

MCAD Communication Network
'All In This Together'

June 1993

Volume 3 Issue 2

From The Editor

Summertime is here and so is our June issue of the Communication Network. Since our January issue, several new MCAD families have contacted us. Welcome to all of you. We hope that the newsletters and networking will help you cope with MCAD individually and as a family.

In this issue, two more families share their feelings about their MCAD experiences. Thank you Christine and Mark McFarland and Jeanne and Mark Barilla for personalizing our newsletter. If other MCAD families would like to share their stories, please send them to Deb by Dec 1, 1993.

Also in this issue questions are answered, pharmaceutical and medical updates are reported, and Love Messages are remembered. We also have 2 articles updating the progress of a special group of Virginia middle school children who 'adopted' MCAD as their yearlong project. They have done a tremendous job of promoting MCAD awareness in Virginia. Maybe the rest of the country will catch on! If anyone is interested in seeing what these children have done, Carolyn Stamm, their teacher, has sent me a videotape of all their appearances. I'd be glad to loan it out, just let me know.

In our January 1994, issue, we hope to initiate a Nutrition/Low-fat Recipe section. If anyone would like to share their knowledge and/or tasty recipes, please send them to Deb.

Again, we hope that you find this issue informative and helpful in networking with other families. If you would like to contribute to our Jan 1994 issue, we would greatly appreciate your suggestions, questions and/or articles.

Deb and Dan Gould, Co-Editors

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Erin Susanne

Our first child, Erin Susanne, was born on August 26, 1988. She was the first grandchild for my parents and she was born on my father's 59th birthday. Mark and I were elated. We felt so lucky.

Our first weeks and months as new parents were not easy ones. We were in the process of finishing our graduate studies and relocating from College Station, Texas to Dallas. It was stressful, at times, and a new baby added to the stress. Erin had a lot of colic and

difficulty with feeding. We spent a great deal of time trying to find the right formula and the most soothing position (lots of bouncing, rocking, and walking) for Erin.

At the beginning of January 1989, we moved to Dallas. Erin was just over 4 months old and things were going much better. The colic seemed to subside and we were really enjoying our little baby. Unfortunately, I had just started a new job and so we had to find daycare for the first time. After less than two weeks with this new arrangement, Erin became ill for the first time in her life. It started one evening after supper. She had eaten quite well and then, without warning, promptly threw up everything. Aside from the vomiting, there were no other obvious symptoms. About 24 hours later, she started having diarrhea. Mark and I were very worried because we had always heard that babies can dehydrate so easily and quickly. We immediately called our pediatrician and she was seen in the office. We left there with a prescription for antibiotics and reassurance.

They obviously thought she would be fine. Later that afternoon, her condition began to worsen. The diarrhea was more frequent and she became more and more lethargic and refused to drink or eat anything. We went back to the doctor's. This time they gave her an injection and a bottle of Pedialyte in the office. She readily took the fluids and we were sent home again with the encouraging words of our pediatrician. Our daughter fell asleep and we felt sure things would be better in the morning.

At 5:30 the next morning, we found Erin in her bed having seizures and we rushed her to the emergency room. In the back of my mind, I knew something was terribly wrong, but I never thought that we would lose her. It seemed to me and to Mark that the emergency room staff was not moving quickly enough; we were so frantic. Shortly after we arrived, Mark noticed that Erin stopped breathing. At this point, the ER staff moved us all to a small waiting room further away.

Every few minutes our pediatrician would come and tell us what was going on. We could tell that it was bad and that things were not going well, but I suppose neither of us took it any further. The longer we waited, the more apparent it became that our doctor did not have a clue as to what was wrong. All he could tell us was that the ER physicians were doing all they could. At 7:30 am, Saturday, January 21, 1989 our precious child died. The shock and utter disbelief are with us still.

I actually feel that our doctor was as stunned as we were. He could not believe it happened either, nor could he offer any explanations or answers. Permission to perform an autopsy was requested and we waited to find out what it was that took our daughter's life. That very evening, someone called from the Medical Examiner's office and for the first time, the term metabolic disorder was mentioned. We had no comprehension of what that meant, needless to say. It took months for us to learn that Erin had died from MCAD.

