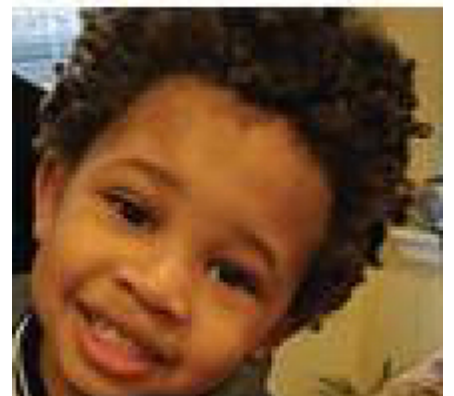
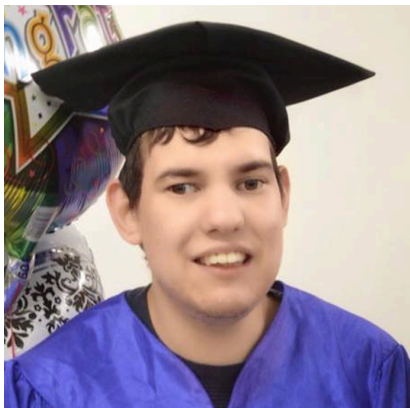
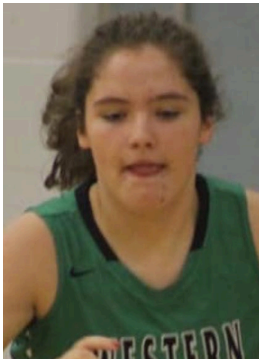


FOD Family Support Group

New Family Packet



Welcome to the FOD (Fatty Oxidation Disorders) Family Support Group

Dear FOD Family Member,

As you open this information kit, we know you likely are struggling with mixed emotions. There may be fear concerning you or a loved one having a rare genetic disorder. There may be anger, confusion, worry, denial, and grief. You may be facing the loss of a child or a lifetime of uncertainty. You may have just received a specific challenging diagnosis or perhaps you have been searching for years to find a diagnosis. We know it can be overwhelming. Regardless of



your diagnosis – or even if you are still searching for one – we hope this information packet gives you some hope and relief. The FOD Family Support Group is here for you. **'We are All in this Together!'**

The FOD Family Support Group has been supporting families such as yours since 1991. Everyone here knows the challenges your family faces as you learn about whichever FOD you or your family member lives with. We have worked tirelessly to provide information, link people to resources, and help educate the public about FODs. **We welcome you to our Group!**

This kit is only the first step in gathering information that is vital to living the best life possible with an FOD and it links you to other valuable resources. We hope you will take advantage of our Facebook group, our website, and our various resources. We are stronger together.

Deb Lee Gould, MEd

Co-Founder & Director, FOD Family Support Group



About the FOD Family Support Group

The FOD (Fatty Oxidation Disorders) Family Support Group™ was created in 1991 by Deb and Dan Gould as a way of dealing with the sudden death of their 21-month old daughter, Kristen, in 1985 from undiagnosed medium-chain acyl Coenzyme A dehydrogenase deficiency (MCAD). Initially, she was given a diagnosis of Reye's Syndrome, but it was not until one year later, when their son, Kevin, was born and diagnosed with MCAD (1986) that they discovered Kristen also had this rare metabolic disorder. Their third child, Brian, is a carrier of MCAD and not directly affected.



Our mission is clear: To connect and network with FOD Families and Professionals around the world and to provide emotional and grief support, family stories, practical information about living with these disorders, and medical updates to inform families of new developments in screening, diagnosis, research, and treatment. In early 2010, we expanded our Mission and Grief Support to include face-to-face and Online support for any bereaved parent/families in the East Lansing, Michigan area, and throughout the US, and not just those dealing with our disorders.



