Immunodeficiency Canada
Immunodéficience Canada

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Patient Support, Education and Research for a Cure for Primary Immunodeficiency

What is Severe Combined Immune Deficiency (SCID)?

The World Health Organization recognizes over 150 different forms of Primary Immunodeficiency ranging in severity. SCID is among the most severe. Newborns with SCID do not have a functioning immune system to fight off infections. They appear healthy at birth, but develop life-threatening infections within the first few months of life. Without a diagnosis, these infants are repeatedly hospitalized and often die before their first birthday.

What is the treatment for SCID?

Once serious infections develop, SCID is fatal unless a working immune system is provided by a donor through a bone marrow transplant.

Why newborn screening for SCID?

Newborn screening for SCID allows babies with the disease to be identified before they get infections, so that early treatment can begin. Evidence suggests that bone marrow transplantation performed before the age of 3.5 months offers the best outcome. *R. Buckley (2011). Transplantation of hematopoietic stem cells in human severe combined immunodeficiency: long-term outcomes. Immunol Res 49: 25-43*

Who else is screening for SCID?

Ontario is the only Canadian province currently screening newborns for SCID. In 2008, Wisconsin was the first jurisdiction in the world to screen newborns for SCID. Several other US states have implemented SCID screening, most recently Pennsylvania and Utah. There are no newborn screening programs outside of North America screening for SCID.

How common is SCID?

Previous estimates showed 1 in 100,000 newborns will have SCID. A May 2011 review of a pilot study involving 961, 625 infants screened in the United States indicated an incidence of 1 in 69,000, with New York state having an incidence as high as 1 in 34, 000. *Secretary's Advisory Committee on Heritable Disorders in Newborns and Children. Newborn Screening for Severe Combined immunodeficiency Disorder. Report on the status of newborn screening for SCID to the US Secretary of the Department of Health and Human Services. May 2011* Approximately 50 infants in Ontario will screen positive each year for SCID, requiring follow-up investigations, and about 5-10 will ultimately be diagnosed.

How was SCID added to Ontario's newborn screening panel?

In July 2012, under the direction and leadership of Professor Chaim Roifman, MD, FRCPC, Chair and Scientific Director of Immunodeficiency Canada and following a nomination process which involved a formal submission, presentations to committees, and letters of encouragement from many families whose children were born with SCID, Immunodeficiency Canada formally asked the Hon. Deborah Matthews, Minister of Health and Long-Term Care, to add SCID to the list of diseases for which all newborns are screened at birth. After a detailed review, the Minister of Health and Long-Term Care approved and committed funding to Newborn Screening Ontario to begin SCID screening in August, 2013.

About Immunodeficiency Canada

Immunodeficiency Canada (Canadian Immunodeficiency Society) was created in 1999 in response to the untimely and unnecessary deaths of children across Canada. Today, it provides patient support, education and research for a cure for Primary Immunodeficiency. For more information, please contact the following Immunodeficiency Canada spokespersons:

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