



Canadian Premature Babies Foundation

UNDERSTANDING PARENT'S KNOWLEDGE OF COMMON WINTER ILLNESSES AND RESPIRATORY SYNCYTIAL VIRUS (RSV)

Report submitted by Martine Elias
Project Lead Marianne Bracht, RN, RSCN
Reviewed by Dr. Bosco Paes, FRCPI, FRCPC, FAAP
June 2020



Photo: Kojo Mensah

A- Introduction:

The Canadian Premature Babies Foundation (CPBF) and Prema-Quebec provide support and education to families of premature babies, before, during and after discharge from the Neonatal Intensive Care Unit (NICU).

These two organizations collaborated to survey parents of a preterm baby/child to assess their experience of obtaining information on Respiratory Syncytial Virus (RSV) and of their understanding of RSV infections, and other winter illnesses.

B- Objectives:

The primary objective of the survey, (English and French), was to gather insights from parents so that each of the two collaborating organizations could ensure that the educational programs they deliver, to parents with babies in the NICU, is relevant and provides them with accurate information on RSV and other respiratory infections. The secondary objective was to share this information with healthcare professionals so they can adapt their programs accordingly.

Methodology:

- A self-developed questionnaire was created by an ex-NICU parent, ex-NICU parent resource nurse, NICU parent and researcher, veteran parent, the executive director of CPBF and an Associate consultant.
- The questionnaire was piloted by 14 veteran parents across Canada and included Family Ambassadors, micro-grant recipients who volunteer in the hospital NICU's and two NICU mothers' who are career researchers.
- Feedback resulted in new suggestions, rephrasing and revision of sentences in the questionnaire and questions were added to improve sensibility and clarity.

The English survey was developed targeting parents as first-line respondents, using the EmailMeForm evaluation tool, and was launched on February 6th 2020 through the CPBF website and included : A Facebook page, the Canadian Preemie Network and other social media channels, Instagram and Twitter to target potential respondents. Reminders were posted regularly on the social media platforms. CPBF also distributed postcards within NICUs and sent information about the survey regularly via E-mail, to other potential respondents across Canada to share on their social media platforms.

The link to the survey was also posted on the Canadian Premature Babies Foundation’s website. In order to ensure complete responses, certain fields were mandatory, and participants could not proceed through the questionnaire without responding to these questions. All responses were anonymous.

The survey took approximately ten minutes to complete and included both open text comments as well as a choice of responses from a predefined list. To encourage participation, the questionnaire comprised 14 simple questions that were easy to complete, a section on demographics and text boxes for individual feedback comments.

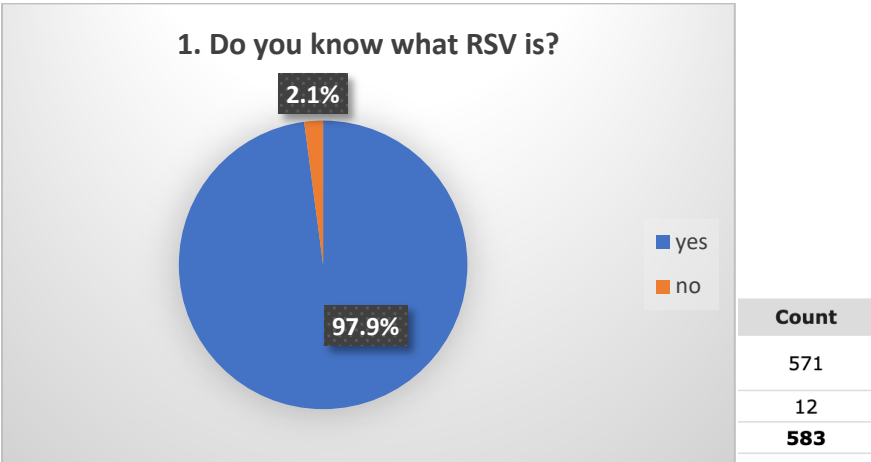
A total of 583 respondents completed the survey between February 6th and March 31st, 2020.

C- Results:

Question 1:

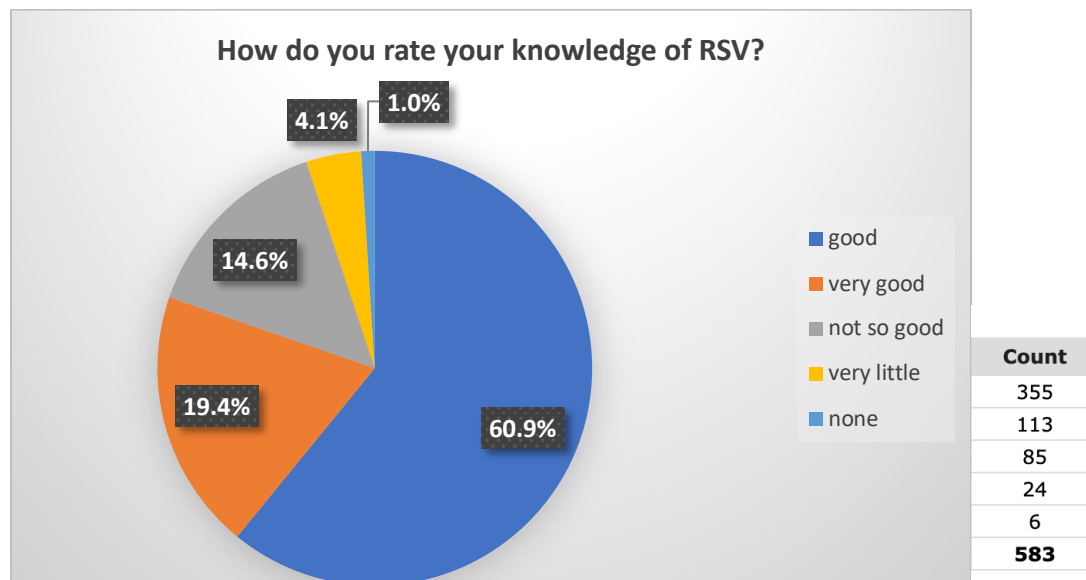
Basic knowledge of RSV.