- Family Support & Networking
- Global Awareness & Advocacy
- Newsletters
- MeetUps/Seminars
- Pro Bono Grief Support

FOD

All in This Together

Family Support Group

Awareness of these disorders is imperative for early diagnosis and treatment, prompting us to be strongly committed to promoting *expanded universal and comprehensive newborn screening* for FODs (and several other metabolic disorders) around the world. We do not want other families to needlessly go through what we have experienced.

Fatty acid Oxidation Disorders (FODs) fall under the umbrella of mitochondrial diseases. The mitochondria are tiny organelles found in every cell in the body except for red blood cells. They produce energy by metabolizing the food, or fuel, a person consumes. Mitochondrial failure causes cell injury that can lead to cell death. If multiple organ cells die, the organs can fail.

FODs are inherited, chronic disorders, that may present at birth or later in life. They can cause physical, developmental, and cognitive disabilities, or, some people may be unaffected under normal circumstances but present with symptoms when ill. If you or a loved one is affected, you are welcome here.

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 Gould

Kristen, Kevin and Brian

PO Box 54 Okemos, MI 48805 517.381.1940 fodsupport.org

FOD Family Support Group FAQs

What is the FOD Family Support Group?

[FOD Family Support Group](#) is an all-volunteer, international/national support Group for families living with the rare metabolic disorders called Fatty Oxidation Disorders (FODs).



Who may join the Group?

Anyone who is diagnosed with, or suspects, an FOD, and/or their family members may join. We also welcome medical professionals who are working with our families clinically or in a research capacity. All of the FODs (See **Disorders and Symptoms**) are represented in the Group with members from all around the world.

[Register for our Group](#) - Completing this form will also help us if you choose to sign up for our private Google Email List or Facebook Group.

Are there any fees associated with Joining and participation?

No. All of our services are free of charge, including grief support.

How large is the Group?

Every year, especially since newborn screening has expanded in the United States and in several other countries, we add about 250 new families and affected adults and children. We have offered support and networking since 1991 when the MCAD Family Support Group was first formed by Deb and Dan Gould. In 1995 we expanded to include all of the various FODs. We began with 10 families and now have more than 6,000+ families in our network.



Are you an approved nonprofit?

We became a 501c3 nonprofit in 2007. All donations go toward our networking, Regional MeetUps/Seminars, grief support, supplies, insurances, raising funds for future Programs and Services, etc. *No* money is paid to any of our board members or volunteers and we do *not* use a paid fundraiser.

What services do you offer?

We offer emotional and practical support, as well as family networking via our [Facebook Group](#)/[Google Email List](#) and phone /Skype or zoom video calls; (in the past) an International Metabolic Conference every two years ~ we now offer smaller [FOD Regional MeetUps](#) in the US; an [online Newsletter](#) twice a year; and an [invaluable](#)

[website](#) of practical and research/medical information for laypersons and professionals. Additionally, as a community outreach, face-to-face [pro bono grief support](#) is offered to adults in the Lansing, Michigan area, as well as to others (and our FOD Families) via phone or skype/zoom, for the death of a family member from any cause. We also offer [Awareness Items](#) to purchase such as bracelets, hats, etc., so families can share their FOD experiences with family, friends and professionals. This is a tax-deductible donation.



What else do you do?

We raise funds for present and future FOD Programs and Services, as well as for our Regional MeetUps and Grief Support services. We have credit union savings accounts and an investment account to hold these funds. If funding is available at MeetUp/Seminar time, we also offer scholarships to help families attend. We also collaborate and support other nonprofits that advocate for various efforts (ie., medical formula legislation, comprehensive newborn screening, etc) that would benefit many people, along with our families.

How are you supported?

We do not do mass phone calls or mailings for support, nor do we do major US fundraising events at this time. Our Awareness Items and other [donation links](#) are through our online presence and word-of-mouth of our members and also when we meet in different cities for MeetUps. Families, however, have created FOD Awareness projects on their own (with the understanding that they are not endorsed/sponsored/solicited by the FOD Group) and then they, as individuals, donate to the Group on their own. These vital support and networking efforts not only help fund us, but also empowers our families to learn more about their disorders so they can help themselves and/or their affected children to stay healthy and active throughout their lives.

