
Speaker: Jennifer Milburn

Jennifer Milburn has been with Newborn Screening Ontario since December 2006, originally as the Business Systems Analyst responsible for the development and implementation of the Newborn Screening Laboratory Information System (LIS).

She assumed the role of Manager of NSO in January 2008, and became Director in 2015. She is responsible for the daily operations of the program, risk and resource management, program evaluation, and any special projects or quality improvement initiatives. Jennifer has an undergraduate degree in Biology and Biotechnology from Carleton University and a Master of Health Administration degree from the University of Ottawa.

**Presentation Title: Screening Tiny Hearts in Ontario: The CCHD Launch**

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.

CCHD is fatal unless treated early, yet CCHD babies look normal at birth and some will not be detected by physical examination alone. The incidence of CCHD is high enough to support a population screening approach. Given the presumed incidence of 1-2 per 1,000, it would be expected at least 145-290 infants with CCHD would be diagnosed in Ontario annually, and only 50% will be identified prenatally or symptomatically.

Pulse oximetry (PO) is a simple, widely available bedside point-of-care test, POCT). The pulse oximeter device is widely available and familiar to most if not all medical personnel (including midwives). In the context of newborn screening, certain modifications are required for use of the pulse oximeter in newborns, and specific algorithms have been published that define normal, intermediate, and abnormal results potentially requiring intervention or repeat screen. It is estimated that the test takes between 5 and 10 minutes to complete. As this is a point of care test, positive results (including false positives) will be addressed immediately at the bedside, ensuring timely care and reducing parental anxiety.

A positive screen will prompt a thorough and cardiac-specific physical examination by a pediatrician (and/or health care provider) and appropriate follow up. Infants who are found to truly have a heart defect would be referred to a pediatric cardiologist for consultation.

Data collected from the CCHD screen would be matched with the newborn screening dried blood spot record. The existing alert system through BORN would be adjusted to notify NSO of missed screens for CCHD, to ensure all infants are offered screening.

NSO is working alongside health care providers involved in newborn screening to ensure the success of this program. This partnership will include the provision of screening equipment, training materials for submitters, and the development of educational materials.

Objectives

1. Understand the importance of a population screening program for CCHD
2. Understand the proposed screening protocol
3. Discuss benefits and challenges of implementation of a POCT pulse oximetry screening program

