

APPROVED: Jun. 13, 2011

We are conducting a survey among patients diagnosed with either mitochondrial trifunctional protein deficiency or long-chain 3-hydroxyacylCoA dehydrogenase deficiency (TFPD or LCHADD). Our survey can be accessed at the following url: <https://octri.ohsu.edu/redcap/surveys/?s=e1745a>.

This study aims to determine which features of these deficiencies may be related to vision loss. We also hope to determine the frequency of certain changes in the DNA in genes that code for trifunctional protein (TFP) in the United States. The investigators of this study are Melanie Gillingham, PhD, RD and Cary O. Harding, MD.

This research study consists of two components. The first component is an online survey to be filled out by the subject or their parent/guardian. The second is a request to review medical records. Participation in either portion of this research study is voluntary. Medical record release is not required for participation in the survey portion of the study.

The online survey component of the study consists of questions about your medical history, and questions from the National Eye Institute Visual Function Questionnaire. There are a maximum of 88 questions, depending upon your answers. We expect that the survey will take no more than 1 hour of your time.

This study was approved by the Oregon Health & Science University. If you would like more background information about this study, please refer to the FODsupport.org newsletter published in January 2011 available online at <http://www.fodsupport.org/documents/Jan2011issue.pdf>. This issue of the newsletter contains a lay review entitled *What causes retinopathy in long-chain 3-hydroxyacylCoA dehydrogenase deficiency?*

If you have questions about this study at any time, please call Autumn Fletcher, study coordinator, at (503) 418-0109 or send an email to fletchea@ohsu.edu.

Thank you for your time.

Sincerely,

Melanie Gillingham, PhD, RD
Cary Harding, MD

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