97.9% (571/583) of the participants had surprisingly heard about RSV, since they all had a premature baby and had been informed about this infection as described further in the survey.



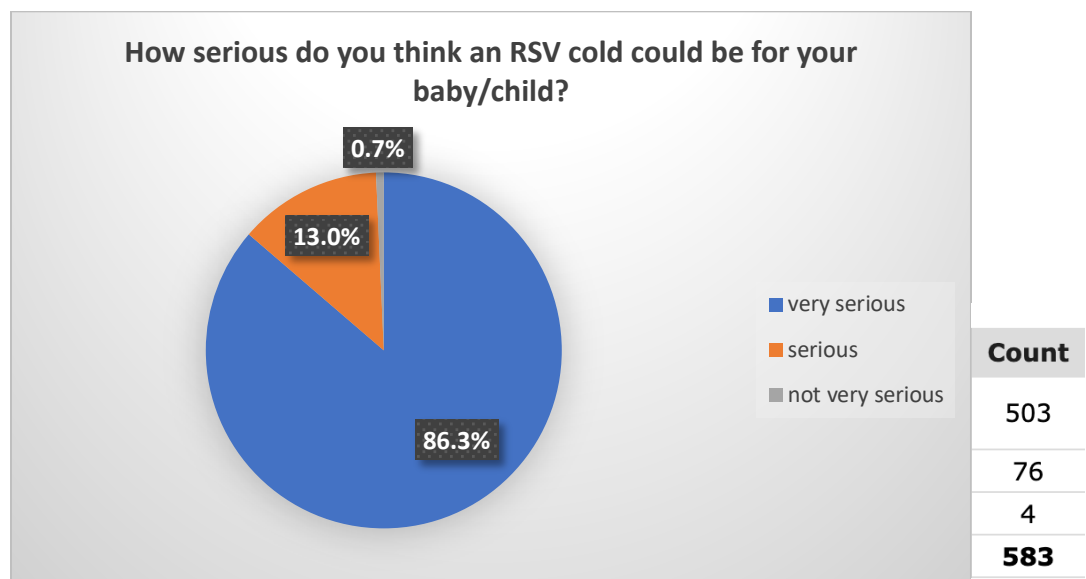
Question 2:

Participants were asked about the level of their knowledge regarding RSV. 60.9% of the individuals surveyed, reported having good knowledge of RSV, and 19.4% had very good knowledge of RSV. 19.7% had little or no knowledge of RSV.



Question 3:

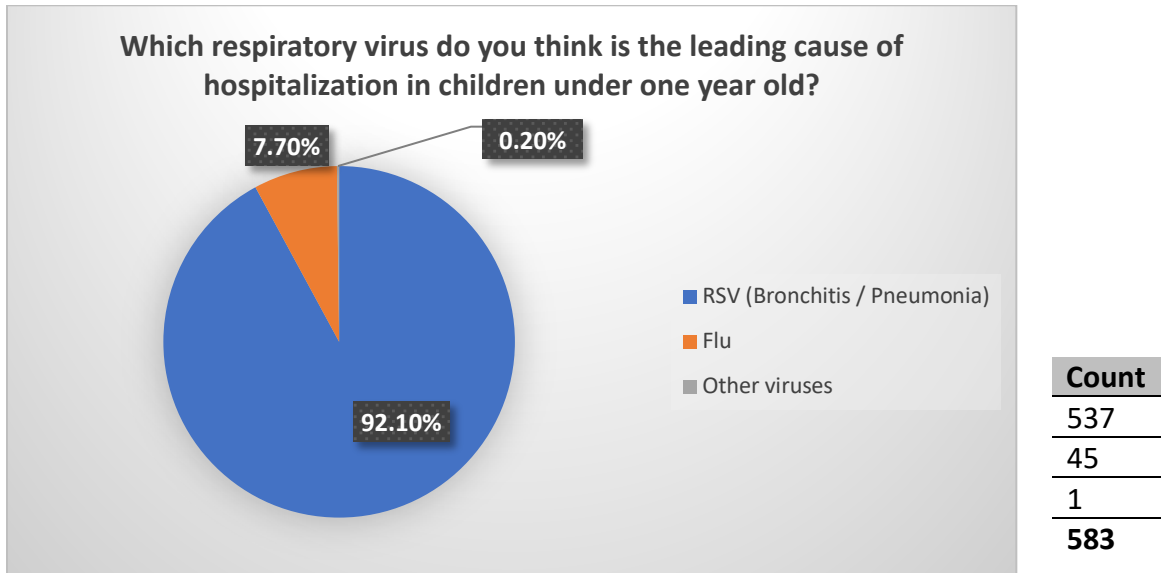
Participants were asked about how serious they believed RSV may be to their child. 86.3% believed that RSV was a very serious condition and 13% considered it to be serious. In essence most participants surveyed understood that RSV could be a major problem for their child.



