Instructions for Participation in University of Washington Research Study
Biomarkers for GM1 Gangliosidosis

Dear GM1 Family,

Cure GM1 Foundation is working with researchers at the University of Washington to collect data on biomarkers in newborn dried blood spots from GM1 patients in order to develop a method for newborn screening for GM1. Newborn screening can be deployed once treatment options are developed. The researchers would like to obtain the newborn dried blood spots from your state’s newborn screening lab from the affected GM1 patient in your family. These dried blood spots will be used to measure the level of specific biomarkers. This information may be useful someday in predicting the severity of the disease in newborns who test positive in newborn screening. If you would like to participate in the study, please follow the instructions listed below:

1) Read and sign the attached University of Washington Consent Form.
2) Complete the attached University of Washington Gelb Laboratory Questionnaire.
3) Complete the attached dried blood spot request form for your state’s newborn screening lab. This form has been partially filled out in some cases. Cure GM1 Foundation will submit the form to the newborn screening laboratory. Please return completed form to Cure GM1 Foundation.
4) Send all of the above forms to us at:
   Attn: Christine Waggoner
   Cure GM1 Foundation
   PO Box 6890, Albany, CA  94706
   Or, email the forms to: christine@curegm1.org

Once Cure GM1 receives the dried blood spots from the state laboratory, we will de-identify the sample and send it to Dr. Gelb at the University of Washington. Each sample will be assigned a code linking the patient’s identity and questionnaire in order to maintain confidentiality.

Please contact Jessica Quintilian at jessica@curegm1.org or Christine Waggoner at christine@curegm1.org if you have questions about the study or need additional information. We can also be reached by phone at 510-560-6154.

Thank you for participating in this valuable research study!