

MCAD Communication Network
'All In This Together'

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Volume 5 Issue 1

The *MCAD 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 Holidays and New Year! Wasn't it just a while ago that we wished you the same thing? Anyway, Dan and I hope that 1995 will be a healthy, happy, and productive year for all of you.

Since our last issue, we have received a few more family and personal experience stories, as well as questions to be answered. As always, these are greatly appreciated. However, we always invite more of you to contribute your own ideas and stories. So if you'd like to contribute anything to our newsletter, please send your things to us by May 1, 1995 so they can be included in our June issue.

In this issue, in response to the last issue's Editorial, Cheryl Rosenberger shares with us her opinion about the benefits of this newsletter. Judy Farrell also shares her story about her daughter, Kari, and how they have dealt with MCAD for 9 years. Thank you to both of you for sharing your thoughts and experiences.

Since several of you have had questions about coping with periodic hospitalizations, I have shared two of Kevin's experiences. If any of you have had a similar or different experience or if you would like to offer any other suggestions on how to cope with hospitalizations or other issues related to dealing with MCAD, please send us your articles. We've also included examples of Emergency Protocol sheets (*see our current website www.fodsupport.org) that can be individualized according to your child's needs and/or the hospital staffs you may be in contact with.

As in other issues, questions are answered, nutrition information is offered, and Medical and Pharmaceutical Updates are discussed.

NEW Families: Please remember to send in the Family Questionnaire (enclosed in the Family Packet I sent you) so you can be included on the networking Family List, as well as continue to receive the newsletter.

Again, we hope that you find this issue informative and helpful in networking with other families.

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Letters to the Editor **'Benefits of the Newsletter'**

Dear Deb and Dan: My name is Cheryl Rosenberger and I am the mother of an MCAD victim. We lost our firstborn daughter, Kylie Ann, back in February of 1990. Even though we now have 3 healthy daughters, MCAD information is still very important to me. And I love to receive and read my latest newsletters to keep up on what you are doing, as well as all the others living with MCAD.

In the last newsletter, the front-page article was written by you (Deb) in response to a health professional telling a family that they may not want the newsletter because it's depressing and all bad news. Well, as a parent who has lost her child and one who will forever be affected by MCAD, I hope that my next few words will be some encouragement to some of you.

If you are one that is facing MCAD, either through a living child or after the loss of one, I think you will find this newsletter very encouraging. Every time I get one and read it through, I do cry. But they are sometimes tears of joy and sometimes they bring up some old hurts. But I really think that is okay. Number one, I talk of my daughter everyday of my life in one way or another. I can't run from it nor can I act like we never had her. It was only 4 days, but those 4 days and the year to follow were probably the biggest changes in my life. She brought joy and MCAD brought grief. But it really helps to read that others are feeling the same things.

Even after 4 years, I remember every occurrence like they happened yesterday and I always feel relief and some peace after reading through the newsletters. So in closing, I guess I just wish to pass on to any health professional or reader that has never felt the loss, a little note ~ This newsletter is **not** depressing. Sure it talks about death, but it talks about the death of our children, and the children of maybe your patient. That Dr. may never know what that personal loss feels like, so this seems depressing. But to those of us that **have** lived through the loss, it's relief and peace and I appreciate all that Deb and Dan do for us, the survivors of MCAD. I truly can't wait for my next issue of our MCAD newsletter. Who knows, we may still encounter MCAD before we are all done.

Thanks Deb and Dan and keep up the good work. It's not only enlightening, it is very good for us and ours. And thanks to Dr. Charles Roe too!! God Bless you all.

Cheryl Rosenberger, Mother of Kylie Ann, 2/7/90 - 2/11/90
Kaleigh Rae, not affected, 6/8/91
Megan Ann & Kristen Kylie, not affected, carrier, 2/5/94
Cedar Springs, MI

Dear Deb: Since writing the last article about Chloe, I have learned that I am hypoglycemic. The reason I was tested was because I suspect Chloe is hypoglycemic too. Do any of you have a hypoglycemic MCAD child? If so, do you know of any good books or other suggestions to increase my knowledge? Please let me know and contact: Simone Miller, RD #2 Box 459 C -Harold Street, New Brighton. PA 15066.

