



## Ontario Infant Hearing Program and Newborn Screening Ontario

### INFORMATION FOR PARENTS/GUARDIANS: My baby has a positive Cytomegalovirus (CMV) screening result

At the time of your baby's hearing screen, or when it was booked, you gave consent to have your baby screened for risk factors for permanent hearing loss (PHL). This screening for risk factors was done on the dried blood sample that the hospital or midwife collected for your baby's newborn (heel prick) screen.

#### Why are babies screened for permanent hearing loss (PHL)?

Hearing screening helps find babies who have PHL or have a higher chance of developing it in early childhood. Finding hearing loss as early as possible allows children with PHL to get the support and services they need to learn language.

#### What are risk factors for permanent hearing loss (PHL)?

There are many different things that can increase a baby's chance to have PHL. Some risk factors are genetic (caused by changes in genes) and some are environmental, such as exposure to certain infections or medications.

Your baby was tested for congenital cytomegalovirus infection and some of the most common genetic risk factors for PHL. Babies with these risk factors have a higher chance of having or developing PHL.

#### What is CMV and how common is it?

Cytomegalovirus (CMV) is a common virus. About 1 in 3 (33%) children have had CMV by 5 years of age and by adulthood most people have had the infection. Most healthy children and adults who get CMV don't even know it because they don't have any signs or symptoms. However, when a pregnant woman is infected with CMV there is a chance it could be passed to the baby. When this happens and a baby is born with CMV it is called *congenital* CMV infection, or cCMV for short. In Ontario, about 1 in 200 babies are born with cCMV.

#### What does a "positive" CMV screening result mean?

A positive CMV screening result means that your baby likely has a cCMV infection. Most babies with cCMV do not have any signs of the infection and remain healthy, but some can have problems and treatment may be an option. An assessment by a pediatrician or Infectious Diseases (ID) doctor is needed to find out if your baby has any signs of the infection.

#### What will the assessment for cCMV include?

Your baby will see a pediatrician or Infectious Diseases (ID) doctor for an assessment that includes a physical exam, blood tests, eye exam and head imaging to find out if your baby has any signs or symptoms of cCMV. A detailed hearing test will also be arranged by the Infant Hearing Program. The results of these tests will help figure out if your baby may benefit from treatment, and what other follow-up may be suggested.

#### What will the assessment for cCMV tell me?

Most babies who have a positive CMV screening result will be confirmed to have cCMV. For babies who are confirmed to have a cCMV infection, there are 2 possible outcomes from the assessment:

- **Your baby has cCMV, but does not have any signs or symptoms (i.e. is asymptomatic)**
  - About 80% to 85% of children with cCMV remain healthy and never have any problems related to the infection.



- Babies with asymptomatic cCMV have about a 10% (1 in 10) chance of developing PHL in early childhood and should have their hearing monitored. This will be arranged by the Infant Hearing Program.
- Babies with asymptomatic cCMV have a slightly higher chance than babies without cCMV to have problems with their development and should be followed by a pediatrician throughout childhood to have their general development monitored.
- **Your baby has cCMV, and may have signs or symptoms (i.e. could be symptomatic)**
  - About 10-15% of babies with cCMV have signs or symptoms of the infection. Symptoms can include: a rash, jaundice, hearing loss, small size during pregnancy and at birth, small head size, enlarged liver and/or spleen, or vision problems.
  - Babies who are possibly symptomatic of cCMV will be referred to an Infectious Diseases (ID) doctor for further assessment.
  - If the ID doctor confirms that your baby is symptomatic, treatment with medication may be an option for some babies. The best time to start treatment in a baby who has symptoms of cCMV is within the first month of life.
  - Babies with symptomatic cCMV have about a 30% (3 in 10) chance of developing PHL in early childhood and should have their hearing monitored. This will be arranged by the Infant Hearing Program.
  - Babies with symptomatic cCMV are at higher risk for developmental problems and will be followed throughout childhood by an Infectious Diseases doctor or a pediatrician to have their general development closely monitored.

### **Do I need to take care of my baby any differently because of cCMV?**

Breastfeeding a baby with cCMV is safe. Breastfeeding is also safe for children whose mothers have CMV. Since CMV infection is extremely common in young children, it is important to practice good hand washing and hygiene habits after changing diapers or handling body secretions (e.g. saliva, mucus) of children with CMV, as would be recommended for all children. When children with cCMV are preparing to attend daycare or school, there is no need to let anyone know about the infection because no changes to care are needed.

### **What does this mean for my family and friends?**

CMV is usually passed on through direct or indirect contact with body fluids such as saliva and urine. One of the most common ways to be exposed to CMV is through contact with young children who have recently had the virus. Parents of young children in child care and people who work with young children have a higher chance of being exposed to the virus.

If you have a family member or friend who is pregnant and they have questions about what they can do to reduce their risk of exposure to CMV, they should speak to their prenatal care provider. They should also remember that this is a very common infection and these simple practices should reduce their risk of many infections (including CMV):

- Regular hand washing with soap and water or hand sanitizer– particularly after possible contact with saliva (feeding or wiping drool) or urine (diaper changes)
- Avoid sharing food, drinks and utensils with young children
- Kiss children on the head instead of the lips
- Regularly clean toys and other objects (pacifiers) and surfaces that may be exposed to body fluids with soap and water



### **Where can I get more information?**

For more information about hearing screening and/or risk factor screening for permanent hearing loss, talk to your health care provider or visit the following websites:

Ontario Infant Hearing Program: [www.ontario.ca/infantheating](http://www.ontario.ca/infantheating)

Newborn Screening Ontario: [www.newbornscreening.on.ca](http://www.newbornscreening.on.ca)

**NOTE TO PARENTS/GUARDIANS:** This information is for parents whose baby has had a positive CMV screening result from risk factor screening available through the Infant Hearing Program and Newborn Screening Ontario. Please remember that this fact sheet was written for information purposes only. The fact sheet should not replace professional medical or audiologic advice, diagnosis, or treatment.

