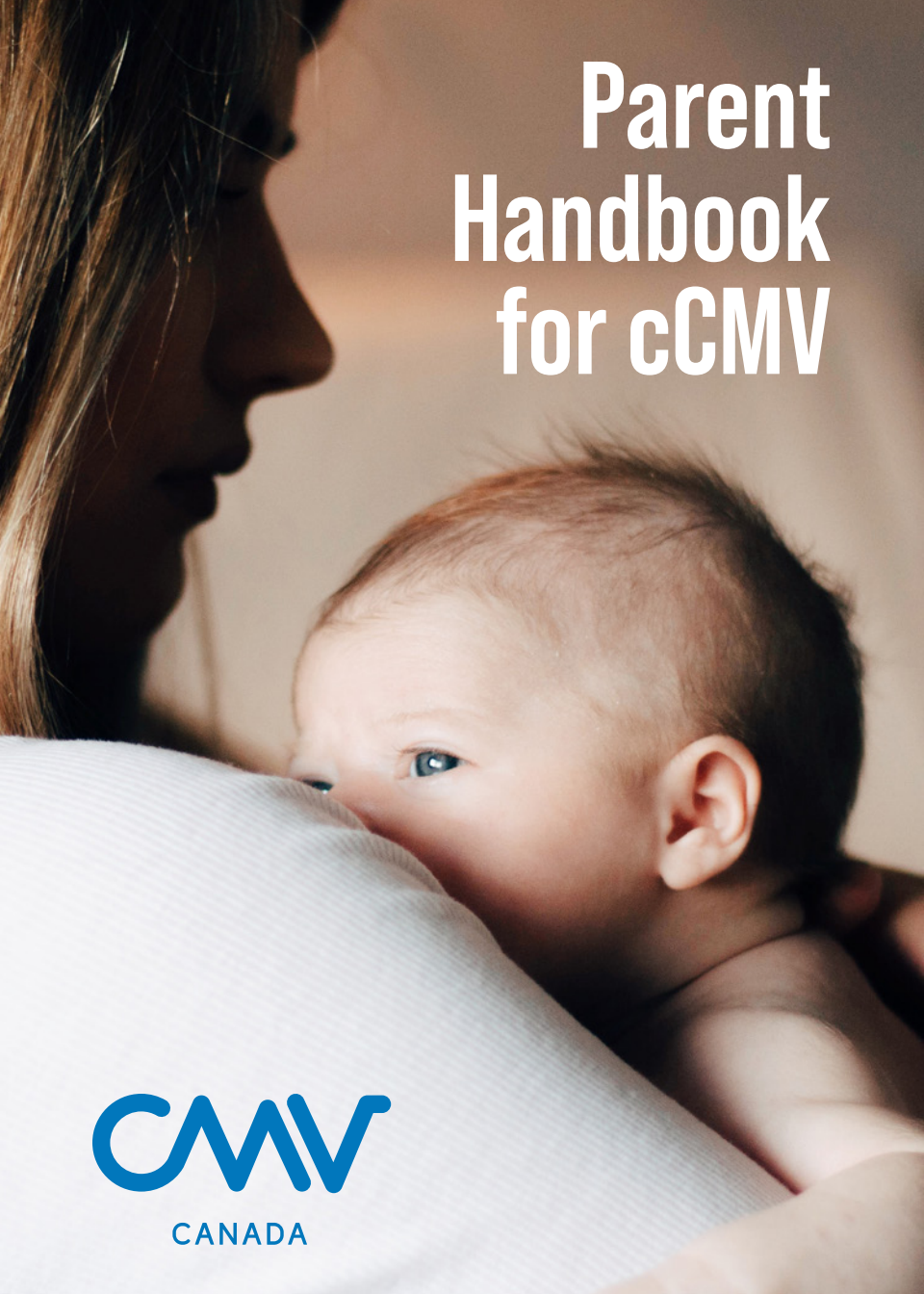
# Parent Handbook for cCMV



CMV CANADA

# *Dear Parents,*

Receiving a congenital CMV (cCMV) diagnosis for a loved one in your life can be an overwhelming and unsettling experience. You are bound to have many questions and feelings to work through. cCMV affects approximately one in every 200 babies to varying degrees. It's essential to remember that while hearing that your child has cCMV can feel isolating, many other children and their families have experienced life with a cCMV diagnosis.

