

**MCAD Communication Network**  
**'All In This Together'**

**February 1991**

**Volume 1 Issue 1**

**From The Editor**

Welcome to the **first issue** of our newsletter, the **MCAD Communication Network**. As parents of a 21-month-old daughter who died nearly 6 years ago as a result of the newly discovered MCAD disorder and a son who currently is treated for it, we have found that practical information about MCAD is difficult to find. In fact, it became clear to us that a need existed for a vehicle to disseminate such information, as well as a need for connecting with other families. For this reason we have started this newsletter.

The **MCAD Communication Network** will include the latest MCAD medical information. Equally important, information and suggestions as how to cope with the struggles of being an MCAD parent, loved one, or affected child/adult will also be presented. It is also our hope that this newsletter will help develop a **social support network** where those of us who are affected in some way by this disorder can obtain caring emotional support from others 'who are walking in the same shoes.' We are convinced that all of us working together can provide an excellent source of practical information on coping and dealing with the MCAD disorder.

In this issue, you will find a practical summary of the latest MCAD research, answers to important questions you may have about helping a child deal with MCAD, nutritional information about low fat diets, and tips on how to deal with the guilt and stress of having a child die from this disorder because it was NOT diagnosed and/or having a living MCAD child. In future issues we hope to further discuss these topics as well as include new information on topics ranging from your favorite low fat recipes to encouraging your child/teenager to maintain the treatment protocol even when his/her friends don't have to follow one.

Because this is our initial attempt at developing an MCAD newsletter, we will make some mistakes while also doing other things fairly well. However, we will need your help to know what is helpful and what is not. So please write us and convey your opinions about the newsletter and, by all means, give us your suggestions. We would also appreciate notes or short articles you feel would be relevant to include in future issues. Most important, if you have questions, medical or practical, please let us know what they are so that we can find and publish answers to them.

It is our hope that you will find this newsletter useful in your efforts to cope with MCAD. Please remember that 'We Are All in This Together!'

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## **Coping with Guilt**

Emotions run rampant when hearing that your child has MCAD. We may have experienced feelings such as disbelief, denial, anger, fear, confusion, emptiness, and Anxiety. One emotion that we often experience when told that our child has a hereditary disorder is guilt. It can be especially intense if a child (children) dies because MCAD was not detected early enough in the illness/episode or if it wasn't detected at all. Unfortunately, many of us have learned about MCAD the hard way ~ only after reading lots of articles, talking with experts, and having autopsy tissues reexamined.

Guilt is not discriminatory; all of us with MCAD children, living or deceased, may possibly experience this common and pervasive emotion to varying degrees. There are various causes for guilt, but the focus of this piece will be on guilt due to the feeling that we are responsible for our child (children) acquiring MCAD, that we have failed him or her, and that he or she may have died because we didn't fulfill our parental duty, albeit unrealistic, of protecting our child from harm at all times.

Even though intellectually we know we cannot control everything, we still feel we should have prevented our child (children) from acquiring MCAD and/or prevented our child's death from occurring. Guilt feelings arise because of the discrepancy between what we think we should ideally be able to control as parents and what we actually achieve and how we behave as parents.

In order to deal with these guilt feelings some may have turned to self-destructive behaviors such as excessive drinking and/or the use of drugs in order to drown or avoid the intense feelings. Coping with guilt takes a great deal of energy and using negative strategies will actually delay and most likely complicate the working through of guilt reactions and 'resolution' of those feelings.

More positive strategies include confronting and admitting to yourself your feelings of guilt, sharing with family and friends your feelings of responsibility for your child acquiring a genetic deficiency, learning more about guilt reactions and discovering how normal they are, and trying to forgive yourself for not being perfect ~ all those should, ought and must statements quickly trigger our feelings of guilt.

Confronting and admitting that your guilt feelings exist is helpful in accepting the reality of the situation. Of course, this does not happen overnight and it takes a lot of emotional and psychological work. In order to cope with the 'negative' feelings, we can try to think of them in a more positive light by the use of rationalization or reality testing. For example, as soon as we heard the MCAD diagnosis, we may have had thoughts such as "Maybe we shouldn't have had children in the first place, look what happened." But once we carefully examine our reasons for having children in the first place (i.e. as an extension of our love, etc.), we can focus on our decision in a more positive manner. Hindsight is always 20/20 ~ we've probably all heard that more than we can count, but when the decision to have children is made, realistically we are going on the information we have at the time and we most likely felt it was the right thing to do.

