

MCAD Communication Network
'All In This Together'

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Volume 4 Issue 2

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
'Editorial'

I recently spoke with an MCAD family in the northwest portion of the United States. After talking with them, it **reinforced my conviction and commitment to getting this newsletter out to families who feel like they are in the dark about MCAD, as well as for many health care professionals who may know very little about the disorder and the stress of coping with it every day.**

This family shared with me some disturbing comments a health professional made to them about this newsletter. She advised the MCAD family that they might not want to call about receiving the newsletter because "It's so negative." The family explained that the professional felt that 9 out of 10 family stories were about dead children and that might be too depressing for them to read.

To be fair and open-minded about the comment, this professional had a point. Our newsletter does include stories about parents who have had children die from MCAD. However, these 'love stories' are featured for two important reasons. First, expressing deep-seated feelings is essential for people to cope with the death of a child ~ it certainly was/is for Dan and me. Hence, many MCAD families don't just deal with MCAD-related medical conditions of living children ~ they also have to deal with losses of loved ones. **We are totally committed to helping MCAD families deal with such losses. In fact, we do not view these articles as negative, but as a positive vehicle for remembering and honoring special children who have died and in so doing, providing information ~ which may help other children live! Many don't realize or understand the healing and inspirational power of talking, writing, and reading about our worst fear...the death of a child. Families need to be allowed to express how MCAD has changed their lives forever, and this newsletter is one avenue for doing so.**

Our second reason for discussing death so openly is straightforward. While highly treatable, MCAD is a serious disorder and kids die from it. As much as we wish this was not the case, it is and MCAD families and significant others need to realize that you don't mess around when it comes to MCAD ~ you need to be informed, maintain emotional control and be ready to act. **Our newsletter is designed to let you know just how serious MCAD is while providing the latest information to equip you to successfully deal with the medical, physical and psychological issues of this disorder.**

While we will never take the 'love stories' out of this newsletter, this professional raised a good point ~ yet it's all in your perspective. **Many that are uncomfortable with such topics as death will often project their uncomfortableness on others, but we cannot 'hide' from reality!** Not talking about it isn't going to make it go away. So let's at least **give ourselves permission to SEE and FEEL reality and LEARN something about ourselves, and this disorder in the PROCESS!**

I'm sure that many of you have MCAD stories to share. However, we need your help. You can help us by letting us know if you/your child are doing well and by sending us 'your story.' But don't hesitate to also tell us about the difficult aspects of living with MCAD ~ it's called LIFE!

While we appreciate the feedback about the need to include more 'positive' pieces in the newsletter, we were upset by this health care professional's comment that this family may not want to call for information because we discuss so-called 'negative' subjects. Everyone who deals with MCAD should read this newsletter and get additional information ~ it can literally mean the difference between life and death. So if you do not like something about the newsletter, don't stop reading. Let us know and we will try to take your comments into consideration and make some improvements, but **never stop reading and learning more about MCAD. Someone's life could depend on it!**

In this issue, Jackie and James Shears share their 'story' about their son, Timothy, and Simone Miller shares some insights on how learning as much as possible about MCAD and its treatment has helped her cope with Chloe's episodes and hospitalizations. In the pharmaceutical and medical updates, Ken Mehrling informs us about his company's intravenous product and Dr. Charles Roe discusses prenatal diagnosis of MCAD. You may need your medical dictionaries for that one! Our personal comments on early diagnosis follow Dr. Roe's abstract. Mary Lingle (*our current webmaster) shares a special poem written by her niece about her daughter, Candice, as well as Candice's favorite song. These were previously printed in the Texas Area Chapter Compassionate Friends Newsletter. Mary, thank you for submitting those touching pieces. Also, questions are answered, Love Messages are remembered, the MCAD Seminar is discussed, and an update on the family list is included (*we will soon have a private online file for the Family List).

NEW Families: Please remember to send in the Family Questionnaire so you can be included on the Family List, as well as continue to receive the newsletter. If you have not returned the Seminar Questionnaire at the end of this newsletter to Deb and Dan, please do so by December 1, 1994. We are trying to see if there is an interest in having a 1-2 day seminar, possibly for next summer. Again, we hope that you find this issue informative and helpful in networking with other families.

