, lessened nutritional and fluid intake, and vigorous exercise. These succeeding episodes were much less severe requiring only 1-2 nights in the hospital.

With each succeeding episode we are learning more about how to avert an episode at its onset, or at least lessen its severity, so that Adam doesn't require hospitalization. He has begun to recognize the initial symptom, 'hurty legs' and be able to differentiate 'hospital hurty legs' from simple muscle fatigue. We have often been able to stop the muscle break down before it progresses to myoglobinuria. Our main treatment is to increase fluid and carbohydrate intake through his special formula, Gatorade, fruit juices, and water. Sometimes it is difficult to get him to take these extra feedings since he does not have a G-tube, and must take everything orally. Also when he is feeling bad he vomits and must be re-fed which is very stressful for him and us. However, he now is getting old enough to understand that cooperating with us will help keep him out of the hospital.

It is very stressful to know that any little cold can upset Adam's metabolism to the point that the preventative measures are ineffective and he must be hospitalized. We have read in the research literature that continued episodes of myoglobinuria can lead to permanent muscle tissue loss and progressive muscle weakness. With myoglobinuria the most important thing is to try to prevent it with increased carbohydrates and hydration during times of metabolic stress.

One research paper[4] suggests that treatment with steroids may be useful to increase muscle tissue. However, severe side effects are known to occur with steroid use. Our second major health worry for Adam is the abnormal retinal pigmentation which seems to be present to some degree in almost all LCHAD children, progressively affecting their vision as they mature. Some research suggests that DHA[5] present in fish oil might help prevent retinitis pigmentosa[6], but some of the side effects of fish oil are severe. Recently a process for extracting a pure form of DHA has been developed and initial trial treatment of LCHAD children may begin soon. The long-term value of this treatment will not be known for quite a while, but hopefully it will be helpful in preventing retinitis pigmentosa.

We were encouraged that Adam had gone 9 months without a major problem after his hospitalization in May 1995. Adam is now better able to communicate to us how he feels so that we can respond rapidly. We have been able to reverse several minor attacks with increased fluid and carbohydrate intake. However, in February Adam had to be hospitalized for two days with myoglobinuria. This was apparently caused by increased exercise combined with insufficient nutritional intake. It is still baffling to us that he is able to exercise vigorously on other occasions with no ill effects. He has been on several

long hikes, and just one week after this last hospitalization he was skiing at over 6000 feet with a wind chill near zero. We are hopeful that we will be able to prevent most serious episodes as our knowledge on what causes the episodes and how to prevent them increases.

We would be interested to hear from other LCHAD parents about myoglobinuria and retinitis pigmentosa.

1. **LCHAD:** Long Chain 3-Hydroxyacyl CoA Dehydrogenase Deficiency.

2. **Adam's Current formula:**
   1/3 Cup Polycose (no longer covered by our insurance)
   1/3 Cup Provimin
   3 Cups Non-fat Milk
   He receives: 15 cc's of carnitine daily
   1 tsp MCT Oil (not covered by insurance @ $80.00 per quart)
   2 teaspoons cornstarch in his morning bottle
   1tsp cornstarch in mid day bottles
   3 tsp cornstarch in his late night bottle
   He drinks 24 ounces of formula a day

3. Myoglobinuria: The myoglobin, a globulin muscle serum, in the urine as in a deficiency of muscle phosphorylase, in crush injuries, and after vigorous and prolonged exercise in susceptible persons.

4. Tein, Donner, Hale, Murphy. 'Clinical and Neurophysilogic Response of Myopathy and Neuropathy in Long Chain 3-Hydroxyacyl-CoA Dehydrogenase Deficiency to Oral Prednisone.' **Pediatric Neurology, 1995, Vol. 12, 1:68-76.**

5. DHA: Docosahexaeonic Acid.
See: **Calson, Werkham, Rhodes, Tolley.** 'Visual Acuity Development in Healthy Pre-term Infants: Effects of Marine Oil Supplementation' **American Journal of Clinical Nutrition, 1993:58:35-42.**
See: **Gang, Rosner, Rees, Berson, Weigel-DiFranco, Schaefer.** 'Plasma Docosahexaenoic Acid Levels in Various Genetic Forms of Retinitis Pigmentosa. **Investigative Opthalmology & Visual Science, 1992:33:2596-2602.**

6. Retinitis Pigmentosa: A group of diseases, frequently hereditary, marked by progressive loss of retinal response.

Don & Valerie Fulton
San Jose, CA
vallchadmom@yahoo.com

Lindsay's Story

Lindsay Anne Bingham ~ 2 years old
Diagnosis of SCAD, ASD Heart Defect
Spinal Hydromyelia, Gross and Fine Motor Delay, Slight Speech Delay

Lindsay turned 2-years-old on 10-18-95. Looking back on the past year, we are amazed and elated at how far she has come, but hope to 'network' with other families that may have a child with these apparently rare defects.

