



Together, for better care.

ANNUAL IMPACT REPORT 2021



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

Treaty 13

CHARITABLE ORGANIZATION NUMBER: 801837287 RR0001

Together, for better care.

ANNUAL IMPACT REPORT 2021



Approximately 30,000 babies are born prematurely every year in Canada.

We are a parent led, charitable organization providing education, support and advocacy for premature babies and their families. We continue to build on our momentum with peer support programs, resources for families and health care professionals, and research leading to improved outcomes and better experiences for babies and families.

Table of Contents



CPBF Impact Report 2021: Together for Better Care	4
A Message from CPBF’s Executive Director.....	5
Highlight	6
CPBF Parent-Partner Network	
New look for the CPBF website	
COVIDCare Program (Now ParentCare)	
The voice for babies & families: Awareness & advocacy	6/7
World Prematurity Day	
Social Media	
RSV and Other Common Respiratory Illnesses Awareness & Campaign	
Support for parents and professionals	8
CareForCarers	
Real-Time Support Group for NICU Parents	
Peer Support Network	
Peer support training	
Early Education Group	
Graduation Bags	
Milestone Cards	
Education & Information	9
Weekly Preemie Chats – LIVE Virtual Education Sessions	
CPBF Blog	
Lactation Workshop	
Research & Engagement.....	9/10
Projects	9/10
Publications CPBF was Involved In	
Key Annual Collaborations	11
FICARE	
EPIQ-CNN	
Canadian Association of Neonatal Nurses (CANN)	
Pan American Health Organization (PAHO)	
Our People	12
Board	
Scientific Advisory Committee	
Family Advisory Committee	
Family Support Committee	
Education Committee	
Project Coordinators	
Interns	
Volunteers	
Parents, families, and kids	
About CPBF	12
To donate	

Your dedication is a constant source of inspiration. In a year of unrelenting change and adaptation, you have helped the Canadian Premature Babies Foundation provide consistent support and education for families of premature and sick babies. In this report, you'll see how your generosity has helped build on our four key areas of focus:

- being the voice of babies and their families,
- providing mental health support,
- delivering evidence-based education, and
- collaborating with researchers.

We couldn't do this without you. Thank you.



Why CBPF?

Every year, approximately 30,000 babies are born prematurely in Canada. As a parent-led charity, CPBF develops peer support programs, distributes helpful materials and resources to families and healthcare professionals, and investigates how we can better the lives and experiences of premature babies and their families.

We impact families, healthcare professionals, researchers, and policymakers by:

- Empowering families whose babies are in or have spent time in neonatal intensive care units (NICUs) by providing evidence-based educational materials;
- Deepening families' understanding and knowledge about prematurity and its long-term impacts; and
- Creating opportunities for learning and interacting in real time with experts, researchers, and parents through virtual learning.

"CPBF does an amazing job of providing preemie parents with opportunities to share their lived experiences and expertise, and to contribute in so many different ways. This year the CPBF has engaged parents through the Family Advisory Committee and brought parent representatives to the virtual EPIQ conference. CPBF was asked to help recruit parents to be on an advisory committee for Dr. Deepak Louis's research into the impact of premature birth on parents across Canada (EIPOP study). Parents are also actively involved in writing blog posts and helping to disseminate the results of research findings from the Parent-EPIQ project with the goal of engaging Canadian preemie parents in sharing their unique family stories. All of these connections facilitated by the CPBF serve to enrich the lives of everyone involved."

Rebecca Pearce, preemie parent and CPBF Family Advisory Committee Chair



A Message from CPBF's Executive Director

2021 has been an exceptional year for CPBF. Not only was it our second year coping with the effects of a global pandemic on the lives of premature babies, their families, and their caregivers — it was a year of exponential growth in terms of our influence.

As you review this report, you'll see that despite the unprecedented times we're living in, we were able to accomplish a number of key initiatives identified by the families we serve or proposed by our board. We also put a great deal of time and energy into the future and sustainability of CPBF, to ensure that we continue to serve our community for years to come.

For me, a particular highlight has been the creation of both a Family Advisory Committee and Scientific Advisory Committee. Parents from across Canada and a multi-disciplinary team of healthcare providers guide us through the creation and implementation of educational materials and programs, and help us establish partnerships and networks of support. Other highlights include the launch of our Parent-Partner Network and the CareForCarers program, and a website refresh that makes our resources and education more accessible.