Question 4:

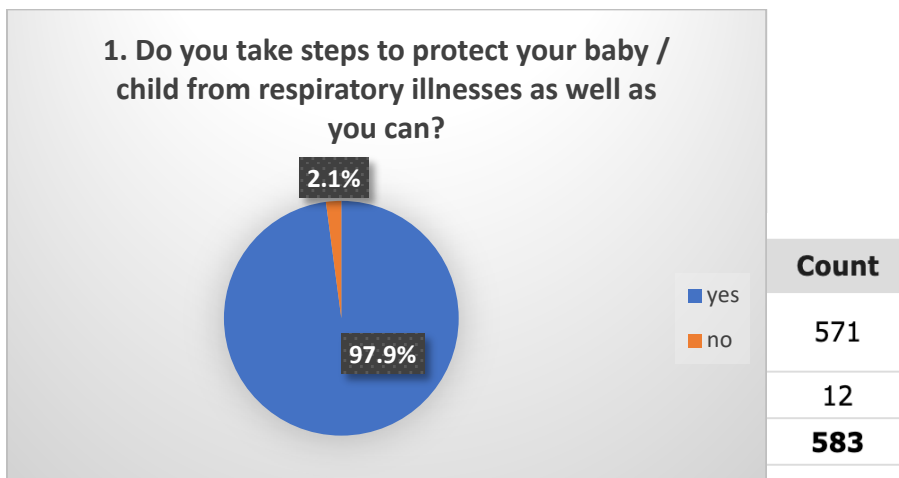
Which respiratory virus do you think is the leading cause of hospitalization in children less than one year of age?

537 of the respondents (92.1%) selected RSV-related bronchitis and pneumonia as the main cause of hospitalization in young children less than one year of age. A few (7.7%) felt that influenza was the most important cause.



Question 5:

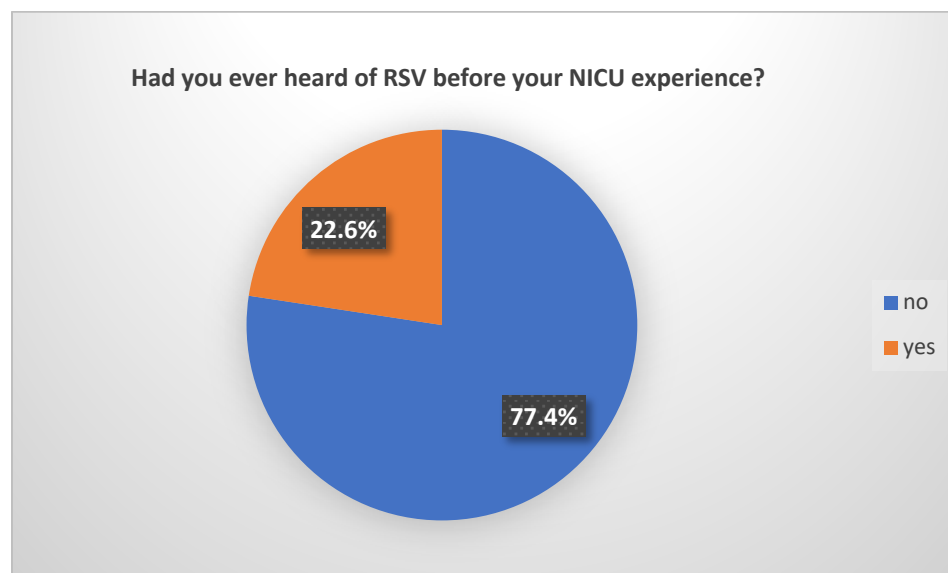
97.9% of parents took steps to protect their child from respiratory illnesses. These parents are likely open to the adoption of prevention strategies with appropriate medical/healthcare guidance. N=583



Question 6:

Participants were asked if they had heard of RSV before they had a premature baby who required NICU care.

Interestingly 77.4% of the respondents had never heard of RSV before the NICU experience with their child. More than 20% had heard about RSV prior to the NICU admission.



The next question explored the source where they had received their knowledge about RSV. N=583

Of the 22.6% who had heard of RSV before their baby was admitted to the NICU, the vast majority had acquired information about the virus through a healthcare professional as well as other sources such as friends, family and social media. Google, Facebook and internet searches were also mentioned. **It is clear that parents of premature babies rely on their healthcare team as the primary source of information, and online searches remain a 'go to' for additional facts.**

Question 6 continued:

The following table illustrates the number of times the different options were selected.

