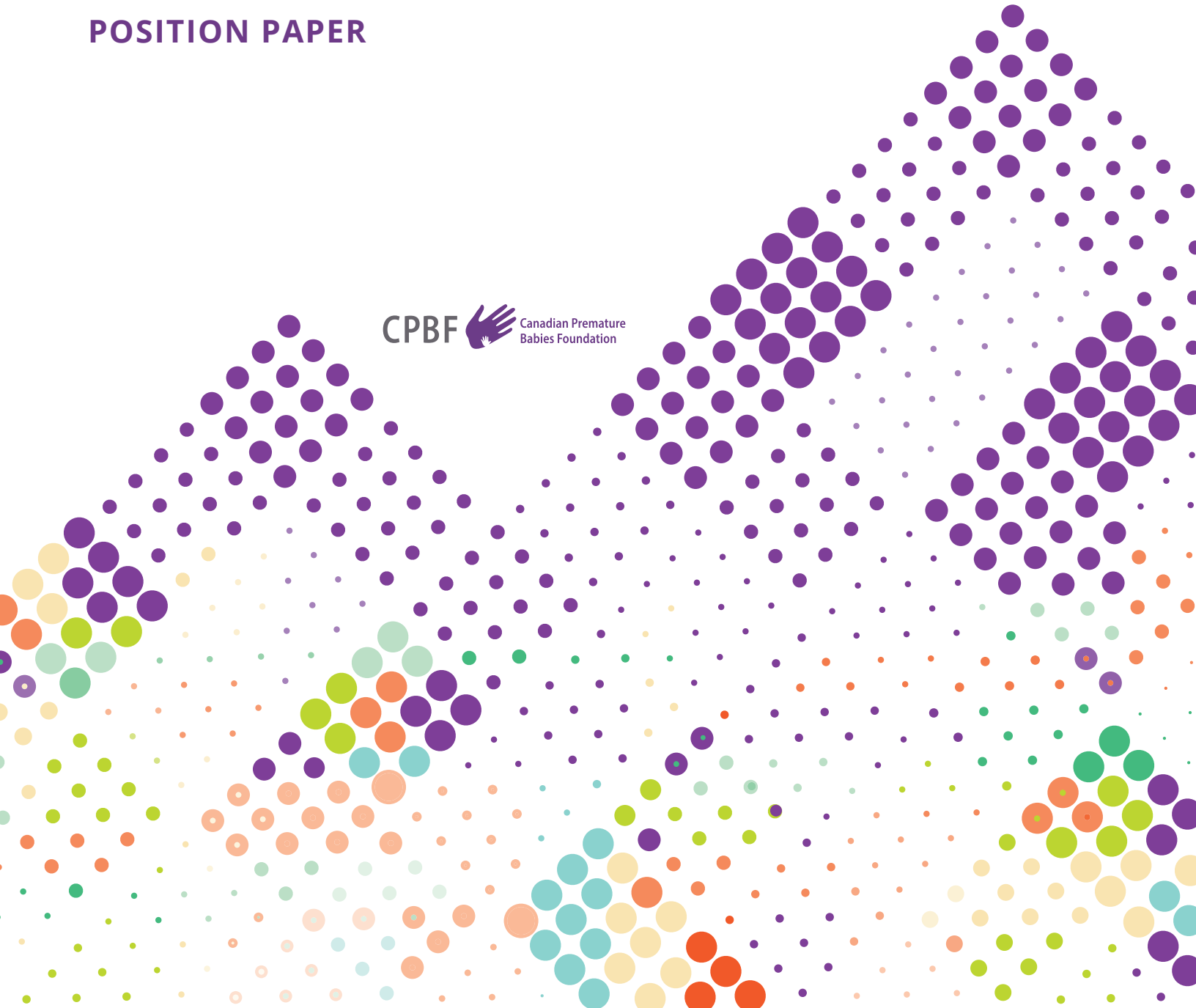
# ENSURING EQUAL ACCESS TO RESPIRATORY SYNCYTIAL VIRUS (RSV) PROPHYLAXIS

FOR PRETERM INFANTS BORN 32-35 WEEKS GESTATIONAL AGE

# SUMMARY OF A NEW COST ANALYSIS

**POSITION PAPER**



# PARENT PERSPECTIVE

*We are grateful for the willingness of this parent to share their story in hopes of promoting better understanding.*

Neither of my children, one born at 34 weeks and the other at 35, qualified for the Respiratory Syncytial Virus Prophylaxis (RSVP). Now, I understand that these qualifying decisions are based on cost. How can we put a price on pain and suffering?

My 34 weeker did in fact contract RSV and was hospitalized because it affected his breathing. After spending three long months in the NICU as in-patients, this RSV hospitalization brought back all the trauma of those long, terrifying days.

You can crunch the numbers about the costs of drugs, hospital beds and staffing, but what is missing in these calculations are financial burdens of mental health flare ups for parents and children that a rehospitalization with RSV causes. Add to this, the cost of workplace hardship, strain on personal finances, travelling for care, and more.

When you are simply looking at cost-effectiveness of the medication, there is still so much missing from this puzzle.

~ Melissa (parent)

> ***Palivizumab can reduce the risk of RSV hospitalization by 82% in infants born 32-35 WGA.[1]***

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CPBF Canadian Premature Babies Foundation

# RATIONALE AND DEVELOPMENT OF POSITION PAPER

> *Whether a high-risk infant receives palivizumab varies across Canada.*[2]

## RESPIRATORY SYNCYTIAL VIRUS (RSV)

RSV is a virus that infects the airways and lungs and typically causes a mild influenza-like illness in babies and infants during the winter months. Some children, however, are at increased risk of severe RSV disease, which can lead to hospital admission and, possibly, need for intensive care. Infants born prematurely (before 35 completed weeks' of gestation; wGA) and those with heart or lung problems are known to be at increased risk. No vaccine or effective treatments are currently available for RSV. The only options to reduce infection are good hygiene and, for high-risk infants, palivizumab, the virus fighting antibody that strengthens the infant's defences against RSV.

