

10 Years of CPBF

ANNUAL REPORT 2022

CPBF  Canadian Premature
Babies Foundation



canadianpreemies.org 4225-B Dundas St. W. Etobicoke, ON M8X 1Y3 info@cpbf-fbpc.org

Treaty 13

CHARITABLE ORGANIZATION NUMBER: 801837287 RR0001



“CPBF has helped our family change our perspective - and not just our nuclear but extended family as well! They celebrate how far these little warriors have come and what they can do... they are working to change the narrative around prematurity and what it can teach all of us about resilience and strength.”

~ Parent

10 Years of CPBF

As we take a look back at the past ten years, we can appreciate how far we have come, and also acknowledge the journey that lies ahead. We are excited to share some of our biggest milestones and achievements from the past ten years, and highlight our proudest accomplishments from 2022.

We know there is still work to do to improve outcomes for premature babies and their families, we know we are heading in the right direction, and we know we have a wonderful community of collaborators and champions who will make sure we get there.

♥ We thank you for your continuous support.

Statement from our Founder

Congratulations on 10 years of Canadian Premature Babies Foundation! My heart is full when I see what the organization has become. The focus remains on support, education, and research, which was part of my vision.

It seems like it was only yesterday that we embarked on this journey. So many people helped along the way. It was also many hours of work and advocacy. Families need the support and I wish premie families strength and the ability to reach out for help.

Wishing you continued success.

~ Katharina Staub

Who we are

We are a parent led, charitable organization providing education, support, and advocacy for premature babies and their families.

What we aim to accomplish

Our mission is to empower families of premature babies every step of the way, through support and education.

Our vision is a brighter future for all premature babies and their families. Our main focus areas are support, education, research, awareness & advocacy.



Why?

Approximately 30,000 babies are born prematurely every year in Canada. That is 1 of every 12 newborns. Any baby born at less than 37 weeks gestation is at risk of long-term complications. Parents of these babies are at a higher risk of postpartum depression, anxiety, and PTSD. Having a premature baby can be an isolating, traumatic experience. Families often do not know whom to turn to or what resources to utilize.

How?

CPBF understands the unique needs of the families of preterm babies. We work in close collaboration with healthcare networks to improve the outcomes of babies born prematurely and influence standards of care across the country. To let families know they are not alone, we offer them peer and professional support. We provide education so parents gain confidence and feel prepared to care for their babies, both in the NICU and at home. We advocate on the behalf of families on a national and international level, making sure they are heard by government policymakers and healthcare providers.



“Your advocacy is so strong and I love all the initiatives the Foundation has put out this year (my sisters both had preemies this year with NICU stays and really appreciated the resources through your website and are looking forward to the Preemi stuffie.”

~ parent

Continuing to make waves

2012 Conducted a major environmental scan to better understand the Canadian landscape around preterm birth and identify what services and programs are needed on local and national levels.

2012 (Ongoing) Collaboration on numerous research initiatives within Canada and internationally, to improve outcomes for infants born preterm.

2014 Launched Canada's only national peer support network for NICU families where we currently have 3000 members.

2015 Collaborated with the Federal Government to help shape benefit design, system improvements, and service delivery to ensure NICU families are eligible to receive PCIC Caregiver Benefits.

2015 Expanded the celebration of World Prematurity Day into a truly national commemoration.

2015, 2016, and 2018 Developed and implemented a cross-country training program for NICU peer parents and conducted training sessions in 6 different provinces.

2016 Launched a microgrant program for hospitals and community centers that run peer support groups for NICU families.

2016 Developed bursary program to support NICU graduates who are moving on to higher education.

2016 Worked with the Ontario government to ensure NICU families can access funding for pumps, so that every NICU baby can benefit from an exclusive human milk diet.

2016 Shared our expertise with the Federal Government to transition the PCIC program to the new Family Caregiver Benefits program.

2017 Sponsored the first ever #NICUFilmFestival, where 5 hospitals received grants to support the creation of educational programming for NICU families.

2018 Created Welcome to the Club booklets for NICU families, which are now available in ten different languages and are free to download from our website.

2019 Launched our online content initiatives, including a popular podcast for NICU Families called *With You in the NICU* and regular online chats via Facebook Live with clinical and family experts.

2020 CPBF met the challenge of the pandemic by expanding our online programming to twice weekly Preemie Chats. We offered online counselling to NICU Families to fill the gap in support caused by COVID-19, and partnered with international organizations on the Zero Separation Campaign.