Because of numerous mistakes on the part of the Medical Examiner's office in Dallas, necessary samples were improperly handled or not taken at all. It seemed that it might be impossible to ever learn the true cause of Erin's death. I don't remember how we were put in contact with Dr. Roe's lab at Duke Medical Center (*in 2000, he is now at Baylor in

Dallas); however, it was Dr. Roe's diligent efforts to locate some (any) appropriate or useful tissue samples upon which to perform his diagnostic assays. Finally, in July of 1990 (18 months after Erin died), we learned conclusively that the cause was MCAD. Our case was particularly confusing and the subject of some debate because Mark and I failed to test as carriers of MCAD when enzymatic testing was performed in another lab.

It was the opinion of these scientists that while our daughter clearly died from a defect in fatty acid metabolism, it was not MCAD. However, as newer technology became available, researchers in Dr. Roe's lab were able to detect the gene for MCAD in both of us as well as in Erin.

Writing about this has proven to be much more difficult than I imagined. I knew it would be hard to find the words to tell our story and to describe our emotions. Despite the passage of time (it has been more than 4 years), it doesn't get easier. It is difficult to accept especially in light of how treatable MCAD is. If only we had known...

We have since had two more children. Our second child, another daughter, was born in January 1991. Mary Grace (or Mimi, as we call her) tested as a carrier for MCAD. This past August, our third child was born. Our son, Tyler, tested genetically normal. Erin paved the way for her sister and brother; they were able to be tested and treated had it been necessary.

There seems no easy way to end this except to say that we love and miss our firstborn. Life will never be the same for any of us.

Christine and Mark McFarland
Morgantown, WV

Michael Paul Barilla

Michael Paul Barilla was born on February 2, 1990. He was a beautiful 8lb. 6oz. dark-haired angel. His big sister, Michelle (7), and his brother, Mark (6), welcomed him with open arms. My husband, Mark, and I were elated that I would be able to finally quit my full-time job and stay home to raise my third baby myself.

Michael was almost the perfect baby. He had the most pleasant personality of any baby I've known. He started to sleep through the night at about 4 weeks old. He hardly showed a temper. Aside from his personality, Michael was probably my healthiest baby (or so we thought). He was hardly ever ill, except for a bout of chicken pox he was exposed to while we were on our summer vacation. But he breezed through that with a few Aveeno baths and days spent in our swimming pool. He wasn't too uncomfortable.

We were amazed when he started to walk at 9 months. Luckily, this provoked me to start videotaping him each day so we could later see the progression of his learning to walk. It was hard to catch Michael without a smile on his face. People would ask me "Doesn't he ever cry?" Ironically, for Halloween Michael was dressed as a devil for Trick-or-Treating.

A few weeks later, I took Michael for his 9-month checkup. Dr. Kherani said he slowed down a little bit on the height chart, but he was developing beautifully. He did have a little ear infection so we started him on an antibiotic and scheduled a follow-up visit. That same week, I finally got around to taking Michael to a studio to have his portrait taken. I kept dawdling because I wanted to do the three kids together. Between all the bruises, cuts, and black eyes waiting to heal, we could never get it together. So I decided, forget it ~ I'll just get Michael's done.

A few days later, it was Thanksgiving. We visited all the relatives and my brothers were all home from college. The next day we went to a Christmas party for all the cousins including some who were in from out-of-town. Even Michael sat on Santa's lap. I videotaped the whole chaotic event, thank God, for this was the last day I have Michael on film.

The next morning, Saturday, seemed as usual. Michael woke up and ate a good breakfast and lunch. But no sooner than I bathed him and changed his clothes, he vomited everything up. I let him take a good nap and I tried to feed him again. He vomited again. I knew there was a 24-hour stomach flu going around. I decided I was probably making things worse by trying to keep feeding him. But I was still concerned about him dehydrating so I kept trying Pedialyte for the rest of the day ~ even that wouldn't stay down.

He did sleep quite a bit that day, but I wasn't too worried because I know I like to sleep a lot when I have this type of virus. Two of my sisters who are registered nurses, both saw him before I put him to bed for the night. They both agreed that he looked good and

didn't seem to be dehydrating. He was still smiling all the while. I ended up putting him to bed at about midnight. I thought about trying to feed him one more time, but I was so exhausted and I talked myself out of it. I thought to myself, he will wake up real early and be starving. I still have many guilty feelings about that decision to this day. Was I being selfish? Could I have seen something happen or known when it happened? Could I have saved him?