When Lindsay was born, after an uncomplicated pregnancy and delivery (I am even a Birthing Center Nurse by profession!), we were all so pleased to have a little girl and Ryan was so excited to have a little sister! Ryan is our extremely healthy, unaffected 6½-year-old son.

Except for an occasional irregular heartbeat, which our pediatrician told us was a 'transient' murmur that would be gone by 2 weeks of age, her growth and development seemed right on track. My concerns began when our lovely, quiet baby who was a wonderful nurser and was never sick, seemed uninterested in bearing weight, bouncing up and down, rolling over, crawling or creeping etc. My frequent voicing of my concerns to her pediatrician were responded by "Don't worry, she is a second child. She may be slower." I asked every visit "When should we be concerned?" "No, don't be," was the response.

As other one-year-olds were pulling up and cruising and taking their first steps, Lindsay would quietly sit and play. At her 15-month check-up her pediatrician finally decided we should be concerned. Hip and leg x-rays were taken and a referral to a neurologist was made. Two weeks later we were faced with the news from the neurologist that Lindsay had an abnormal EMG with denervation of her leg muscles, hypotonia, and no reflexes. She was given the 'probable" diagnosis of degenerative Spinal Muscular Atrophy (which thankfully wasn't correct!).

After a bout with the flu and chicken pox, Lindsay had a Grand Mal seizure. I'm curious to know what her blood sugar level was preceding that episode. If only we knew then what we know now! After numerous blood tests, urine tests and a skin biopsy sent to Dr. Roe's lab at Baylor University, the diagnosis of SCAD was made. The MRI of Lindsay's brain and spine showed the congenital birth defect of cervical and lumbar hvdromvelia with no Arnold-Chiari formation. And an Echocardiogram showed a hole in the wall of the atrium of her heart.

In this whirlwind of overwhelming information about our beautiful little red-haired angel, we were blessed to find a wonderful, compassionate pediatrician, Dr. Steve Koslov, who always takes the time to carefully listen to our concerns and needs. We were also referred to the Waisman Center at U. W. Madison, where we have found the nutritionists and genetic counselors extremely helpful and informative. Dr. John Wolff, who works

specifically with biochemical genetic disorders, has been most supportive in our daily regimen for Lindsay, which consists of a high carbohydrate, low fat diet (20-27gms daily), Carnitor liquid (20cc daily) and B-complex vitamins high in riboflavin. She also has her 'special shake' twice daily which consists of a tablespoon of cornstarch dissolved in Choc-O-Riffic milk! We also have PT once a week.

We are pleased to report that Lindsay has improved 150%! She began pulling up, cruising, and then walking all in her 23rd month and now 2 months later she is running and dancing with her big brother. Her fine motor skills are continuing to improve also and we have cut back on her PT to once weekly. Her speech is really taking off, but we are continuing to monitor it closely. She is beginning to act and appear as any 'typical' two-year-old does, if there is such a concept!

Lindsay seems to be unusually bright with an excellent memory and imagination. She is extremely sensitive to others needs and is very nurturing to other children. She has not had any further seizures since the one in March and had a normal EEG. Our next hurdle is monitoring her heart defect to see if the hole will close on its own or if it will need surgical closure sometime in the next year. We are glad she has not had any episodes of hypoglycemia and she has tolerated overnight fasting and illness as well.

We do however have a protocol on hand just in case of an episode or if hospitalization is necessary. So far her appetite is very good and she is average for her weight (31lbs) and tall for her age (36in).

Lindsay is a happy, although 'strong-willed' strawberry blonde angel who has touched all of our lives more than any of us could have dreamed. I wrote this letter in hopes of finding other families out there who may have had similar experiences or a child with similar symptoms or characteristics. Please feel free to write or call me.