2020 Created a partnership which provided eight NICUs across Canada with technology grants enhancing parent/caregiver connectivity during the pandemic.

A Word from Our

Executive Director



Fabiana Bacchini

We accomplished so much in 2022 including several key initiatives identified by the families we serve.

We created many new resources and educational tools that are all free to access and download on our website. As you read this annual report, you'll see how important your support is to our continued growth, and how we continue to bring value to our community.

In addition to strengthening the position of CPBF as the main source of information and support for families of premature babies, we have nationally and internationally aligned our organization to offer more strategic input on research studies, while raising awareness about prematurity on a global and societal scale. We have had ten incredible years and I am so grateful for everything we have achieved.

A Look Back at 2022

For me, two particular highlights of the past year were the launch of educational materials for Indigenous families with The Martin Family Initiative, and the launch of the position paper, Ensuring Equal Access to Respiratory Syncytial Virus (RSV) Prophylaxis for Preterm Infants Born 32-35 weeks Gestational Age: Summary of a New Cost Analysis. These were new ventures for CPBF, and we were honored to have had these opportunities.

We celebrated World Prematurity Day in person, and it was wonderful to be able to share this special day with our community. It also gave us a platform to show our appreciation for some of our amazing volunteers including Kate Robson, Marianne Bracht, and Shakeera Baker.

Our outreach has been growing and I look forward to the new connections and opportunities 2023 will bring.



Our Partners

The accomplishments of CPBF wouldn't be possible without our partners, sponsors, and research colleagues.

Partnerships are vital in raising awareness and educating the wider public, as well as in empowering families and healthcare workers with the right tools to navigate prematurity. We are not only grateful for their support and knowledge, but honoured to work alongside them to drive our mission forward.

“The Canadian Premature Babies Foundation is an incredible organization making a hugely positive difference to neonatal families and communities across Canada. Their passion and ethos are inspiring and we're proud to be able to contribute to the support they offer families through educational video resources.”

~ Laura Brockbank, Marketing and Communications Manager, vCreate

“The Canadian Premature Babies Foundation is a trusted source of information and a dedicated support and resource for parents and caregivers of premature babies. AstraZeneca is proud to partner with CPBF and support their efforts to protect the most vulnerable babies from common respiratory illnesses, like respiratory syncytial virus (RSV).”

– Chris Politis, Senior Manager, Patient Engagement and Policy Strategy, AstraZeneca

“Prolacta Bioscience is honored to continue our partnership with The Canadian Premature Babies Foundation (CPBF). Our work to advance the science of human milk includes efforts to educate parents and clinicians. It is our sincere pleasure to work with Fabiana and her team, and we look forward to many more collaborative projects together. Thank you Fabiana and the CPBF team for all you do to improve the quality of lives for premature babies and their families.”

~ Maria Rudyk, Senior Clinical Specialist, Prolacta





Our Impact

CPBF has outlined four core needs in our community, and together we are working to meet them.



CPBF has taken action to address these needs, and our impact is outlined in the following pages, related to each of our areas of focus:

- 1. Support**
- 2. Education**
- 3. Research**
- 4. Awareness & Advocacy**

Finding ways to fill these needs is helping parents to minimize the impact of the NICU on their lives and on the lives of their children born preterm.

Take a closer look at how **CPBF is taking action** >

1. Support

What we learned:

Parents of preterm infants experience mental health challenges that can persist long after they leave the NICU.

Peer support and connection is powerful, and evidence has repeatedly shown its positive impact.



What CPBF provides:

In addition to the clinicians and caregivers who tirelessly care for our families, we recognize that connecting families with similar lived experience is also deeply beneficial.

Currently CPBF's online peer group has over 3,000 parents supporting and encouraging one another!

We have a roster of almost 200 parents trained in providing peer support. Having collaborated with NICU graduate parents, healthcare providers, and hospitals from our very beginning, we now share a common goal of championing peer support and parent groups in Canada's hospitals, communities and online.

CPBF's Virtual Peer Support Group held 48 weekly sessions in 2022 alone. Facilitated by a perinatal mental health specialist (who is also a preemie parent!)

Parent Care provided NICU parents with 4 free therapy sessions, facilitated by 12 perinatal mental health specialists from across Canada. Hundreds of Canadian families benefited from professional mental health support, thanks to our team of healthcare providers.