When I woke up and looked at my alarm clock and saw that it was 8:30 am, I got a terrible feeling that something was wrong. I rushed to Michael's room and peeked in from the doorway, almost afraid to look. I had a sick feeling in the pit of my stomach when I saw his face. I could tell right away. His eyes were not closed all the way and his mouth and nose were up against the bumper pad. I immediately picked him up and at the same time screamed for Mark to call 911. His face was almost whitish and a bit splotchy looking on his cheeks. I could tell by the feel of his little body that it was too late to do anything to save him. He was even a bit cold already. I just couldn't believe he left me while I was sleeping. I was crushed I didn't even get to tell him I loved him one more time or say good-bye. It is so hard to describe the first emotions you feel when the worst thing possible happens to you, like losing your baby. I kept hoping it was just a bad dream and I would wake up soon, hopefully.

The rescue squad came and immediately grabbed him and ran out without saying anything. It seemed like forever at the hospital before the ER doctor came to tell us the words I knew were inevitable. Since they took so long, I started to feel some false hope. Finally he came and told us they couldn't do anything to revive him. We were able to hold Michael one last time, even his sister, Michelle, sat with him in a rocking chair for a while. I was concerned about her. She was like his second mother. She helped feed him every morning before school and she followed him around like she was his worried little mom. My husband and I passed him back and forth. I remember how hard it was to just lay him down and leave him there. Our time with him had to be cut short because we had decided to donate his big beautiful blue eyes, and it needed to be done urgently since we didn't know how long it had been since he had been gone.

The next days are pretty much a blur to me. We planned Michael's wake and funeral and we had him buried in the baby section with all the other angels. My mother-in-law bought Michael a brand new stuffed Big Bird so I could keep the one that he had slept with every night. It still smelled like him. Somehow, with God's help and a great deal of support from our families and friends, we made it through all the stages one goes through when losing a child ~ shock, numbness, anger, fear, and Guilt, and rivers and rivers of tears and finally acceptance.

The tears still come and go, even 2-3 years later. Three weeks after Michael's death we received his autopsy report ~ SIDS. It said he appeared to be healthy and no cause of death was found. That did take some of the guilt off my shoulders. But the thought of never truly knowing how he died was very frustrating.

Two months later I was pregnant again ~ a time of mixed emotions. I wasn't sure if I should be happy, sad, or scared. When Matthew Christopher was born on Oct. 19, 1991 (10lbs 8oz), I hadn't felt feelings of happiness like this in so long I really felt guilty about it at first. I didn't think it was okay to feel happy so soon after my son died. I thought about it and I know Michael would want me to be happy again.

While we were still in the hospital, our pediatrician Dr. Kherani, came to see me and said Matthew looked great, he seems to be a very healthy boy, but that there was one thing she wanted to check out. She knew of another family who had a baby die about 5 years ago with similar symptoms as Michael ~ and they just recently found out by Dr. Roe at Duke University that this child died from something called MCAD. She asked me if we could send Matthew's PKU card to Duke just to rule MCAD out. I said fine, anything she wanted to do as far as SIDS research was fine with us.

About 10days after bringing Matthew home, Dr. Kherani called. The test came back positive for MCAD. I don't know if she or I was more shocked. I could feel the excitement in her voice. I said "Oh my God, that must be what Michael died from!" She said it was very likely. I contacted the coroner's office the next day not even sure if they had saved any samples from a whole year earlier. But they did.

Weeks later it was confirmed that Michael did die from MCAD. We had our other two children also tested and Michelle (10) is a carrier and my "lucky" Mark (9) has MCAD also. Thank God we found out in time because Matthew became ill at 4 months old and had to be hospitalized and then 2 other times up till now. If we hadn't known about MCAD, I'm sure we would have lost him. I feel so very grateful to have such a wonderful pediatrician.