Deb and Dan Gould, Co-Editors

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Love Story: Timothy

On October 3, 1991, God gave us Timothy, a beautiful little boy with blonde hair and big blue eyes. His sister, Tiffany, and his brother, James, loved him so much.

When Tiffany was born, she weighed 2 lbs 9 oz and we always feared that we might lose her, but not Timothy. He was a very healthy baby, was never sick, and was growing very well. On his first birthday, October 3, 1992, he was fine and did lots of playing outside that day. He was walking and talking up a storm.

We put him to bed that Saturday night at 11 o'clock and he was fine. He woke up Sunday morning with an upset stomach. I tried to give him food after awhile, but he wouldn't eat. He got really tired and sleepy and slept most of the day. I called the Doctor and he said that Timothy probably had the flu and to let him rest.

At 5 o'clock on October 4, 1992, I took him to the hospital. The Dr. said that he had an ear infection and a touch of the flu. We were told to take him home and let him rest. At 9 o'clock he didn't want to wake up. My mom and I took him back to the hospital. My mother kept trying to wake him, but he just wouldn't wake up.

The Dr. at the Children's Hospital in Columbus, Ohio, started running tests on him. My mother asked the Dr. what was wrong with Timothy and he said he was fine and it wasn't like he was going to die. Five minutes later Timothy's heart stopped. They tried to bring him back, but they couldn't.

Later, on his death certificate, they put unknown cause. I could not understand all this. One minute he was here and the next minute he was gone. It wasn't until 4 months after the autopsy that we found out Timothy had MCAD. His brother is a carrier and his sister is not.

God be with my family as we go through all this. Maybe with our help, being part of the research, they (Doctors/researchers) can find out what's going on with a child before it ends in a death. I will never forget my little angel and he will always live within my heart.

Jackie and James Shears
Columbus, Ohio

Miller Highlights

Well, Chloe had another episode since our last newsletter. She is doing marvelously now though. I can't stress enough how valuable my trip to Duke University to see Dr. Roe has been (* in 2000, he is at Baylor in Dallas). This was Chloe's second episode. We didn't know about carnitine during her first one, but she wasn't too sick and 24 hours on IV glucose did the trick.

The RSV virus was the intercurrent illness that prompted the second episode. This is a common respiratory virus that seems to linger for about two weeks. I think we may have lost Chloe without the IV Carnitor®. It was quite a feat educating our local hospital and physicians as to what MCAD is, what carnitine is, and how vitally important it is that the IV glucose/Carnitor® be administered quickly.

For those parents who have also experienced the difficulty in getting physicians and hospital staffs to listen and cooperate with you in meeting your child's needs during an episode, let me just say, you are not alone. However, I am optimistic that if and when we need to hospitalize Chloe during another episode in the future, this should not be the case.

We now have a primary nurse, Maria Rexroad, who has a special file on Chloe at the hospital. And one of our local physicians, Dr. Jansma, has agreed to consult with Dr. Roe and Dr. Kahler (* in 2000, in Australia) at Duke, and coordinate his knowledge of the intercurrent illness and their knowledge of MCAD with the local hospital staff. We have also revised our protocol sheet to simplify a few things in terms more suitable to our local hospital. Dr. Jansma, our coordinating physician, was a huge help in accomplishing these revisions.

I would also like to point out that talking with other MCAD parents on the Family List during Chloe's past episode was wonderful. I encourage any of you during good times or bad times to please call me or someone else on the List. It can really make a difference! Special thanks to my husband, Mike, and his family, my family and friends, the Goulds and the Warners (from the MCAD Family Support Group), Maria Rexroad (RN at the Medical Center and Drs. Jansma, Roe, Kahler, Rachael Slauch (genetic counselor at Washington University in St. Louis), and of course, Michael "Dylan," Chloe's big brother whose bravery and mortality has saved her life, and Chloe Monet for her bravery and perseverance.