Whether a high-risk infant receives palivizumab varies across the 10 provinces and three territories in Canada[2], despite published recommendations for who and when to treat from national bodies such as the Canadian Paediatric Society (CPS)[3] and The National Advisory Committee on Immunization (NACI).[4]
Access to palivizumab is particularly variable in children born at moderate-to-late preterm (32-35 wGA).
These policy differences are largely driven by cost considerations and potentially create inequality in the health system, with palivizumab use varying depending on where an infant is born.

**"It would have been a little bit of peace of mind to have been able to get the RSV prophylaxis, for both girls [32 and 35 weeks' gestational age]. We just didn't qualify..."** *~ parent*

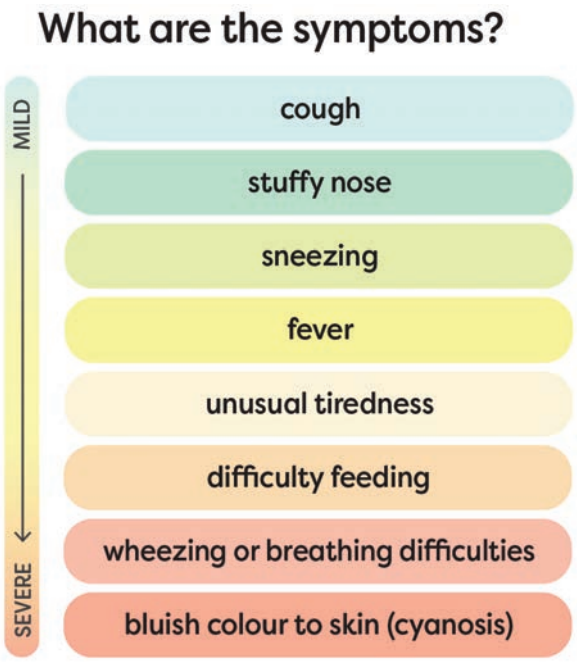
Policy on who should receive medicines is often guided by cost-effectiveness analyses, which consider the financial cost of a medicine against cost savings from reduced illness and the value of improved health to the patient. Cost-effectiveness can be improved by identifying those at greatest risk of severe disease. Two tools to identify infants born 32-35 wGA at greatest risk of hospitalization due to RSV have been developed; the Canadian risk scoring tool (CRST)[5] and the International risk scoring tool (IRST)[6]. Both tools use risk factors, such as the age of the infant and the number of brothers or sisters they have, to determine the likelihood of developing a severe RSV infection. The impact of the CRST on the cost-effectiveness of palivizumab in Canadian infants born 32-35 wGA was last assessed in 2010.[7] The more recently developed IRST as well as the CRST have recently been assessed in a new cost-effectiveness analysis for Canada.

This position paper was developed by RSV experts (see acknowledgements) and the Canadian Premature Babies Foundation (CPBF) to provide a summary of the new cost-effectiveness analysis and to offer recommendations on how this presents an opportunity to standardize palivizumab use in infants born 32-35 wGA across Canada.

# BACKGROUND

### WHAT IS RSV?

RSV is a common virus that causes mild cold-like symptoms lasting one to three weeks in most infants. In some cases, RSV can cause infections of the airways and lungs, known as bronchiolitis and pneumonia, which are the leading causes of hospitalization in infants less than (<) 1 year.[8] Most RSV infections occur between Fall and Spring, but they can happen at any time throughout the year. Almost all children will have their first RSV infection by the time they are two years old, and anyone can be infected more than once.[8]




### BURDEN OF RSV

RSV infection can cause a significant burden to families, healthcare systems, and society.

**Globally, it has been estimated that RSV is responsible for approximately 33 million severe respiratory infections, resulting in 3.6 million hospital admissions and over 100,000 deaths in children <5 years of age every year.[8]**

**Over 400,000 of these hospitalizations occur each year in high-income countries[8] such as Canada.**

In addition to hospitalizations, many more RSV infections are treated in the community or in emergency rooms (ERs).[8] RSV infections can have a devastating impact on families causing high levels of stress and anxiety during the hospital admission as well as longer-term concerns about their infant's health.[9,10]

In Ontario, Canada, an estimated 6 of every 1,000 children <2 years of age are hospitalized with RSV each year.[11] Every infant hospitalized with RSV is estimated to cost the Canadian healthcare system, on average, an additional $9,240 compared to a non-hospitalized infant. Importantly, for infants born prematurely, the cost may be even higher (average additional cost of $11,220 for those born at 33-35 wGA).[11]

# BACKGROUND

## BURDEN OF RSV *(cont.)*

RSV infections can also have significant effects on the long-term health of children. Several studies have shown that RSV infection in early childhood is associated with long-term wheezing and asthma and impaired lung function.[12] This can negatively impact the overall quality of life of children and their families, as well as placing further strain on the healthcare system.

