

To whom it may concern:

We are reaching out to you because your patient is enrolled in our research study, Simons Searchlight, a study that has been reviewed and approved by an ethics committee (Geisinger IRB 2011-0320), on rare genetic conditions that impact brain development. If you'd like to learn more about our study, feel free to visit our website, SimonsSearchlight.org.

As part of the study, your patient and/or their family has opted to donate a **blood sample** to us. Contributing a blood sample allows researchers to gain access to biological samples on our participants, in addition to the phenotypic information they are providing. Qualified researchers apply for the sample(s) and undergo a formal review process. We remove identifying information from the samples and store them in a secure facility. We do this to help advance our knowledge of these conditions and work to develop treatments.

Participants in the United States have the option to have blood samples collected at a local Quest Diagnostics center. Your patient has indicated that their local Quest Diagnostics center is not an option for them. As one of their regular providers, they are asking if you would be willing to complete the blood draw. If you would like any documents showing our research approvals, such as our consent, protocol, etc., we can supply them to you.

The blood draw itself is straightforward, and we provide the patient with the materials to complete the process. The tubes are drawn in the order of yellow top – purple top – yellow top – purple top. For younger patients, there may be less than four tubes, but the draw order of yellow, purple, yellow should still be followed. Once drawn, the tubes need to be placed back in the package and sealed for shipping (pre-paid by us). Either you or the patient may schedule FedEx to pick up the sample. You do not need to process the samples in any way, and the package is shipped ambient (not on ice). The kit will include all necessary shipping items, including the prepaid FedEx label. If at any point, any problems arise, you or your staff can call us at 1-855-329-5638 or email us at coordinator@simonssearchlight.org.

We appreciate your consideration in helping us conduct our research. Please feel free to reach out to us with any questions or concerns!

Thank you,

Wendy Chung, M.D., Ph.D.

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Principal Investigator