Newly-graduated NICU families were offered a 6-week support group program in 2022. This closed therapy connected preemie families with similar lived experiences to discuss NICU stays, post-NICU, perinatal mood & anxiety disorders, trauma, and grief, plus strategies to address NICU trauma and life post-discharge.

"Can't tell you enough how grateful I am for this program. Having someone listen to what I went through and was going through while providing constructive feedback on how I could better process my trauma and move forward has been a lifeline when I felt like I was drowning."

~ program participant

Prematurity puts families on a journey with many ups and downs. We encourage families to celebrate every accomplishment and happy moment, so we created Milestones Cards most recently shared with 25 Canadian NICUs along with NICU graduation certificates.

(Milestone cards are free to download in English and French from our website.)



2. Education

What we learned:

More education, empowerment, access to resources and opportunities to participate are needed for preemie parents.

Our focus on resources for families and professionals, amplifying preemie-focused research, and learning from families is on the mark.



What CPBF provides:

Keeping an active dialogue with preemie families is vital for CPBF to better understand and support the struggles they face. These priorities help guide us to source, improve and distribute free, relevant educational resources to both families and healthcare professionals for better outcomes.

Our virtual education ‘Preemie Chats’ sessions have become a wonderful way to share gathered knowledge, and hear from experts, academics, and other preemie parents.

Delivered live on CPBF’s YouTube, Twitter, and Facebook channels, the weekly interactive chats are free and are often attended by guests from all over the world! We hosted 46 Preemie Chats in 2022, and on YouTube alone, we received over 1 million impressions!

Applying current new research and best practice, we continue to expand our series of high quality Educational Infographics with experts. Our ever growing selection provides evidence-based information on relevant topics for families and teaching tools for healthcare professionals covering topics of Neonatal Follow-Up, Kangaroo Care, and ROP.

We launched 3 animated videos – *A Day in Neonatal Follow-up Clinic, Dad's experience in the NICU, and Adjusting to a new baby in the NICU for Indigenous families.* We work for all preemie families to feel included, seen, and understood. *Thanks to our media partner, vCreate.* CPBF has been working with *The Martin Family Initiative (MFI)* to develop culturally adapted resources for Indigenous families with children born prematurely. In addition to the vCreate video, CPBF designed content for MFI’s ‘toolbox’ kit. Creating materials for underrepresented families is important, and we look forward to expanding our materials.

"It has been such a pleasure for our team at MFI Early Years to collaborate with CPBF throughout 2022. Integrating CPBF's expertise on preterm birth and the NICU with the lived experiences of Indigenous parents and families supported the creation of culturally adapted resources for Indigenous families with children born prematurely."

- Rachel Pacione, MFI



(2. Education cont.)

With hospitalization of children for common viruses on the rise internationally, we launched a Respiratory Syncytial Virus (RSV) Education infographic - this time translated into 16 languages to help all families understand how to reduce the risk. RSV remains a topic of extreme importance as premature babies are among some of the most at-risk individuals likely to develop complications.

Together with the Newborn Brain Society, our new podcast series SMALL BRAIN, BIG DREAMS was created! The first season offers 4 episodes featuring world-renowned pediatric neurologists who discuss their careers, mentorship, collaboration with parents in research, and what's new and coming up in this field.

We joined forces with the amazing Canadian Neonatal Follow-up Network to create a campaign called Parent Voices, Outcomes of Prematurity: From Knowledge to Care.

Designed to share evidence-based understanding and awareness to healthcare professionals and the community at large about what really matters to parents when it comes to the outcomes of their premature children.

Through *Parent Voices*, we seek to fundamentally change the way neonatal follow-up clinics measure preemie development by partnering with preemie parents and caregivers. The resulting partnerships help to design studies and amplify outcomes that matter most.

“Our partnership with the Canadian Premature Babies Foundation has profoundly changed how we report on outcomes of prematurity. We are now shifting to a more balanced perspective, integrating parental values and priorities in research. This collaboration is very enriching and humbling.

~ Dr. Thuy Mai Luu, University of Montréal

3. Research

What we learned:

The lack of parental voice in academic studies and research results in only partial understanding of their challenges and needs.

Our scientific advisory committee's framework for parental engagement is making waves, as is taking part in and facilitating research.



