



Deb Lee Gould, MEd, Director
MCAD Parent and Grief Consultant
Grief Support for Bereaved Parents and Families

PO Box 54
Okemos, MI 48805-0054

Office/Cell: 517.381.1940
Fax: 866.290.5206

Email: deb@fodsupport.org
Website: www.fodsupport.org

Board of Directors

Deb Lee Gould, MEd
FOD Parent, Director, and President

Daniel R Gould, PhD
FOD Parent and Treasurer

Mary Lingle
FOD Parent, Webmaster, and Secretary

Honorary Directors

Kevin Gould, MCAD Adult
Brian Gould, MCAD Sibling

Board of Medical Advisors

Charles R Roe, MD
Consultant
Dallas, TX

Mark Korson, MD
Tufts-New England Medical Center
Boston, MA

Jerry Vockley, MD, PhD
Children's Hospital of Pittsburgh
Pittsburgh, PA

Stephen G Kahler, MD
University of Arkansas for
Medical Sciences
Little Rock, AR

Gary Siskin, MD
Albany Medical College
Albany, NY

Andrew Morris, PhD, FRCPCH
Royal Manchester Children's Hospital
Manchester, UK

Arnold Strauss, MD
Cincinnati Children's Research Foundation
Cincinnati, OH

Barb Marriage, PhD, RD
Ross Metabolics/Abbott Nutrition
Columbus, OH

Janice Fletcher, MD, FRACP, FRCPA
Women and Children's Hospital
North Adelaide, Australia

James Gibson, MD, PhD
Specially for Children
Austin, TX

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 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, phone calls, and National Conference every two years 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 that are listed on our Family 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 homepage for the General Fund, Clinical Fund, Research Fund and for Grief Consults.

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 (VLCAD); Short Chain Acyl CoA Dehydrogenase Deficiency (SCAD); 3-Hydroxy Acyl CoA Dehydrogenase Deficiency (HADH, formerly called SCHAD); Electron Transfer Flavoprotein Dehydrogenase Deficiency (ETF – GA2/MADD); Trifunctional Protein Deficiency (TFP); Carnitine Transport Defect (Primary Carnitine Deficiency); Carnitine-Acylcarnitine Translocase Deficiency; 2, 4 Dienoyl-CoA Reductase Deficiency; 3-Hydroxy-3 Methyl Glutaric Deficiency (HMG); Unclassified FODs

The FOD Family Support Group is an all Volunteer Family-based Group and a tax-exempt 501c3 Non-Profit Corporation

All donations are tax-deductible ~ Federal Tax ID # 83-0471342

Thank you to **all** that have donated over the years so that we may continue to provide our support and information to Families and interested professionals around the world. Your donations help to cover copying and postage costs, phone calls to new FOD Families (US and abroad), website fees, Conference costs, as well as for raising funds for future clinical and research activities by our FOD professionals.

THANK YOU from ALL of us!