

September 27, 2013

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RE: Chapter 246-650 WAC Newborn Screening

We are very excited about initiating newborn screening for Severe Combined Immune Deficiency (SCID) in the state of Washington. As clinical Immunologists, we have watched a number of patients with SCID die because they were too sick to survive due to their severe infections. It is particularly agonizing given that we have curative therapies that are highly successful if patients do not have life-threatening infections at the time they come to transplant. We are committed to assisting the DOH to make this program successful. We will provide support for SCID Newborn screening in the state of Washington in four specific ways:

First, we will provide any needed technical assistance related to running the screening assay. The team from the Department of Health (DOH) lab has already visited our Immunology Diagnostic Lab (IDL) where we have the this technique established as a clinical assay.

Second, Drs. Troy Torgerson and Suzanne Skoda-Smith will serve as the primary points of contact within the Immunology Division for babies identified by newborn screening. They will coordinate and interpret the confirmatory flow cytometry testing that will be performed on infants with a positive screen. Our goal will be to evaluate all potential SCID patients picked up by the screen within 1 week in our Immunology Clinic at Seattle Children's Hospital. This will allow us to initiate prophylactic therapies and then begin the process of identifying a suitable bone marrow donor or gene therapy protocol.

Third, we will utilize the capabilities of our CLIA-approved Immunology Diagnostic Lab (IDL) to provide rapid molecular characterization of all infants who are identified with SCID.

Fourth, we will treat all identified SCID patients with definitive, life-saving therapies. We have a well-established and nationally recognized program for bone marrow transplantation for non-malignant diseases including all forms of SCID. This program co-directed by Dr. Lauri Burroughs at the Fred Hutchinson Cancer Research Center and Dr. Troy Torgerson in the Division of Immunology.

Immunology

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We look forward to being able to start screening in the state and are grateful to be able to continue the excellent collaborative relationship that we have built with the team at the DOH lab over the past 3 years.

Sincerely,

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