Simone Miller
New Brighton, PA

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 1994, 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 am trying to promote healthy eating in my family. Can you offer any suggestions or tips for low fat eating and cooking?

Answer: Several of the following tips were printed in the February 2, 1994, **Greensboro (NC) News and Record** and written by Bea Lewis. These are helpful tips for both children and adults. Of course, modifications can be made to fit your needs and/or tastes. Although the dietary guidelines are not as stringent as they were 8-10 years ago, most MCAD researchers continue to recommend a 20% low fat heart-healthy diet.

- Eliminate butter on your morning toast ~ Instead, spread all-fruit preserves and a dollop of non-fat yogurt or sprinkle the yogurt with cinnamon. Every unused teaspoon of butter or margarine saves 5 grams of fat.
- Try bagels instead of oversized muffins or croissants and save at least 10 grams of fat. Remember to watch portion sizes.
- Add your own fruit to nonfat yogurt; it's fat-free and calcium-rich.
- Pizza is OK~ try not to have the high calorie/fat toppings too often.
- Tuna sandwiches made with water-packed tuna and no-fat mayonnaise has 15 grams of fat less than one with oil-packed tuna and regular mayo. Tuna is great in pita bread. Watch the tuna at deli counters, usually loaded with fat.
- Satisfy a chocolate craving with a one-ounce Tootsie Roll instead of a one-ounce chocolate bar and save 8 grams of fat. Hot chocolate made with skim milk instead of whole milk saves 8 grams of fat also.
- Pretzels, popcorn without butter, pita chips, rice cakes, jellybeans, gumdrops and lemon drops are virtually fat-free.
- Fill up the fridge with fruits and vegetables.
- Try oven-baked French fries instead of regular fries to save 15 grams of fat. Cut 2 large baking potatoes lengthwise into thin wedges. Coat with a mixture of 2 tablespoons Parmesan cheese and a few dashes of paprika. Bake on cookie sheet in 425-degree oven for 30 minutes or until crisp. Serve with ketchup or salsa.
- When baking cookies or fruit crisps, replace some of the nuts and coconut with oatmeal. Toasting nuts before adding them to the batter will intensify the nutty flavor.
- Top a casserole with breadcrumbs tossed with some olive oil instead of high fat cheese.
- The easiest way to cut saturated fat is to serve smaller portions of meat. A 3-ounce serving (deck of cards size) of chicken or meat is plenty.

- Don't deprive yourself of dessert. Poach a pear or apple and serve it with a dollop of cinnamon-spiked yogurt and chopped raisins. Drizzle a tablespoon of chocolate syrup on frozen vanilla no-fat yogurt. Enjoy!

Question: My 10-year-old daughter is involved in a lot of sports. Are those 'sport drinks' okay for her to drink before, during, and after exercise or are fruit juices better?

Answer: The following suggestions were written by Covert Bailey and printed in the Spring 1994 issue of the Covert Bailey Newsletter. Permission was given to us to reprint his information.

Sports drinks are designed for longer, harder events. Studies have shown that after long bouts of exercise or hard work, sports drinks re-hydrate you faster and more thoroughly than water alone. Drinking water tends to shut down the thirst mechanism, so most people stop drinking water when they are only 68% re-hydrated. Water also stimulates the production of urine, something you do not want more of when you are dehydrated. The minerals in the sports drinks, particularly sodium, prolong your thirst so you are most likely to keep drinking until fully hydrated. The minerals also inhibit urine production. People who re-hydrate with a sports drink keep drinking until they are about 82% re-hydrated.

Drinking a sports drink containing glucose and other sugars **before** an event presents a problem. The sugar causes blood insulin to rise, and insulin inhibits the release of fatty acids from fat cells. For the first half hour of the event, your fat cells won't release the fat. With fatty acids unavailable, your muscles are forced to use stored glycogen and then the sugar in the blood. This means that sugar supplies are burned up even more quickly than normal. Taking a sugar drink so you won't run out of sugar will, in fact, cause you to run out of sugar sooner (* **Be sure to discuss all of these comments with your Dr. or nutritionist in relation to MCAD and how fat can't be used for energy, as well as whether to use glucose, cornstarch, and/or fructose as a supplement in the drink during heavy exercise**).