We've created this handbook to help answer some of the questions you and your family might have in the beginning. The questions outlined in this handbook are questions that have been asked and answered by parents in the CMV Canada community. We encourage you to educate yourself about your options, and stay involved in the journey. We are here to help you along the way.

Sincerely,
The CMV Canada Community

# What is CMV? What is cCMV?

CMV stands for cytomegalovirus. “Congenital” means the virus is in the baby before birth, and the baby is born with the virus. If babies get the virus from their mothers before they are born (congenital CMV, or cCMV), it can cause problems for the baby. CMV is a very common virus, and if a person gets this virus for the first time as a child or adult it is not very serious and will not cause permanent problems. Only congenital CMV (cCMV) is a risk for a baby.

Every year, about one in 200 babies are born with cCMV. It is the most common infection passed from a mother to her unborn baby. CMV is transmitted through body fluids, such as blood, tears, saliva, urine, breast milk, and during sex. A lot of the time mothers get CMV from young children they are taking care of. It is very important to know that mothers almost never know that they have the virus, and they are not to blame if their baby is born with cCMV. It is not their fault.

## How is CMV diagnosed?

cCMV is diagnosed by detection of CMV in the urine, saliva (preferred specimens), or blood, within three weeks after birth. Beyond the first three weeks of life, CMV detected in urine or saliva may indicate an infection at or after delivery, which rarely causes long-term adverse outcomes in term infants. If you suspect a cCMV infection, ask your health care provider to test your child's dried blood spot card.

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

A positive CMV screening result means that a baby has a high chance of having a cCMV infection. Most babies with cCMV do not have any signs of the infection at birth and remain healthy, but some can have complications and treatment may be an option. An assessment by a pediatrician or infectious disease doctor is needed to find out if the baby has any signs of the infection.

## What does the assessment for cCMV include?

Babies who have a CMV screen positive result are referred to a pediatrician or infectious disease doctor for an assessment that includes confirmatory urine CMV testing, a physical exam, blood tests, and head imaging. If other symptoms are present, an eye exam is also necessary. The results of these tests help figure out if the baby may benefit from treatment, and what other forms of follow-up may be necessary.

# How are babies affected by cCMV?

The symptoms of cCMV vary. Approximately nine out of 10 babies with a cCMV infection will not have any symptoms at birth. This is called a "silent" infection. Silent infections often go unnoticed. However, approximately one in 10 children with no symptoms at birth will later experience complications (like learning or developmental delays, or vision abnormalities) as a result of their CMV infection.

Children who do have signs of CMV infection a birth may have any of the following symptoms:

- **Premature birth**
- **Small size at birth**
- **Red or purple spots on the body caused by bleeding under the skin (Petechiae / Purpura)**
- **Yellow skin and eyes caused by increased bilirubin in the blood (Jaundice)**
- **Calcifications (scars) in the brain**
- **Abnormal muscle tone**
- **Liver enlargement or inflammation**
- **Spleen enlargement**
- **Small head / small brain (Microcephaly)**
- **Feeding problems**
- **Seizures**

These babies are also at risk for hearing, vision, neurological, and developmental complications. CMV is the most common cause of non-genetic hearing loss at birth. Hearing loss may be mild or severe, and it may begin shortly after birth or later in childhood. About half of the children with hearing loss due to cCMV have hearing loss in only one ear. Usually, children with this type of hearing loss can function typically with minimal assistance.

# Is there treatment for cCMV?

Newborns may benefit from treatment when they display signs and symptoms of a cCMV infection. The type of treatment depends on the symptom severity. The most common treatment is antiviral medication, which can slow the reproduction of the virus but can't eliminate it. Your child's physician may recommend antiviral medication if they display signs and symptoms of a significant cCMV infection. Researchers are studying new medications and vaccines to treat and prevent CMV.

Parents may want to ask their child's physician about follow-up with other services to monitor for problems that can arise from cCMV, and to support healthy development. Additional services may include:

- **Physical Therapy**
- **Occupational Therapy**
- **Speech & Language Therapy**
- **Audiology**
- **Ophthalmology**
- **Radiology**
- **Infectiology (Infectious Diseases)**

# What type of follow-up is recommended for babies with cCMV?

All children with a confirmed cCMV infection should receive regularly scheduled hearing tests. These tests should be done more frequently in the first two to three years of life and then yearly after that. If any changes in hearing are observed, more frequent testing may be necessary. In addition, an eye exam should be done for babies with other symptoms of cCMV, or if there are any vision concerns.