They learn they are NOT alone in their challenges and that **'We are All in This Together!'**

Meet our Team and Board

Director/President: Deb Lee Gould, MEd (Counseling, 1993)



Deb co-founded FOD Family Support Group with her husband, Dan, in 1991 and has been the full-time Director since then. She and Dan are parents of two affected MCAD children: Kristen was undiagnosed when she died suddenly in 1985 at age 21 months and Kevin was diagnosed at birth in 1986. They also have one son who is a carrier, Brian. Deb has also offered pro bono grief consulting services since that time. Her practice details are on www.bereavedparent.com. As Director/President, she is responsible for presiding at all meetings of the Board. She has the general powers to manage the day-to-day workings of the FOD Group and to be the official spokesperson for the Group. She also provides a networking service (via the google email list and Facebook group) for FOD families and professionals and writes and publishes the Online newsletter twice a year (on pause), monitors the email/Facebook groups, and planned/directed an International Metabolic Conference for 2 decades. At present, the FOD Group is moving more toward a Regional MeetUps in different states every year or two versus a large Conference. Refer to www.fodsupport.org. Before having children, Deb taught K-4 Physical Education (Univ of Illinois, BS/MS 1977/78) and continues to be an avid exerciser. She enjoys walking outside, spending time with her yorkie, Gracie, and fishing on Michigan's lakes when Dan has summer break, before the busy fall semester begins. Email: deb@fodsupport.org

Director/Treasurer: Daniel R Gould, PhD (Sport Psychology, 1977)



As stated above, Dan and Deb co-founded the FOD Group. He has many years of experience dealing with budgets, and presently he is retired from being the Director of the Institute for the Study of Youth Sports at Michigan State University and was responsible for writing grants and managing a budget of @\$200,000 at the Institute. As chief financial officer of the FOD Family Support Group, Dan keeps and maintains correct accounts of the financial transactions of the corporation and sends to the Board the financial statements and reports as required by law or bylaws. As Treasurer, he performs all duties of President if the President or Secretary is unable to perform the duties for any reason. This position is part-time. Dan enjoys swimming and biking. He loves when Gracie snuggles up with him while resting and watching TV at night. He looks forward to enjoying our lakehouse.

Director/Secretary: Mary Lingle



Mary has been a longtime member of the FOD Group and is a bereaved parent of 2-year-old, Candice, who suddenly died in 1993 due to undiagnosed MCAD. She is also the FOD Group's Webmaster and keeps the site up-to-date. She has been an active volunteer with various organizations in the state of Texas. She is on the steering committee for The Compassionate Friends, Tyler, TX chapter, web designer, newsletter editor and their former treasurer. Formerly, she was on the steering committee for the East Texas March of Dimes. As FOD Secretary, she keeps a book of minutes of all meetings of the Board and its committees and a copy of the bylaws of the corporation. In the absence or disability of the President, the Secretary shall perform all duties of the President, and when so acting shall have all the powers of and be subject to all the same restrictions as the President. This is a part-time position. When she's not busy volunteering, she enjoys traveling and sailing and being home with her pets. Email: cartwrightcreative@gmail.com

Disorders and Symptoms

Fatty Oxidation Disorders (FODs), also called fatty acid oxidation disorders, comprise a number of both known and as yet, undescribed, disorders. The following are those that are known:

- Carnitine Transport/Uptake Defect (CUD) (Primary Carnitine Deficiency)
- Carnitine-Acylcarnitine Translocase (CACT) Deficiency
- Carnitine Palmitoyl Transferase I & II (CPT I & II) Deficiency
- Very Long Chain Acyl-CoA Dehydrogenase (VLCAD) Deficiency
- Long Chain 3-Hydroxyacyl-CoA Dehydrogenase (LCHAD) Deficiency
- Trifunctional Protein (TFP) Deficiency
- Medium Chain Acyl-CoA Dehydrogenase (MCAD) Deficiency
- Medium/Short-Chain 3 Hydroxyacyl CoA Dehydrogenase (MCHAD/SCHAD) Deficiency
- Medium-Chain 3 Ketoacyl-CoA Thiolase (MCKAT/MCAT) Deficiency
- 2,4 Dienoyl-CoA Reductase Deficiency (DE RED)
- Short Chain Acyl-CoA Dehydrogenase (SCAD) Deficiency
- Short Chain L-3-Hydroxyacyl-CoA Dehydrogenase (SCHAD) Deficiency (now called 3-Hydroxy Acyl CoA Dehydrogenase Deficiency HADH)
- Electron Transfer Flavoprotein (ETF) Dehydrogenase Deficiency (MADD/GA 2)
- 3-Hydroxy-3 Methylglutaryl-CoA Lyase (HMG) Deficiency
- ACAD9 Deficiency
- Unclassified FODs



There is a **wide variation in the presentation of FODs, even within the same family**. Individuals, both children and adults, may respond to a disorder differently. Some may be without major symptoms, while others may have many hospitalizations, especially during the first years of life. Symptoms will also depend upon the disorder involved. The progression of symptoms in FODs can result in a metabolic crisis, where the body's production of cellular energy falls below the level necessary to sustain life. This most often happens when an illness or injury causes a sudden demand for energy, especially when accompanied by a lack of appetite or sudden decline in the intake of calories. Note that this may occur with relatively minor illnesses such as a stomach virus or flu. This may lead to coma and death if not addressed. However, blood glucose levels should not be solely relied upon as the only indicator of a possible crisis. FODs must not be compared

to diabetes! Blood levels such as ammonia, liver enzymes and creatine phosphokinase (CP or CPK) should also be monitored.



Most FODs are treatable, but one NEEDS to work with their medical professionals to help them manage their daily diet and/or medications and supplements, activities, etc. It is possible to live a long and healthy life with an FOD ~ the KEY is diagnosing/treating it as early as possible and then being proactive in following daily treatment and emergency recommendations.

Also having an INDIVIDUALIZED [Emergency Protocol](#) from your specialist is vital so ER staff know what is necessary to avoid and/or treat a metabolic crisis for your specific FOD and situation.

[More information on these specific disorders](#)

Because FODs are rare, and often even medical personnel are unfamiliar with the signs and treatment, families must be proactive in educating those with whom they interact so that in the event of crisis, no time is lost arguing about treatment.

Typical Symptoms

- Lethargy
- Hypoglycemia
- Extreme sleepiness
- Muscle pain
- Weakness
- Behavior changes/irritability
- Unconsciousness
- Breathing problems
- Cardiac problems
- Coma



Diagnosis

Diagnosing Fatty Oxidation Disorders (FODs), as with any mitochondrial disorder, is difficult because these diseases lack specific biomarkers that would simplify the process. Some FODs may be indicated on the newborn screen while others may require more extensive, costly, and even invasive testing. A diagnosis may take months, or even years.



These disorders are diagnosed in a variety of ways at [specialized laboratories](#) across the country and the world.

Not all FODs are diagnosed with the same tests. Blood, urine, skin fibroblasts, amniocytes (from amniotic fluid) and muscle and liver tissue are some of the specimens analyzed. The diagnostic tests often include an acylcarnitine profile, urine organic acid analysis, carnitine levels and enzyme assays in fibroblasts. The acylcarnitine profile taken at birth, a blood drop on a 'PKU card' (filter paper card), also known as the newborn screen, is the first test administered and will flag many FODs. Not all FODs will be caught on this test. Definitive diagnosis may require more extensive testing under various conditions.

Ultrasound studies of the heart and liver may be required. Neuroimaging, electromyography (EMG) which measures muscle activity, and nerve conduction studies may be required. Many doctors are now also prescribing whole exome or genome testing, especially if some of the other testing is inconclusive. Together, these tests may create enough of a picture for a diagnosis.