Dear Deb: I would like to connect with other MCAD families dealing with seizures and developmental delay concerns. Please contact: Sue Ryder at 3816 3rd Street A, East Moline, IL 61244. Thank you!

My Story

On Kari's first birthday she woke up sick. She would vomit and then seem okay. We celebrated as usual with gifts, cake ice cream etc. Kari didn't really want to open her gifts. She had a slight fever, but nothing major.

We put her to bed at the usual time. About 4:00 the next morning I woke up to the sound of Kari moaning. I went in her room to see if she was okay. I tried to wake her up, but couldn't. So I wrapped her in a blanket and drove her to the hospital about 5 miles away. They told me she was in a coma and her blood sugar level was at zero. I was told if I hadn't brought her in right then, she would have been dead. They actually said she was on "Death's Door." I couldn't believe what I was hearing. They started a glucose IV and it didn't take long for Kari to come out of the coma. She was in the hospital for days while they tried to figure out what happened. They labeled it as Reye's Syndrome even though they weren't sure what it was. Kari's tests all returned to normal so she was released. We were very glad to have her home. We figured we'd probably never know the cause.

Five months later, I thought Kari had the flu. We later found out it was an ear infection in both ears. Anyway, I tried to wake her up that night, but couldn't. She'd open her eyes when I'd shake her or call her name, but they'd go back shut right away.

This time I called the ambulance because it looked like Kari was vomiting up blood. The EMT said it was probably the lining of her stomach. Russ rode with them to the hospital while I dropped our son off at his Grandma's. Again Kari was in a coma. This time her blood sugar level was at 9. If we had waited until morning to check on her, she would have been dead. Again I was hearing this. I remember them trying to find a healthy vein and having to use one in her head. We discussed our last experience with the staff because Kari didn't respond as quickly this time. There were also little things that were different this time. They wanted to send her to the University Hospital in Madison. There they could run tests that the hospital here couldn't. I didn't want her to go, but after family discussions and finding someone to stay with Kari in Madison, we let them take her.

She went down by ambulance and her dad followed in the car. While in Madison. The communication was terrible, even between the doctors. There were too many involved. Kari was in Madison for a couple of days before she was diagnosed with MCAD. By this

time all of her levels had returned to normal. After 4 days they gave us all the information they could, but still did not want to release Kari. They had no carnitine to send home with Kari and wanted her to stay in the hospital until they could get some, which would take a few days. Well, I did not want Kari to stay in Madison that much longer. You all know how long the days are in a hospital. Thanks to the quick thinking on the part of my mom and sister, they had no choice but to let Kari come home. They had the carnitine sent to my home within a couple of days.

We had 1 scare after that. In December of the following year, Kari was sick and began vomiting. We took her to the Emergency Room to have her blood sugar tested. The level was fine, but trying to get the nurses to run the test was ridiculous. My rudeness didn't help anything. I tried explaining the urgency of this test, but they had to run their own tests first. After that incident, my doctor had a note put in the computer so the staff would know to run the blood sugar test first and why. After that, Kari suffered recurring ear infections that scared me. I was always afraid we'd be back at the hospital. We never needed to go back. Kari hasn't had an "episode" since. She's now 9-years-old, smart, happy, and healthy!

Judy Farrell
Menasha, WI

‘Welcome To Holland’

Emily Perl Kingsley

I am often asked to describe the experience of raising a child with a disability to try to help people who have not shared that unique experience to understand it, to imagine how it would feel. It's like this...

When you're going to have a baby, it's like planning a fabulous vacation trip to Italy. You buy a bunch of guidebooks and make your wonderful plans. The Coliseum. The Michelangelo David. The gondolas in Venice. You may learn some handy phrases in Italian. It's all very exciting.

After months of eager anticipation, the day finally arrives. You pack your bags and off you go. Several hours later, the plane lands. The stewardess comes in and says, "Welcome to Holland."

"Holland?!?" you say. "What do you mean Holland?? I signed up for Italy! I'm supposed to be in Italy. All my life I dreamed of going to Italy."

But there's been a change in the flight plan. They've landed in Holland and there you must stay.