If yes, click all that apply:

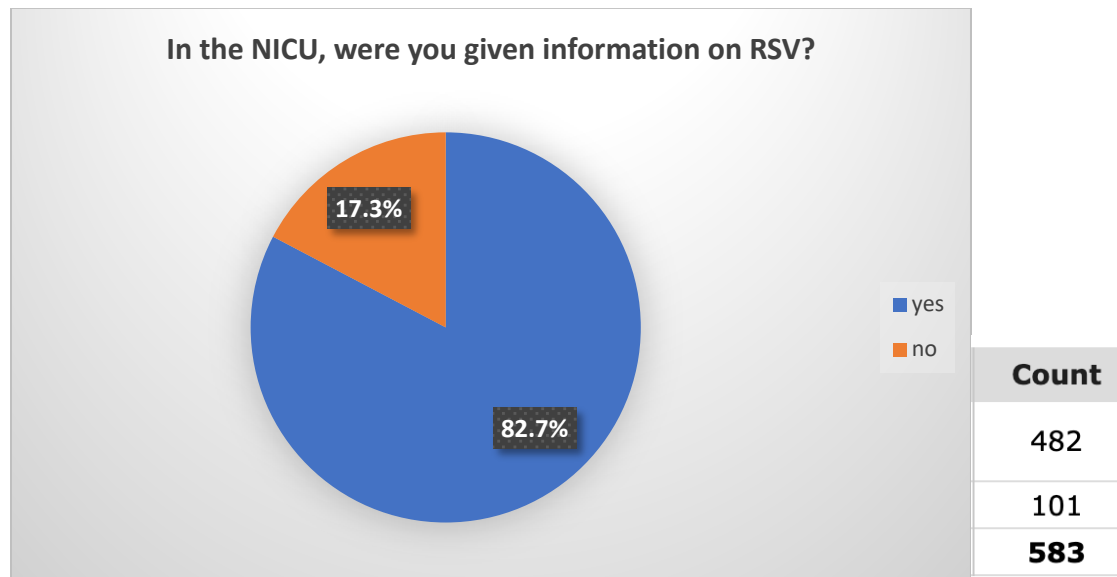
Healthcare Professionals	87
Friends/family	78
Social media (e.g. Facebook, blogs)	58
Previous Experience with RSV	32
Internet search	32

Participants were asked to think about the time they were in the NICU to answer the next questions (7 and 8).

Question 7:

In the NICU, were you given information on RSV?

The vast majority of respondents (82.7%) received information about RSV while their baby was in the NICU. Participants were asked a follow up question to define how they were provided with information about RSV. Of the 583 respondents 101 (17.3%) had not received information about RSV while their child was in the hospital which is surprising because most NICUs have resources/handouts and educational sessions about RSV infection. However, this may reflect that the information is not well-shared because of overriding professional demands preferentially centred on direct patient care.



If yes: How did you get the information?

A total of 494 participants answered the follow-up question, indicating that some may have answered “no” to the previous question but reconsidered the available options.

Question 7 continued:

The following table illustrates the number of times the different options were selected.

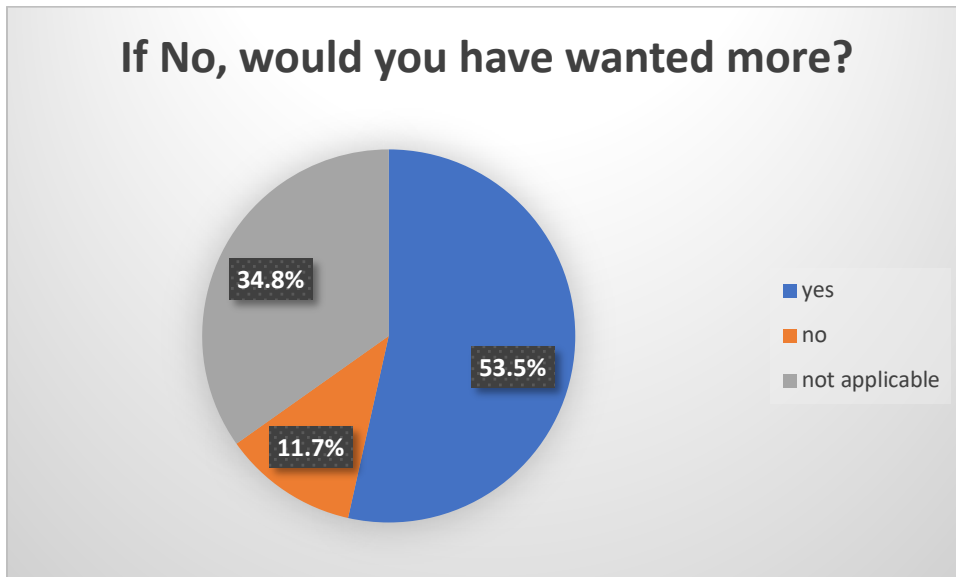
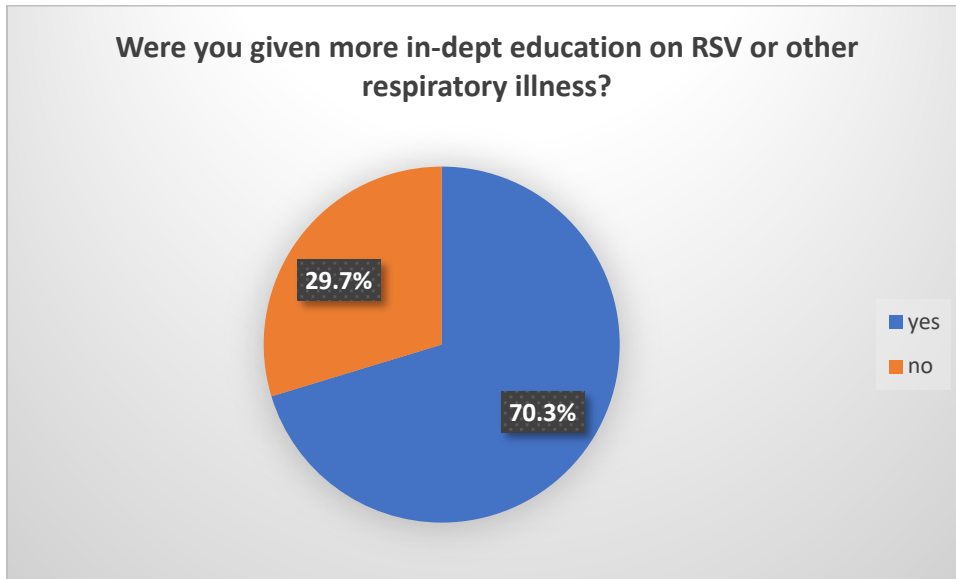
Baby's nurse	412
Printed pamphlets	329
Doctor	264
Internet search	68
Parent education sessions	60
Social media (e.g. Facebook, blogs)	60
Other parents	45
Friends/family	29
Canadian Premature Babies Foundation (CPBF) website	28
Other	28
Prema-Quebec website	3