What CPBF provides:

In order to improve outcomes for premature babies, CPBF continues to facilitate and engage fully in research. Through our Scientific Advisory Committee, a framework for parental engagement in research is being refined. We continue to be active collaborators on numerous research studies and publications both in Canada, and globally. We are making space for family perspectives at research tables with recruited parent advisors. CPBF endeavors to engage as many parents as possible to help bridge the gaps. Current research falls short of reflecting the true struggles that preemie families face. It takes all of us to make change.

Researchers from across Canada came together to develop the PRESENCE STUDY project, launching in 2023. As a partner we are focusing our efforts with the study team on recommendations and guidelines to ensure parental presence in the NICU (zero separation).

"It was a wonderful experience working with parents on my project evaluating the impact of prematurity on families. CPBF facilitated identifying a diverse group of mothers and fathers who were interested in this project. Being part of our advisory group, they were able to guide us in our research decisions. It is crucial that parents be involved more and more and their perspectives sought for in research related to prematurity. Involving them as research partners will play a major role in making newborn research wholesome."

- Dr. Deepak Louis, Neonatologist
Children's Hospital Research Institute, Manitoba

4. Awareness & Advocacy

What we learned:

Lack of understanding around prematurity, long term outcomes and the struggles that families face, impacts progress forward.

Advocating for policies, collaborating for advancement, calling our community to action means improvements for preemie families.



What CPBF provides:

Through our commitment to advocate for families to establish policies that have their best interests at heart, we published a Position Paper with RSV experts. *Ensuring Equal Access To Respiratory Syncytial Virus (RSV) Prophylaxis RSV*, provides a summary of a new cost analysis, as well as a call to action to end inconsistencies in the use of palivizumab. This is another step towards our goal for equal access for all parents of preterm infants born 32-35 weeks gestation.

Our Zero Separation policy brief was deployed to ensure parents maintained access to their babies in the NICU. This document represents our action in support of evidence that overwhelmingly demonstrates the benefit of parent-infant contact - not only for the health outcomes of the baby but for parents as well.

CPBF continues to break down obstacles for parents and their premature infants. Parent partners from across the country participated in conferences (including FICare, EPIQ-CNN, and Child-Bright). They shared and learned from experts and formed new pathways for collaboration.

“The importance of family engagement in improving the health and development of preterm babies has been well-documented. However, supporting NICU families requires significant effort, and the CPBF plays a vital role in advocating for them. In partnership with the CPBF, the Canadian Neonatal Network is dedicated to ongoing research and the development and implementation of best practices to make family-centered care a reality across Canada. Healthy families are key to promoting the health and well-being of preterm babies.”

~ Marc Beltempo,

Neonatologist, Montreal Children’s Hospital - McGill University Health Centre, Associate Director, Canadian Neonatal Network



(4. Awareness & Advocacy cont.)

The cornerstone of CPBF’s awareness efforts, World Prematurity Day (WPD) amplifies the voices of premie parents and those who care for them. At our first in-person event since the pandemic, we celebrated the strength of premie babies together. Our annual illumination campaign saw 36 monuments across Canada lit with ‘preemie purple’ lights including Niagara Falls, Toronto’s CN Tower, Olympic Park in Montreal, and more! We also had the honor of speaking at Niagara Region Public Health about the importance of CPBF’s work in advocating for awareness around prematurity. #preemiepower

A Special WPD Edition of ‘Preemie Chats’ on November 17th put Kangaroo Care in the spotlight. CPBF distributed posters and buttons to 54 NICUs across the country.

Internationally CPBF and ONG Prematuridade (Brazil) co-hosted a Special Live streaming event on November 10th together with EFCNI. People from over 66 countries tuned in.

One of the most exciting (and cutest!) initiatives of 2022 was the release of our Preemi™ stuffed animal. This lion stuffie is the first of its kind; developed specifically for premature babies by DDB. Preemi™ was an immediate sensation, generating a buzz of conversation in our community. Over 200 people signed the waitlist for the Preemi™ release. Promotions for Preemi™ also received 1.2 million online impressions.

“Thank you, the Canadian Premature Babies foundation, for advocating on behalf of our premies and their families. You make a difference!”