Kathy Bingham
Madison, WI

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 VLCAD child is taking MCT oil. Mead Johnson only has quart size bottles. Do you have a suggestion on how we might be able to travel with a smaller amount and not have it leak all over the place?

Answer: As printed in the Organic Acidemia newsletter, Yezmin Perilla, a genetics counselor at Yale University, suggested emptying out a travel size liquor bottle. The MCT oil has to be kept in a glass bottle with a metal top. The oil doesn't leak out or eat away like it does with plastic bottles. It may sound like a strange idea, but it works!

Question: How can we get our states to include the Fatty Oxidation Disorders as part of their routine Newborn Screening?

Answer: As suggested in the Jan '96 FOD issue, a 'mass attack' of supportive letters to your local and state legislators, health department directors and even national politicians may make an impact. You can take the information from the ABCD survey results and supplement your personal family experience with FOD with their statistics, stating how FOD Newborn Screening could save lives! (*see our current online newsletter under Newborn Screening for more information and FOD Survey Results).

Question: What is music therapy and how can it be helpful with an FOD child or family?

Answer: Music therapy is the use of music to influence and/or change behavior. It is the use of a specifically prescribed music activity under supervision of a qualified therapist in order to aid in the physical, psychological, and emotional integration of an individual during the treatment of an illness.

Music therapy developed as a profession at the end of World War II when it was used as a treatment in veteran's hospitals. There are now over 3,000 music therapists in the United States who work in a variety of settings. Music therapy is used with individuals with a variety of needs such as psychiatric disorders, Attention Deficit Disorder (with or without Hyperactivity), behavior disorders, drug and alcohol abuse, emotionally disturbed, learning disabled, hearing impaired, visually impaired, developmentally delayed, hospital patients, senior citizens, and prisoners. Music therapy has been proven to be an effective treatment modality that is used in some hospitals in the following areas of medicine: general hospital, surgery, labor and delivery, pediatrics, intensive care units, rehabilitation, respiratory care, pain management, and oncology.

There is a wide spectrum for music therapy's applications including: listening to or performing music for relaxation and leisure, participating in activities for addressing rehabilitative or physical needs, and promoting family interaction. It is a non-threatening, painless treatment that is cost-effective, has few if any side effects, and is often fun.

Children especially enjoy participating in music therapy activities. It can help make painful procedures and physical exercises more tolerable, it can help provide relaxation, and it can be a fun activity that all family members can participate in together. Other goals for music therapy with children include: providing stimulation through music, decreasing fear and anxiety, increasing relaxation and sleep, improving quality of life, providing an opportunity for creative expression and self-expression, increasing self-esteem, and aiding in the development of motor, perceptual, language, social, and cognitive skills.

This article has proven a basic introduction to music therapy. Future articles will provide ideas for activities that can be used both at home and in the hospital for a variety of needs, recommendations for music for relaxation purposes, and stress management suggestions for parents and families. If you have any questions about music therapy or specific needs you would like addressed please feel free to contact me.

Lisa M. Gallagher, M.A.
Registered & Certified Music Therapist
Brookview Heights, OH

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My name is Eileen McMullin. I have a wonderful three-year-old daughter named Sean. Sean is diagnosed with having a Fatty Acid Oxidation Disorder. Her/our story is for another time. Suffice to say that Sean is a playful, active child who is healthy most of the time and really sick some of the time. Her job is to 'grow and learn,' ~ my job is to ensure that she has the opportunity to grow and learn.

I work from my home office as a Disability and Elder Services Consultant. Once upon a time I determined eligibility for Connecticut State Medicaid. I denied many applications. I did so because most people did not know how to apply. The populations that had the most difficulty applying successfully were the disabled and the elderly. It appeared difficult for them to obtain any of the entitlements ~ Social Security, Medicaid, Public Assistance, etc.

So I decided to leave the public sector and use my insider's knowledge to help people obtain entitlement.