Note: Participants responded with more than one source of information and often chose more than one option.

The baby's nurse was by far the most overwhelming choice, selected by the respondents. Pamphlets distributed in the NICU were the next main source of information. Third, was the doctor. It is likely that the pamphlet was given to a parent either by the baby's nurse or the NICU doctor. It is unclear if the pamphlet provided was issued by the hospital or by an alternative education source. Twenty-eight responses mentioned the CPBF website as a source of information, while some acquired information through web searches. Facebook, blogs and other social medial platforms were named as well, but most often along with other sources. A large number of respondents obtained their information from 3 or more sources, which indicated their keen interest to learn as much as they could, when faced with the birth of a premature baby. Most of the parental resources included the baby's nurse and the doctor.

Question 8:

When asked if the respondent was given more in-dept education on RSV or other respiratory illness, the majority (70.3%) answered “yes.” **Of those who did not receive in-depth information (29.7%), more than half (53.2%) said they would have liked to receive this information. Only 11.7% said they would not have wanted more information.**



Question 9:

Participants were asked about their confidence when they took their baby home to protect their child from respiratory illnesses. This question was addressed to those parents who had already taken their baby home.

51.2% of the participants felt very confident or confident about their ability to protect their baby when they returned home. Forty percent felt somewhat confident and 7.4% were not at all confident. In total the responses were equally divided between being confident and not being completely confident.

When you took your baby home, how confident did you feel in protecting your baby from respiratory illnesses?

Choices	Percentage
Somewhat confident	40%
Confident	37.6%
Very Confident	13.6%
Not at all confident	7.4%

Question 10: Deleted.

This question was ONLY for families who still had babies in the NICU at the time of the questionnaire (N=31). Unfortunately, some parents whose babies' had already been discharged home also responded to this question. Therefore it was deleted due to the flawed results.

Question 11:

Participants were asked if they had NOT received information on RSV in the hospital, did they receive any information following their baby's hospital discharge. Of those who did not receive information while their baby was in hospital, 52.1% did not receive information after their baby was discharged home. A total of 49.7% did receive information post discharge.

Participants who responded to the follow-up question (n=173) regarding information received post discharge, reported the source of their information.

A nurse was most often the source of information followed by the doctor and printed pamphlets. Interestingly, some received information from other parents in the NICU. Several respondents tapped into three or more sources of information, with doctors or nurses being most commonly named as one of the sources.

Question 11 continued:

If yes, how did you receive the information after discharge (n=173):

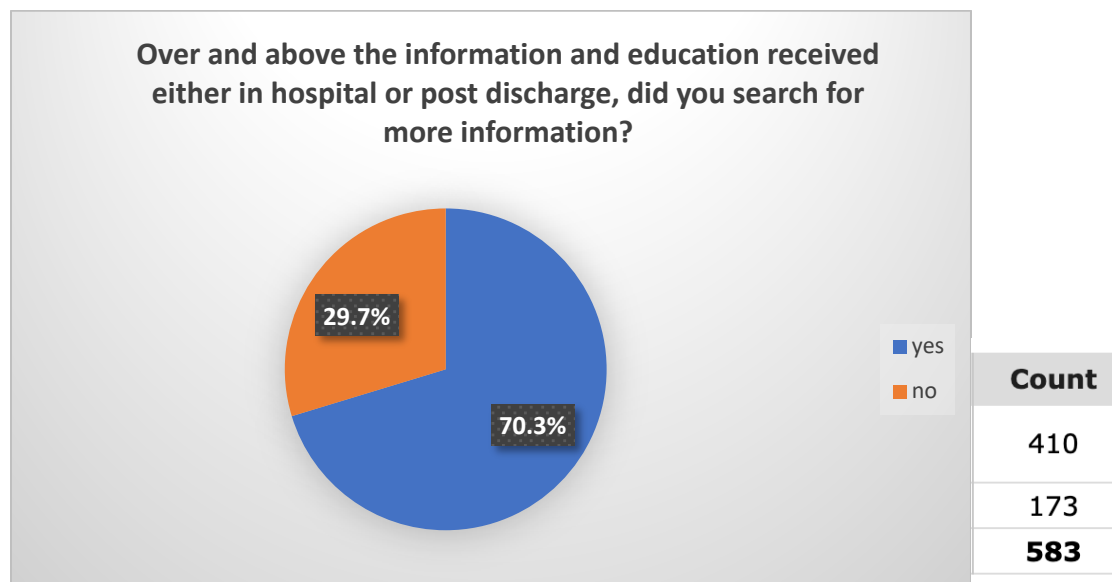
The following table illustrates the number of times the different options were selected.