Because of her spreading the word, I know there have been at least a few babies just in our hospital's NICU who have been diagnosed as MCAD. I am presently involved with the SIDS chapter in our area (Cleveland) to make sure that MCAD is heard about for these families. Who knows, maybe it will save some other child's life. One thing I remember back when Mark was born in April of 1984 the nurses took him to NICU because his respirations were twice as fast as they should have been. They weren't sure what was wrong with him. Even after 4 days they still didn't know, but he seemed to bounce back after being tube fed a calcium/glucose mixture. All they told me was that he was hypoglycemic, but now he's okay (Little did I know).

We are presently expecting our fifth child in August. We are praying for a healthy non-MCAD child. The odds should be with us. They say each child has a 1 in 4 chance of having MCAD. So far, we are 3 for 4. Even so, we have a beautiful guardian angel watching over us. Our Michael was born 2-2-90 and went to heaven on 11-25-90.

Jeanne & Mark Barilla
Fairview Park, OH

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 1993, 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 6-month-old son was recently diagnosed with MCAD. He is not on any special diet or medicine. In networking with other MCAD families, it seems that most of the children are on a carnitine supplement and/or a low fat diet. How can I approach my physician concerning a possible alternate treatment?

Answer: There is strong research evidence that L-carnitine helps to biochemically remove toxic acyl-Coenzyme A effectively and safely. If you have a concern about your child's treatment or lack of treatment, then it would be in your child's best interest to ask your physician his/her specific reasons (maybe even ask for research documentation) for not using carnitine and/or a low fat diet. Often, those with MCAD have a secondary carnitine deficiency. Plasma carnitine levels can be checked by your lab to determine if there is a deficiency. Please also remember that if other medications are taken (i.e. seizure meds), they can deplete the carnitine in the body and supplementation most likely would be beneficial. It is then up to you to decide if you want to seek further opinions from MCAD specialists from around the country. Sigma-Tau, makers of Carnitor®, have sent me several research papers on the use and effectiveness of carnitine supplementation. I will list some of those resources in a future issue or call me for the references. Dr. Susan Winter (winter2571@aol.com) in Fresno, CA has also done extensive research with carnitine and would be a good resource.

Question: Is there any update on the use of riboflavin as another treatment for MCAD?

Answer: In two studies conducted on one MCAD child (with one of the specific mutations), riboflavin was unfortunately not shown to be an effective treatment. It was originally hypothesized (and hoped for by the parents!) that the riboflavin might help to biochemically convert the child from an active state to a carrier state. Because of the not-so-positive study's results, however, future investigations are not planned.

Pharmaceutical News

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 contact them, contact Ken Mehrling, Director of Marketing & Sales (* in 2000 he is now a VP), at 1-800-447-016.

Medical Update

This issue's update is a brief summary of an article submitted to the **Journal of Pediatrics** by Drs. Kim Iafolla, Robert Thompson, and Charles Roe (formerly of Duke University Medical Center, DUMC), entitled "Medium Chain Acyl-CoA Dehydrogenase Deficiency: Clinical, Biochemical, and Molecular Aspects of 120 Affected Children."

NOTE: If any of you are involved with other MCAD researchers, please ask them if they would like to contribute an update on their research efforts and findings. We would like to know what others are working on across the country in regard to MCAD.

By reviewing medical records and autopsy reports, phone interviews, and physician and parent questionnaires, data was collected on 120 MCAD patients (96 families) identified through the Mass Spectrometry Facility at the DUMC from Nov. '81 to Dec. '91. **The purpose of the survey was to determine the clinical course and natural history of MCAD and to determine the effect of treatment, if any, on the outcome of the disease.** Because MCAD occurs in 1 in 23,000 live births, this information would help in counseling patients, families, and their physicians. This also **underscores the need for neonatal screening, which may have prevented many of the deaths in this survey. Also, if autopsy biochemical testing was routine, some of the recurrent deaths in families may have been prevented.**

In the survey there were 65 females and 55 males from age 3 days to 20 years. One was Native American, 1 African-American, and 118 were Caucasian with parental origin predominantly Northern European; few families were from France/Spain and none originating in Greece, Italy, East Europe, or Asia. First illness episode ranged from 2 days to 6.5 years and most presented with several symptoms such as: lethargy, vomiting, brain swelling, respiratory & cardiac arrest, seizures., apnea, "Reye-like" illness, and/or sudden death. Upon presentation at the doctor's, 85% of the patients also had an intercurrent illness such as: virus/fever, gastroenteritis, and upper respiratory symptoms/ear infection. After the first illness episode, it took an average of 1.8 years before an MCAD diagnosis was made.

