Welcome to our Main FOD Email List ~ List Rules & Etiquette

We are a very focused List SPECIFIC to FODs (as a primary or secondary diagnosis) and not a broad based List dealing with various other mitochondrial type disorders. There are several other Lists and Message Boards available on the internet that are not as focused as this List and are open to the public. Our List is open to FOD Families (and family members) and professionals working with FOD Families.

Our Main FOD List is for emotional and practical support for FODs only, as well as our subGroup (see MCAD List below)~

Messages are sent worldwide to hundreds of members. We have a very diverse group of members as far as ethnic background, religious beliefs, political beliefs, etc ~ and that is to be respected. However, **this List is for FOD related issues ONLY and is not a faith-based public religious or political forum.** There are other internet Lists for such a purpose. Please keep that in mind when posting your FOD concern or question.

***Please note that our Group's disclaimer (on the website at http://www.fodsupport.org/disclaimer.htm) is in effect for every message posted or responded to by any member. Medical, legal etc advice is **not** to be given over this List ~ please contact your Family's professionals for that type of information. Sharing what you have done in regard to your or your child's treatment is okay, but please be sure to post that you are following your professionals' advice. For liability reasons, please also refrain from naming names if you've had a bad experience with a medical professional/hospital.

SAVE the links below and to avoid missing messages (by having them go into spam files) put these addresses on your safe list:

The email address for this MAIN FOD List is FODsupport@googlegroups.com

The List Web page for this MAIN FOD List is http://groups.google.com/group/FODsupport

You can choose your List, read past messages/discussions, change password and mailing preferences from the List Web page.

Please sign <u>EACH</u> post with your 1st name/child's name and disorder/state or country.

Example: John, dad Mary, 34 yrs/adult onset CPT 2

Hunter, 2 yrs old/MCAD or Australia

New York

Enjoy this great way to network!

Take care...

Deb Lee Gould, MEd Mary, webmaster: mcartwrite@aol.com

Director, FOD Family Support Group

deb@fodsupport.org [backup address - fodgroup@gmail.com]

We also offer an MCAD subGroup that you can choose to join in addition to our MAIN FOD List. It is offered as a complement to the Main List. Because it is a more active subGroup, it will remain open for posting - however our 2 other subGroups below will not be open for posting - you can still view the Archives from their List webpage however.:

MCAD subGroup List web address and signup: http://groups.google.com/group/fodsupport-mcad MCAD subGroup List email address: fodsupportmcad@googlegroups.com

We had originally set up the 2 subGroups below but because there are other Lists on the internet that are more active (we have some FOD Families that had started a yahoo list several years ago and it is very active) - **we have deactivated these 2 subGroups for posting only**. If you are interested, you can still sign up and **read the archived messages but you will not be able to post**. If you have problems viewing the archive please let me know and I will try and adjust the settings for that List.

VLCAD/LCHAD/TFP subGroup List web address and signup: http://groups.google.com/group/fodsupport-vlcad-lchad-tfp

SCAD/GA2/CPT 1& 2 subGroup List web address and signup: http://groups.google.com/group/fodsupport-scad-ga2-cpt

Our <u>OLD</u> <u>Listserve Archives</u>: Use the Username 'FOD' and Password '1991' to read years of past messages http://fodsupport.org/oldlistarchives/

*** Disclaimer and Requests for List Content and Behavior:

This list is a link to other families (some medical and health-related professionals are also on this List) living with a Fatty Oxidation Disorder (FOD). It is to be used to convey emotional support and practical information, to ask questions, and/or to share experiences ~ in a mature and responsible manner (please avoid naming names and name-calling, especially when criticizing a person/place/situation you may have had difficulty with).

*** Please be aware that the Disclaimer on our website's homepage left sidebar (www.fodsupport.org) applies to our Email List as well, so please make sure to read that immediately. Even though families may share their child's/their own medical or nutritional situation/treatment, IN NO WAY does any member of the FOD Family Support Group or anyone on this List endorse other families making changes in their child's/their own treatment based on what is written/read on this List or on the website! That is to be decided between their Dr and specialists and themselves. So please remember if you choose to share that information make it a point to also write out a statement that you are not endorsing any changes in anyone's treatment. Changes should ONLY be made after discussing the situation/concerns with your own Drs and/or FOD specialists.

**To ALL health care/medical professionals on the List ~ note that if you respond to a member's MEDICAL question and answer as a function of your specialty or present job position, please make sure you share your comments with your 'direct supervisor' or colleagues before you post so the information is as accurate and as clear as can be. Be aware of your own institution's policies as well.

Also, Please do not use this List for the propagation of 'unsolicited' email, including jokes, advertisements, or other forms of 'junk' email or FORWARDED personal or public messages, such as recall messages or funny stories etc. Also do not directly forward any messages from our List to another List (unless you get emailed permission from the original sender) -- confidentiality will be breached. Violations of this request may cause your removal from this list.

This List has hundreds of members and is a very diverse group of individuals with different ethnic backgrounds, faiths and beliefs ~ please do not use this List as a forum for your religious or political etc beliefs. There are other Lists on the internet that allow messages to contain explicit religious, political etc content ~ THIS List is for FOD related concerns only. If one chooses to make religious, political etc comments, please write them to individual members OFF the List and not to the entire List. Thank you for understanding our position on this issue. Be aware that spirituality is different than religious dogma, and stating that a family is in your prayers and thoughts is certainly appreciated.

It is STRONGLY encouraged that you have an ANTIVIRUS program activated on your computer so viruses are not sent through the List via messages or document attachments.

When posting or responding to a message over any of our Lists, be sure to type a SUBJECT and if you want to change TOPICS please start a new thread of messages. Please sign EACH post with at least your 1st name, disorder you/your child has, and your state or country.

Some 'signatures' have gotten too long and explicit ~ if you'd like to share more than the specific FOD in your signature please use the Profile feature in your google account. The MAIN List will not allow members to see the Member List and all the email addresses but you will be able to see the Member List in the MCAD subGroup (however, we may change that if it's abused.). Again, please use the Profile feature to share further appropriate information (within our List 'Rules').

Thank you in advance for your attention to these requests.

Again, welcome to the FODsupport Email List. We hope that you will find this to be a valuable source of support and information while dealing with your child's/childrens' FOD, your own FOD, or if you are a professional in the field of FODs.

Please SAVE these links.

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The List Webpage address for the MAIN FOD List is http://groups.google.com/group/FODsupport