Muscle and tissue biopsies may be used to evaluate the an FOD's enzyme activity. These tests will reveal how much enzyme/protein is being made by the affected gene. While invasive, these tests may be required to determine treatment options.

Fatty Oxidation Disorders (FODs) are genetic, autosomal recessive disorders affecting both males and females. Both parents must be carriers of an abnormal gene, so that when two abnormal genes are contributed, the resulting child will have the FOD determined by the affected gene. With two carrier parents, there is a 25 percent chance for each child born to the couple, to either have an FOD or be totally unaffected and a 50 percent chance of being a carrier. If one child is diagnosed with an FOD, their siblings should also be tested for that FOD, even if they are asymptomatic. The odds remain the same for each child conceived, regardless of how many children are born with the disorder. We do have some families with both a parent and a child/children with an FOD.



Treatment

Mitochondrial diseases, including FODs, are not currently curable. However, science is working on therapies to treat and cure these diseases. Current treatments for fatty oxidation disorders can delay or prevent the most serious consequences of FODs but are not curative. Treatment must be considered as two different protocols: one for use in daily life when well, and the other during illness or crisis. A metabolic crisis occurs when the mitochondria are over-taxed by fasting, illness, injury, extreme heat or cold, or overuse. (See Symptoms page.)

When Well

Daily treatment is determined by which FOD is present and the evaluation of the medical team.



For all FODs, diet is currently the only treatment, along with some possible prescriptions and supplements. As FODs limit the production of energy within the cell, care must be taken to provide the body with frequent and appropriate nutrition to avoid crisis. Which foods are appropriate are dependent upon the disorder and its severity. For many with FODs, a lowfat/high carbohydrate diet may be recommended.

Fasting beyond 8-12 hours for anyone with an FOD can result in a metabolic crisis, a life-threatening event. This is the length for an overnight sleep for a child or adult, when well. However, for infants under age six months, around-the-clock feedings every two-to-four hours is required. Most children and adults with an FOD eat often throughout their waking hours, about every 3-6 hours. The interval will depend on their specific circumstances. Note that fasting times can vary, not only from person-to-person but also according to the disorder present. A fasting state, especially while ill, can trigger a crisis leading to lethargy and hospitalization.

Some people with FODs experience hypoglycemia (even with frequent meals). It may be helpful to mix one-to-three tablespoons of raw corn starch (i.e. Argo) into a cold sugar-free liquid or food at night in order to help decrease the frequency of low blood sugar in the morning. Be aware that too much corn starch can be constipating and may promote cavities, so be sure to brush after consuming the cornstarch. Also, note that cornstarch is *not* recommended for children under one year of age because they often lack the necessary pancreatic amylase to digest the cornstarch. **Always consult with your medical professionals.**



Prescriptions and Supplementation

The effects of some FODs can be avoided or minimized with the use of some prescriptions and supplements. As each unique FOD affects the body differently, such supplementation must be done under medical supervision. [Levocarnitine](#) is one such prescription. Carnitine is normally made within the body, but supplementation may be necessary when carnitine deficiency is the primary or secondary disorder. Physicians prescribe the FDA-approved drug Carnitor®, (manufactured by [Leadiant Biosciences](#)), or its generic, levocarnitine. **Note that the carnitine available over-the-counter is *not* the same as the prescribed drug Carnitor®, or its prescription generic, and using it in place of the prescribed drug may be dangerous.** Also note that carnitine may not be necessary or advisable for some people. Follow your doctor's guidance.



Other supplements may be suggested, such as medium-chain triglyceride oil (MCT oil) for those with long-chain disorders. Note that MCT oil (or [c7 Oil – triheptanoin](#)) is *never* used for MCAD as the medium chain triglycerides it contains cannot be broken down. Some FODs are also treated with the use of CoQ10 or riboflavin.

As with any medical condition, discussing treatment options with your physician(s) and FOD specialist is necessary. Do not make any changes in your child's or your own treatment without first consulting with your physician(s).