Before a diagnosis could be made, however, 23 (age 3 days-4.1 years) of the 120 children died during an episode. Twenty of the 23 children who died at their first episode were between the ages of 3 days and 2.1 years. After surviving an initial episode, some of the children went undiagnosed for 2 months to 3 years before dying during another episode. Autopsy reports revealed a variety of findings: fatty livers, kidneys, and hearts; brain swelling; lung congestion and hemorrhage; small adrenal glands; and GI bleeding. **There have been no metabolic deaths after diagnosis (those diagnosed at DUMC).**

Before being diagnosed with MCAD, 85 children were given alternate diagnosis for their illnesses ~ Reye's Syndrome being the most common misdiagnosis. Others included: hypoglycemia, SIDS, Carnitine Deficiency, hepatitis, and LCAD.

Following diagnosis, the 95 surviving MCAD children received some dietary or medical treatment: 70 children were placed on an L-carnitine supplement, 60 followed a low fat diet, 1 was on riboflavin and L-carnitine, and 2 were on glycine supplementation but no L-carnitine or low fat diet.

A time delay (3 months) between the initial episode and starting treatment correlated with a high risk for developing muscle weakness. Other developmental and/or behavior problems were noted such as: speech, attention deficit disorder (mostly females), failure to thrive, cerebral palsy, asthma, chronic headaches, abdominal pain, and hypoglycemia. **The incidence of learning/behavioral disabilities (especially speech) in the 12-18 month old group was unexpected and significantly higher than in the general population.**

Normal development apparently occurred before an initial illness episode. It is suggested that during a metabolic illness, damage may occur to the speech centers of the brain. Most of the children regained significant speech ability within 2-3 years of starting therapy.

When ill, those patients who had attention deficit disorder all had symptoms associated with brain swelling. They were also more likely to have had many episodes of illness both before and after diagnosis and were diagnosed at an older age. This supports the need for early diagnosis and treatment.

The study's findings suggest that MCAD patients are at significant risk of sudden death in early childhood, as well as somatic illness and developmental disabilities. Long-term evaluation of MCAD patients is suggested to determine the complications and implications of MCAD in adulthood.

Love Messages

(Please see our most current online issue)

**A.I.M.ing High Against Infant Mortality:
General Assembly Resolution Initiated by Kempsville Middle School
Students
Virginia Beach, Virginia
Written by: 7th graders Jennifer Allen and Jessica Daniels**

Seventh and eighth grade students from the Special Projects for the Gifted class at Kempsville Middle School have recently been studying the genetic disease MCAD ~ (Medium Chain Acyl CoA Dehydrogenase Deficiency). **MCAD is a genetic disorder in which an enzyme is either missing or does not work correctly.** With this enzyme missing, MCAD patients **cannot break down fats to make life-sustaining energy.** MCAD episodes can come on suddenly and. 25% of MCAD babies die with their first

episode. **MCAD is often misdiagnosed as Sudden Infant Death Syndrome, or SIDS, and Reye's Syndrome. Out of the 7,000 babies that died last year from SIDS, researchers say 1 -3% of those deaths are actually due to MCAD.**

Under the direction of teacher Carolyn Stamm, **the students are working to promote public awareness of MCAD and the expansion of state infant screening to include testing for MCAD.** Their team name is Team A.I.M. (Against Infant Mortality). They initiated a state resolution from the Virginia General Assembly that recently passed unanimously from the House and Senate.

The resolution, HJR #657, requests that the State Department of Health study the expansion of current required screening tests for infants to include testing for certain metabolic and other disorders, including MCAD. The study shall include an examination of mass spectrometry technology and its potential effect on the reduction of death, disease, and disability. The Junior League and the State Health Department have endorsed the resolution.

On February 2nd, Mayor Meyera Oberndorf proclaimed an 'MCAD Awareness Day' in a special ceremony. Eighth graders, Wendy Williams and Michelle Piccioni spoke at the City Council meeting and urged the City Council to pass a resolution supporting HJR #657 and the students' work at the General Assembly.

