October 31, 2018

Dear MPS Family,

The National MPS Society is working with researchers at the University of Washington to improve the precision in newborn screening for MPS syndromes. The researchers would like to obtain the newborn dried blood spot from your state's newborn screening lab from the affected patient in your family. This dried blood spot will be used to measure the level of specific biomarkers (glycosaminoglycans) in the sample by an analytical technique called mass spectrometry. The goal of the study is to see if the levels of specific biomarkers can predict the type of MPS syndromes, and the severity in terms of the age of onset of syndrome-specific symptoms. This information will be critical in improving newborn screening and the diagnosis for MPS. Several states have started to screen for MPS I, and so the study is timely and will be useful for all MPS syndromes.

If you would like to participate in this study, please follow the instructions listed below.

***You may begin sending these forms immediately, but all forms must be returned by January 15, 2019.***

**Return all forms to NATIONAL MPS SOCIETY, PO Box 14686, Durham NC 27709.**

1. Read the **UNIVERSITY OF WASHINGTON CONSENT FORM**, and if you agree, please sign the form and return this to the National MPS Society.
2. Please fill out the **UNIVERSITY OF WASHINGTON QUESTIONNAIRE FOR STUDY** form and return it to the National MPS Society.
3. Enclosed is the **dried blood spot request form for your state's newborn screening laboratory.** It has been partially filled out in some cases. Please also include any additional items that the newborn screening laboratory asks in their request form (self-explanatory). The National MPS Society will submit the form to the newborn screening laboratory. Please complete the form and return to the National MPS Society.

If you have questions about the study please feel free to contact Leslie Urdaneta, at leslie@mpssociety.org or Katelyn Blackman at katelyn@mpssociety.org. You may call directly at 919.806.0101.

Thank you in advance for your valuable time and assistance with this study.

Sincerely,

Terri Klein, President and CEO