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## **A first in Canada, Ontario newborns to be screened for fatal but curable genetic disorder**

**Screening for Severe Combined Immune Deficiency (SCID) expected to save lives**

**AUGUST 20, 2013—OTTAWA—** Imagine being able to save a baby's life with a simple test for a deadly illness. Thanks to funding from the Ontario government, Ontario is the first jurisdiction in Canada to test every infant born in the province for Severe Combined Immune Deficiency (SCID), a deadly disorder previously known as "Bubble Boy Disease". Newborn Screening Ontario (NSO), based at the Children's Hospital of Eastern Ontario (CHEO), will conduct the screening.

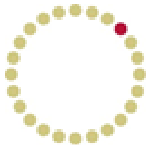
SCID is a genetic disorder that is only detectable with screening. There are usually no clues at birth that a baby has SCID, although these babies are prone to recurrent, life-threatening infections in the first 6 months of life because of faulty immune systems. They eventually die from complications. Currently, many infants with SCID do not receive a diagnosis until it is too late for treatment to be effective. SCID can often be cured with a bone marrow transplant.

NSO now screens all babies born in the province for 29 disorders, including SCID which was added August 12. This is the first time that screening can offer not only effective treatment, but a complete cure for a disease.

"Our daughter Brooklyn died of SCID because there was no screening for the disorder," says Lori Peters. "However, we had our son Ethan tested when he was a baby and he is now a healthy 8 year-old, thanks to early detection, the care of Dr. Roifman and a bone marrow transplant. It is absolutely critical that every baby is screened for this disorder."

"This is a monumental triumph to children born with SCID and to their families" says Dr. Chaim Roifman, Pediatric Immunologist and Scientist at The Hospital for Sick Children in Toronto, Director of the Jeffrey Modell Centre for Primary Immunodeficiency and Chairman of Immunodeficiency Canada. "Newborn screening will detect this problem early before complications develop, and allow for prompt life-saving interventions. It will no doubt save many lives and prevent suffering of children." Dr. Roifman nominated SCID to be added to newborn screening in Ontario.

"With this simple screen, we will be able to save the lives of the 5-10 babies born with SCID in Ontario each year," says Dr. Pranesh Chakraborty, Director of Newborn Screening Ontario. "We are very thankful that the Government of Ontario made the



decision to screen every newborn for SCID, and provided the funding for us to do this. Newborn screening gives kids with rare diseases the chance to access the treatments that can literally save their lives"

"Our government remains committed to ensuring that Ontario newborns get the best possible start in life," says Deb Matthews, Minister of Health and Long-Term Care. "The inclusion of testing for Severe Combined Immune Deficiency (SCID) for all babies in the province, firmly establishes Ontario's newborn screening program as the most comprehensive in Canada."

This life-saving test is made possible by a \$1 million investment by the province of Ontario in new screening equipment and training costs and an annual operating investment of \$1 million. SCID screening will be performed from the screening samples that are currently collected and no additional blood collection will be required.

"Screening for SCID will not only change lives, it will save lives in Ontario," says Alex Munter, CHEO's President and CEO. "CHEO is very pleased to be part of this initiative that leads the way in Canada."

### **About NSO**

Newborn Screening Ontario (NSO) has tested over one million newborns for rare diseases that are treatable. Since NSO started at CHEO in 2006, over 1250 newborn babies with these diseases have been diagnosed through newborn screening. NSO is the most comprehensive newborn screening program in Canada, and is one of the largest and most modern programs in the world.

CHEO is a pediatric health and research center providing outstanding family-centered patient care, pioneering breakthrough research, and training the health care professionals of tomorrow.

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**Online media kit available at [www.newbornscreening.on.ca](http://www.newbornscreening.on.ca)**

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