During Crisis

If someone with an FOD experiences a period of fasting, such as might occur with an illness that



induces fever or vomiting, or if extreme heat, cold, or exercise brings on symptoms of crisis and the person must be hospitalized, *it is imperative that a 10% dextrose IV (5% is NOT enough) is started immediately after blood sampling.* Waiting hours for test results before receiving this can *be fatal* when an FOD child/adult is in crisis. The 10% dextrose/glucose gives needed fuel to the brain and body that the normal saline IV cannot provide. Also, note that even though the child/adult may appear to be hydrated, it does not mean a crisis will not occur. Fluids alone are not enough; *calories* are needed to prevent or survive a metabolic crisis. Many experts also recommend the use of

carnitine ([Carnitor®](#) or [Levocarnitine](#) – **prescribed drugs**, not over-the-counter carnitine) during

crisis. If one cannot keep oral carnitine down due to vomiting, there is an intravenous carnitine available for emergencies. Blood levels such as ammonia, liver enzymes and creatine phosphokinase (CP or CPK) should also be monitored.

During triage, it is important to present the protocol letter from the patient's doctor, copies of which should be carried at all times. A frequent problem for those with FODs is that their presentation at the emergency room with a normally mild illness is misinterpreted. The lethargy, sleepiness, and vomiting are judged as normal when these are actually indicators that a full-blown metabolic crisis is threatening. Insist that D-10 be started, blood and urine chemistries be done, and if met with resistance, call one's geneticist or primary doctor and have them instruct the emergency room personnel. Waiting is not an option!

Energy Well Spent

Energy is required for life. Even when one is sitting still, one's cells are busy creating energy in the mitochondria for all life processes. When the mitochondria are impaired, the production of energy is impaired.

When a mitochondrial disorder is present, efforts must be made to conserve energy. Sleep and rest help everyone recharge, but for those with energy deficiencies, these are even more important. Care should be taken to pace activities so as not to deplete one's energy. Staying well, fed, and hydrated also help the mitochondria work well.



Stress, both physical and emotional, can also drain one's energy. Even positive stress, such as that experienced at a wedding, birth, or other event, can tax the mitochondria. Stress is unavoidable but understanding its role in energy depletion can help one avoid this. Extra rest, food, and hydration should be taken when stress is anticipated.



Exercise in moderation is good but pushing beyond one's limits is unwise for those with FODs. Pain, fatigue, and even organ failure is the result of ignoring the body's needs.

Whenever possible, avoid extreme temperatures, infections, over-exertion, and learn to moderate intense moods. This can help maximize energy and avoid metabolic crisis.

Most people will learn their own, or their child's, indications that their energy is being drained at an alarming rate. This may vary by individual, even within families. Becoming aware of changes in the following can help avoid crisis:

- Skin color
- Vital signs (heart rate, blood pressure, etc.)
- Overall behavior
- Gastrointestinal disturbances
- Drops in energy or alertness

Monitoring these regularly will reveal patterns that indicate when intervention is necessary. Keep in mind that the goal is to keep the body well rested, nourished, and hydrated. Plan ahead for physically or emotionally stressful events. **It is not necessary to withdraw from life, but it is necessary to understand your body and treat it well.**



Clinical Trials

Clinical trials are key components of clinical research and lead to all medical advances. They add to medical knowledge by systematically seeking answers to specific questions regarding treatments and their effectiveness and safety. Typically, trials are done with a large number of participants over a specified period of time. While that is not always possible when testing treatments for FODs, there are several trials that are either ongoing or recently completed. Clinical trials may require more than one phase and the results are dependent on voluntary participation. For more information on clinical trials generally, as well as [those involving FODs](#), go to the [National Institutes of Health](#). You may also [search here](#).

