

Ontario celebrates first anniversary of “bubble boy” testing as new study shows it is twice as common among newborns

August 20, 2014, Ottawa, Ontario – Newborn Screening Ontario (NSO), based at the Children’s Hospital of Eastern Ontario (CHEO), this month celebrates the first anniversary of screening newborns across the province of Ontario for Severe Combined Immune Deficiency (SCID), a deadly disorder previously known as “Bubble Boy Disease”. According to a new study published today in the [Journal of the American Medical Association](#), SCID affects 1 in 58,000 newborns, not 1 in 100,000 as previously thought.

Ontario, where 40% of Canadian babies are born, is the only jurisdiction in Canada to test every infant born for SCID, a genetic disorder that is only detectable with screening. Since August 2013, thanks to funding from Ontario Ministry of Health, NSO has tested over 145,000 babies for SCID using a new testing approach that was pioneered in the laboratory at CHEO. At least 1 baby has been diagnosed with SCID and is receiving lifesaving treatment.

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. Prior to screening, many infants with SCID would not receive a diagnosis until it was too late for treatment to be effective. SCID can often be cured with a bone marrow transplant.

“We are pleased to see a collaboration of this magnitude amongst our newborn screening colleagues in the US as we complete our first full year of SCID screening,” says Dr. Michael Geraghty, Medical Advisor for Newborn Screening Ontario. “We have already identified and diagnosed some children with SCID, but it will be some time before we are able to determine its true prevalence in Ontario.”

About NSO

Newborn Screening Ontario (NSO) has tested over 1.2 million newborns for rare diseases that are treatable. Since NSO started at CHEO in 2006, over 1,500 newborn babies with these diseases have been diagnosed through newborn screening. NSO screens for 29 diseases, is the most comprehensive newborn screening programs 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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Twitter: @CHEOhospital

YouTube: www.youtube.com/user/CHEOvideos

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NSO Social Media:

Website: www.newbornscreening.on.ca

Twitter: @NBS_Ontario

YouTube: www.youtube.com/user/NBSOntario

