



EXPANDED HEARING SCREENING AND THE COMMUNITY PEDIATRICIAN Information about Your Participation

In July 2019, Newborn Screening Ontario (NSO) and the Infant Hearing Program (IHP) are launching Expanded Hearing Screening, which involves dried blood spot testing for cytomegalovirus (CMV) and common mutations in genes associated with permanent hearing loss.

How can I become involved?

- NSO is looking to identify pediatricians throughout the province who will agree to accept infants with CMV screen positive results generated through Expanded Hearing Screening.
- Based on the estimates and distribution of screen positive infants anticipated throughout the province, NSO is looking for approximately 75 pediatricians over 13 regions (i.e. 2-10 physicians per region).
- After the selection process, only successful applicants in each region will participate and receive CMV screen positive referrals from NSO.

What is expected of me?

- There are **two** main responsibilities for pediatricians selected to be involved with Expanded Hearing Screening:
 1. **Initial diagnostic evaluation of CMV screen positive infants** to determine the presence of symptoms and indication for urgent referral to an Infectious Diseases Clinic.
Investigations proposed include:
 - Urine PCR to confirm CMV infection
 - Laboratory investigations
 - Physical exam
 - Head ultrasound
 - Ophthalmology assessment, if possible
 - Priority ABR testing, i.e. diagnostic audiology, to establish hearing status (to be coordinated by the Infant Hearing Program)
 2. **Developmental surveillance** up to 6 years of age for children confirmed to have congenital CMV (cCMV) infection subsequent to a screen positive result
 - Surveillance will involve standardized parent reported tools (ASQ and Looksee Checklist), which both require **minimal time for the pediatrician to score and review**
 - The surveillance tool will be provided to participating pediatricians at no cost
 - The developmental surveillance schedule for each child is expected to be 3 times a year until the age of 6 years
- We anticipate that each participating pediatrician will be referred between 5 to 15 infants each year with CMV screen positive results, depending on region.
- An infant with a positive screen for CMV should ideally be assessed within 1 to 2 business days after referral.
- Although the time commitment is ongoing with these infants, this is meant to be non-disruptive to your day to day practice.



Why has NSO chosen to partner with community pediatricians?

- While there are health and developmental risks for children with cCMV infection, the vast majority (~85%) of children will remain asymptomatic and suffer no sequelae.
- Pediatricians in the community can ensure timely diagnostic evaluation of infants in the context of acknowledging the relatively low likelihood of symptomatology, and encourage families to stay motivated to adhere to long term developmental surveillance.
- Most parents must be reassured that their children are well. Parents also need to have a trusted resource to help them identify concerns (if any) related to cCMV early, and acknowledge and respond to questions as they arise.
- Children and their families will have access to a physician with focused expertise, and receive care that is **consistent, comprehensive and close to home** - values that are the foundation for community-based pediatrics care.
- In turn, pediatricians involved with following children with cCMV identified through screening will have the opportunity to:
 - Influence the shape and direction of this innovative screening initiative
 - Contribute to an area where research literature is limited
 - Be a pioneer in defining and spotlighting the value of community-based pediatricians across Ontario
 - Apply the experience gained to consider other province-wide community pediatrician networks for children's health screening programs
 - Elevate the level of respect for community pediatricians from decision makers, the profession and the public

How will I be remunerated?

- We will encourage participating pediatricians to bill and track use of the K119 (Pediatric Developmental At Risk or PDA) code.
- To bill K119, developmental surveillance with a recognized screening tool must be performed and documented at least 3 times per year billed, and this can be billed once every 365 days up to the age of 6 years (ie K119 x 6).
- Counselling codes may also be billed as appropriate.

How long of a commitment is NSO looking for?

- For those who are selected, NSO is looking for an initial commitment of 3 years to receive new referrals of CMV screen positive infants, with the option to renew.
- This length of time will ideally enable each pediatrician to build sufficient patient volume to establish and maintain clinical familiarity, and to develop a strong rapport with the children who are receiving developmental surveillance.

What if the baby has a family physician or a primary care pediatrician?

- NSO is exploring several possible models of care for babies with CMV screen positive results who have a primary care pediatrician and/or family physician involved.
- NSO welcomes your feedback and suggestions regarding potential ways to include both the physician who has an existing (or intended) relationship with a baby who is identified with a CMV screen positive result and one of the community pediatricians involved in Expanded Hearing Screening.