~ Hospital Social Worker

Your Support Matters

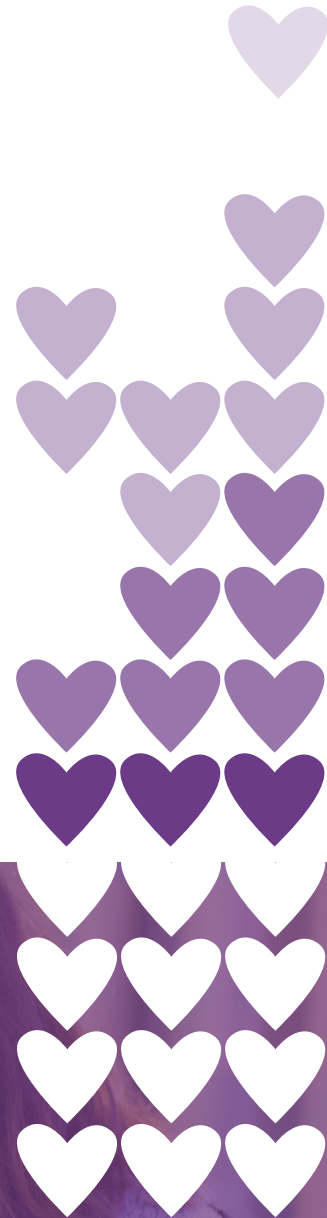
CPBF is built on a solid foundation of volunteers; without them, we would not be able to do what we do. Our Board of Directors, and the members of our four different committees are all volunteers. They are very experienced and involved physicians, scientists, nurses, parents, and adults born preterm.

Our Goals for 2023

We plan to continue to provide evidence-based education, collaborate with healthcare networks to bring parents' voices to research, influence best practices and standards of care, support parents during and after their time in the NICU, and expand our parent-partner network and involvement in NICUs across Canada.

How to be part of our story

Visit us at canadianpreemies.org for more resources and programs focused on preemie babies and their families.



Instagram
@canadianpreemies

Facebook
@canadianpreemies

Canadian Premie Parent Support Network – CBPF-FBPC
private Facebook group

Twitter
@canadianpreemie

LinkedIn / YouTube
@Canadian Premature Babies Foundation

Join us!



Big love.

**The support of partners and sponsors is vital to our mission.
We are honored to work with such amazing people.**

Partners

CANN (Canadian Association of Neonatal Nurses)
CNFUN (Canadian Neonatal Follow-up Network)
CNN (Canadian Neonatal Network)
CPTBN (Canadian Preterm Birth Network)
CHILD-BRIGHT Network
EFCNI (European Foundation for the Care of Newborn Infants)
EPIQ (Evidence-based Practice for Improving Quality)
FICare (Family Integrated Care)
GLANCE (Global Alliance for Newborn Care)
MFI (The Martin Family Initiative)
Newborn Brain Society
PAHO (Pan American Health Organization)
SKIP (Solutions for Kids in Pain)
University of Toronto, Mississauga

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Q5
MAS (Management Advisory Services)

We would like to express our gratitude and appreciation to all the contributors and perinatal mental health specialists across Canada for being part of our Parent Care program in 2022.



Contributors

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Our Mission

To empower families of premature babies every step of the way, through support and education.

Our Vision

A brighter future for all premature babies and their families.



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Project Coordinators

Shakeera Baker, Parent Care Program
Andrea Wiebe, Milestone Cards
Melissa Jones, Parent Voices
Patricia Almeida, Premie Chats
Rami Garg, Position Paper
Lindsay Harris, World Prematurity Day

Interns

For a fourth year, CPBF counted on the assistance of students from the University of Toronto in Mississauga to support our communications team.

Volunteers

Our cross-Canada network of volunteers is now 40 strong! Adult preemies, nurses, neonatologists, parents, and community members are supporting our work.

"I have found a resilience and healing through my volunteer work with CPBF. I've been able to lend my voice and perspective as a NICU mom during the pandemic towards the continued effort to establish national recommendations on parental involvement in the NICU for all premature babies. Thank you for letting me play a small role in the wonderful work you do, CPBF!"

~ Addie Chilcott, Volunteer

Love ♥ Letter

To our community of donors, volunteers, families, and health care professionals:

You make it possible for us to continue to support, educate, advocate, and collaborate with researchers to improve outcomes and help families build resilience.

“Thank you, CPBF, for everything you do to support preemie parents like myself. It is such a meaningful cause and please keep doing the amazing things that you do!”

~ Premie Parent

Join us in creating a brighter future for babies born too soon.



Visit us online for more resources and programs focused on preemie babies and their families.

canadianpreemies.org



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