**"Our second daughter was born at 35 weeks 5 days ...at 8 weeks old, she got RSV and ended up in the hospital on oxygen for 8 days. She sustained damage to her lungs from the infection and has been on puffers daily since she was 10 months old. She is now four." *~ parent***

Evaluation of parental knowledge of RSV and other respiratory infections in preterm infants was undertaken in a CPBF survey in 2020.[13] It was reported that most parents of preterm infants (86%) believed that RSV was a very serious condition. The parents also identified RSV-related bronchitis and pneumonia as the main cause of hospitalization in their young infants <1 year of age during the winter season (92%).[13] In addition to the mental and emotional strain of RSV,[9] families face difficulties related to the financial burden associated with lost work time and costs associated with child care of siblings at home, travel, parking, and eating out when caring for their infant in hospital.[10]

**"It's very hard to put a price on mental health." *- parent***

The burden associated with RSV can be particularly large for Indigenous families or those living in remote communities. An increased number of environmental and socio-demographic risk factors are often found in these populations, resulting in increased rates of RSV infection and hospitalization.[14] These populations may also face additional barriers to easily accessing healthcare such as long distances to local hospitals and the necessity for air transport to out-of-region hospitals for intensive care. Indigenous families are often underrepresented in current national surveillance systems to monitor RSV outbreaks.[15]

## CHILDREN AT HIGH-RISK OF SEVERE RSV

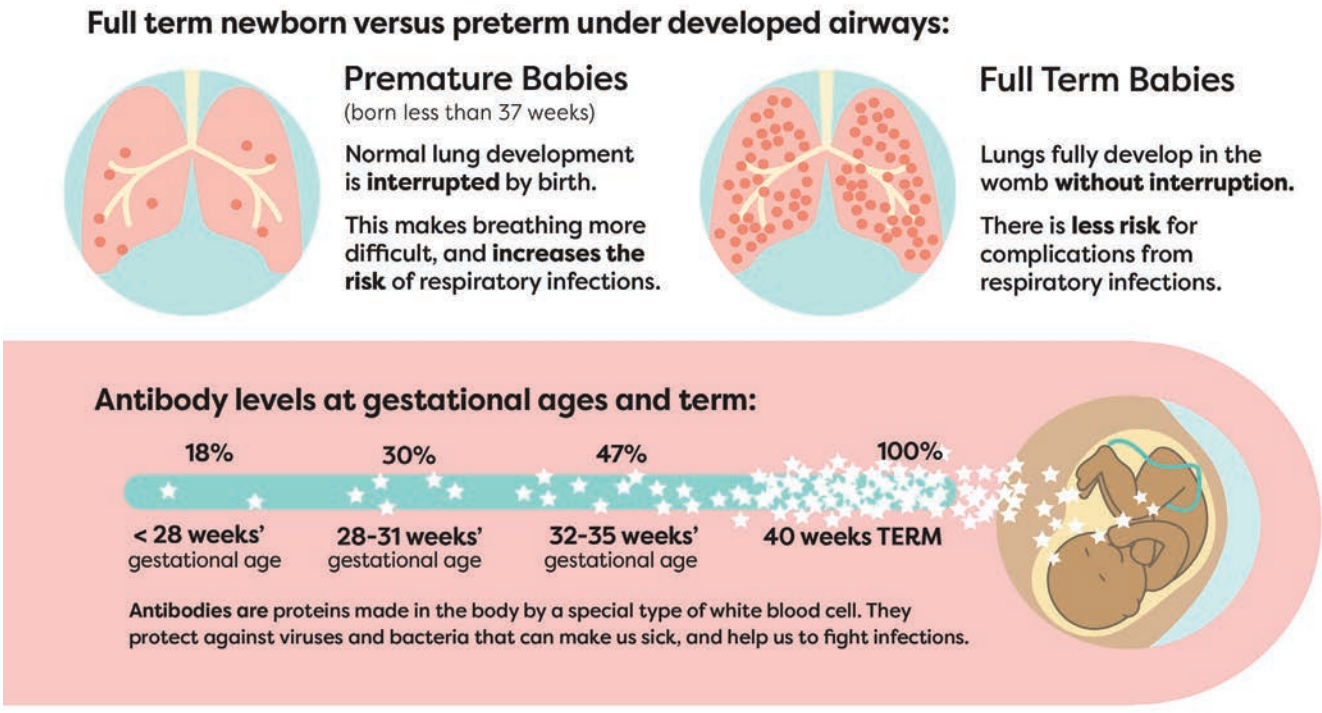
Some children are particularly vulnerable to severe RSV and have an increased risk of being hospitalized and requiring intensive care and help with breathing.[16] These high-risk children include those who need additional oxygen for a long time after birth (known as bronchopulmonary dysplasia [BPD] or chronic lung disease [CLD]), those with heart problems (congenital heart disease [CHD]), and all those born prematurely at less than or equal to (≤) 35 completed weeks' gestational age (wGA). Preterm infants are at higher risk of RSV for two main reasons.

# BACKGROUND

**CHILDREN AT HIGH-RISK OF SEVERE RSV** *(cont.)*

Firstly, they may have underdeveloped lungs making breathing more difficult and increasing the risk of respiratory infections. Secondly, preterm infants can have fewer protective antibodies to fight infection as these are mostly passed from the mother to the infant in the last weeks of pregnancy. Although the likelihood of severe RSV disease requiring hospitalization is greatest in babies born very prematurely, moderate-to-late preterm infants – those born 32-35 wGA – are also known to be at increased risk.[17]

> *"Some children are particularly vulnerable to severe RSV and have an increased risk of being hospitalized and requiring intensive care and help with breathing.[16]*




*Yeung CY, Hobbs JR. Lancet. 1968;7553:1167-70. Courtesy A. Campbell*

# DECREASING THE RISK OF SEVERE RSV

**DECREASING THE RISK**

Spread of RSV from one person to another mostly occurs through sneezing or coughing, by direct contact with an infected person or via surfaces that they have touched.

