



Newborn Screening Bulletin 2016-4

June 22, 2016

The 30th screen is being added to the newborn screening panel!

At the request of the Ministry of Health and Long-Term Care, NSO is working to implement screening for **Critical Congenital Heart Disease (CCHD)** by pulse oximetry for all newborns in Ontario. The addition of CCHD screening is expected to allow earlier detection and improved outcomes for about 50-100 babies each year. Congenital heart disease occurs in approximately 9 per 1000 live births, and approximately 25% (1-2 per 1000) will have CCHD, defined as needing surgery or catheter intervention in the first year of life. CCHD accounts for more deaths than any other congenital malformation, but 10-30% of CCHD diagnoses are not made prior to discharge from hospital. The implementation of newborn screening for CCHD will aim to identify and treat affected infants early to prevent adverse health outcomes. To do so, every infant must be offered high quality and timely screening, and this will require the collaboration of health care providers across the province of Ontario. We look forward to working with you all to achieve the highest quality CCHD screening system for Ontario kids.

Pulse oximetry is a simple, non-invasive bedside point-of-care test that measures the level of oxygenation in the arterial blood. It is quick to perform (5 to 10 minutes) and specific algorithms have been defined for newborn screening to identify normal, abnormal, and intermediate results. Infants with abnormal results will require immediate follow-up by a physician for examination, and possible referral to a specialist or transfer to another unit or hospital if further investigation or treatment is needed. Using these algorithms, we expect approximately 300 infants per year across Ontario will require follow-up.

A number of Ontario birthing hospitals have initiated routine pulse oximetry screening for CCHD, or have taken initial steps towards implementation. The experience of these institutions already screening for CCHD is invaluable. The attached survey is intended for all submitters across the province and will provide NSO with information of your current screening practices for CCHD. Your input is greatly appreciated.

Survey link: <http://fluidsurveys.com/surveys/nso/critical-congenital-heart-disease/>

NSO will work alongside newborn screening submitters in Ontario to ensure the success of this program. This partnership will include the provision of screening equipment, provincial standards, training materials for submitters, educational materials for families, and the development of a robust quality assurance system.

The timeline for CCHD screening implementation is Fall-Winter 2016. The initial phase will involve manual data collection via modified newborn screening bloodspot cards, and then will evolve to an electronic CCHD data collection system to quality assure the CCHD screening system. We have also started work with BORN Ontario to further develop the NSO Diagnostic Evaluation Report Form system, currently operational in BORN, to support this work.

We will keep you informed of the progress of screening implementation over the months to come. We will be striking a number of advisory groups to guide this work - if you have interest in participating in one of these, or have any questions, please feel free to contact us at NewbornScreening@cheo.on.ca.