As you read this impact report, you'll see how valuable the Foundation is to our community and how important your support is to our continued growth. In addition to strengthening and positioning CPBF as the main source of information and support for families of premature babies, we have aligned our organization to offer more strategic input on research nationally and internationally.

We are truly grateful to our volunteers, partners, and sponsors who believed in the vision and mission of CPBF from the beginning. We are also grateful to our new sponsors and partners, national and international, who even during this very difficult time decided to join forces with CPBF to create a brighter future for premature babies and their families.

What a year! I look forward to building more momentum with all of you in 2022.

With gratitude,

Fabiana Bacchini

CPBF Parent-Partner Network

Launched in 2021, our Parent-Partner Network is a made up of preemie parents working or volunteering in NICUs across Canada. The Network works to:

- Create opportunities for NICU parents to connect
- Share information about quality improvement initiatives and projects
- Provide a forum for sharing resources
- Advocate for increased parent involvement in NICUs.

CPBF also facilitates the participation of parents at conferences, meetings, and workshops in Canada, including EPIQ, FICare, and CANN.

“Learning from one another’s experience and expertise helps NICU parent partners better support current NICU families and advance the delivery of family integrated care in their NICUs.”

~ Karen Bong, parent-partner Sunnybrook Health Sciences

New look for the CPBF website

The new-look CPBF website was a hub of information for families and health care professionals in 2021:

Unique visits = 13,000+

Site visits = 21,000+

Average time spent per visit = 19 minutes

November 2021 World Prematurity Day-related visits = up 65%, with special events page views up 3,843%

Watch for more CPBF website upgrades in 2022!



COVIDCare Program (Now ParentCare)



Meeting the emerging mental health crisis brought on by the global pandemic, CPBF launched a pilot program in 2020 and has continued to offer free online individual therapy for families currently in the NICU and those discharged within the last 12 months, more than 50 families completed the program in 2021 and it continues to be a success. CPBF brought more therapists from across the country to keep up with the demand.

“I knew I needed to seek help when I couldn’t manage my PTSD alone. I enrolled in the program and it was the best decision I made to help me and my family move forward.”

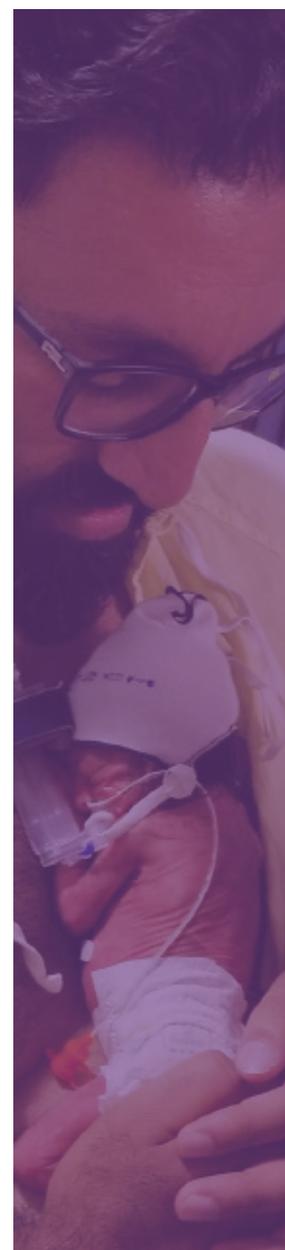
~ Program Participant

The voice for babies & families: #ZeroSeparation

Awareness & advocacy

Research shows the importance and benefit of parental presence and involvement in a baby’s care while they are hospitalized – for both parents and babies. For two years, the COVID-19 pandemic has meant hospitals across Canada have placed restrictions on parental presence in the NICU. CPBF has been advocating alongside clinicians and researchers on the impact of these restrictions.

CPBF participated in publications, research, the international #zeroseparation campaign with the Global Alliance for Newborn Care (GLANCE); delivered several presentations at national and international conferences; maintained a social media campaign throughout the year; and provided live online sessions about the latest evidence and recommendations to keep parents and babies together safely.



World Prematurity Day



On November 17th, 2021, CPBF joined 100 countries all over the world in recognizing World Prematurity Day. This year's theme was **Act now: Keep parents and babies born too soon together.**

CPBF is a leader in raising awareness of WPD across Canada, and partners with several organizations to promote nationwide programming. We support the International Global Illumination Project, which illuminates significant landmarks in purple to honour preemies, their families, and their caregivers. CPBF also hosted two LIVE Special Edition Premie Chats, bringing in 19 speakers from around the world, and distributed materials, posters, and buttons to NICUs across the country.