The important thing is that they haven't taken you to a horrible, disgusting, filthy place, full of pestilence, famine and disease. It's just a different place.

So you must go out and buy new guidebooks. And you must learn a whole new language. And you will meet a whole new group of people you would never have met.

It's just a **different** place. It's slower-paced than Italy, less flashy than Italy. But after you've been there for a while and you catch your breath, you look around and you begin to notice that Holland has windmills... and Holland has tulips. Holland even has Rembrandts.

But everyone you know is busy coming and going from Italy...and they're all bragging about what a wonderful time they had there. And for the rest of your life, you will say "Yes, that's where I was supposed to go. That's what I had planned."

And the pain of that will never, ever, ever, ever go away ... because the loss of that dream is a very, very significant loss.

But ... if you spend your life mourning the fact that you didn't get to Italy, you may never be free to enjoy the very special, the very lovely things ... about Holland.

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‘Will Somebody Listen to Me!’

In March and April of 1993, Kevin had his first two hospitalizations. Even though both were short stays, they were fraught with frustration. As Judy mentioned in the above article, I'm sure some of you can relate to those feelings of frustration when dealing with some medical personnel and agencies.

Both of Kevin's episodes began with stomach viruses. He couldn't keep down anything, even his Carnitor®. After 3 or 4 unsuccessful attempts (over several hours) to keep fluids down, we called the pediatrician. Our doctor was off that day, so we saw one of the other doctors in the fairly large practice.

Kevin was dehydrated and lethargic when we arrived at the office. The physicians we saw (during both hospitalizations) were not familiar with MCAD, even though I had given our doctor all the articles and asked him to circulate them within the practice. So I immediately had to fill them in.

With our first hospitalization, the doctor was very insensitive and abrupt in his demeanor as he went about the exam ‘matter-of-factly’ in the office. In my mind, I perceived his actions to be saying "Oh, here we go again. Another over-reacting mother telling me how to do my job! He doesn't look that bad." He asked why we didn't wait at home longer and continue to try to give fluids. In other words, even after I explained to him that kids with MCAD can go into crisis very quickly, he minimized my concerns and invalidated my feelings and anxieties.

Not wanting to make a 'scene' in front of Kevin and just wanting to get him treated as quickly as possible, as stated on our Protocol sheet, I tried to remain calm and focused, which was not an easy task for me as my frustration mounted. I reiterated my concerns, asserted myself, and asked them to call Dr. Roe to consult if they felt they weren't sure how to proceed. Dr. Roe was finally called and he suggested hospitalization for Kevin.

When at the hospital, the pediatric resident spent 45 minutes asking question after question, since he was unfamiliar with MCAD. As Kevin was getting more lethargic, I kept telling them to go ahead and put the glucose IV in while they asked their questions. It was almost as if the resident was so intrigued by the rarity of this disease that he forgot about the fact that Kevin needed treatment NOW, not 45 minutes later! This long wait fortunately did not happen during Kevin's second hospitalization.

Again, I'm sure neither doctor appreciated me ‘telling’ them what to do, but as a parent who has already lost one child to MCAD, I wasn't going to sit back, wait, and make sure I didn't damage their egos. **When it comes to the care of children, egos need to be put aside and the best interest of the child needs to be paramount.** And oftentimes, **because some diseases are so rare, many parents know more about the protocol than the doctors do. So why shouldn't they listen to us, as well as consult other doctors who are more knowledgeable and experienced with the treatment?**

I guess what I'd like to get across to families and professionals, is that we need to put the care of our children first. **Sometimes professionals disregard the fact that most parents know their kids better than they do, especially when they aren't feeling well. Parents need to be listened to and heard.** And if they feel they're not, they may want to search for professionals that WILL listen to their concerns. We place our trust in the knowledge/experience of the medical staff. Yet, at the same time, because doctors are not 'all-knowing,' we must empower ourselves to assert our own 'knowledge' of our children so as to receive the best possible care. That doesn't mean, however, that we have to be aggressive and overbearing. Although, I'll have to admit to having a feeling like 'shaking some sense into them' attitude at times!