This won't happen if you take the drink during or after exercise because the fatty acids have already entered the bloodstream. The sugar in a sports drink consumed during exercise is easily tolerated and, in fact, enhances performance by prolonging endurance. Sports drinks, taken every 15-20 minutes during exercise provide a steady trickle of glucose that spares the glycogen in the muscle. The trick is to find a drink that has enough glucose to be useful to the muscles, but not so much that it can't be absorbed quickly. Sports drinks containing 5-7% glucose do just that. Fruit juices usually contain glucose and fructose concentrations of 10% or more making their absorption more difficult.

When sugars aren't absorbed rapidly, gastric distress and diarrhea can result. Most of us know that salt attracts water. In a humid environment, salt in a shaker gets all caked together. Sugar has similar properties. So when a sugary drink gets to the intestinal tract,

it draws water out of the blood into the intestine. Sports drinks with glucose are absorbed into the bloodstream before this intestinal flooding can occur.

Sugar drinks containing fructose (fruit juices) remain in the gut longer and draw in substantial amounts of water, which can lead to cramping and diarrhea. Note: Besides fluid intake, a healthy diet of high carbohydrate/low fat foods will also be beneficial to performance, as well as to your overall health.

Question: What is Hepatitis B and is the Hepatitis B vaccine recommended for MCAD children?

Answer: All of the following information is taken from the **1994 American Academy of Pediatrics' Red Book**.

Hepatitis B Virus (HBV) causes a variety of infections. Chronically infected persons are at an increased risk for developing chronic liver disease (i.e., chronic active hepatitis, cirrhosis, chronic persistent hepatitis) in later life. Persons infected as infants or young children appear to be at higher risk of death from liver disease than those infected as adults.

Hepatitis B Virus is transmitted through body fluids or blood. Blood and serum have the highest quantities of virus; saliva contains the lowest. HBV is not transmitted through the fecal-oral route.

“To accomplish universal vaccination most rapidly, immunization of all children during or before adolescence is necessary and recommended” (p. 227). “If resources are insufficient to allow concurrent immunization of both infants and adolescents or preadolescents, infants should be preferentially immunized before all adolescents are vaccinated” (p. 227). Three intramuscular doses of the safe and highly effective Hepatitis B vaccine are required to induce protective antibody response. The most frequently reported side effects are pain at the injection site and a temperature. Allergic reactions occur infrequently. Long-term studies of children and adults indicate that the vaccine may protect the person for 10 years or more. For adults and children with normal immune status, routine booster doses are not currently recommended. Additional information and research is necessary. In regard to MCAD children, Dr. Kim Iafolla, Duke University Medical Center (*in 2000, in Rockville, MD), agrees with the **Red Book** recommendations and sees no reason why MCAD children should not be vaccinated. Of course, she stated that you should definitely discuss this issue with your child's physician before having your child immunized.

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 Carnitor®(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. Note (from Deb): If your child has had some episodes that have required hospitalization, it might be a good idea to speak with your Dr. about having the IVs on hand at your local hospital. In the past, we have kept some at home as well, so when we traveled we had them available in case of an emergency. That way we KNEW the hospital would have the IVs to use, especially if they had never heard of this disorder before and didn't have any carnitine in their pharmacy. You never know when you just might need it!

Medical Update

MCAD researchers are continuing to make major advances ~ the latest being in the prenatal testing and diagnosis area. In this section of the newsletter we will overview these developments.

What Is Prenatal Testing? Prenatal MCAD testing involves sampling an unborn infant's amniotic fluid and cells, and molecularly and biochemically testing them to determine if the unborn child has MCAD or not. Acylcarnitine profiles are also done. Researchers at the Duke University Medical Center have recently been able to do this [For those who have mastered the ability to read 'doctorese,' a medical abstract written by Dr. Charles Roe of Duke University Medical Center (*in 2000, at Baylor in Dallas) follows, and then our comments about prenatal testing/diagnosis follows Dr. Roe's one-paragraph abstract.]