Children with a cCMV infection should also be watched closely for typical growth and development, including:

- **Head size**
- **Feeding progression**
- **Developmental milestones**
  - **Crawling**
  - **Walking**
  - **Talking**

Depending on the symptoms your baby has, other special tests may be needed such as specific blood work to determine how organs in the body have been affected by the virus. Children with cCMV should have the same routine follow-up visits (with their primary care providers) that are recommended for all children.

# Can I prevent cCMV?

Although scientists are working to develop a vaccine to provide immunity to CMV, there is currently no vaccine available and no cure for the infection. However, we can all help prevent the spread of CMV by taking simple measures to avoid the body fluids that transmit CMV. These are especially important measures that are recommended for pregnant women:

- **Wash your hands often with soap and water, especially after changing a child's diaper**
- **Ensure that you do not share food, beverages, or eating utensils with young children**
- **Avoid putting a child's pacifier in your mouth**
- **Kiss young children on the forehead instead of on the lips**
- **Frequently clean toys, countertops, and other surfaces that come in contact with children's bodily fluids**

# How do I cope?

There are many ways parents typically cope when they learn that their child has CMV. Adapting to a diagnosis is different for each family. Here are some of the feelings that parents have experienced:

*"Why didn't I know about CMV?"*

Sadness
Frustration
Disappointment
Anger
Guilt and Self-Reproach
Anxiety
Helplessness

*"What did I do wrong to cause this?"*

If you are experiencing some of the feelings described above, you may benefit from additional support from other families who have been through what you are currently dealing with. You can contact the Canadian CMV Foundation to help you to connect to other parents.

# The Robinson Family

Innisfail, Alberta

cCMV was a completely unknown risk to Lisa and T.J. before they received the diagnosis of a severe fetal infection at 23 weeks into their second pregnancy. Because of early detection and access to excellent care and treatment options, their daughter Georgia was born much stronger than doctors predicted. Despite multiple challenges due to neurological consequences caused by cCMV, Georgia continues to exceed expectations and bring joy to those around her.

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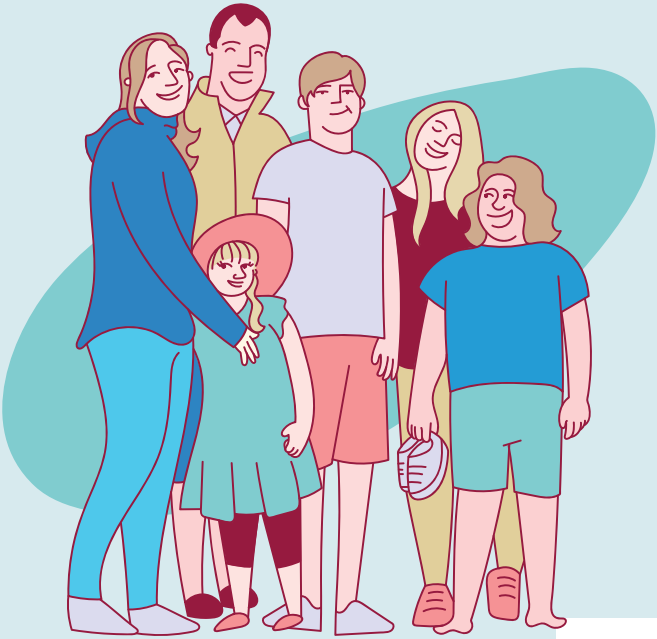
# The Tétrault Family

Winnipeg, Manitoba

Before Rob and Michelle Tétrault's son Alexandre was born, they had never heard of cCMV. If it weren't for a late ultrasound, Alexandre's infection likely would never have been caught. Because of early identification and intervention, they were given the opportunity to start treatment and put therapies in place that would drastically improve Alexandre's outcomes. Today, Alexandre is doing exceptionally well.



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# About the Canadian CMV Foundation

The Canadian CMV Foundation is a national charity committed to preventing cCMV and improving the quality of life and care for those affected. Our vision is a world without cCMV. We are focused on raising awareness, supporting the CMV community, advocating for change, and championing innovative research.

Are you experiencing a new or existing CMV diagnosis? Want to talk with someone whose baby has been treated for CMV? Email **info@cmvcanada.com** to connect with us.

Most people are unaware of CMV, including 91% of women. Raising awareness of CMV and how to prevent cCMV is one of CMV Canada's main goals. **Now that you know, you can tell people as well.**

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