The following are recent Ongoing or Completed clinical trials relating to FODs:



The Oregon Health and Science University is currently studying [fatty acid oxidation defects and insulin sensitivity](#). Its purpose is to learn more about what causes insulin resistance. The investigators want to find out if having an FOD could have an influence on insulin action. They are including both healthy people and those with FOD disorders in the study. They are specifically looking at very long-chain acyl-CoA dehydrogenase (VLCAD), trifunctional protein (TFP) including long-chain3-hydroxyacyl-CoA dehydrogenase (LCHAD) and medium-chain acyl-CoA dehydrogenase (MCAD). The hypothesis under this study is that intrinsic defects in mitochondrial function involving oxidation of long-chain, but not medium-chain, fatty acids are sufficient to prevent insulin resistance. Last updated 2018.

Another study sponsored by **The Oregon Health and Science University, in collaboration with the Children's Hospital of Pittsburgh, is on the use of Triheptanoin for the treatment of long-chain fatty acid disorder.** This study will determine if a new, experimental oil called Triheptanoin (c7) can decrease the muscle pain associated with this FOD and increase heart function. Triheptanoin is a clear, odorless oil that can be mixed with foods and used in cooking to increase the intake of usable fatty acids. Unlike most naturally occurring oils, which are even in chain-length number, Triheptanoin has an odd number of carbon chains. [Dr. Jerry Vockley](#) is the lead investigator of the study. Study Completed - Dojolvi link(c7) is now an FDA drug.

A phase 2 study of Triheptanoin is completed. This study included subjects with long-chain FODs, including VLCAD, LCHAD, TFP, and carnitine palmitoyl transferase (CPT2). Last updated 2018.

A study to determine the long-term safety and efficacy of Triheptanoin is underway at University of California, San Francisco and the University of Utah. This study looks at those with long-chain

FODs who previously enrolled in Triheptanoin studies. This is an open study and participants must have previously participated in Triheptanoin studies. They also must have confirmed long-chain disorders. Study Completed.

A longitudinal [study of mitochondrial hepatopathies](#) is not currently recruiting at the University of California, San Francisco. This study wants to determine the clinical phenotypes and natural history of FODs and to determine the correlation between the genotype (actual defect in the gene) and the phenotype (the manifestation of disease in the person).

In Japan, a [clinical trial of bezafibrate treatment](#) in patients with FODs aimed to establish the *in vivo* (in life) efficacy of this peroxisome proliferator-activated receptor agonist. This study is completed, but a small trial population limited its conclusions. Previous studies on bezafibrate returned mixed results.

Clinical trials are categorized as treatment trials, natural history trials, prevention trials, diagnostic trials, screening trials, or quality of life trials. Participation in any trial is always voluntary and may carry risks. However, many safeguards are in place to ensure safety. The Federal Drug Administration (FDA) must approve any new drug applications and hospitals and research institutions have review boards that oversee trials. Additionally, the Data Safety Monitoring Board (DSMB) are experts who are uninvolved in any trial and who can review trials underway and recommend changes or discontinuation, if warranted.

Please [contact us](#) if you are aware of any updated Clinical Trials or updated information about the above trial info.

More Resources

Many families are initially lost when a family member is diagnosed with or suspected to have an



FOD. Just because they are rare disorders and even family doctors may struggle with clear information about these disorders, doesn't mean there are no resources available. Start with this information packet, but then take a deep dive into [our website](#). There you will find links to other programs and resources related to FODs as well as a wealth of information on many related topics.

At <https://fodsupport.org/newsletters/> you can read how our Group and FOD information has transformed from the formation of our Group in 1991 to the present, as well as how we have networked over the years via past Conferences and now via [Regional MeetUps](#).

Perhaps nothing helps a family more than connection with other families who have gone before them or are currently traveling the same path. FOD families connect daily on the FOD Facebook page. Request to join at <https://www.facebook.com/groups/FODFamilySupportGroup/> - be sure to answer the 3 questions or there will be no activation. If you have any questions Contact Deb at deb@fodsupport.org and ask to be added.

For those with metabolic disorders such as FODs, the word 'crisis' means a loved one is in imminent danger. Be prepared with the resources found here: <https://fodsupport.org/urgent/>. This sets out in plain language why emergency room personnel must prioritize the FOD patient and gives you the resources to make this happen.