Title: PRENATAL DIAGNOSIS OF MITOCHONDRIAL FATTY ACID OXIDATION DISORDERS. Authors: Nada, M.A. (1), Wappner, R., Ding, J.H. (1) and Roe, C.R. (1). (1)= Department of Pediatrics, Duke University Medical Center, P.O. Box 14991 RTP NC 27709.

Text: We describe a novel simplified, diagnostic procedure based on in vitro incubation of 18, 18, 17, 17-²H₄ -linoleate and L-carnitine with fibroblasts obtained from patients with mitochondrial fatty acid oxidation defects (ref). There is a need for families and their physicians for information on subsequent pregnancies to prepare for early intervention. The prenatal diagnosis of these disorders may provide for the institution of therapy in the neonatal period. A family that lost a child to MCAD deficiency at 2 days of age (homozygous A985G) is expecting their second child. In vitro probe of amniocytes from this pregnancy using [16-²H₃] palmitate and [²H₄] linoleate showed increased amounts of labeled medium-chain intermediates in this pregnancy consistent with MCAD deficiency. DNA analysis for the A985G confirmed the fetus is homozygous. Amniocytes from controls were entirely normal. Since the precursors utilize the entire beta-oxidative pathway, it is likely that amniocytes, like fibroblasts, will reveal each of these disorders providing prenatal diagnosis and an opportunity for treatment intervention at birth.

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The Benefits or Prenatal Diagnosis: Prenatal MCAD testing has a number of advantages. First, it allows some parents to learn that their soon-to-be-born child does not have MCAD. Second, some unborn children will be found to have MCAD and while this would not please any parent, it has the advantage of allowing medical personnel to initiate MCAD treatment right away; hence, the likelihood of maximizing the child's health and safety. Third, while it will be upsetting to any parent to learn that their child has a rare disorder like MCAD, knowing prior to birth allows time for the parents to emotionally cope with the news and, most importantly, prepare to deal with it.

Are Their Drawbacks To Prenatal MCAD Testing? Some parents may be hesitant to have their unborn child tested prenatally for MCAD. After all, knowing that an unborn child has MCAD may cause additional worry for a family. Yet, the medical benefits far outweigh this drawback and if approached in the right manner early knowledge of MCAD is a blessing. Parents have time to deal with the emotions of such news and equally important have time to network and learn about this disorder. This increases both their perception of and actual control over the situation and makes the best out of a less than desirable situation.

It's Your Call: The decision to pursue prenatal MCAD testing is your own. Of course, there are risks to any type of invasive medical procedure (amniocentesis), and these should be discussed with your physician. However, if you are thinking about having more children and you are interested in the prenatal testing, please contact Dr. Roe and he will be able to provide all the necessary information to you and your physician.

Early MCAD Detection ~ A Case Study: It is an indescribable feeling when a family experiences the death of a child. It's even more overwhelming when the cause of death is undetermined or unclear, such as in SIDS or Reye's Syndrome.

When a child dies, parents feel an extreme sense of helplessness, powerlessness, and loss of control. One way of trying to make sense out of the most incomprehensible of experiences and to gain a bit of control is to find out as much information as possible, especially if the parents wish to continue their family. Not knowing the cause of their child's death is not only gutwrenching and frustrating, but it can be a major complicating factor in their grief journey.

Several of us (MCAD families) have experienced this ultimate tragedy, and many of us have continued our families with some children being diagnosed with MCAD or as a carrier and others not affected. Unfortunately, many of us learned about MCAD only after a child's (or several) death ~ for some, years after the death.

In our own situation, Dan and I often asked "**What if** we had found out about MCAD **before** Kristen got so sick (for the first and only time) that she died?" Our lives would be so different today. When our second child, Kevin, was diagnosed soon after birth, Dan

and I were thankful that we had found out, but it hurt so much that we were able to save Kevin in time, but not Kristen. It seemed so unfair.

