



STATE OF MICHIGAN

DEPARTMENT OF COMMUNITY HEALTH  
LANSING

RICK SNYDER  
GOVERNOR

OLGA DAZZO  
DIRECTOR

September 30, 2011

## **Newborn Screening for Severe Combined Immunodeficiency Implementation October 1, 2011**

To Directors of Pediatrics, Special Care Nurseries and Neonatal Intensive Care Units:

We are asking you to inform your newborn nursery and NICU attending physicians that beginning October 1, 2011 severe combined immunodeficiency (SCID) and other primary immunodeficiency disorders will be added to the dried blood spot newborn screening panel for a total of more than 50 disorders.

SCID represents a group of more than a dozen inherited disorders that lack functional T-cells and B-cells responsible for cellular and humoral immunity, respectively. Newborns with SCID are unable to mount an immune response to infection by viruses, bacteria and fungi. The usual treatment for SCID is hematopoietic stem cell transplantation (HSCT).

The objective of newborn screening for SCID and related disorders is to allow for early diagnosis and treatment, before the onset of infection. The optimal time for bone marrow transplant, which is often curative, is prior to three and a half months of age. Babies who are not diagnosed and treated early typically acquire multiple severe and chronic infections. As a result, they rarely live beyond one year of age.

Approximately 1/35,000 – 1/100,000 individuals is affected with SCID. We anticipate that each year about 150 Michigan newborns will have a positive SCID screen; of these, two or three babies will be confirmed to have SCID. Others will have a different primary immunodeficiency disease (PIDD) or genetic syndrome with impaired immune function requiring treatment. For affected infants, genetic testing will be arranged by the PIDD referral center to identify the type of SCID or other primary immunodeficiency and appropriate treatment regimens. There are currently three designated PIDD care centers in Michigan:

- Children's Hospital of Michigan (Detroit), which will serve as the State Primary Immunodeficiency Coordinating Center: **(313) 461-5245** [Dr. Secord]
- UM- C.S. Mott Children's Hospital (Ann Arbor): **(734) 936-9814** [Dr. Walkovich or Dr. Connelly]
- DeVos Children's Hospital (Grand Rapids): **(616) 267-2300** [Dr. Dahl]

Infants with a positive newborn screen will require prompt confirmation of their diagnosis by complete blood count with differential and flow cytometry in conjunction with consultation by a pediatric immunologist or infectious disease specialist. However, most infants with a positive newborn screen will be found to have normal immune function after further testing. Prompt interpretation of results and communication with the patient's primary care physician will be provided by Michigan Department of Community Health and PIDD Coordinating Center staff. If you have any questions or concerns, please contact us at 1-866-673-9939 or by e-mail at [NewbornScreening@Michigan.gov](mailto:NewbornScreening@Michigan.gov).

Sincerely,

William Young, PhD  
Manager, Newborn Screening Follow-up Program

CAPITOL VIEW BUILDING • 201 TOWNSEND STREET • LANSING, MICHIGAN 48913  
[www.michigan.gov](http://www.michigan.gov) • 517-373-3740