If you have questions about prescription carnitine for your FOD, see <https://fodsupport.org/pharmaceuticals/> for more information. This also links families to financial assistance for medications.

At <https://fodsupport.org/nutrition/> you will find links to nutrition sites, information about food allergies, recipes for fat-free or low-protein meals, nutrition guidelines, heart-healthy cooking, dietary supplements, nutritional charts, and more.

At <https://fodsupport.org/sites/> you will find information on medical identification jewelry, how to travel safely, a listing of US hospitals, children's hospitals, and genetic clinics, which medications to avoid, G-tube care, special equipment, maternal health, links to other support groups for related issues such as developmental delays, and many other helpful health links.

At <https://fodsupport.org/child/> you will find answers to questions you might have about such issues as when to go to the hospital, what blood sugar means with an FOD, what an emergency protocol letter is and how to get one, and other issues related to having a child with an FOD.



If you are struggling though the loss of a family member, you may find comfort and healing through reading some stories of those who have also suffered this loss. These are available at <https://fodsupport.org/coping/> along with other links that may be helpful. Remember, [grief support is available at no charge](#) to all FOD families (Adults only). Email Deb at deb@bereavedparent.com or call 517.381.1940. [Deb](#) has a Masters in Counseling (specialization in Grief Counseling) and has been offering support since 1991. We have also recently expanded our group's mission to include face-to-face grief support in the local East Lansing, Michigan area for any family death. Online video support for the death of a child is also available to those elsewhere in the United States.

Educational concerns for those with FODs may encompass everything from disabilities to convincing your child's school that an FOD is serious. You will find helpful information and links here <https://fodsupport.org/educational/>.

For questions regarding insurance, government programs, and state laws governing Medicaid, see the link at <https://fodsupport.org/insurance/>.

For reviews about books related to parenting or having an FOD, see our link at <https://fodsupport.org/book>.

In a world where the news is always on, it is difficult to locate pertinent information that is up-to-date. <https://fodsupport.org/in-the-news> simplifies this with an extensive list of articles and news about all things relating to FODs from news about the newborn screen, to various other health issues.



The FOD Family Support Group is international and at <https://fodsupport.org/support/> those both inside and outside of the United States can find support resources close to home. This also includes other metabolic and bereavement resources.

Join the Cause

FOD Family Support Group needs your help to continue to provide help and hope to families with these disorders. You can help in a number of ways found on [our site](#):

- You can purchase many different [FOD Awareness Items](#) to show your pride in being an FOD Family!
- If you purchase items on Amazon, specify FOD Family Support Group in your AmazonSmile or Prime account as your Charity and remember to always go to your AmazonSmile link when you order. A portion of your purchase will automatically support the FOD Group.
- Shop hundreds of online stores with [iGive.com](#). A percentage of your purchases from each store are given to the FOD Group. iGive often has bonus amounts for signing up and for shopping.
- Hold a local run or walk or other [family fundraiser](#) to create FOD Awareness and send a check directly to us. Note: you cannot pass on our tax deduction to those who participate unless their checks are made payable to FOD Family Support. If they pay you cash, you get the deduction based on what you contribute in a check to the FOD Group and mailed to [their address](#).
- Participate in local health fairs, community events, or Medical rounds where you can educate your community and health professionals about FODs. You may be able to make presentations at schools, churches, or other events. You are welcome to print off anything from our site to share.
- Host a local FOD MeetUp. This would be a wonderful way to network with local FOD Families and share experiences. The FOD Group can assist you, but your MeetUp would be your event to run. [Deb](#) can share an outline for planning a local meetup.
- You can donate through United Way, Network for Good, facebook fundraisers or through the [FOD website](#). Your personal contribution is always welcome and is tax deductible. If you prefer, you may send your check made out to 'FOD Group' directly to:
Deb Lee Gould, MEd, FOD Family Support Group, PO Box 54, Okemos, MI 48805-0054.





PO Box 54 Okemos, MI 48805

517.381.1940

fodsupport.org