Nurse	101
Doctor	91
Printed pamphlets	87
Social media (e.g. Facebook, blogs)	29
Other NICU parents	24
Internet search	23
Friends/family	13
Parent education sessions	11
Canadian Premature Babies Foundation (CPBF) website	10
Other	10
Prema-Quebec website	0

Question 12:

Participants were asked if they searched other sources of information than what they had received in hospital or post discharge.

The majority, 70.3% had searched other sources of information other than those provided at the hospital or at the time of their baby's discharge. About 30% were satisfied and did not seek more information.



Question 12 continued:

Of those who did seek more information, the following question was to identify the source of information they gravitated towards to receive their facts. Of the 416 who responded the most recognized source for additional information was internet searches followed by the family doctor / pediatrician. Social media represented the third most sought after source of information. Some reached out to the CPBF website to learn more about RSV.

If yes, where did you get more information? Please click all that apply:

The following table illustrates the number of times the different options were selected.

Internet search	345
Family Doctor, pediatrician	191
Social media (e.g. Facebook, blogs)	103
Other NICU parents	97
Canadian Premature Babies Foundation (CPBF) website	55
Friends/family	13
Other	10
Prema-Quebec website	4

Question 13:

Participants were asked if you received all the information and education on RSV and respiratory infections, to click all the answers below that applied.

Majority felt they had all the tools and information required to look after their baby / child. A small proportion did not get enough information or education.

If you received all the information and education on RSV and respiratory infections, please click all that apply:

The following table illustrates the number of times the different options were selected.

I took all the precaution/advice to keep my baby/ child as healthy as possible	460
I understood all the risks	324
I was able to advocate for my child	308
I did not get enough information/ education	103

Question 14

Participants were asked for their advice about ways to educate and provide information to **new families** with premature babies in the NICU to keep their babies as healthy as possible. Several choices were provided to the respondents and the overwhelming proportion suggested the nurse and the doctor were the best way to provide information to new parents of a premature baby. Printed pamphlets were also very popular. Over 480 participants cited 3 or more sources of information as appropriate for education. Parent education sessions and videos were of interest to many. Some reported that Canadian sources of information was the most valuable resource for parents.

Utilizing several education resources in combination will reach more parents and bring them up to speed with the information they need or want.

Thinking about new families in the NICU, what would you recommend to be the best way for all NICU families to receive the correct information and education to keep their baby/child as healthy as possible? Please click all that apply.

The following table illustrates the number of times the different options were selected.

Nurse	531
Printed pamphlet	480
Doctor	438
Parent education sessions	395
Canadian sources (i.e. websites)	207
Social media (i.e. Facebook, blogs)	157
Videos	130
Internet search	96
Podcasts	74

Question 15:

What is the most effective way the Canadian Premature Babies Foundation (CPBF) could deliver RSV information to you?

Respondents could choose more than one option.

The most popular was CPBF Facebook group, CPBF website, and pamphlets. Most respondents had 3 or more suggestions / combinations thereof to provide necessary information. The least attractive sources were blogs, podcasts and Twitter.

The following table illustrates the number of times the different options were selected.

Facebook group	402
CPBF website	368
Pamphlets	353
Instagram	223
Support group	219
Videos	187
Webinars	142
Blog	114
Podcasts	109
Twitter	96
Other	23

D- DEMOGRAPHIC DATA

In which setting is your premature baby now located?

Of the total participants in the survey 94.7% of the babies had already been discharged home, while 5.3% had their baby still in the hospital.