For those of us who have continued our families after a child's (children) death and now armed with the knowledge of MCAD, guilt feelings about passing the gene on may still be present, but may be somewhat temporarily overshadowed by the feelings of fear and anxiety of what lies ahead if another child is diagnosed with MCAD. These feelings must also be confronted and dealt with. Coping with these emotions will be addressed in a future newsletter column.

The main point, though, is that guilt is very common and very pervasive. It can ebb and flow over time and in order to cope with these feelings we first must confront and admit that these feelings exist. In many cases, moving through guilt can evoke intense feelings that must be dealt with in order to have some sense of 'healing.'

Another way of coping with guilt is by changing our irrational beliefs of "I must be a perfect parent", "I should have known about MCAD" and "If I was doing my job as a parent, this shouldn't have happened." Again, once we examine how unrealistic these statements are, we can put them in perspective. We, as parents, are so hard on ourselves and we may have to learn how to forgive ourselves (which is much easier said than done!) for not being 'perfect and all-knowing.' Forgiving ourselves is often very difficult to do, especially when just thinking about it. Writing your thoughts down in a journal may be helpful in that you have something tangible to read and you can better see some changes when you look back at earlier entries. Those of us who have had a child die have probably utilized this suggestion in order to release our feelings, lower their intensity over time, and to understand our beliefs and feelings in a more realistic manner.

Although it will not bring our other children back, we are probably thankful that we now at least know about MCAD and we can try to be as hopeful and positive about our present and future MCAD children. Their lives are not doomed for death. Yes, there is stress involved with the everyday medications, making sure they eat, and when they get sick, but the positive prognosis for a normal lifespan is very encouraging. Focusing on what we CAN do in the here and now often seems to lessen the intensity of guilt feelings.

Lastly, **reaching out to other MCAD families** can be a way of discovering that **we are not alone** in our feelings of guilt, as well as a myriad of other emotions. Of course, the doctors that specialize in inherited disorders are familiar with the medical aspects of MCAD, and hopefully your family physicians are becoming better educated about how to deal with your child's circumstances, but we, as parents, are the ones who are dealing with the day-to-day practical and emotional situations. It may be comforting and encouraging if we can communicate with one another to pass along helpful suggestions on how to deal with certain issues. Expression and communication of those feelings are important aspects of dealing with life issues. **We hope that this newsletter will spark not only communication within your own families, but with families across the country.**

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 1991, 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:** I have an 8-year-old son who is very self-conscious about taking his oral carnitine at school. I'm worried that he'll stop taking it during the day. What can I do?

**Answer:** Some children feel uncomfortable and different from the other kids because they have to take daily medications/vitamins (\*the drug Carnitor® is a vitamin/enzyme supplement, see our current website, [www.fodsupport.org](http://www.fodsupport.org), under Pharmaceutical Update for more information). Maybe your son feels singled out and embarrassed if the teacher/nurse comes to give him his medication in front of the entire class. If it's possible, your son could go down to the office/nurse's office during a time when the class is getting ready to have a snack or going outside, and then he can join the class in the activity without feeling as if everyone is looking at him. Snacks are important for MCAD kids so if everyone has one then he wouldn't be the only one. However, if the class does not have one, it might be a good idea to have his snack when he's at the office for his carnitine.

If your son feels comfortable, taking carnitine tablets may be an easier alternative than the liquid. They can be swallowed quickly and there is less of a chance of making a mess. In school, medication is often kept in the office, but outside of school, tablets can be kept in his pocket, out-of-sight of the other children, and taken without drawing attention to himself. Of course, it also depends on how much your son understands about carnitine and what it does for his body ~ that it's used to help keep his blood sugar levels steady (otherwise he'll feel very tired and irritable at school), and to help him use some of the fatty acids for energy, and to remove the toxic wastes from his body ~ all of those functions help him feel a lot better during his school day, along with him eating often. If you explain to your son that at both home and school, it is vital that he takes the carnitine, and that others also take vitamins everyday as well to help their bodies, then maybe he won't feel so self-conscious. Additionally, letting him know that you'll talk with the teacher about options for when and where to take his carnitine during the school day, will show him that you really do care how he feels about his daily treatment plan.

**Question:** I am expecting our second child in 4 months and if she or he has MCAD, I am not sure if I should bottle or breastfeed. Is one preferred over the other?