**There is significant concern in how RSV is spread through contact with many surfaces.**

> *Premature babies that have BPD, breathing problems, and babies that have lung or heart problems can become very sick. Some babies with RSV bronchiolitis may need oxygen or breathing assistance (mechanical ventilation).*




*Infographic re-illustrated from Hall et al. J Infect Dis 1980;141(1):98-102.*

# DECREASING THE RISK OF SEVERE RSV

**DECREASING THE RISK** *(cont.)*

There are several simple and effective ways for a family with a preterm or ill infant to reduce the risk of not only RSV infection, but other viruses, such as COVID-19, and bacterial infections.

Frequent and proper handwashing, for example using soap and water and thoroughly rubbing all areas of hands for 15 seconds

Hand sanitizer should contain 60-70% alcohol. *Many hand sanitizers that are sold have limited or no alcohol*

Keeping surfaces and objects clean

Covering mouth and nose with a tissue when coughing or sneezing

Keeping anyone with cold symptoms, cough, or fever away from babies

Avoiding crowded places, particularly during the RSV season (usually November to March of the following year)

Protecting babies from second-hand smoke as this can increase the risk for respiratory and other illnesses

# DECREASING THE RISK OF SEVERE RSV

## WHAT IS PALIVIZUMAB?

At present, there is no vaccine to prevent RSV and, much like the common cold, there is little protection following infection. Palivizumab is an antibody that can help the body fight an RSV infection before it reaches the lungs. Palivizumab is usually given in five monthly injections during the winter months (RSV season) with the dosage determined by the weight of the infant.[18] Palivizumab has been proven to be safe and effective in several clinical studies, reducing the overall risk of a child being hospitalized for RSV by 56%.[19] In infants born 32-35 wGA, palivizumab has been reported to reduce the risk of RSV hospitalization by 82%.[1] Palivizumab was approved for use in high-risk Canadian infants in 2002. It is important to appreciate that preventive measures should be implemented as the primary method for reducing the risk of RSV infection both in infants who do and do not qualify for palivizumab, since palivizumab **does not** provide 100% protection against an RSV infection.[1]

## WHO DECIDES WHICH CHILDREN RECEIVE PALIVIZUMAB?

The Canadian Paediatric Society (CPS) and the Public Health Agency of Canada/National Advisory Committee on Immunization (NACI) make recommendations on which high-risk infants should receive palivizumab.

The latest CPS guidelines,[3] reaffirmed in 2021, recommend palivizumab for:

*1) Infants with chronic lung disease (CLD) or congenital heart disease (CHD) in the first year of life and in certain infants with continuing CLD in the second season;*

*2) Infants without CLD born ≤30 wGA and who are <6 months at the start of the RSV season; and,*

*3) Infants without CLD ≤36 wGA living in remote communities and who are <6 months at the start of the RSV season.*

The NACI guidelines[4] are similar to those from the CPS although they state that palivizumab may also be considered for premature infants of 30-32 wGA and age <3 months who are at high risk for RSV infection. How the guidelines are followed and what funding is made available for palivizumab is then the decision of the health authorities in the individual provinces and territories.

**"As a parent you want to take as many precautions as you can." ~ *parent***

## WHAT IS THE CURRENT USE OF PALIVIZUMAB ACROSS CANADA FOR INFANTS BORN 32-35 WGA?

There is currently considerable variability across the 10 provinces and three territories about which infants should receive palivizumab each winter. A review undertaken for the 2018–2019 winter season reported that for infants born at 32-35 wGA policies varied from no use at all to availability for some infants deemed at higher risk based on certain risk factors (e.g. birth during the winter months, presence of siblings).[2]

# DECREASING THE RISK OF SEVERE RSV

**"She did not receive the palivizumab as we live in a small town. And her older sister was at a small home day care. We had low risk factors. Our 32 weeker also didn't qualify as an infant, and she has been hospitalized twice for respiratory distress." ~ *parent***

## HOW IS IT DECIDED WHICH INFANTS RECEIVE PALIVIZUMAB?

For any medicine, the health authorities typically assess the costs versus the benefits of treatment to decide whether this should be funded and given to patients or not. A key aid when they make decisions is what is called a cost-effectiveness analysis*. In brief, this analysis involves dividing the cost of a medicine by the expected health benefit (often expressed as the cost of gaining one year of perfect health) or a death prevented by administering the medication. Cost-effectiveness analysis can therefore provide understanding on how much palivizumab may cost per unit of health gained, compared to not giving it.

If the cost per unit of health gained for a medication is below a certain number of dollars set by the decision makers based on how much they are willing to pay, the medicine will be approved as being cost-effective. In Canada, the level that is set for approval of a medicine as being cost-effective is typically stated as $50,000 per unit of health gained, though this can sometimes be higher. So, for example, if the costs versus the benefits of a medicine was calculated as being $60,000 per unit of health gained, it would generally not be funded, as it exceeds $50,000, which is the cost-effective limit. On the other hand, if the costs versus the benefits of the medicine was calculated as being $40,000 per unit of health gained, it generally would be funded, as it is less than the cost-effective limit of $50,000. In general, the more effective and cheaper a medicine is, the more cost-effective it is.

**"The idea that decisions around which babies receive potentially life-saving medicines is based on cost-effectiveness is 'a hard pill to swallow'." ~ *parent***

For infants born at 32-35 wGA, cost-effectiveness can be difficult to achieve as there is a relatively large number of these infants born every year compared with other high-risk groups. In Canada in 2020 there were 11,830 infants born at 32-35 wGA, representing around 75% of all births before 36 wGA.[20] The ability to identify those infants born at greatest risk of severe RSV infection via the use of risk factors, therefore, becomes particularly important when determining cost-effectiveness.

