



MARK B HORTON, MD, MSPH  
*Director*

State of California—Health and Human Services Agency  
California Department of Public Health



ARNOLD SCHWARZENEGGER  
*Governor*

August 13, 2010

Dear Pediatric Primary Care Provider:

As you know, in the past five years the California Newborn Screening (NBS) panel has been expanded to include screening for numerous metabolic disorders via tandem mass spectrometry, as well as screening for congenital adrenal hyperplasia, cystic fibrosis and biotinidase deficiency. In January 2010, the United States Department of Health and Human Services (DHHS) Secretary's Advisory Committee on Genetics, Health, and Society (SACGHS) recommended that severe combined immunodeficiency (SCID) be added to the list of disorders that all newborn screening programs in the country include in their testing panels. HHS Secretary Kathleen Sebelius recently accepted and endorsed those recommendations.

To make sure our State meets the most current medical standards, the California Newborn Screening Program has begun development efforts to move toward adding SCID to the California Newborn Screening panel. Therefore, beginning in mid August 2010, once our regional laboratories have completed standard newborn screening on the dried blood spots, we will be using part of the remaining NBS specimen to test for SCID. Although it is unlikely (because SCID is rare), you may be contacted by the newborn screening follow-up coordinator if one of your patients has a positive or an inconclusive SCID screening result that requires follow-up.

The additional testing to confirm or rule out SCID will be provided by the Newborn Screening Program at no additional cost to you or the patient's insurance company or family. While we will be testing all newborns for SCID during this program development phase, we will not be reporting out negative SCID screening results. We will report out positive and inconclusive results, via both telephone and written report. The SCID report will be separate from the standard newborn screening report. After the program development phase when SCID screening becomes part of the routine newborn screening panel, the results (both positive and negative) will be added to the printed newborn screening result mailer that you receive on all your patients. We expect that to occur sometime late in 2011.

For more information on SCID please see the below websites:

<http://primaryimmune.org/>

<http://www.info4pi.org/>

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If you have additional questions, please contact your local newborn screening follow-up coordinator at the number listed on the bottom of the newborn screening results you receive.

If you have questions specifically on this group of immune disorders please contact one of the two following specialists working with our program.

In Northern California:

**Jennifer Puck, M.D.**  
**University of California San Francisco**  
**(415) 476-3181**

In Southern California:

**Sean McGhee, M.D.**  
**University of California, Los Angeles**  
**(310) 825-6481**

Sincerely,



Fred Lorey, Ph.D.  
Acting Chief, Genetic Disease Screening Program  
California Department of Public Health

cc: Jennifer Puck, M.D.  
Sean McGhee, M.D.  
Erica Gordon, MA  
Karen Whitney, MS  
Newborn Screening Follow-up Coordinators