We had a lot of mixed emotions when we were planning our next pregnancy and even more so when we got Kevin's diagnosis. Just having lost Kristen 1 year earlier, we were completely devastated and felt like our world was caving in all around us. We were excited that Kevin was here, yet we automatically thought that he was going to die too. It was not until we gathered more information and talked with Dr. Charles Roe and his colleagues at Duke that we slowly began to believe that Kevin's prognosis for a 'normal' lifetime was very good.

We were thankful that Kevin began treatment immediately upon diagnosis. Today, he is a very strong, active, and healthy 8-year-old (*in 2000, Kevin is an even stronger and more active 14 year old!). That may not have been the case if his diagnosis had been delayed for several months or years or never made in the first place, as with Kristen. Some MCAD children who have been MISdiagnosed and/or diagnosed after already experiencing several episodes, have experienced developmental, speech, and behavioral disabilities, as well as medical concerns. Some of these include: muscle weakness, seizure disorder, failure to thrive, 'cerebral palsy,' and attention deficit disorder.

Early diagnosis and treatment intervention are the keys to a very positive prognosis.

As you read in the Medical Update, Dr. Roe and his colleagues have been able to diagnose MCAD prenatally. This not only means early detection and treatment, but it may also mean decreased anxiety for the parents/family, especially if the prenatal test is negative. Remember, that each child has a 75% chance of **not** having MCAD. Knowing ahead of time that your child is not affected may decrease your stress during the pregnancy and make for a more relaxed atmosphere for everyone.

What might happen if the test is positive for MCAD? In our situation, I think I would have been just as stressed out as when we got the diagnosis after birth. However, I feel that if I knew before Kevin was born that he had MCAD, it would have given me more time to emotionally adjust to the situation and over the long run, decrease my anxiety about how we were going to all deal with this disorder.

As with any issue, it is necessary to assess the pros and the cons for yourselves and also to discuss them with your doctors. As mentioned earlier, if you or your physician have any questions, feel free to contact Dr. Roe.

‘CANDICE’

When I look at my feet
As I walk up the street
I wish Candice could walk with me.
When I meet a new face
Or go to a new place,
I wish Candice could be there then.
I remember how she'd cheat
When we played hide and go seek,
Or she'd wrinkle up her nose
And call me stupid.
How she'd sing her favorite song
But get some of the words wrong.
It was too cute to make right
So we didn't even try.
So remember the fun we had
And don't be too sad
Because Candice doesn't feel bad
Right now in heaven.

With love, Elizabeth, 1993 For Candice Lingle
By Elizabeth Williams -Age 10, (Candice's cousin)

Love Messages

(Please see our most current online issue)

‘MORE THAN A SONG’

As we all know, children are so very special, precious, loving and tender and give us so much joy and happiness. When a child dies, there are special things that they leave with us to remember them by ~ a smile, a laugh, the cute way they talk or do things, and so many things that can't be put into words. Our 2 1/2 year old daughter Candice died November 8, 1993. Candice had a favorite song that she would always sing, and we would like to dedicate it in memory of her and other children who have put a song in our hearts.

Love, Daddy
(Rusty Lingle)

**ONCE UPON A DREAM
(CANDICE'S FAVORITE SONG)**

I know you! I walked with you once upon a
dream.
I know you! The gleam in your eyes is so
familiar a gleam.
Yet, I know it's true that visions are seldom
all they seem.
But if I know you, I know what you'll do;
You'll love me at once the way you did
once upon a dream.

From Sleeping Beauty
Adapted from Tchaikovsky
by Sammy Fain and Jack Lawrence

We love you best!
Mom and your big sister Erin, and your entire family
Mary & Erin Lingle
Gladewater, TX

Nutrition Resources

The 99Percent Fat-Free Cookbook by Barry Bluestein & Kevin Morrissey.
The Wellness Low-Fat Cookbook by the editors of the University of California at
Berkeley Wellness Letter and the Wellness Cooking School.

Resources

Submitted by Diane Kennedy of Livermore, CA:
Suggested Reading for parents and families to help them cope with the ups and downs of
life:

- * The **Bible**
- * **Closer to the light** by Melvin Morse, M.D.

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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, Newborn screening, treatment recommendations, research, and names of FOD researchers/Labs.]