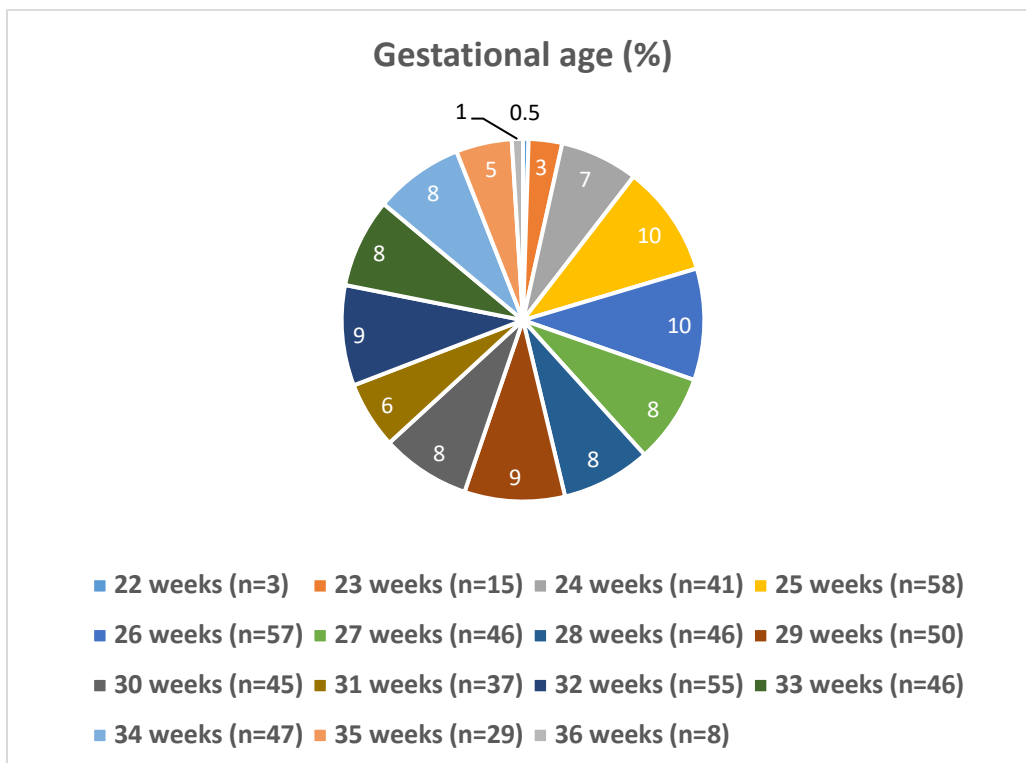
Is your baby/child:

Choices	Percentage	Count
At home	94.7%	552
In the hospital	5.3%	31
Total		583

Participants were asked to indicate what year did the premature birth occur.

The majority of children were born in 2019 (23.7%) and 2018 (21.6%). 12.7% of the participants' babies were born in 2017 and approximately 8% each in 2016 and 2015. The birth of the remainder of the infants, spanned the years 1988 -2014.

Participants were asked what was their baby/ babies gestational age at delivery.






Mother's age at the baby's birth:

The vast number of participants at the time of birth of their baby were between the ages of 26 and 35 years (67.6%). The next age group was represented by 23.7% who were between 36 and 45 years of age. A few were below 25 years (8.2%) and only 0.5% were aged 46 to 55 years.

Gender of the participants:



An overwhelming majority of the respondents were female (96.9%), 2.9% were male and 0.2% were other.

Are you:

Choices	Percentage	Count
Mother	 96.9%	565
Father	 2.9%	17
Other	 0.2%	1
Total		583

Other children in the family:

An equal number of respondents did or did not have other children.
Do you have/had other children?

Choices	Percentage	Count
Yes	 50.8%	296
No	 49.2%	287
Total		583

Level of education of participants:

344 (59%) of the respondents had a University degree, 136 (23.3%) had a College degree, 69 (11.8%) had a high school education, and 4 (less than 1%) had not completed their high school.

Province of residence of the participants:

The majority of respondents were from Ontario (36.5%) followed by Alberta (27.8%) and British Columbia (9.9%). Only 15 respondents were from Quebec as they had a separate survey in French which was done in collaboration with Préma-Québec that posed the same questions.

province

Choices	Percentage	Count
Ontario	36.5%	213
Alberta	27.8%	162
British Columbia	9.9%	58
Manitoba	6.5%	38
Nova Scotia	5.8%	34
Saskatchewan	3.4%	20
Newfoundland and Labrador	2.9%	17
Quebec	2.6%	15
Prince Edward Island	2.1%	12
New Brunswick	1.9%	11
Yukon	0.3%	2
Nunavut	0.2%	1
	Total	583

Geographical description of residency:

A total of 382 (65.5%) participants lived in a large city, 131 (22.5%) lived in a small community and 68 (11.8) in a rural community.

Birth hospital:

Sixteen were born in a community hospital, and 567 were born in a large hospital.

E- HIGH LEVEL RECOMMENDATIONS:

A multitude of educational formats were recommended by the parents who participated in this survey, but the nurse, doctor and pamphlets remain the most popular sources for information. New and emerging resources found on social media (such as websites, Facebook groups, blogs) are well used and their popularity is increasing. The most important source of web-based information is the CPBF website. It is of utmost importance to ensure it is up to date and designed to boost search engine optimization. The profile of the website should also be enhanced by investing in a robust search engine marketing platform.

- It is recommended that CPBF invests significant effort to ensure that the information on their website is current, medically reviewed and trustworthy.
- The Facebook page and private Facebook group mostly exist to share stories, find a peer, provide some educational content and importantly guide parents to the CPBF website.
- It is recommended that CPBF collaborate with NICUs nationally, to provide an educational tool kit for parents of premature babies. This is of prime importance since pamphlets offer key information and educational material that are the most effective tool to educate parents of premature babies about RSV and respiratory illnesses in the NICU setting.
- It is recommended that doctors and nurses should be educated on all the resources available for parents in the NICU setting.
- It is recommended that the presence of social media should be increased by greater investment in paid social media ads (google ads) and by geotargeting NICU hospital postal codes as this will centralize electronic searches while parents are in the hospital and increase usage of the CPBF website.
- It is recommended that when a baby is being discharged home, parents are supported and educated with the use of a pamphlet that covers what to do and provides information about protecting the health of every baby. This information will help to reassure parents and will increase their confidence.
- It is recommended that parents whose babies qualify for RSV know and understand the criteria and appreciate the next steps for receiving RSV prophylaxis.
- It is recommended that tools be developed for parents to communicate to family and friends about the risks of RSV premature babies and the proper hygiene protocols required to reduce the risk.

