# Cytomegalovirus (CMV)

# Raising awareness of a critical public health issue for pregnant women







In partnership with @PEMBANetwork



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### What is CMV?

Cytomegalovirus (CMV) is a common virus that can infect anyone. CMV is related to the viruses that cause chickenpox, herpes (simplex) and mononucleosis. Most people don't know they have CMV, because it rarely shows any signs or causes symptoms. However, newborns infected with CMV before birth (congenital CMV or cCMV) and infants who become infected during or shortly after birth are more likely to experience symptoms. People with weakened immune systems are also at greater risk. There is no cure for CMV, however, antiviral medications and other therapies can help treat newborns and people with weakened immune systems to decrease the impact of associated complications.

# Why are we interested in CMV?

One in four pregnant women living with a young child infected with CMV is at risk of developing the infection herself. While likely harmless to her, the impact on an unborn child can be lifelong. Yet, not enough people know about CMV and not enough people – including health care providers – are talking about it.

This report provides an overview of CMV and why it is a critical public health issue facing pregnant women and their infants. Just how big is this issue? Approximately 1 in 200 Canadian infants are infected with CMV during pregnancy and 1 in 5 of those will have a permanent disability. Neurological and physical developmental delays, as well as hearing loss, are just a few of the many consequences of cCMV. Diagnosing a CMV infection early can vastly improve outcomes – just like it did for Georgia (whose story you'll read below). But without better awareness of the virus, most cases are currently being missed.

To help address this problem, we consulted with over 350 parents in the Calgary area in the fall of 2018. Using social media network groups, we asked whether they had heard about CMV and what they know about the risks. We also asked parents to weigh in on an infographic tool we developed that targets pregnant women, their families and health care providers across Canada. By speaking with parents, we are not only promoting awareness of the risks of CMV, but we are also helping parents use this knowledge to take action to protect themselves and their families.

# Georgia's Story

Georgia's parents headed in for a regular ultrasound at about 19 weeks of pregnancy, excited to be expecting their second child. The ultrasound revealed an anomaly on their baby's bowel – it looked too bright compared to the adjacent bone. Finding this echogenic bowel – a calcium deposit – prompted a follow-up amniocentesis. At 23 weeks, Georgia's parents learned their baby had a severe CMV infection and their baby might not even survive the pregnancy.

Their situation was unique. Knowing ahead of time allowed them to draw on extra resources and treatment almost right away. Most families don't know their baby has cCMV until they are born. And, due to very little education and information on this congenital viral condition, some parents have children with developmental delays or deafness – but never get to know the cause.

Prenatal ultrasounds showed Georgia had an enlarged liver, spleen and heart, and had calcification in her brain. She had become anemic from the virus in utero, and was covered in a "blueberry rash" at birth. Her mom received hyperimmunoglobulin treatments – compiled immunity from blood donors originally designed for transplant patients receiving an organ from a CMV-positive donor. Knowing there was weak scientific evidence showing this highly controversial treatment would be effective, she had a series of four-to-five-hour blood transfusions - thankful to have this option that might help their baby.

Georgia was welcomed into the world in January 2012. With a severe case of cCMV, her parents were told to expect the worst. The conditions of babies with CMV are unpredictable – ranging from symptom-free for life to infant mortality.

After Georgia was born, she spent time in the neonatal unit, receiving antiviral medication and oxygen. At two days, an MRI revealed her brain was underdeveloped. She was diagnosed with polymicrogyria (disorganized neuron development with too many folds). Her brain folds were smaller and unable to process information like a normal brain.

Surprisingly, Georgia nursed well. Her parents had mixed reactions to this good news. They were afraid to be relieved, afraid to hope that their baby's condition was better than they were told to expect.



Over time, the impact of Georgia's condition – while still far better than anticipated – would reveal itself. Learning to chew and swallow took time. She was diagnosed with cerebral palsy and gross motor delays kept her from walking until she was two-and-a half years old.

Knowing Georgia was living with cCMV enabled her parents to get her early intervention – physical, occupational, and speech and language therapy and educational psychology. Georgia goes for regular Botox treatments to treat the muscles in her cerebral-palsy-impacted limbs.

For Georgia's family, there's a lot of extra work associated with having a child with extra needs. Her parents spend extra time on eating, dressing – everything takes longer. Her 11-year-old brother is sweet. He watches out for her on the playground at school because Georgia's safety awareness is low. Her parents have to manage fatigue and burnout, make time for extra appointments, cover extra costs and juggle work schedules so they can spend time in the morning getting Georgia ready for school.