Team A.I.M. students have written letters to Delegates of the State Health, Welfare, and Institutions Committee, and they designed flyers to give out at pediatricians' offices. They have made presentations to State Delegate Leo C. Wardrup, Jr. and State Senator Clarence Holland (patrons of the resolution), the State Maternal and Child Health Directors, and the YWCA lecture series. Team A.I.M. spoke to the State Genetics Advisory Board in Richmond and recently held a seminar about MCAD for the Genetics and Pediatric Residents of Georgetown University Hospital in Washington, D.C.

The resolution is Team A.I.M.'S first step to changing the current mandatory infant screening tests in Virginia. MCAD is more deadly than some of the disorders currently tested for in this screening program. If infants aren't tested for MCAD, they could become part of these preventable statistics. Approximately 500 new cases of MCAD are expected to occur in the U.S. each year.

The students feel it is a horrible waste of human life to allow these infants to continue to die in our midst when the technology for saving them is so near.

City Report: Students push for state screening of babies

(The Beacon, Virginia Beach, VA, February 21, 1993)

By Elizabeth Theil
Staff Writer

“But you can’t put a price on life,” said 12-year-old Jessica Daniels, a seventh-grader in Carolyn Stamm’s class

Anyone who doubts kid power should spend a little time with Carolyn C. Stamm's gifted and talented class at Kempsville Middle School.

These seventh and eighth-graders could give professional lobbyists a run for their money.

Last year, their crusade to improve toy safety took some of them all the way to Washington to testify before Congress, and landed them on national television.

Now they're back on the trail, this time advocating changes in state Department of Health regulations on disease screenings for infants.

The students' research shows that many infant deaths are wrongly attributed to Sudden Infant Death or Reye's Syndrome, when actually the babies have been killed by a metabolic disorder called Medium Chain Acyl CoA Dehydrogenase Deficiency ~ a mouthful usually just called MCAD.

MCAD, the students' research shows, is genetic, caused by a missing or non-functioning enzyme that prevents the baby's body from breaking down fats properly and converting it into energy necessary to live.

The students found that of the 7,000 infants nationally whose deaths were attributed to Sudden Infant Death Syndrome in 1991, an estimated 1 to 3 percent were actually due to MCAD.

With proper treatment, doctors have been able to keep children diagnosed with MCAD alive and well with special diets and medicine.

Calling themselves Team AIM ~ Against Infant Mortality ~ Stamm's students are hoping to convince the state Health Department to include testing for metabolic disorders like MCAD among the mandatory screenings all infants must now undergo.

"It doesn't have to be fatal," said 13-year-old Kyle Massey, a seventh-grader.

"We want to get the number of deaths down."

The students are well on their way to their goal. At the kids' behest, the General Assembly last week passed a resolution asking the state Health Department to study making the MCAD test mandatory for infants.

The department also is charged with looking into the use of the mass spectrometry machine, a device that has been used with some success at Duke University to test for MCAD and other diseases. The device is expensive, \$300,000 to \$500,000, the students said.

"But you can't put a price on life," said 12-year-old Jessica Daniels, a seventh-grader in Stamm's class.

The students became interested in the cause when they were studying genetics in class and heard a talk by a mother whose baby had died of MCAD, but was misdiagnosed as Sudden Infant Death Syndrome.

"We were just amazed and we wanted to do something about it," Massey said.

The students spoke to state Maternal and Child Health officials, and testified before the Genetics Advisory Board of the state Department of Health,

They appeared before City Council earlier this month, convincing council members to pass a resolution supporting their cause and prompting Mayor Meyera Oberndorf to declare February 2 an MCAD Awareness Day.

To rally legislators to their cause, the students had to present their case before Delegate Leo C. Wardrup, R-Virginia Beach and state Senator Clarence A. Holland, D-Virginia Beach and before a Senate committee.

Wardrup and Holland co-sponsored the resolution.

"They're amazing," said Holland, a physician. "Sometimes I think we ought to give these projects to children instead of adults. They cut right through the trash and get right down to the bottom line most of the time."

"I think we're learning that we can make a difference," Massey said.

"And we don't have to leave it all up to older people," Daniels said.

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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.]