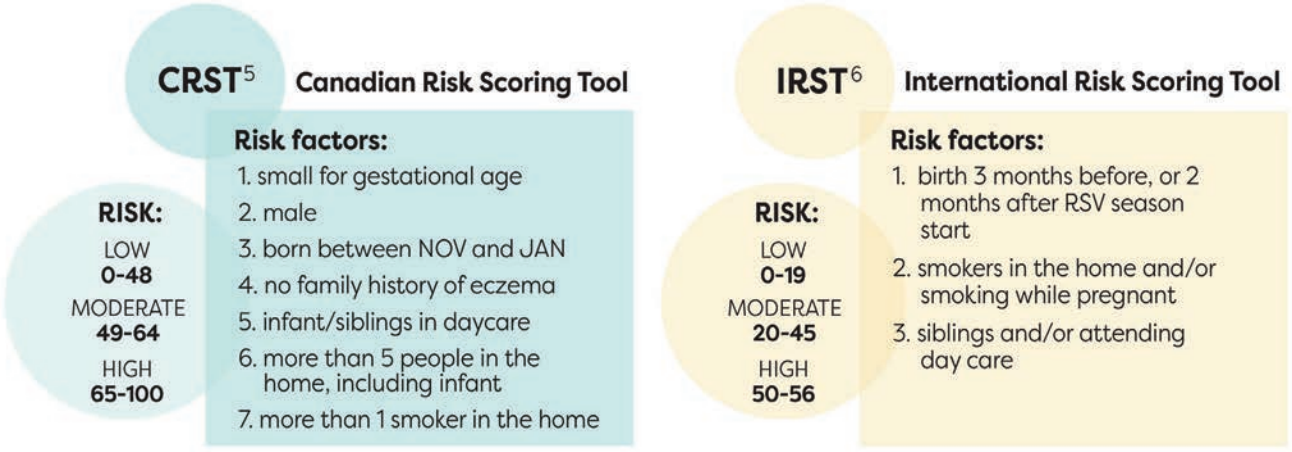
**"We briefly considered funding it ourselves but couldn't afford it. So we stayed isolated and kept him from daycare until a year old corrected which meant I had to take an unpaid leave from work." ~ *parent***

**It should be noted that this is not the only method for deciding whether a medicine should be funded; however, it is an important one, as it directly relates the financial and health effects of a medicine.*

# DECREASING THE RISK OF SEVERE RSV

## HOW DO RISK FACTORS HELP TO IDENTIFY THE HIGHEST RISK INFANTS WHO SHOULD RECEIVE PALIVIZUMAB?

To help identify those infants born 32-35 wGA at great risk of severe RSV infection, several risk scoring tools (RSTs) have been developed. These include one from Canada (CRST) as well as a more recently developed international tool (IRST) that was built using data from multiple countries, including Canada.[5,6] The CRST includes seven risk factors whereas the IRST includes three risk factors (see below). Key risk factors relate to young age of the child during the winter months, close contact with other children (day care and siblings), as well as smoking near the child. Education about these risk factors is important, particularly those that can be changed by parents to reduce the risk of RSV, such as avoiding crowds with the infant during the winter months.

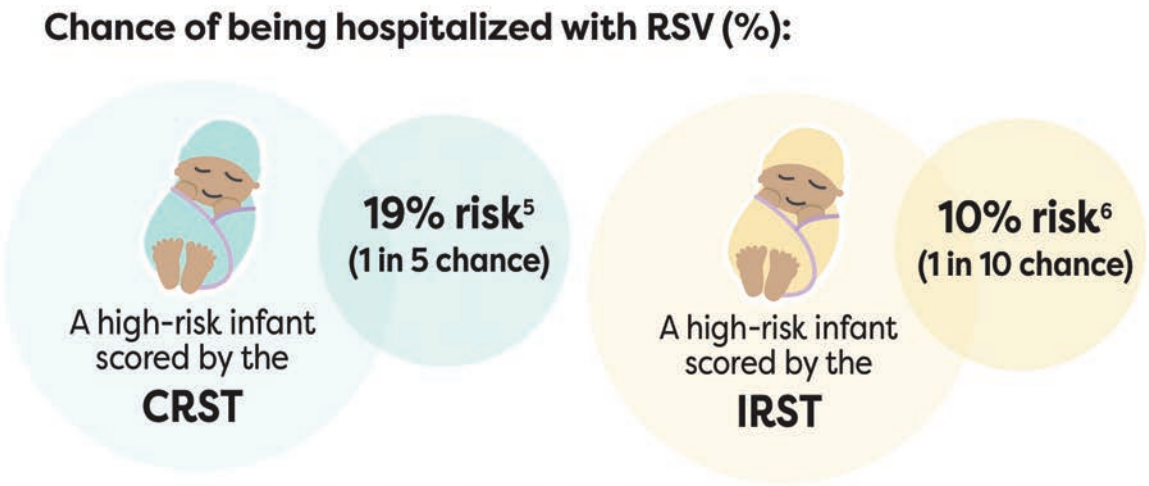


# DECREASING THE RISK OF SEVERE RSV

**HOW DO RISK FACTORS HELP TO IDENTIFY THE HIGHEST RISK INFANTS WHO SHOULD RECEIVE PALIVIZUMAB?** *(cont.)*

Both RSTs classify infants based on their risk factors as low-, moderate- or high-risk for RSV infection and are considered to be equally good.[21] The RSTs, however, do differ in what each risk group means:

> *Education about these risk factors is important, particularly those that can be changed by parents to reduce the risk of RSV, such as avoiding crowding near the infant during the winter months.*




To put this into context, the average RSV hospitalization risk for every otherwise healthy infant born at 32-35 wGA is around 4% (1 in 25 chance). *Law et al. Pediatr Infect Dis J 2004;23:806-14.*

Due in large part to the IRST having a lower cut-off point for classifying an infant as high- and, indeed, moderate-risk, the IRST captures a higher proportion of infants who are at risk for RSV-related hospitalization than the CRST (85% vs 54%, respectively).[21] This also means that using the IRST rather than the CRST would result in more infants receiving palivizumab. This is an important difference between the two RSTs and has implications when considering cost-effectiveness.