Georgia is now six. Her mom says they are fortunate. Georgia has normal hearing in one ear, only mildly delayed expressive speech and language and is physically healthy. It's the neurological differences that create challenges. Her dad describes Georgia as a full-time job for one person. She doesn't yet use the toilet, and her language processing delays require repetition of new instructions and information.

A happy, positive part of her grade one class, Georgia has a full-time educational assistant, endears herself to her classmates and enjoys having friends over. Her parents love her strong, unique character and can't imagine her any other way.

That said, Georgia's mom wouldn't wish CMV on anyone. Georgia's family is actively involved in raising awareness of the condition. Right now, very few people know about it and health care professionals don't actively talk about it.

Strange, given that CMV causes more birth defects than Down syndrome.

Had she known about CMV and that she was in a high-risk category – with a toddler of her own and working with children as a speech and language pathologist – she could have taken more preventative measures.

But, since treatment for congenital CMV is complicated, and doctors don't always agree on what is most effective, most provinces don't screen pregnant mothers or newborn babies. Ontario is currently the only province that screens every baby for cCMV at birth.

Georgia's parents are hoping for a shift – where doctors realize public awareness is important and we screen and watch babies more closely. At least then, babies born with serious cCMV infections can receive oral antiviral medications to prevent further damage from the virus, be monitored for the long-term effects of infection, and receive early intervention and tests for later-onset hearing loss.

That's the best we can do, until we have a vaccine for CMV. Appendix A in this report provides a detailed overview of what cause CMV, who is at risk, what are the symptoms, what are the complications and how do we prevent it.



# Promoting CMV Awareness and Action

The CMV outreach project is a great example of patient-oriented research wherein a clinician and patient worked hand in hand to determine a research gap/health need, designed and implemented a study, and disseminated the results. Lisa Robinson, whose daughter has CMV worked with Dr. Eliana Castillo, and a team of researchers, to co-develop the CMV online survey to evaluate the effectiveness of a CMV infographic.

Dr. Castillo is a clinical associate professor with the Cumming School of Medicine at the University of Calgary. Her medical and teaching practice focus on medical disorders in pregnancy and reproductive infectious disease. She has been active in the area of immunization during pregnancy, congenital CMV infection and maternal mortality at a local and national level through her work with the Society of Obstetrics and Gynecologists of Canada, Alberta Perinatal Health Program and National Advisory Committee for Immunization.

# The Survey

An online survey was developed to seek input from Calgary-based parents on their awareness of CMV and their input on the existing CMV infographic. Facebook was used as the online social networking tool to identify relevant parent groups. The following search terms were identified in order to yield the highest number of respondents: "Calgary mom"; "Calgary dad"; and "Calgary parent". Specific selection criteria were used to determine which groups would be included.

To be included for survey participation, the Facebook group had to focus on parents in Calgary area and have a minimum membership of 50+ members for father-specific and parent general groups, and 500+ members for motherspecific groups. These criteria were added because of the greater proportion of mother-specific parent groups that exist. Groups were excluded if they were a Facebook page (versus group), were inactive (defined as zero posts within the last 30 days), and/or had a specific purpose of buying, selling or trading childrelated items.

Thirty-five Facebook groups were identified. Administrators of each group were privately messaged about posting the link to the survey and promoting participation through the group. In total, 9 Facebook groups participated, allowing access to 16,421 Facebook members. A message was posted in each group at the beginning of the survey period and one reminder prior to the end of the survey.

A total of 378 Facebook group members completed the survey. 166 additional people partially completed the survey and their responses were not included in the analysis given, the data was only descriptive in nature (e.g., number of children).

The survey explored respondents' awareness of CMV, the effectiveness of the infographic, and communication/messaging opportunities for CMV. At the end of the survey, respondents were able to identify whether or not they'd like to participate in a focus group about CMV by providing their contact information. Only 5 of 378 individuals indicated that they would be interested in pursuing that opportunity.

## The Responses

This section of the report will outline who completed the survey, what they knew about CMV and their reflections on the infographic.

### Who participated in the survey?

About 92% (n=351) of survey respondents identified themselves as either parents or as expectant parents (Figure 1). The other 8% were individuals who do not yet have children but are considering becoming pregnant. For the purpose of this report, the entire sample will be referred to as 'parents'.