#WorldPrematurityDay2021
#PremiePowerCanada
#zeroseparation #smallbutmighty

The numbers

Illuminations across Canada = 40
Provinces involved = 8
Territories involved = 1
Premie Chat registrants = 430+
Premie Chat reach on social media = 5000+

Social Media

Our active and responsive social media channels allow CPBF to connect, share, and collaborate with parents, caregivers, clinicians, researchers, and organizations across Canada and around the world. Interactions include shares and tags from high profile Canadians, all levels of government, partner organizations, and other groups supporting child and family health.

Instagram @canadianpreemies
Followers: 1,823+

Facebook @canadianpreemies
Followers: 7,853+

Canadian Premie Parent Support Network – CPBF-FBPC
private group: 2,720 members and 13 moderators

Twitter @canadianpreemie
Followers: 1,745+



RSV and Other Common Respiratory Illnesses Awareness & Campaign

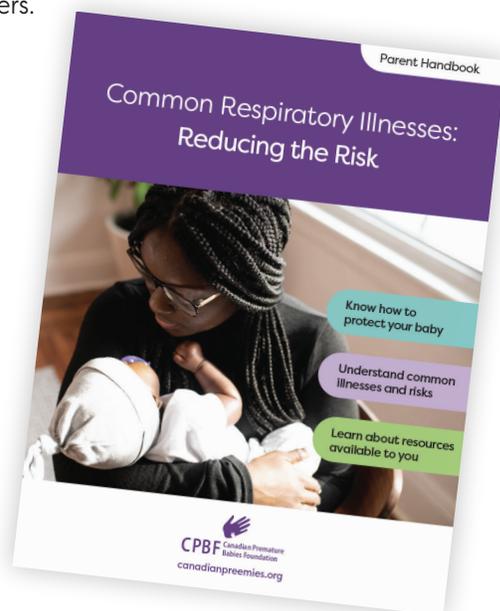
CPBF is committed to educating parents about RSV, the most common respiratory virus and the most common cause of lower respiratory tract infection in premature babies, and other common respiratory illnesses. Our work includes: New Parent Handbook of Respiratory Illnesses

Quick Q & A resources

A social media awareness campaign in October that reached 3,809 people on Facebook and 988 people on Twitter

Support for parents and professionals

With all in-person programs in hospitals cancelled, CPBF continued to provide free support online for families and healthcare providers.



Includes Premie Chats, Premie Health Talks, information and resources, expert advice, and the latest evidence and research.

Support for parents and professionals

With all in-person programs in hospitals cancelled, CPBF continued to provide free support online for families and healthcare providers.

CareForCarers

CareForCarers is a free six-week program delivered by a mental health specialist and designed to support healthcare providers who care for premature babies and their families. This is an important first step towards developing a mental health curriculum for NICU clinicians and caregivers.

109 carers registered • 67 carers attended 2 or more sessions • weekly attendance ranged from 27 to 48 – excellent for a free program

What carers are saying:

"I would like to take this opportunity to thank you for sharing your time and for cultivating a wonderful community and resources for us all. I have very much enjoyed the Care for Carers sessions!"

"Thank you for the Care for Carers session. They came at the exact right time for me. It's been so stressful and our Tuesday sessions feel like going to the spa."

"Please do more. This has been fantastic and I think all NICU nurses deserve a chance to do this."

Real-Time Support Group for NICU Parents

This group is facilitated live online once a week by a perinatal mental health specialist who is also a premie parent, and averages 12 participants per session.

"I was feeling lost and alone for a long time. Here I met people whose challenges might differ from mine but we all come together to support one another."

~ Group Participant

Milestone Cards

Our babies experience so many milestones during their NICU journeys. Our series of printable cards will help you celebrate each special moment. Our Milestone Cards program is now available in 22 hospitals across Canada (any hospital can apply and it's free) and we continue to offer them all online – free to download.

"The length is great! Of course sometimes we wish it could be longer cause I enjoy it so much!"

~ Program Participant

Peer Support Network

Our online peer support network has more than 2700 members across Canada. In this closed Facebook group, parents can share experiences, resources, and challenges as well as celebrate their babies' milestones. It's a place of comfort with people who have walked in the same shoes.

Peer support training

CPBF delivered virtual peer mentor training in two hospitals implementing peer support programs.

"As a future veteran parent at our local hospital, I appreciate getting the training to feel confident to support current NICU families."

~ Program Participant

"As a health care professional who attended a peer-to-peer training, it gave me the tools to bring veteran parents into our NICU and feel that they will be a successful member of our healthcare team in supporting parents. Excellent training!"