Again, we must keep the main goal in mind and **work together as a team.** That way **our children will receive what they deserve ~ the best possible care.**

Parents: It may be a good idea to keep an Emergency Protocol sheet with you, as well as in your child's medical file. Going over it with your doctors is helpful, so they will have some idea of what needs to be done immediately. Some parents also keep a Carnitor® IV at the local hospital and/or at their home for when they travel out-of-town. That way, if you have to make an emergency room visit, the staff will have an IV available if needed. You can contact your pharmacy or Sigma-Tau Pharmaceuticals, Inc., if you want more information about purchasing the IV solution.

Additionally, we have provided EXAMPLES of Emergency Protocol sheets (*see our current website). Variations may occur depending on which MCAD professionals you are working with. In any case, some **emergency procedure form should be worked out BEFORE you need it and HOPEFULLY it will be followed!**

Deb Lee Gould, Director

Questions and Answers

[Please Note: This question and answer column is designed to answer questions, both medical and practical, on MCAD and its treatment. Answers to questions are solicited from those who have had firsthand experience dealing with MCAD. These include physicians, parents of MCAD children and children 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, (at printing of this newsletter in 1995, he was at Duke University Medical School and now, in 2000, 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 2-year-old MCAD child has been acting out at school and at home. He is hitting people and throwing toys at them. Should I consider some type of evaluation for him or is this fairly normal behavior for a toddler?

Answer: According to Dr. Kim Iafolla, Duke University Medical Center (*in 2000, in Rockville, MD, your child may benefit from an evaluation for psychological, behavioral, and developmental concerns. As discussed in the Medical Update section of this newsletter, some MCAD children have experienced some psychological, as well as physical and developmental disabilities especially if they've experienced repeated and/or intense episodes before diagnosis. Once an evaluation has been done, various strategies for treatment can be discussed and implemented both at home and at school.

Question: What is the relationship of communication and/or developmental delays and seizure disorder in MCAD children?

Answer: Again, as mentioned in the article summary in the Medical Update section, a child who is having seizures has a much higher risk of developing a variety of disabilities such as speech difficulties and attention deficit disorder. The early detection of MCAD lowers the risk of developing these difficulties. Newborn screening for MCAD as well as early treatment would help in possibly preventing these developmental delays. It was also found that speech therapy over a long period of time helped MCAD children with their speech problems.

Question: Are you familiar with any other support organizations for metabolic diseases that MCAD families might be interested in?

Answer: Also see our current website under **Support Resources**

Organic Acidemia Association: Contact person ~ Kathy Stagni, OANews@aol.com. Newsletter (3 times/year) and networking for families and professionals dealing with any of the inherited organic acidemias, of which MCAD is under that 'umbrella' of disorders. Donation of \$18 per year is suggested. www.oanews.org

The Cox Foundation for Mitochondrial Disease: Contact person ~ Joyce Vaught. P.O. Box 156. Hartman, Arkansas 72840-0156. 501-497-1563. Includes families of children who have any one of the mitochondrial diseases. They provide a newsletter, as well as an Education and Support Exchange. This network is setup to link families dealing with the same disease. MCAD is listed as one of the diseases represented in their Education and Support Exchange. The primary purpose of the Cox Foundation is to conduct parental research and educate parents and professionals who provide care to children with Cytochrome C Oxidase Deficiency, which is a genetic metabolic disorder in the respiratory chain.

MUMS (Mothers United for Moral Support, Inc): Contact person ~ Julie Gordon, 150 Custer Court, Green Bay, WI, 54301-1243. www.netnet.net/mums. This is a national Parent-to-Parent organization for parents or care providers of a child with any disability, chromosomal abnormality, or health condition. It provides support by matching them with other families dealing with the same or similar disorder. They have a database of

over 3700 families and 800 disorders (*in 2000 those numbers have more than doubled). A quarterly newsletter is provided. No dues for parents. \$15.00 for professionals.

National Parent to Parent Support and Information System, Inc.: Contact ~ PO Box 907, Blue Ridge, GA 30513, 1-800-651-1151. NPPSIS is searching for parents that are interested in being part of a National Parent to Parent Database.