### How aware are parents about CMV?

Over half of parents reported they had never heard about CMV (53%, n=197). For those who were aware of CMV, they most frequently learned about the virus after hearing about the diagnosis of a child (their own or a relative's or friend's). Very few reported hearing about CMV from a health care provider and many parents noted surprise and concern that their health care provider never brought it to their attention through their first or subsequent pregnancies. This may suggest that providers are unaware of CMV and the risks or that the risk of CMV is downplayed compared to other viruses or infections that put pregnant women and their unborn child at risk.

### How effective is the CMV Awareness Infographic?

The infographic did a good job in defining CMV. Parents reported understanding the definition of CMV as written (79%, n=296). Furthermore, parents felt the infographic was attractive, simple and easy to read. The information included is valuable in promoting awareness of CMV and its risks.

The messaging around CMV prevention and treatment is clear. After reviewing the relevant section of the infographic, nearly all parents said they understood how to prevent the transmission of CMV (92%, n=342) (Figure 2) and will take the necessary actions to test for CMV as appropriate (89%, n=333) (Figure 3).

#### Figure 1. Survey Respondent Characteristics











When asked what would make parents most likely to take action in preventing CMV transmission, parents acknowledged that they are already doing these things – avoiding kissing on the mouth and sharing food utensils - to reduce likelihood of sickness or infection between themselves and their child, or other members of the family. CMV prevention therefore could be considered as part of routine illness prevention and risk management. However, it should not be ignored that some parents did suggest that limiting contact by kissing and other forms of affection is difficult because of how they share their lives with their children at home. An initial targeted blast to raise awareness in all stakeholders could be considered before a fully integrated approach.

Despite the positive feedback and overall satisfaction with the infographic, there are still opportunities for improvement. Several parents still reported having questions about CMV after reading the infographic. Priority areas for consideration include:

- More in-depth information on what the virus actually is
- How and when to test for CMV
- The impacts of CMV beyond hearing impairment
- Treatment options, including vaccines for prevention
- CMV screening in pregnancy and newborns

Some parents also suggested that the Infographic could benefit from further clarifying the messaging around risk – including prevalence of disease and the implications. There were also additional comments about improving the design of the infographic to include more colours, increase font size, and limit the amount of text included to make the steps more clear on what needs to be done. Regardless of these changes, parents felt strongly about keeping the focus of the infographic on preventing CMV. This suggests parents wish to be empowered in having some control in mitigating the risk for themselves and their children.

### Where are parents receiving prenatal care?

When asked about prenatal care, parents described receiving care most often from a family doctor or general practitioner (69%, n=258), obstetrician/gynaecologist (60%, n=226), midwife (20%, n=76), nurser practitioner (18.4%, n=69) or doula (6.4%, n=24).

### How do parents want to hear about CMV?

Understanding the different ways people are interested in receiving information is essential in building awareness. Parents prefer hearing about CMV in:

- Pre-natal appointments/classes (71% (n=261), and in
- Educational material offered in these sessions (70%, n=257).
- Directly from their family doctor (63%, n=232),
- Obstetrical provider (55.3%, n=203), and
- Other care providers (68.7%, n=252)(Figure 4)

Parent preference on hearing about CMV directly from their health care provider is concerning, given how few of them reported hearing about CMV through that channel. This highlights an opportunity to work directly with health care providers in promoting awareness of CMV and how best to inform patients.

Fewer parents felt that media or pharmacists should be responsible for providing information about CMV: radio and television ads (21%, n=76), text messaging (4%, n=16) and communication from pharmacists (25%, n=90). Nonetheless, if used as part of a comprehensive social marketing strategy to raise awareness and increase preventive practices related to CMV, it still may be worth considering.



#### Figure 4. How parents prefer to receive information about CMV

## Summary and Conclusions

The survey of parents on their awareness of CMV and their reactions to the infographic provided four points for consideration moving forward.

#### 1. Awareness of CMV and its complications remain largely hidden.

Despite the widespread impact and longterm complications, awareness of CMV is limited most often to those who have been personally affected by it. More effort is needed to promote awareness and understanding of CMV as a risk factor, and the options for screening and treatment. Parents expect that they should be made aware of CMV given its prevalence in Canada and the impact that it could have on their lives. This should be leveraged in promoting awareness efforts among stakeholders (e.g., public health and primary care).