~ Program Participant

Early Education Group

The Early Education Group helps families prepare children born prematurely for school. This weekly pilot program took place online for four weeks, and families participated through active discussions with each other and an early childhood resource consultant.

"This group has given me a whole new level of education, which allows me to be better at being a Mom."

~ Program Participant

Graduation Bags

CPBF distributed 7,000 graduation bags to 36 NICUs across Canada between January and June 2021. Each bag had a package of Pampers diapers and a graduation certificate to help families celebrate this important milestone.



Education & Information

What parents are saying about Weekly Preemie Chats:

“My son was born at 31+6 and even though he's 5 now, I still find all of your resources so helpful and comforting. Especially the talks on Fridays. I love when the presenters talk about prem's brains as I feel like I didn't have that knowledge 5 years ago, or I didn't have the capacity to find it and consume it and understand it like I do now. Thank you so much!!”

“The chats are a nice way to feel connected to the preemie community. I enjoy watching them when I get some time for myself.”

Lactation Workshop

CPBF hosted two free lactation workshops for health care professionals in October and November 2021.

- **1061 people registered**
- **422 participated live**
- **100% of survey respondents stated that they would use this information in their practice as an educational tool for new mothers and their babies**

“You all have been pulling out some phenomenal content recently! As a preemie parent, previous community facilitator for a preemie playdate and now a midwifery student I love the evidence based and current information. I've passed on the link to the workshop to our midwifery department and shared with my classmates. Thanks again!”

Weekly Preemie Chats – LIVE Virtual Education Sessions

In 2021, CPBF hosted 110 free LIVE Virtual Education Sessions viewed in 14 countries. Our weekly sessions bring experts, researchers, parents, and adults who were born preterm to share their experiences and knowledge. Throughout the year, we hosted special sessions to discuss #zeroseparation, the COVID year in review, breastfeeding, and much more.

In November 2021 alone, we reached more than 4,093 people. With an audience that includes parents, parent-partners, and healthcare professionals (neonatologists, nurses, social workers, community partners), we're proud to have produced 150 live sessions with over 100 speakers from around the world since 2020. All sessions are recorded and available on the CPBF website and on our YouTube channel, with some sessions also added to the Newborn Brain Society portal, the PREMSTEM project, Child-Bright Network and other resource hubs.

CPBF Blog

Guest blogger Dr. Namrata Todurkar, neonatologist, brought relevant information for parents every other month. She explains the main issues babies born preterm can experience, such as ROP, NEC, BPD, and PDA.

Research & Engagement

Across Canada and internationally, CPBF fosters a culture of engaging preemie parents in research projects. This results in meaningful research that focuses on what really matters to families, and improved outcomes for babies born too soon or too sick.

CPBF continued to bring parents' voices to many research tables in Canada and worldwide in 2021. For the first time in Canada, last year, a CPBF preemie parent participated in a research project as principal investigator. This was a huge step for parents to be recognized and valued as true experts and collaborators.

Projects

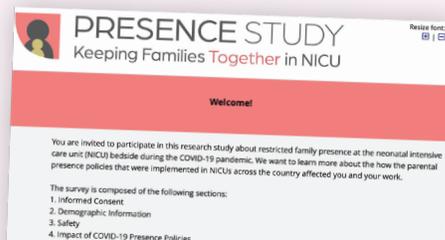
Our team is fully engaged in many projects, from co-design to advising to knowledge translation and dissemination.

CNFUN (Canadian Neonatal Follow-Up Network): The Parents' Voice Project.

This project examined the perspectives of parents related to the health of their premature children, the impact of prematurity on their lives, their need for information about prematurity, and any regrets they had surrounding their child's premature birth.

The PRESENCE Study

A research study about restricted family presence in the NICU bedside during the COVID-19 pandemic.