Pharmaceutical Update

Some of you have requested information about Sigma-Tau Pharmaceuticals. Inc., the producer of Carnitor® and the financial backer of our newsletter. If you would like to correspond with them, call 1-800-447-0169. Ken Mehrling would also like you to know about the commercial availability of the Camitor®(Levocarnitine) Injection product. It has been available since December of 1992. It is important for physicians to know that their local hospital should be able to purchase this intravenous product locally from their wholesale druggist.

Medical Update

Birth Announcement: Duke University Medical Center's **first in utero MCAD diagnosed baby** was born to Jacque and Mike Bradford.

Alec was born on July 23, 1994 and weighed 8lbs 5oz
Congratulations to the Bradfords!!!

The following is a detailed summary (in some places word-for-word!) of an article printed in the March 1994 issue of the **Journal of Pediatrics** (pp. 409-415). The article was written by Drs. Kim Iafolla, Robert Thompson, and Charles Roe of Duke University Medical Center (DUMC). It's entitled "**Medium chain acyl - coenzyme A dehydrogenase deficiency: Clinical course in 120 affected children.**"

NOTE: If any of you have read other research articles that may be of interest to MCAD families, please feel free to let us know about them. Or even write up your own summary and send it to us. We're always interested to know what other researchers are working on.

MCAD occurs in 1 in 23,000 live births, mostly in white children of northern European ancestry (i.e., United Kingdom, Germany, France). In the US and Great Britain it is suggested that the carrier rate may be 1 in 68 for the most common genetic mutation A985G.

The purpose of the study was to collect biochemical, medical, psychodevelopmental, clinical, and family history information from 120 MCAD patients (55 male, 65 female) who were referred to DUMC for biochemical testing. The results would assist professionals in counseling physicians and families regarding the mortality and morbidity rates for MCAD deficiency.

Of the 120 subjects, 118 were white, 1 black, and 1 Native American; 112 from the US, 8 from United Kingdom, Canada, Australia, or Ireland. 32% of the patients with symptoms either had a sibling with MCAD or one that had died of SIDS. 15 symptom-free patients were tested because a sibling died of SIDS or the sibling had MCAD. The MCAD diagnosis for 23 children came after death. 19 of them had no previous illness and 4 were treated for an episode of hypoglycemia. No child has died of a biochemically-related illness after being diagnosed with MCAD.

Onset of symptoms ranged from 2 days to 6.5 years; with 14 children diagnosed with MCAD at the onset of illness. Various other diagnoses were given to 106 children such as Reye's Syndrome (25), idiopathic hypoglycemia (21), and SIDS (16).

95% of the patients required hospitalization or emergency care upon illness. In all the MCAD patients, at first evaluation, urine ketones were either "absent or had lower values than expected." 9 patients had elevated creatinine kinase values and 3 had increased serum cortisol values. 85% of the children had symptoms of infection (vomiting, diarrhea, or upper respiratory tract problem) at onset. 18 had ear infections and 6 had upper gastrointestinal tract bleeding which developed during their illness. 5 of these 6 patients died. Upon autopsy, it was determined that 4 had penetrating ulcers of the upper GI tract.

Before diagnosis the average number of episodes (illness/hospitalization) was 2; 42 patients had more than 1 episode before diagnosis. The time to MCAD diagnosis after clinical onset ranged from 0-13.9 years, with an average of 1.8 years. Those unrecognized patients who died, died within 2mos - 3 years of initial manifestations. 12 died at less than 2 years of age; 11 attributed to SIDS and 1 to Reye's Syndrome. 2 older children died from gastrointestinal hemorrhage and adrenal insufficiency.

After diagnosis, all 97 of the surviving MCAD patients had medical or dietary interventions. All were asked to avoid fasting; 74% received supplemental L-carnitine; 2 were given glycine and riboflavin; and 63% had a low fat diet.

Of the 70 (62 living) siblings tested, 23 had MCAD, 26 were carriers, and 21 were normal. Of the 97 survivors, 71% had no clinical episode after diagnosis and starting treatment. However, 29% had between 1 and 14 (average 3) episodes. The type of treatment and number of subsequent episodes had no correlation.