# **NEW COST-ANALYSIS OF PALIVIZUMAB** USING RISK SCORING TOOLS (RSTS)

## NEW COST-ANALYSIS

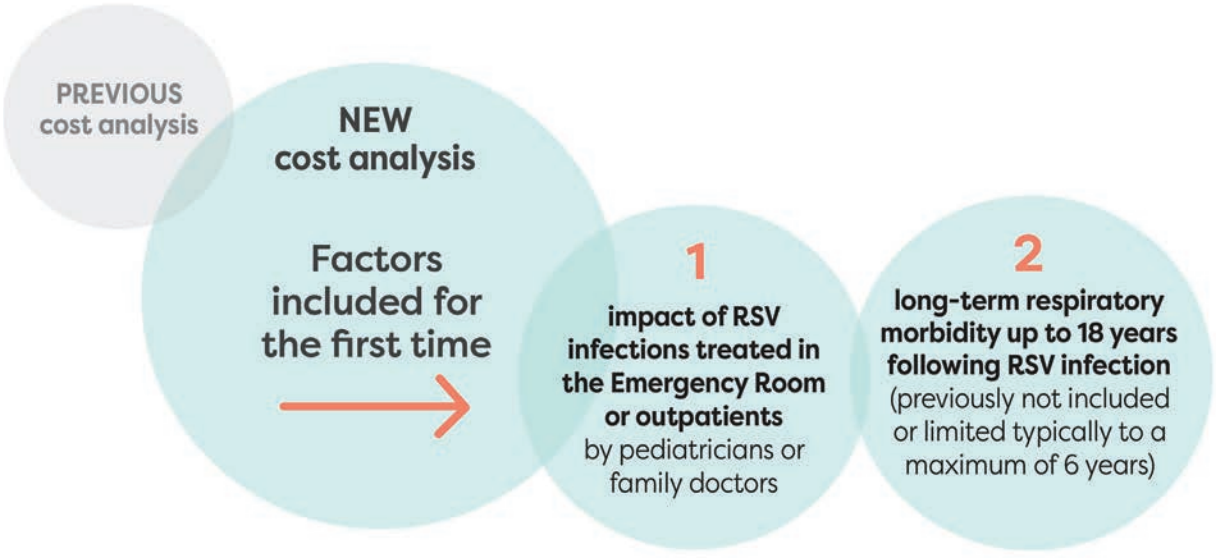
A Canadian cost analysis published in 2010 reported that palivizumab was cost-effective in moderate-to-high risk infants born at 32-35 wGA, as defined by the Canadian risk scoring tool (CRST). Cost-effectiveness was $5,274 in high-risk infants and $34,438 in moderate-risk infants,[7] which is well below the cut-off level of $50,000, that is used by policy makers when deciding a medication is cost-effective. An updated and completely new analysis has recently been published that assessed the cost-effectiveness of administering palivizumab versus not receiving palivizumab in premature infants born at 32–35 wGA in Canada, using both the CRST and the international risk scoring tool (IRST).[22] Details of this new analysis are provided below.

> *"An updated and completely new analysis has recently been published.[22]*

# NEW COST-ANALYSIS OF **PALIVIZUMAB** USING RISK SCORING TOOLS (RSTS)

## DEVELOPMENT OF THE NEW COST ANALYSIS

The new cost analysis was developed following a review of the latest evidence in RSV by experts in RSV and health economics and all previously published cost-effectiveness studies of palivizumab in infants born at 32-35 wGA. The new cost analysis was similar to previous analyses in that it considered criteria such as RSV hospitalization, intensive care unit (ICU) admission, and mortality following RSV infection. **However, the model also included the impact of RSV infections that require treatment in the emergency room (ER) or outpatients, which had not been previously included in a cost analysis of palivizumab use in infants born 32-35 wGA. Moreover, the new analysis placed particular focus on the potential long-term effects following RSV infection in infancy, such as wheezing and asthma, for up to 18 years. Older analyses did not include such long-term effects or limited them to a certain number of years during childhood and adolescence. Of note, the new analysis included both costs to the healthcare system (direct costs) and those to parents and families (indirect or societal costs).**




**Importantly, the data used in the new analysis included the effectiveness of palivizumab, the risk of RSV hospitalization, and healthcare resource use for infants who developed RSV infection, that were extracted from Canadian sources and published studies.**[23-26]

