I am the parent of two children with MCAD Deficiency, a Fatty Oxidation Disorder. My daughter, Kristen, died in 1985 when she was 21-months-old because it went undetected and was misdiagnosed as Reye's Syndrome. It wasn't until one year later when my son, Kevin, was born and diagnosed with MCAD that we learned she died from the same disorder. Our third child, Brian, is a carrier and not directly affected. To say the least, my family has been changed forever by this disorder.

In order to cope with all of our life experiences, my husband, Dan, and I formed a National MCAD Family Support Group in 1991 to 'connect' with other MCAD Families. Then in 1996, we expanded our Group throughout the world to include all Fatty Oxidation Disorders (FODs). Through our newsletters, website, Email List, and Networking/Seminars we provide emotional/grief support, practical information about living with these disorders, and inform Families of new developments in screening, diagnosis, treatment, and research, as well as encourage them to network with other Families via our facebook Group and google Email List.

We are asking for your help ~ as FOD Families or as Professionals interested in FODs ~ to spread the word about these disorders and our Support Group. Additionally, if you would like to contribute to our Mission or newsletter/website about your own Family Story or about the research/clinical work you are pursuing on a particular disorder, we would like to hear from you. Your financial help (tax deductible) would also help us continue our Mission to support Families around the world free of charge ~ we have a Donation link on our site to help with daily costs, future Regional MeetUps/Seminars, and probono Grief Support.

Again, we would greatly appreciate your help in educating others about the diagnosis and treatment of these disorders, expanded Newborn Screening for FODs and several other metabolic disorders, and our FOD Family Support Group ~ it just may save a life!

Take care...

Deb Lee Gould, MEd, Director

Fatty Oxidation Disorders: Medium Chain Acyl CoA Dehydrogenase Deficiency (MCAD); L-3-Hydroxy Acyl CoA Dehydrogenase Deficiency (LCHAD); Carnitine Palmitoyl Transferase I and II (CPT I & II); Very Long Chain Acyl CoA Dehydrogenase Deficiency (VLCAAD); Short Chain Acyl CoA Dehydrogenase Deficiency (SCAD); 3-Hydroxy Acyl CoA Dehydrogenase Deficiency (HADH, formerly called SCHED); Electron Transfer Flavoprotein Dehydrogenase Deficiency (ETF – GA2/MADD); Trifunctional Protein Deficiency (TFP); Carnitine Transport Defect (Primary Carnitine Deficiency); Carnitine-Acylcarnitine Translocase Deficiency; 2, 4 Diencyl-CoA Reductase Deficiency; 3-Hydroxy-3 Methyl Glutaric Deficiency (HMG); Unclassified FODs