



## FOD Family Support Group

---

Deb Lee Gould, MEd  
MCAD Parent/Grief Consultant  
805 Montrose Drive  
Greensboro, NC 27410

Phone: (336) 547-8682  
Email: [deb@fodsupport.org](mailto:deb@fodsupport.org)  
Web: <http://www.fodsupport.org>

Mother's Day, 2001

I am writing to you as a concerned parent, as well as the Director of an international Family Support Group, that was 'born' out of the death of our daughter, Kristen, who was born on October 6, 1983 ~ then died suddenly 21 months later on July 21, 1985, all because she was **not diagnosed AT BIRTH with a DIAGNOSABLE and TREATABLE genetic metabolic disorder called MCAD. If she was diagnosed and treated, she would be a 17-year-old young woman graduating from high school this May.**

**The FOD (Fatty Oxidation Disorders) Family Support Group is a strong advocate for expanding Newborn Screening.** Of course, I would personally like to see ALL of the 30+ disorders detected through tandem mass spectrometry, as well as all the disorders that are diagnosed through conventional testing methods, screened for in EVERY state, but that will take time and a lot of perseverance. I can tell you, however, for ALL of our 500+ Families, especially those that have experienced a child's death, **that time can't come soon enough!** Those of us that have been tragically thrust into bereavement and/or are presently living with FOD children are **channeling our grief and daily challenges into advocating change in this country's newborn screening procedures.**

I am **strongly encouraging you to take a positive step forward in expanding your state's mandated newborn screening tests for the benefit of all of your families.** I have enclosed information that SHOWS how expanded testing would **definitely SAVE CHILDRENS' LIVES and much heartache.** This information is **specific to our Group's disorders,** but I am sure there are **MANY Groups across this country that unfortunately could replicate our results.**

In 1999, I surveyed our Families (52 Families responded ~ see enclosed **FOD Cost Benefit Analysis Survey Results**) to determine the **Costs of having an infant diagnosed at birth versus those not diagnosed at all or diagnosed months to years after one or several critical metabolic episodes** resulting in severe medical, cognitive, physical and emotional complications or death.

Although our sample may be small, the **Results** definitely showed that **EARLY DIAGNOSIS and TREATMENT at BIRTH saved lives, as well as prevented debilitating COSTLY complications and death.**

**My family, as well as over 75 others in our Group** (not all responded to the Survey), are living the ramifications of NOT having MCAD (or the other detectable FODs) diagnosed at birth, **experiencing 1, 2 and even 3 deaths BEFORE a diagnosis was ever made.** Several of those deaths were **MISdiagnosed as SIDS or Reye's Syndrome** leaving families to grieve the unknown and **literally putting their other children and future children at great risk.**

My family lived for 1 year with the nebulous 'diagnosis' of Reye's Syndrome as the cause of our daughter's sudden death before we finally discovered it was MCAD, when our 2<sup>nd</sup> child was born and tested positive for MCAD. Fortunately, the Medical Examiner in Illinois had saved some of Kristen's liver tissue and the frozen specimen was tested by Dr. Charles Roe when he was still at the Duke University Medical Center (presently at Baylor University Medical Center in Dallas). I believe she was the first documented post-mortem MCAD diagnosis in this country. It was definitely not an 'honor' that we wanted, but at least we finally knew why she died.

If we hadn't insisted on testing our son at birth and discovered his metabolic disorder, he too most likely would have died or experienced severe complications at 6 months of age when he had his first illness. **Because we KNEW he had MCAD, we KNEW what to do in case of an emergency. We weren't given that chance with our daughter!**

My point is that **these deaths, and deaths that are presently occurring** because many states have NOT implemented this VITAL testing, **could have been and can be PREVENTED!** Because the technology is already in place, **these disorders do not have to go UNDETECTED and UNTREATED!**

Our Survey Results may show the **high monetary costs of late diagnosis or no diagnosis** but there is **no way anyone can put a cost on the EMOTIONAL TOLL those deaths have taken and are taking on our Families! No Family should have to endure such a tragic loss.**

I am **URGING you to expand your Newborn Screening** so that ALL families in your state will have that chance to live. **EVERY family DESERVES that!**

Sincerely,

Deb Lee Gould, MEd  
Director, FOD Family Support Group  
MCAD Parent and Grief Consultant  
805 Montrose Drive  
Greensboro, NC 27410  
336-547-8682  
[www.fodsupport.org](http://www.fodsupport.org)  
[deb@fodsupport.org](mailto:deb@fodsupport.org)



**Kristen Marie Gould**

•••

**Born October 6, 1983 ~ Died July 21, 1985  
Undiagnosed MCAD  
(originally misdiagnosed as Reye's Syndrome)**