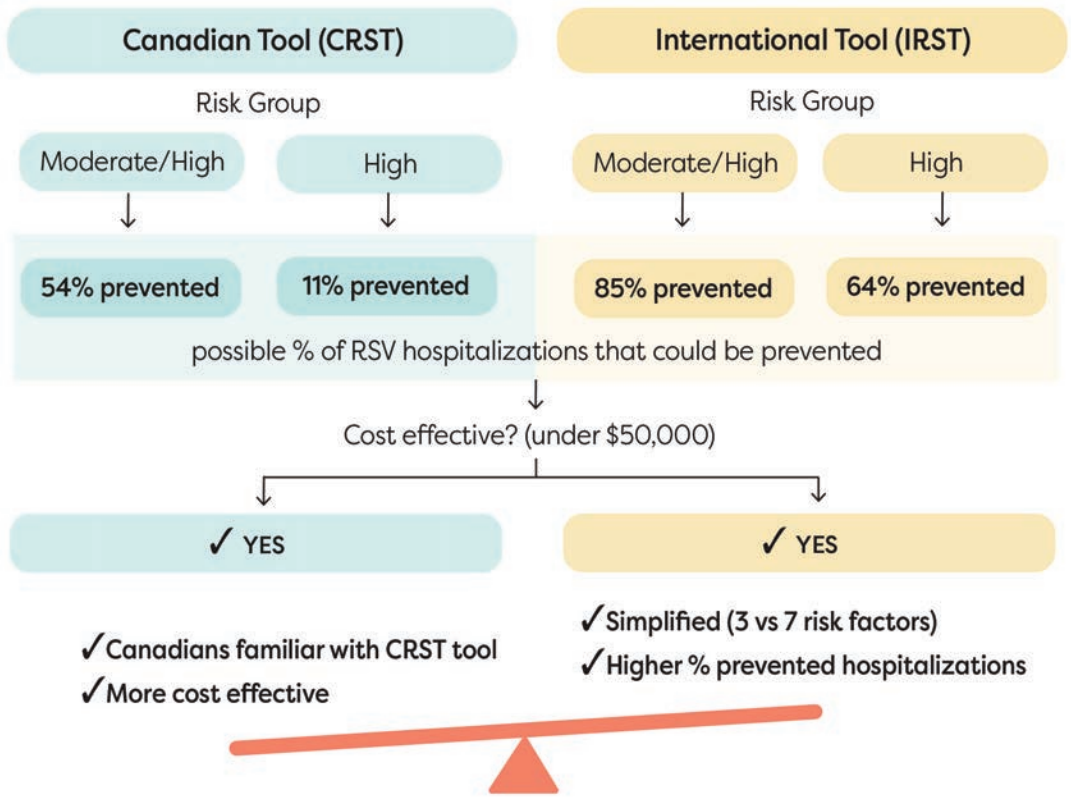
# NEW COST-ANALYSIS OF PALIVIZUMAB USING RISK SCORING TOOLS (RSTS)

## RESULTS OF THE NEW COST-ANALYSIS

**Palivizumab was found to be highly cost-effective when the IRST ($30,051) or CRST ($16,199) were used to guide its use in high- and moderate-risk infants who are at risk for RSV infection and subsequent hospitalization (see below).**

**Palivizumab was also found to be cost-effective in moderate-risk infants alone.** All results were below the cut-off level of $50,000 that is applied by policy decision makers when they consider the use of a cost-effective medication.

Figure: Palivizumab demonstrated to be cost-effective using both the CRST and IRST



## **INTERPRETATION OF THE RESULTS** OF THE NEW COST ANALYSIS OF PALIVIZUMAB

Given the lack of other effective medications in the prevention of RSV infection, and the absence of drugs to actively treat RSV infection when an infant is hospitalized apart from general medical support, palivizumab remains the only option to reduce the significant burden of severe RSV infection. This new cost analysis, based on the latest data and input from experts, provides parents, healthcare professionals and policy makers the necessary confidence that an RST can be efficiently utilized to guide the use of palivizumab for infants born at 32-35 wGA who are considered moderate- and high-risk for RSV infection, while also providing an important educational resource for parents. Moreover, the RST provides an effective and financially justifiable use of healthcare resources in Canada.

> ***Both the CRST and the IRST provide an effective and financially justifiable use of healthcare resources in Canada.***[22]

# **NEED FOR EVIDENCE-BASED INFORMATION** FOR PARENTS AND HEALTHCARE PROFESSIONALS

### RESULTS OF THE NEW COST-ANALYSIS

It is crucial that there is consistent education about RSV and palivizumab derived from up-to-date scientific literature for both parents and healthcare professionals across Canada. This was highlighted in the CPBF survey, which reported that almost one-third (30%) of parents reported receiving limited information on RSV following their child's admission to hospital.[13] Some received no RSV education either in the NICU or from a healthcare professional following discharge from hospital. More than half (53%) of these parents wished that they had received in-depth information on RSV.[13]

This education should occur throughout the year and focus on risk reduction, while also ensuring that parents of infants who do or do not receive palivizumab are fully educated on the reasons why and what this means for them and their child. The parents of children due to receive palivizumab should be informed of the importance of monthly injections throughout the winter months to maintain adequate infant protection against RSV. It is equally important to recognize that RSV infection may still occur in children who receive palivizumab because prevention with the antibody is not 100%, but in most cases the disease will be relatively mild and will not require intensive care if the child is admitted to hospital.[27]

> ***"It is crucial that there is consistent education about RSV and Palvizumab derived from up-to-date scientific literature for both parents and healthcare professionals across Canada.***

### CPBF SURVEY HIGHLIGHTS[13]

*- Majority of parents had never heard of RSV prior to admission to the NICU*

*- Most parents considered the knowledge that they received in NICU to be good and understood RSV to be serious. Only 13% believed it to be a major problem.*

*- More than half the families felt confident taking their infant home, yet many continued to seek more information*

*- Parents identified the nurse as being the most valuable resource and their first source of information*

*- 92% identified that RSV was the leading cause of hospitalization in children under 1 year, yet did not fully understand the implications*

# CONCLUSION

***Variation in access to palivizumab across provinces and territories can be extremely distressing to families and raises the issue of equity.***

"We hope with education we can move towards a more fair and equitable experience for babies at risk with the goal of all families receiving education and support following discharge."