I know I have hefty balances left after my family's medical bills come in, so I thought some of you might, too. Also, I know that the degree of each of our problems varies and programs for the disabled may be needed by some. I asked Deb if she thought the readers of this newsletter might have some interest in entitlement. She thought that some of you might. So, I put together a few general questions that I am asked regularly. If you have any specific questions, please feel free to contact me at ~ eiei@mailcity.com

[General Disclaimer: I am not an attorney. This is therefore not legal advice. The policies and procedures of entitlement programs vary from state-to-state. Terminology also varies from state-to-state. For example, Connecticut uses the term 'assets' while Kentucky uses 'resources.']

Question: My husband and I both work. My spouse, the children and I are all covered by medical insurance. We still have many medical bills for which we are responsible. Is there any help for us?

Answer: There may very well be. Each state has put together, under federal guidelines, programs to assist children of employed parents. These programs have income limits but no asset (resource) limits. As long as your income falls within the limits (usually 185% of the poverty level), you can have assets (a house, cars, bank accounts, etc.) and your child will still be eligible. Eligibility is dependent upon income and the age of the children involved. These programs usually provide medical coverage for the children only. These programs can usually be backdated up to 3 months (if eligible) from the date of application. Even though the program may not help with medical bills before that date, these programs will help with future bills. Check with the department that administers Medicaid in your state. By the way, the names of these programs often have the word 'health' in it. For example, Connecticut has the 'Healthy Start' program.

Question: My son was just in the hospital. Our insurance will only cover a portion of the medical bill. I have already checked with our Department of Social Services and any program we might be eligible for will not cover this particular bill. Is there anything that we can do?

Answer: In the early 90's it became a requirement for all not-for-profit hospitals to give away free medical care equal to the dollar amount of their tax exemption. If this is not done the hospital could lose its tax-exempt status. The main requirement of these programs is that the person applying for the program be willing, but unable, to pay their hospital bill. Each hospital has its own name and application for its programs. Frequently you have to know that this program exists and ask for it. It is, unfortunately, not always offered voluntarily.

Question: My daughter is developmentally delayed. I am able to care for her now, but I worry about the time I am no longer around to do so. Are there any programs available to help her?

Answer: There are many programs available. As for whether or not your daughter will be eligible, I cannot give you an answer. Each application is judged on an individual basis. This is true for each program. The best advice I can give you is to be persistent. For this answer, I am going to assume that you are married, one of you works and your disabled child is under the age of ten.

1. Apply for Social Supplemental Insurance (SSI) for your child. Call 1-800-772-1213 and ask specifically for SSI. This is a cash only program. Eligibility for your child will depend on the level of disability and the family's combined income and assets.

2. Call the Department in your state that administers Medicaid programs. Ask if there are any programs for an intact family (where the mother and the father of the child live in the same household as the child). These programs can either be with (as described in Q1) or without an asset limit. The programs with the asset limit also have an income limit. If all other eligibility requirements are met, but the income and/or the assets are too high, the family is put in a 'spend-down.' This means that there is a 'deductible' that has to be met before Medicaid becomes active. Just like a regular medical insurance. Disability of your child is not a requirement for these programs. 'Deprivation,' however, may be a requirement. This means that your child must be 'deprived,' through the physical separation from a parent, illness of one of the parents, or due to the unemployment of the family's primary wage earner.

3. Call your Town or County Clerk. Ask if there are any medical or emergency assistance programs offered to the residents. Ask if there is a Town Social Worker. Many towns (cities, counties, townships, etc.) have Social Workers whose job it is to assist people with Medicaid, Social Security, and SSI applications.

Recipes

(1st 3 offered by the Organic Acidemia Association and 2nd 3 by Judy Farrell)

Raspberry Punch
5 tea bags
¼ Cup orange juice
1 TB sugar
1-1/2 C fresh or frozen raspberries, thawed
2/3 C frozen lemonade concentrate, thawed

Combine 4 cups cold water and tea bags in 2-quart pitcher. Cover and let stand until tea reaches desired strength (2-4 hrs). Remove tea bags. Stir in orange juice and sugar. Place raspberries in a blender and process until smooth. Strain through a sieve or colander to remove seeds. Add raspberry puree and lemonade concentrate and 2 cups cold water to tea mixture. Stir to mix. Chill until ready to serve. Makes 8 Cups; each cup has 80 kcals, no protein or fat.

Frozen 'Banana Split'
1 banana
1 TB chocolate syrup
1 maraschino cherry
pressurized whipping cream

Peel banana and partially slit lengthwise. Freeze for 6-8 hours. Remove from freezer and place 2 TB (squirts) of whipping cream in slit. Drizzle chocolate over banana and top with a cherry. Makes 1 serving; 160 kcal, <lg protein, 1g fat.