Some of the medical complaints by the survivors included: hypoglycemia, muscle weakness (16%), seizure disorder (14%), failure to thrive (10%), and cerebral palsy (9%). There was a strong correlation between "seizures at clinical onset and development of subsequent seizure disorder or cerebral palsy."

Development of muscle weakness strongly correlated with the time between onset and diagnosis. Those with muscle weakness were older at diagnosis (>3years of age), had more episodes (4.3 vs 1.7) and had more hospitalizations (3.6 vs 1.5) before diagnosis.

There was an increased risk of chronic muscle weakness with a delay in diagnosis of only 1 month after clinical onset.

Psychodevelopmental information on 73 patients revealed that 44 were judged to be "normal" and 29 had abnormal screening results. All were thought to have had normal development before the clinical onset of MCAD. 12 patients had global developmental disability without behavioral disabilities; 7 had isolated behavioral abnormalities; and 4 had both developmental and behavioral disabilities.

16 had speech disabilities. There was a high correlation between development of speech problems and clinical onset between 12 and 18 months of age that included encephalopathy or seizures. There also was a strong association between female gender and the development of attention deficit disorder (ADD); 8 children (1 male, 7 female) had ADD. ADD patients more likely had seizures, encephalopathy, and hyperammonemia at the time of onset; had more illness episodes before and after diagnosis; and were older at diagnosis than patients without ADD. "No patient in whom MCAD was diagnosed before the onset of symptoms had ADD."

The data from this study on ethnicity was consistent with other reports. MCAD was concluded to be a disease of white persons of northern European ancestry. 2 nonwhite MCAD families may have had unrecognized European ancestors.

In this study, 1 in 5 children died during a clinical episode; thus the incidence of sudden death appeared to be higher in MCAD patients. After diagnosis there were no deaths from MCAD, even with several episodes.

5 of the children that died might still be alive today if their siblings, who died of SIDS, were tested for an inborn error of metabolism. **The study's authors recommend that "inborn errors of metabolism should be included in the differential diagnosis of the cause of sudden death in infancy and childhood."** Evaluation for hypoglycemia and inborn errors may have also saved 4 children who died after recurrent hypoglycemic episodes. It was noted that **"the presence of ketones does not eliminate the diagnosis of MCAD; 29% of the patients in whom MCAD deficiency was subsequently diagnosed had ketones in their urine at time of onset."**

The study suggested that MCAD children might be at a higher risk of death from profound hypoglycemia because they may not have appropriate endocrine counter-regulatory mechanisms. These abnormal counter-regulatory responses to hypoglycemia may develop even after 1 episode, and during chronic hypoglycemia, the sensitivity to these mechanisms decreases.

Some of the upper GI tract ulceration and gastritis noted in some of the patients may be due to hypoglycemia counter-regulatory mechanisms. When there is profound hypoglycemia, there is an increase in cortisol and gastric acid secretion; thus "stress" ulcers may develop and cause life-threatening hemorrhage. GI hemorrhage in 4 of the study's patients may have contributed to their deaths. In MCAD patients, an exaggerated

endocrine response to hypoglycemia may place patients at a "higher risk of cortisol-induced ulcerations and therefore, of GI bleeding during periods of profound hypoglycemia."

In most children, especially small ones, an intercurrent illness may have led to decreased oral intake, which hastened hypoglycemia. The fasting may be the initiating factor, rather than the underlying infection.

As for chronic muscle weakness, there is a correlation between that and multiple episodes before diagnosis. It is suggested that early diagnosis and treatment may prevent that.

It was hypothesized that abnormal metabolites may affect the brain and cause various learning disorders. In this study, one-third of the children older than 2, had developmental disorders. Speech disorders were especially noted. There was a strong correlation with seizures or encephalopathy at clinical onset, suggesting a brain injury and not a developmental disorder. Acquired aphasia (sudden loss of normal speech) is suggested since appropriate speech development was reported until onset of episode and then followed by the return of speech ability after years of therapy.

Another strong relationship was found between ADD and brain injury. Impulsivity, distractibility, short attention span, and sometimes hypersensitivity are characteristics of ADD. In this study, the incidence of ADD was almost twice that expected on the basis of frequencies in the general population. Again, early diagnosis and treatment may prevent these complications.