*~ parents and nurses at CPBF Round Table discussion*

## CALL TO ACTION

To end these inconsistencies and equitably provide all preterm infants born 32-35 wGA with the same level of care, the Canadian Premature Babies Foundation supports the following position statements:

### 1. Standardize the availability of Palivizumab

**Palivizumab should be made available to all moderate and high-risk infants born between 32-35 weeks' gestational age (wGA) in Canada**

*Moderate and high-risk infants should be identified using a validated risk scoring tool (RST), either the Canadian RST or International RST.*

*The choice of an RST should be decided by the individual provinces/territories and should take into consideration simplicity, ease of adoption by healthcare providers, and familiarity, and should be incorporated into local health care budgets.*

### 2. Present RSV information individually with education

**RSV education should be accurate, reliable and consistent. All parents should be educated by a health care professional, not just provided pamphlets. Special attention should be taken to educate families with infants at risk of severe RSV**

*What is RSV and how the risk of severe disease can be reduced by preventive measures (e.g. by hand washing).*

*What is palivizumab, which children should receive it and why, how it is given, and the importance of following the monthly schedule.*

*Tools that inform family and friends about the risks for RSV for infants born preterm, resources that are reliable and Canada-specific.*

### 3. Provide year-round healthcare professional education

**All healthcare professionals across Canada involved in the treatment and management of babies and young children, should receive regular year-round education on RSV**

*Use a range of materials available from well-founded resources such as the Canadian Premature Babies Foundation, to provide them with the skills to converse with and educate a diverse population of families.*

*Families of infants who do not qualify should should be directed to reliable community resources to answer questions and access additional support.*

**CPBF reinforces the importance of ensuring professional education for healthcare professionals to enable recommendations 2 & 3.**

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# APPENDIX, GLOSSARY

## ABBREVIATIONS

<: less than
≤: less than or equal to
BPD: bronchopulmonary dysplasia
CHD: congenital heart disease
CLD: chronic lung disease
CPS: Canadian Paediatric Society
CRST: Canadian Risk Scoring Tool
ICU: intensive care unit
IRST: International Risk Scoring Tool
LRTI: lower respiratory tract infection
MARI: medically attended respiratory infections
NACI: National Advisory Committee on Immunization
NICU: neonatal intensive care unit
PICU: pediatric intensive care unit
QALY: quality adjusted life year
RST: Risk Scoring Tools
RSV: respiratory syncytial virus
RSVH: respiratory syncytial virus hospitalization
wGA: weeks' gestational age

## GLOSSARY

**Antibodies** -proteins made in the body by a special type of white blood cell. They protect against viruses and bacteria that can make us sick and help us to fight infections.

**Asthma** - common long-term lung condition characterized by inflammation and narrowing of the airways resulting in symptoms like coughing, wheezing, feeling breathless.

**Bronchiolitis** - common infection of the lower respiratory airways, which is mostly caused by RSV. It is mainly seen in infants and young children and results in inflammation and congestion of the smaller airways (bronchial tubes). Symptoms are often similar to those of a common cold but occasionally progresses to coughing, wheezing, and breathing difficulties.

**Bronchopulmonary dysplasia/chronic lung disease** - long-term respiratory condition that affects premature infants whose lungs have not fully developed. Infants often require oxygen, mechanical ventilation and medications to manage their condition.

**Congenital heart disease** - general term for a range of birth defects of the heart that affect the normal way the heart works.

**Cost-effectiveness** - reflects the degree to which a medication provides a gain (improvement) in health relative to its cost.

**Gestational age** - amount of time an infant was in the womb before birth. Term birth is between 37 to 40 weeks of gestation.

**Mechanical ventilation** - involves a machine that does the breathing for an infant.

**Medically attended respiratory infections** - respiratory infections that result in patients seeking medical help, for example attending the Emergency Department, but do not result in admission to hospital.

**Pneumonia** - an acute infection caused by viruses or bacteria which results in inflammation of the lung tissue, commonly the small air sacs (alveoli).

**Preterm birth** - defined by the World Health Organization as birth before 37 weeks of pregnancy are completed. There are subcategories of preterm birth, based on gestational age:
*- extremely preterm (less than 28 weeks gestational age)*
*- very preterm (28 to less than 32 weeks gestational age)*
*- moderate-to-late preterm (32 to less than 37 weeks gestational age).*

**Prophylaxis** - protective measure taken to maintain health and decrease the risk of disease.

**Quality adjusted life year** - measure of health outcome used to quantify the effectiveness of a particular drug or medical treatment. It combines both the quality and the duration of life lived (e.g., 1 QALY = a person lives for one year in perfect health).

**Wheeze** - high-pitched whistling sound which is usually heard when a child is finding it difficult to breathe.

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## SUPPORTING ORGANIZATIONS

Asthma.ca Asthma Canada

The Canadian Neonatal Network™

EPIQ Evidence-based Practice for Improving Quality

Canadian Association of NeonatalNurse

EFCNI european foundation for the care of newborn infants

iCare Family Integrated Care

global alliance for newborn care

LWAB Foundation Supporting Maternal Mental Health

MULTIPLE BIRTHS CANADA naissancesmultiplescanada

PRÉMA-QUÉBEC Pour les enfants prématurés For Preemies

**In addition to CanadianPreemies.org, visit these Canadian websites for reliable information for parents of preterm babies.**

Caring for Kids .cps.ca — caringforkids.cps.ca

AboutKidsHealth — aboutkidshealth.ca

*By creating programs and engaging in research, CPBF supports best standards of care and give premature babies and their families a voice across Canada.*

**Visit us online at CanadianPreemies.org for more resources and programs focused on preterm babies and their families.**

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The Canadian Premature Babies Foundation (CPBF) is a parent led, charitable organization providing education, support and advocacy for premature babies and their families. Approximately 30,000 babies are born prematurely every year in Canada. By creating programs and engaging in research, we support best standards of care and give premature babies and their families a voice across Canada. **CBPF relies financially on supporters like you, who recognize that our work answers real needs, and effects real change. Thank you for your consideration and generosity.**

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