**Answer:** If at all possible, try to breastfeed every 2-3 hours, but always be aware that if he/she has MCAD, you most likely will also need to use some kind of supplementation because breast milk does not come in for several days and you DO NOT want an MCAD baby to go into a fasting state. Hypoglycemia (low blood sugar) can trigger a metabolic crisis. A benefit of breastfeeding is that it passes valuable antibodies on to your child, as well as carnitine, which is necessary in ALL our bodies. However, if your child is carnitine deficient, which often occurs as a secondary disorder to the MCAD, then he/she may also be prescribed oral carnitine. MCAD babies should eat something every 2-4 hours around the clock, at least until they are @ 1 year old (longer if necessary) to avoid a fasting state. When an MCAD infant is not feeling well, he/she may not want to nurse/eat so be especially aware that you may need to go to the Drs. or the ER for an IV Glucose. (\*See Protocol Sheets on our present website – [www.fodsupport.org](http://www.fodsupport.org))

**Question:** I know eating a low fat/high carbohydrate diet is very important for an MCAD child, but what is the best eating schedule to follow throughout the day?

**Answer:** It is suggested that several small meals and snacks be eaten throughout the day, every 3 to 4 hours. Right before bed, your child should have a snack that should hold him/her until breakfast. Some families also use uncooked cornstarch (1-2 Tbs) mixed in a cold drink or food before bed ~ it acts as a slow-releasing carbohydrate and helps keep the blood sugar levels steady so the child won't wake up with low blood sugar.

If your child is over 1 year and is healthy, there is no need to wake him/her during the night. If your child is sick and not taking foods very well, offer lots of juices, Gatorade (not for infants) or other high calorie drinks often throughout the day. Offer drinks during the night, as well, if you have to wake your child for a nighttime carnitine dose or if they aren't eating well due to illness. When your child is sick, it is suggested to double each carnitine dose (\*see MCAD Protocol Sheet on our current website) and switch to a 6-hour schedule through the day and night (i.e., 6am, 12 noon, 6pm, 12 midnight) until the fever etc. subsides. Of course, talk with your Dr about what individual treatment protocol you will follow on well days and during illness. The key though is to keep enough sugar/carbos in your child's body throughout the day to avoid fasting, since he/she can't use fats for energy.

**Question:** My 6-year-old daughter feels that she is being deprived of eating certain foods such as cakes, chocolate chip cookies, etc. How can I help her deal with that?

**Answer:** Yes, many dessert foods are high in fat, but your child does not have to be deprived of eating them. For MCAD, it is often recommended that the diet consist of 20% fat (of daily calories) and high in carbohydrates. As long as the overall diet is monitored for being 20% fat, then an occasional higher than usual treat is OK (i.e. chocolate cupcakes at a school party). As far as everyday snacks, there are a wide variety of low fat treats. The food companies, for example, are now making very delicious cupcakes, etc., with lower fat content. It also helps the MCAD child if he or she knows that the entire family is concerned about their overall health and participates in healthy

eating habits. Educating your child and family about making responsible food choices will have a lifelong affect, one that is actually better for your overall health in the long run. Ask your family Doctor about talking with a nutritionist if you have any questions regarding low fat foods and meals.

## **Pharmaceutical News**

If you are not sure where you can purchase L-carnitine in your area, Bruce Robbins, Southeast Area Manager, or Ken Mehrling, Director of Marketing & Sales, of Sigma-Tau Pharmaceuticals, Inc. (\* in 2000 these individuals are now in upper level positions ~ if you need info on L-carnitine just call the 800# and ask for either the marketing or medical info personnel), would be glad to tell you where the Carnitor® (L-carnitine) wholesale dealer is in your area. Your regular pharmacy can then purchase it from the wholesaler. Of course, a prescription from your child's Dr. is required first. Also, if the need arises for intravenous carnitine, it can also be physician requested. The carnitine IV has been tested, is non-toxic, and appears to be effective, although it has not yet been approved by the FDA (\* in 1991 it was not yet approved but presently it is an FDA-approved drug). The number for Sigma-Tau is 1-800-447-0169.

## **Medical Update**

Dr. Roe informed us that last summer it was reported by MCAD researchers that a mutation was found in the DNA of persons with MCAD that may account for 90% of all MCAD cases. It involves the substitution of one amino acid for another in the enzyme protein, which affects the activity of the enzyme. The other 10% of the population with MCAD is thought to involve several different mutations. The common thread between the two groups, though, is the decreased activity of the enzyme. Once a family has been identified as having a child with MCAD, it is recommended that other family members especially siblings be tested. When the most common mutation exists in the family, DNA testing to determine who carries the gene can be helpful for family planning and determining risk. It is now made easier through the use of PKU cards and blood spots. It has also been reported by researchers that recognition of MCAD can now be done by DNA studies from tissue embedded in paraffin blocks. There was an MCAD case diagnosed from tissue saved from 1958. This is a tremendous breakthrough for families that were left wondering what the cause of death was ~ now they know for sure.

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**[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, treatment recommendations, research, and names of FOD researchers/Labs.]**