#### 2. CMV prevention is similar to prevention of other viruses and infections.

Several parents indicated they were already 'unknowingly' preventing the transmission of the CMV virus through routine efforts to reduce sickness and spread of germs in their home. Promoting awareness within the context of what parents are already doing may improve the uptake and likelihood of action in a population group that is already committed to infection control.

# 3. The infographic is a useful communication tool in promoting awareness and considering opportunities for action.

Adjustments can be made to improve its relevancy around how CMV is transmitted (i..e through fluids), and what an individual should do if they are concerned about being at risk for CMV or their child. The outputs of this survey can help tailor the respective sections, and may be an interesting consideration depending on the jurisdiction. More consideration to design and layout (e.g. colour, font) may also improve the effectiveness of the awareness tool.

# 4. Despite ever-changing forms of global communication, parents still expect to learn about health risks from their primary health care providers.

This includes traditional vehicles like physical and digital educational materials, pamphlets and identification through parent-relevant reading materials (e.g., pregnancy books/resource guides). Given this preference, supporting health care providers to promote CMV awareness is a critical entry point to limit the risk of CMV transmission.

## Next Steps

From this survey exercise and identification of key considerations, the following next steps can be considered identified:

# 1. Consultation on proposed changes to further assess the effectiveness of the CMV Awareness Infographic. .

Be clear on what is working and what is not working. Also include opportunities for further suggestions parents may have to improve the ability for the Infographic to promote awareness of CMV. Focus groups or key informant interviews are an effective way to achieve this task.

# 2. Consider how best to support health care providers in promoting the awareness of CMV as part of their regular pre-natal care.

Promote understanding among health care practitioners about patient expectations in communicating about risk, efforts for prevention, and opportunities for screening and/or treatment.

#### 3. Continue to advocate for CMV to be recognized as a critical public health issue for pregnant women, whether it be in research, to develop vaccines, or other forms of education and prevention.

This includes developing broader public health messaging that can be disseminated along with other existing prenatal care population health messages (i.e., folic acid supplementation for those who are trying to or have the ability to get pregnant).

### Appendix A: More about CMV

### What causes CMV?

Cytomegalovirus spreads from person to person through bodily fluids, such as blood, saliva, tears, urine, semen, vaginal fluids and breast milk. Once infected with CMV, your body retains the virus for life. In healthy individuals, CMV usually remains dormant and there are few signs or symptoms. This means CMV often goes undiagnosed.

CMV is spread in a number of ways:

- Touching your eyes or the inside of your nose or mouth after coming into contact with the body fluids of an infected person. This is the most common way CMV is spread because it's absorbed through the mucous membranes;
- Through sexual contact with an infected person;
- Through the breast milk of an infected mother;
- Through organ transplantation or blood transfusions; and
- Through the placenta, from an infected mother to her unborn child, or during birth

### Who is at risk for CMV?

CMV is a widespread and common virus that can infect anyone. CMV infection is not a significant risk for most health people. However, women of child-bearing age who acquire CMV for the first time may be at increased risk for passing CMV to their babies in utero (congenital CMV). Infants may also become infected during birth or shortly afterwards, including babies infected through breast milk. People with weakened immune systems are also at greater risk for experiencing signs or more severe symptoms of CMV.

### What are the symptoms of CMV?

For otherwise health adults, CMV presents itself similarly to mono (infectious mononucleosis), including symptoms of fatigue, fever, sore throat and muscle aches.

Most babies who are infected before they're born appear healthy at birth. Sometimes the symptoms of CMV do not show up for months or years after birth. These symptoms usually show up with hearing loss, developmental delays and in some babies, even vision problems.

Some babies show signs and symptoms of a CMV infection right away. These can include:

- Yellow skin and eyes (jaundice)
- Purple skin splotches or a rash or both
- Small size at birth (or low birth weight)
- Enlarged spleen
- Enlarged and poorly functioning liver
- Pneumonia
- Seizures

### What are the complications of congenital CMV?

Complications due to CMV infection are rare for otherwise healthy individuals. For infants, complications are more likely if the mother contracted CMV for the first time during her pregnancy, instead of having the virus reactivated.

Complications for the baby can include:

- Hearing loss
- Intellectual disability
- Vision problems
- Seizures
- Lack of coordination
- Weakness or problems using muscles

### How do we prevent CMV?

Careful hygiene is the best way to protect against the CMV virus. This includes hand washing and cleaning surfaces often that come into contact with bodily fluids. Avoid sharing utensils that come in contact with saliva. Practicing safe sex using a condom is another way to help prevent spreading the virus.