Honey--Mustard Potato Salad
2 lb red potatoes
1/2 C fat-free mayonnaise
1 tsp Dijon mustard
1 clove minced garlic
1/2 C sliced carrot
1/2 C chopped red pepper
1/2 C sliced celery
¼ C sliced green onions
water
1TB honey
1 tsp celery seed

Slice potatoes and place in a 4-quart Dutch oven and add enough water to cover. Bring to a boil for 10-12 minutes or until cooked through. Drain and rinse the potatoes in cold water. Combine the mayonnaise, honey, mustard, celery seed, and garlic in a large bowl and mix well. Add the cooked potatoes, pepper, carrots, celery, and onions and mix lightly. Refrigerate until ready to serve. Per serving: Protein < 1gm, Fat < 1gm

Chicken Nuggets
Chicken breasts, boneless and skinless
Seasoned breadcrumbs
Egg whites
Salt and pepper, to taste

Cut chicken into bite-sized pieces. Dip in egg whites and roll in breadcrumbs. Place and bake them on a wire rack at 350F for 20-25 minutes. Flip the nuggets halfway through cooking.

'I Don't Know Chicken'
Chicken breasts, boneless & skinless
Seasoned breadcrumbs
Cheese, fat-free or low fat (Cheddar, American, Mozzarella)
2TB sugar
¼ tsp cinnamon
2 TB low fat margarine

Rinse chicken and coat with breadcrumbs. Sandwich cheese between two halves of the breast. Place on wire rack or cookie sheet or in broiler pan. Bake at 400F for 25-30 minutes.

Dirt Dessert
1 20oz package Reduced-fat Oreos/Hydrox
1/2 stick light margarine
1 8oz fat free cream cheese
1 C powered sugar
3-1/2 C skim milk
6oz fat free French vanilla instant pudding
1 12oz bowl low fat Cool Whip

Crush cookies. Cream butter, cream cheese and powdered sugar together and layer alternatively with the crushed cookies. Layers should end with cookies on top. This can be layered in one large bowl or single serving dishes. Freezing optional.

Pharmaceutical Update

Some of you have requested information about Sigma-Tau Pharmaceuticals, Inc., the producer of the liquid, tablet, and IV Carnitor® and the financial backer of our newsletter. If you would like to correspond with them, contact Justina Lambert at 1-800-447-0169. Their NEW address is: 800 South Frederick Avenue Suite 300, Gaithersburg, MD 20877.

Medical Update

NOTE: If any of you, parents or professionals, have information about the other disorders, please feel free to write and let us all know what you know! We're always interested to know what other researchers are working on, as well as how you are coping as families with the different treatment protocols.

Resources

Internet site that might be helpful to FOD families: www.fodsupport.org (our Web page)

Disability Research Network
Free information for IL residents ($10 for other states), about disability related topics and adaptive equipment, agencies, financial aide, laws and other educational information/resources.
1-800-447-4221(v/tty)
Fax 217-523-0427

Love Messages

(Please see our most current online issue)

Everyone has a purpose in life…
A unique gift or special talent to give others.
And when we blend this unique talent with service to others
We experience the ecstasy and exaltation of our own spirit
Which is the ultimate goal of goals.
Deepak Chopra

It is crucial that we not resist the tides
But instead give in to them
And trust that after each wave
We will be brought safely back to shore.
Laynee Wild

Kids Korner

Asking For Help!! If you are an FOD child with a question or idea, or if you'd like to tell your story in your own words, please send your information to us by December 10, 1996. Kids have great ideas too ~ please share them with us!

Donations Received

Even though our newsletter is provided through the generosity of Sigma-Tau Pharmaceuticals, Inc., we greatly appreciate any family or professional donations. However, please be aware that because we are not a non-profit organization, any donation is not tax-deductible. Thank you Mark and Pam Held for your generous donation to the FOD Family Support Group.

Reminders

I have listed all the NEW families that returned the Family Questionnaire. If you do not see your name listed, it means you did not return the questionnaire. So please take the time to fill it out and return it to me so I can list you in our next Issue. Thank you.

July 1996
Volume 6 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.]