This study has shown that unrecognized MCAD patients are at high risk for sudden death and that survivors of severe clinical episodes may be at high risk for developmental disabilities. Thus, because MCAD satisfies the criteria for newborn screening, it should be a part of the newborn screening battery that is already in place nationally.

Examples of Emergency Protocols

(See our current website www.fodsupport.org)

Miller Highlights

In this newsletter, I would like to share with you some interesting observations about my mourning process. Our son, Michael "Dylan," died August 27, 1991 (two and a half days after he was born) due to MCAD. At first I was totally at peace in what I later learned is called "Christ" consciousness.

Some time later, I started to go over and over the experience in my mind, which created feelings of grief, guilt, anger, fear (especially since I was pregnant again) and so on. As time passed, I focused less on the details of our tragedy and more on the blessings "our

little angel" had given us. Ironically, during this phase physical symptoms started to develop such as: migraine headaches, severe PMS, and neck and muscle stiffness.

Digging deeper into learning why these physical things were happening has opened "new" doorways for me. In addition to gaining knowledge about nutrition, herbs, massage, Tai Chi, yoga (which in turn will help my living child, Chloe) and learning more about my own personal makeup, I have opened my mind to the realm of spirituality.

We have often heard that the key to understanding life and ourselves better is developing our knowledge of mind, body, and spirit. One of the many blessings my son has given me is an increased desire to learn as much as "humanly" possible about the mind, body, and spirit connection.

Simone Miller
New Brighton. PA

Recipe

Low Fat Quick Brownies

(Submitted by Elizabeth Turman, Missoula, MT)

Ingredients:

- Brownie Mix (Don't use Lite or Microwave Mix)
- One-half cup plain nonfat or low fat yogurt
- Amount of water as shown on mix
- Chocolate packet, if included in mix

Preheat oven to 350 degrees (325 for glass pan). Grease bottom of 13"x9"x2" pan. Combine ingredients and mix well. Spread in pan. Bake 30 minutes or until brownies begin to pull away from edge. Cool before cutting. Makes approx. 24 brownies.

Focus On Fitness

‘What to Eat While Rushing About and Trying To Be Healthy’

**By Becky Kaplan, RD
Greensboro, NC**

Here are some fast ideas for fast food that are not loaded with fast calories, cholesterol, and fat.

- **Make a wise choice at a fast food place. How?**

Eat a salad, go light on the salad dressing or keep a bottle of your own low-calorie dressing at work.

Eat a 1/4 lb burger or less and load on the lettuce, tomato, and other veggies if available and go light on mayo and ketchup. Eliminate French fries and milkshakes.

- **Pack a brown bag.**

Make a chicken or tuna sandwich on whole grain bread. Add fresh fruit or vegetables. Grab a carton of low fat milk.

Bring a carton of low fat yogurt, fresh fruit, and some soda crackers.

Pack a thermos of soup and bring bread and margarine.

Bring last night's dinner and microwave it. The more you do the night before, the quicker you can be in the morning.

- **Order ahead at a full-service restaurant.**

Order a broiled, grilled or baked main item.

Avoid fried foods and ask for sauces or dressings on the side.

Order a chicken, turkey or fish sandwich on whole grain. Hold the French fries or chips. Ask for a small salad or cut veggies.

- **Be choosy in any cafeteria line.**

Look for any of the above items.

Soups and green or veggie salads are good choices. Watch the dressings.

Ask if an item can be grilled or baked.

Inquire about preparation of foods.

Request low fat items.

Avoid fried fatty and creamed foods. Ask for sauces and dressings on the side. Limit prepared sweets. Enjoy your fast choice knowing you put some thought and health into your lunch.

Love Messages

(Please see our most current online issue)

‘Our losses change us and change the course of our lives. It's not that one can never again be happy following the experience of loss. The reality is simply that one can never be the same.’

Ann Kaiser Stearns

Living Through Personal Crisis

*‘Cherish
the memories of yesterday.
Savor
the Joys of today.
Nurture
The promise of tomorrow.’*

From the Richmond Compassionate Friends Chapter Newsletter

January 1995
Volume 5 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.]