F- ANALYSIS AND RECOMMENDATIONS FROM COMMENTS COLLECTED FROM THE CPBF/ Préma-Québec SURVEY

CPBF/ Préma-Québec conducted a survey to collect information about the experiences of parents in their learning about respiratory syncytial virus (RSV) and winter illnesses. The objective of the survey was to gain feedback from parents' of preterm infants, on their experiences and knowledge about RSV and winter illnesses and to understand how this information was provided to them.

The feedback from this survey will be primarily used to improve the delivery of educational materials and tools to NICU parents in hospital and post discharge. The assembled information will also provide health care professionals with a better understanding of parental needs, and the ability to address these needs through targeted education and support.

Narrative Review of Comments

Education Among Healthcare Professionals about RSV

Among survey participants' comments, there appeared to be inconsistent transfer of knowledge from healthcare professionals to parents.

Some participants felt that other NICU parents and hospital staff needed more education about the risk of RSV more particularly to reduce the spread of RSV within the NICU and PICU wards. One suggestion was to increase the visibility of signage within hospitals as to the risk of RSV and to enforce safe hygiene protocols especially within NICU settings. Some respondents stated that their NICU doctors and nurses did not identify RSV as a specific risk for their child but did inform them about the risk of respiratory infections and concomitant illness.

In the comments section, only one survey participant shared their concerns with CPBF that they had learned about CBPF through their hospital's peer support worker.

Some survey participants wished that their healthcare professionals took more time to educate them about RSV instead of providing them with a booklet.

Educational Materials for Family and Friends

Survey participants shared that they often struggled with educating family and friends about the importance of implementing protective hygiene protocols around their premature babies, both while in the NICU and after discharge. This points to a need to educate the broader public about the increased risk that premature babies face in contracting RSV and other illnesses.

Some respondents expressed struggles with family and friends about the institution of strict hygiene protocols and taking preventive measures seriously. This created an added burden of stress on parents of premature babies. Some participants shared that explicit signage around proper hygiene protocols in the NICU were invaluable and helped visiting family and friends to fully appreciate the serious risk of RSV to premature babies.

Education about RSV for Parents

Many survey participants expressed that they did feel that they received adequate information about RSV from their healthcare practitioners in the NICU. However, some respondents felt they received inadequate or hardly any information about the risk of RSV to their baby, and what they could do to minimize the risk.

As such, some suggested a need for educational tools on what RSV is, what symptoms to recognize, how to advocate for their child, including what questions to ask doctors, what symptoms to bring to the nurse or doctor's attention, and how to describe RSV symptoms accurately. One survey participant shared the need for visual educational tools, like videos, to help identify the symptoms and signs of RSV.

Survey participants suggested that CPBF provide parents with booklets about RSV and **RSV prophylaxis (RSVP)** upon discharge from the NICU. Parents should also have the ability to request follow-up visits for further discussion on RSV issues by healthcare professionals. Respondents also expressed a greater need for education on what to expect when returning home with their babies.

One survey participant shared that they received accurate information about RSV, but misinformation about how Respiratory Syncytial Virus Prophylaxis (RSVP) actually works and provides protection against RSV. This highlights the need for greater education about RSVP and safe hygiene practices for a baby that has received RSVP.

Experience of Parents with Premature Babies

Some survey participants expressed that the experience of having a premature baby is overwhelming and isolating, signalling a need to receive information and education about RSV and RSVP before birth, during the NICU stay, and post discharge. Respondents further

shared that they would like to have greater access to peer support with other parents with premature babies.

Additionally, survey participants explained that the extra anxiety of navigating the healthcare system to get access to RSVP was unduly stressful. The feelings of isolation, abandonment and stress featured prominently across survey participant's experiences of caring for a new premature baby. As such, it is recommended that mental health and peer support resources be made more accessible and available to parents.

Accessibility of RSVP

Many respondents felt that RSVP should be more readily available. Many expressed that it was difficult to understand the guidelines for eligibility and that in some cases, those babies that were eligible were not approved for RSVP. One survey participant shared that their child's cardiologist, respirologist and pediatrician all declined to apply for RSVP, despite the child meeting all the eligibility criteria. The same participant expressed that receiving RSVP would have been less traumatic for their child and family than experiencing months of serious hospitalization.

Some survey participants shared that their healthcare practitioners in the NICU were not aware of RSVP. Similarly, among survey participants' experiences, there appears to be a need to decrease the disparity across the provinces with regard to the eligibility criteria for RSVP for premature babies.

Many survey participants expressed frustration over a lack of access to RSVP for their child after the first year of life. Many of the respondents also shared that their child contracted RSV within the second year of life or later. There appears to be large support for the RSVP prevention program to be offered for more than one year.

Survey participants also expressed desire for support from healthcare professionals in applying for RSVP, as the process can be overwhelming and difficult or confusing to fully comprehend. Additionally, they expressed the need for having information about how doctors assess who qualifies for RSVP.