



Deb Lee Gould, MEd, Director  
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**FAMILY QUESTIONNAIRE**

**Date:** \_\_\_\_\_ **Specific Disorder:** \_\_\_\_\_ **Affected:** Child/ren or Adult

**Name(s) of Affected Individual(s)** \_\_\_\_\_

**Present Age:** \_\_\_\_\_ **Age at Diagnosis:** \_\_\_\_\_ **Living or Deceased?** **Birth Date:** \_\_\_\_\_ **Death Date:** \_\_\_\_\_

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**Was the Diagnosis made after Expanded Newborn Screening?** Yes \_\_\_\_\_ No \_\_\_\_\_ **After Death?** Yes \_\_\_\_\_ No \_\_\_\_\_



**Parent/Your Name (print):** \_\_\_\_\_ **Phone:** \_\_\_\_\_

**Address:** \_\_\_\_\_

\_\_\_\_\_ **Country:** \_\_\_\_\_

**Email Address:** \_\_\_\_\_ **Fax:** \_\_\_\_\_

**Would you like to be listed on our printed Family List?** Yes \_\_\_\_\_ No \_\_\_\_\_

**Do we have your permission to share your information from this Questionnaire with other FOD Families and/or interested Professionals for networking purposes?** Yes \_\_\_\_\_ No \_\_\_\_\_

**Do we have your permission to share/publish any Family Stories, articles, pictures, etc, that you may submit for our website or online/printed newsletter?** Yes \_\_\_\_\_ No \_\_\_\_\_

●●● **SIGNATURE:** \_\_\_\_\_ **DATE:** \_\_\_\_\_



**How did you first hear about your/your child's disorder?** \_\_\_\_\_

\_\_\_\_\_

**Who made the diagnosis?** \_\_\_\_\_

**Was there a MISdiagnosis (what was it) before the correct diagnosis?** Yes \_\_\_\_\_ No \_\_\_\_\_

\_\_\_\_\_

**How long did you search for a diagnosis?** \_\_\_ year(s) \_\_\_ months

(more on the back)

Did you/your child have any severe episodes that resulted in residual effects BEFORE a diagnosis?

Yes \_\_\_\_ No \_\_\_\_

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Do you/your child utilize any special services, such as physical therapy, special ed classes etc? Yes \_\_\_ No \_\_\_

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Current Treatment (ie, lowfat/high carbo diet, MCT oil, carnitine, cornstarch, g-tube etc): \_\_\_\_\_

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Do you have other UNAFFECTED children? Yes \_\_\_\_ No \_\_\_\_

Name (M/F): \_\_\_\_\_ Present Age: \_\_\_\_\_

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Name (M/F): \_\_\_\_\_ Present Age: \_\_\_\_\_

Other Comments, Concerns, Suggestions for the Newsletter or Website??

♥♥♥ Please Return this Signed and Dated Questionnaire to Deb Lee Gould  
(address on the letterhead) ASAP if you wish to be listed in our next updated  
FOD Family List.

Take Care...

*Deb Lee Gould, MEd*

*Director, FOD Family Support Group*