

## **The Power of Support ~ Creating Worldwide Family Support for Fatty Oxidation Disorders (FODs)**

Deb Lee Gould, MEd  
[deb@fodsupport.org](mailto:deb@fodsupport.org) / [deb@bereavedparent.com](mailto:deb@bereavedparent.com)

My husband, Dan, and I were thrust into the world of bereavement on a warm sunny day in July 1985. Little did we know how that traumatic experience was going to change our lives forever. And that there was even a possibility of 'healing' from such an overwhelming and incomprehensible loss.

Our 21-month-old daughter, Kristen, had joyfully been running through the sprinkler the night before, and by the next morning she woke up projectile vomiting. Being a Sunday, I called the on-call RN and she said "Let her sleep, the flu is going around." I did that for several hours, but became concerned she might be dehydrated so I called again. I was told again to let her sleep. By late afternoon, I was very concerned that she wasn't drinking enough so I called again. As I was on the phone with the RN, Kristen stopped breathing! The RN called 911 for me immediately, Dan and I began CPR...and we waited what seemed like forever for the paramedics to arrive.

Her heart was barely beating. We made it to the ER and as we were whisked to a private area, we were bombarded by questions - if she got into any medications or if she had eaten something. We explained that we had been in contact with the RN all day and that she thought Kristen had the flu.

The wondering and waiting was excruciatingly painful...then the Dr came to us to say that there was nothing more they could do and that we should come in and see Kristen. After our time with her, we hugged and kissed our daughter...then gave them permission to stop the machines. No words can ever capture those moments.

As we waited for autopsy results we kept racking our brains trying to figure out why Kristen died so suddenly. Weeks later it was determined that Kristen died from 'Reye's Syndrome' which has often been associated with aspirin use or having had the chicken pox. Kristen had neither. It was based on her having a fatty liver, fatty heart, and high ammonia levels. Dan and I KNEW that wasn't the reason, but we didn't have any other reason to offer. Thus began my daily journey to the University of Illinois Medical Library to FIND that reason. Because Dan was on staff at the university, I was able to have access to the 'stacks' and other parts of the library.

As we road the rollercoaster of grief that 1<sup>st</sup> year, Dan and I made the conscious decision to continue our family and just as I passed my 5<sup>th</sup> month, we were given a wonderful gift by one of my sister's Drs that knew about Kristen's death. She sent us a medical article she just read about how this rare genetic metabolic disorder called MCAD ([medium-chain acyl-CoA dehydrogenase deficiency](#)), mimics what they find in 'Reye's Syndrome.' When undiagnosed and untreated, individuals often

experience fatty liver and heart and high ammonia levels, and often don't survive their 1<sup>st</sup> illness. That was exactly what Kristen experienced ~ she had projectile vomited because she didn't have the 'fuel' or carbohydrates onboard for her brain and organs to function...and her body became toxic and shut down.

We took this information to our Drs and they pretty much dismissed us and said, "They are rare disorders...she couldn't have had that." We STRONGLY disagreed and INSISTED that when Kevin was born he would be tested for this disorder. Our living in limbo was about to end.

Within 24 hours after sending Kevin's specimen to Duke Medical Center we received a call. **A call that pierced our hearts again...Kevin had MCAD.** We then KNEW in our hearts that's what Kristen most likely had too. And it was definitely determined when they tested frozen liver tissue saved from her autopsy one year earlier.

**Medical Examiners take note ~ SAVE TISSUES!**

Because MCAD was just discovered in 1982 we didn't know what Kevin's prognosis was going to be. We were learning alongside the Drs. But as we took each day one at a time we learned how to keep his body fueled and what to do in case of an emergency. We then continued on and had a second son, Brian, who is a carrier of MCAD.

Living with a rare disorder and not knowing anyone else in the world with it made us often feel like we were all alone on this journey. Then a few years later, Kevin's specialist, Dr Charles Roe, asked if we wanted to try reaching out to other Families living with MCAD. We thought...how wonderful that would be!

By February 1991 we printed our 1<sup>st</sup> Newsletter and mailed it to 10 MCAD Families. Since then we have expanded to include all of the Fatty Oxidation Disorders (@15 disorders) and have a network of @4000 Families around the world ~ thanks to the internet! We now post all Newsletters online at [www.fodsupport.org](http://www.fodsupport.org).

We wanted to create an 'anchor' for ourselves the 1<sup>st</sup> few years of Kevin's life and then 'throw a line' to others so they didn't feel so alone in that ocean of life and chronic disorders. When new Families join our Group I either try to call them or skype. Sharing with someone across the world in Thailand or Australia etc., that things will be challenging and that we will be here to support you throughout the years can be empowering and comforting for Families.

Over the last 23 years we also have offered a National Metabolic Conference every two years in various parts of the US. It's a wonderful opportunity for Families to meet others experiencing their disorders face-to-face and talk with many of our FOD experts. The actual meeting of Families goes way beyond what our facebook and google networking can capture. Yet, having the ongoing internet groups can be a lifeline for many ~ especially when a Family is in the middle of a hospitalization.

**They KNOW they are NOT alone!**

Our Families cross all ages ~ we have newborns being diagnosed at birth, children & teens that experienced severe metabolic crises and medical complications early on before getting a diagnosis, and also adults just now receiving a diagnosis after living decades not knowing why they were having complications (often told it was all in their head!).

Within our Group, many Families have also tragically experienced a death as we have. One of my personal dreams was to be able to offer not only grief support for our FOD Families via phone/skype, but to also offer probono local face-to-face community outreach for anyone living with the death of a loved one no matter what the cause ~ a safe place to share their journey toward hope and healing. You can read more on how we keep Kristen's 'light' alive through our grief support at [www.bereavedparent.com](http://www.bereavedparent.com).

All of these efforts are about creating awareness of not only FODs, but also to remind others to **never underestimate the power of SUPPORT and CONNECTION!**

I get asked all the time "Why don't you have a celebrity speak up about FODs?" The simple answer is that I strongly believe that **each and every FOD Family no matter where they live in the world has the power to make a difference and be a voice for creating that most needed awareness ~ we ALL have that voice ~** and that is part of the reason our Group's saying/motto is **'We're ALL in This Together!'**

I want to thank you, CoSozo Living Magazine, for giving me this forum, as well as printing the two previous articles about FODs, to once again create even further awareness of FODs and their impact when they are NOT diagnosed and treated early ~ **so please share this information with your families, friends, and medical professionals.**

I hope this will add to your knowledge of rare and invisible disorders. Especially when having this information may have helped Drs when a child or adult came into the ER with what they initially thought was a 'simple flu or cold' and then they were told to "Go home and sleep" as we were told in a similar way almost 30 years ago.

Instead, it is my hope that the medical professionals will pause, think outside the usual medical toolbox, and say to themselves, "Maybe, just maybe, it could be one of those rare Fatty Oxidation Disorders that I recently read about."

That pause...**just may SAVE a LIFE!**

[CoSozo is no longer online]