To Request More Information:

Please answer the following questions and mail to Deb at the address below:

I am a:  Check all that apply:

☐ FOD Family
☐ FOD Familymember
☐ Professional

Comments:

Name and/or Professional Title

Address 1

Address 2

Phone [Deb calls new Families in the US and abroad]

Fax

Email

Please mail to:

FOD Family Support Group
Deb Lee Gould, MEd, Director
PO Box 54
Okemos, MI 48805

Phone: 517.381.1940
Fax: 866.290.5206

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

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Federal Tax ID # 83-0471342

FOD Family Support Group

FODs Defined

Fatty Oxidation Disorders are genetic metabolic deficiencies in which the body is unable to oxidize (breakdown) fatty acids to make energy because an enzyme is either missing or not working correctly. The main source of energy for the body is a sugar called glucose. Normally when the glucose runs out, fat is broken down into energy. However, that energy is not readily available to a child or adult with an FOD. If undiagnosed and untreated, these disorders can lead to serious complications affecting the liver, heart, eyes, and general muscle development, and possibly death. These disorders are sometimes misdiagnosed as SIDS and Reye’s Syndrome.

Symptoms

There is a wide variation in the presentation of FODs, even within the same Family. Not every individual responds to a disorder in the same way. Some may be without major symptoms, yet others may have chronic bouts of low blood sugar or illnesses leading to hospitalizations. Please note that blood sugar levels should not be totally relied on as the only indicator of a possible crisis – the levels may even look normal. However, some of our children/adults are symptomatic with glucose levels of even 70 or 80mg/dl. Do NOT compare FODs with diabetes! Changes in behavior, irritability, lethargy (sleepy), and blood levels such as liver enzymes, acylcarnitines, ammonia, and ck (cpk) should also be monitored.

An emergency situation exists when a ‘metabolic crisis’ occurs. A crisis is often preceded by a period of fasting, possibly due to vomiting or an infection. Other symptoms may include diarrhea, seizures, coma and difficulty breathing.

Awareness of how to diagnose and treat these disorders is vital, because during a metabolic crisis, an undiagnosed individual may experience excessive buildup of fat in the liver, heart and kidneys, along with some brain swelling...all of which can lead to death.

For Families Living with a Fatty Oxidation Disorder

Our History and Mission

The Fatty Oxidation Disorders (FOD) Family Support Group was ‘born’ in 1991 as a way of dealing with the sudden death of our 21-month-old daughter, Kristen, in 1985 from undiagnosed MCAD. Initially she was ‘diagnosed’ with Reye’s Syndrome and it was not until one year later, when our son, Kevin, was born and diagnosed with MCAD that we discovered Kristen also had this rare metabolic disorder. Our third child, Brian, is a carrier and not directly affected. To say the least, our Family has been changed forever by this genetic disorder.

Our Mission is clear...to connect and network with FOD Families and Professionals around the world. Through our online newsletters, website, phone calls, and Email/facebook List, we provide emotional support, practical information about living with these disorders, and inform Families of new developments in screening, diagnosis, treatment, and research.

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Awareness of these disorders is imperative for early diagnosis and treatment, prompting us to be committed advocates for Expanded Universal and Comprehensive Newborn Screening and longterm follow-up care for FODs and several other metabolic disorders. We do not want other Families to needlessly go through what we experienced.

From our Family to yours, we want you to know...

You are NOT alone

and ‘We Are All in This Together’

Take care...

Deb and Dan
Kristen, Kevin and Brian Gould

Our hearts give immortality to those we love in memory...

[Image of email and fax information]

[Image of website and phone number]

[Image of address and contact information]

[Image of donation and launch information]
A fasting state, especially while ill, can trigger a "metabolic crisis" leading to lethargy and hospitalization. If hospitalized, it is imperative according to FOD experts, that a 10% dextrose IV is started immediately following blood chemistry samplings. Waiting hours for the lab test results before putting in the IV can be fatal when an FOD child/adult is in crisis. (Note: Experts also recommend avoiding aspirin, oral products that contain salicylates, long term steroid medications, lactated ringers, and fat binding/producing anesthesia medication).

Several snacks and meals of lowfat/high carbohydrate foods such as pasta, cereal, and other high complex carbohydrates (as well as sugar drinks when not well) are recommended throughout the day. Additionally, some Families use MCT Oil (not used for all FODs - i.e., MCAD and SCAD, since the medium chain triglycerides cannot be broken down). Hydrate with caloric drinks such as Gatorade while in heat and during exercise. Infants under 6 months should continue to have at least one night feed/snack as they should not go 10-12 hours without eating. If the FOD child/adult has experienced hypoglycemia (even with frequent meals), in order to help decrease the frequency or blood sugar in the morning, some find it helpful to mix in 1-3 tablespoons of raw cornstarch (i.e., Argo) to a cold sugar-free liquid or food at night. Be aware that too much cornstarch can be constipating for some and may be hard on teeth. Be sure to brush after eating or drinking it. Also note that cornstarch should be given to an infant under age one (they lack the necessary pancreatic amylase to digest the cornstarch.

Some physicians may also prescribe Levo-carnitine (FDA-approved Carnitor® or an FDA-approved generic form—these are NOT the same as the healthfood store carnitine), especially if a secondary carnitine deficiency is involved. Although carnitine is made within the body, sometimes supplementation is necessary. It is useful in stabilizing blood sugar levels, increasing muscle tone, and removing metabolic waste products from the cells so a build up of toxins will not occur.

As with any medical condition, discussing treatment options with your physician(s) and FOD specialists is necessary for the well-being of anyone with an FOD. Please do NOT make any changes in your child’s or your own treatment without first consulting with your physicians.

Additional Metabolic Family Support Resources

Organic Acidemia Association (OAA)
Kathy Stagni, Director
9000 De Adult Street
Golden Valley, MN 55427
763.559.1797 phone
https://www.oaanews.org
kstagni@oaanews.org

United Mitochondrial Disease Foundation (UMDF) 8085 Salisbury Road, Suite 201 Pittsburgh, PA 15239
412.793.8077 or toll free 888.317.8633 phone
412.793.6477 fax
https://www.umdf.org
info@umdf.org

Metabolic Support UK (formerly CLIMB)
Unit 11-12 Gwenfair, Technology Park
Croesnewdd Rd
Wrexham, Wales LL13 7YP
0845.241.2173 phone
http://metabolicsupportuk.org
https://www.metabolicsupportuk.org/contact-us/

Expanded NBS & FOD Diagnostic Testing: (more Labs are listed on the fodsupport.org, Medical Info page)

Mayo Molecular Laboratories (Rochester, MN)
800.533.1710 phone for NBS testing,
Diagnostic testing, and Consultation
507.284.1759 fax

baby’s first step (Newborn Screening Resource) Natasha Bonhomme
https://www.babysfirsttest.org/

Mayo Genetics Laboratory
9841 Washingtonian Blvd, Suite 9040 Duluth Street
Minneapolis, MN 55435
1.800.404.2279 phone

Leadiant Biosciences
9841 Washingtonian Blvd, Suite 9040 Duluth Street
Minneapolis, MN 55435
1.800.404.2279 phone

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Early Screening, Diagnosis and Treatment will prevent needless deaths

You are not alone...