CPBF was involved in the following publications:

Two-Thirds of Preterm Parents Would Participate in a Randomized Controlled Trial Comparing Double Doses of Steroids to a Single Dose and Placebo
McDonald, Sarah D. et al., Journal of Obstetrics and Gynaecology Canada, Volume 43, Issue 12, 1429 – 1433, 2021

Supporting Parents as Essential Care Partners in Neonatal Units during the SARS-CoV-2 Pandemic
N.R. van Veenendaal, A. Deierl, F. Bacchini, K. O'Brien, L.S. Franck, and the International Steering Committee for Family Integrated Care, Acta Paediatrica, 26 March 2021

Rates and Determinants of Mother's Own Milk Feeding in Infants Born Very Preterm
Dharel, DineshAbenheim, Haim et al., The Journal of Pediatrics, Volume 236, 21 - 27.e4

The international Perinatal Outcomes in the Pandemic (iPOP) study: protocol
Stock SJ, Zoega H, Brockway M et al., Wellcome Open Res 2021, 6:21

A survey of parental knowledge of respiratory syncytial virus and other respiratory infections in preterm infants
Bracht M., Bacchini F., Paes B., Neonatal Network 2021; 40(1):14-24

Key Annual Collaborations

FiCare

CPBF is a member of the National and International FiCare (Family Integrated Care) Steering Committees to bring the parent's voice to the table. In 2021, CPBF brought parent-partners from around the world to FiCare's international online conference, where we hosted two parent panels.

EPIQ-CNN

CPBF is collaborating with EPIQ (Evidence-Based Practice for Improving Quality) and CNN (Canadian Neonatal Network) to educate families and healthcare professionals about how to engage families in quality improvement projects to advance positive outcomes for babies born preterm. Parents who volunteer or work in NICUs as parent partners need a voice at the table and the opportunity to co-design projects.

“We are so grateful to have you being part of our EPIQ/CNN meetings to provide your perspectives on how we can improve neonatal care. Your participation allows the health care professional to better understand and respond to the parents and families' needs.”

Dr. Joseph Ting, Staff Neonatologist, Alberta Health Services (Edmonton Zone); Associate Director, Evidence-based Practice for Improving Quality (EPIQ); Canadian Neonatal Network

Canadian Association of Neonatal Nurses (CANN)

CPBF continued to collaborate with CANN to mobilize knowledge, and participated in the annual CANN conference by bringing parents and sharing relevant information from our parent community.

Pan American Health Organization (PAHO)

CPBF hosted the first Latin American parent organization meeting online in May in collaboration with PAHO (World Health Organization/WHO). Representatives from Canada and 13 other countries came together to discuss common challenges and explore opportunities to work together to improve best practices and outcomes.

EFCNI – GLANCE

CPBF continued to collaborate with EFCNI (European Foundation for the Care of Newborn Infants) and GLANCE (Global Alliance for Newborn Care) on global awareness campaigns, such as Kangaroo Care, Pre-eclampsia, RSV, Breastmilk, World Prematurity Day and Zero Separation.

Together for better care! Infant and family-centred developmental care in times of COVID-19

This global survey of parents' experiences was distributed in Canada by CPBF. We also shared the final report with recommendations.

(<https://www.glance-network.org/covid-19/survey/>)



photo credit: Rebecca Thomas

Our People

Board

Doris Sawatzky-Dickson, Chair
Dr. Jennifer Toye, Director
Jan Marin, Director
Karen Netzel, Director
Karen Beatie, Director
Dr. Yenge Diambomba, Director
Fabiana Bacchini, Director

Scientific Advisory Committee

Dr. Marsha Campbell-Yeo, Chair
Dr. Nancy Feeley
Dr. Thierry Lacaze
Dr. Michael Narvey
Dr. Steven Miller
Dr. Karel O'Brien

Family Advisory Committee

Rebecca Pearce, Chair
Cristina Galifi
Jenna Morton
Kojo Mensah
Cynthia Sanders
Michelle Peltier
Aruna Boodram
Tiffany Richards

Family Support Committee

Kate Robson, Chair

Education Committee

Marianne Bracht, Chair

Project Coordinators

Shakeera Baker, Parent Care Program
Andrea Wiebe, Milestone Cards
Melissa Jones, Parent Voices
Patricia Almeida, Premie Chats
Mary-Jane Mikkelsen, Graduation Package Program
Amrita Subramanian, Volunteer Coordinator

Interns

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

Volunteers

Our volunteers rock! We have 50 volunteers across Canada supporting our work, including adult preemies, nurses, neonatologists, parents, and community members.

"In May 2020, I decided to reach out to Canadian Premature Babies Foundation (CPBF) because I was interested in exploring volunteer opportunities. I was very interested in supporting this organization as I was born prematurely. As a Project Coordinator, I have enjoyed connecting families with mental health clinicians around Canada and working with a great team of clinicians. The highlight of my work has been coordinating "World Prematurity Day 2021" through reaching out to dozens of organizations and encouraging them to light up their landmarks in purple. I am excited to continue supporting families with premature babies in 2022."

~ Shakeera Baker

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 for creating a brighter future for babies born too soon!

About CPBF

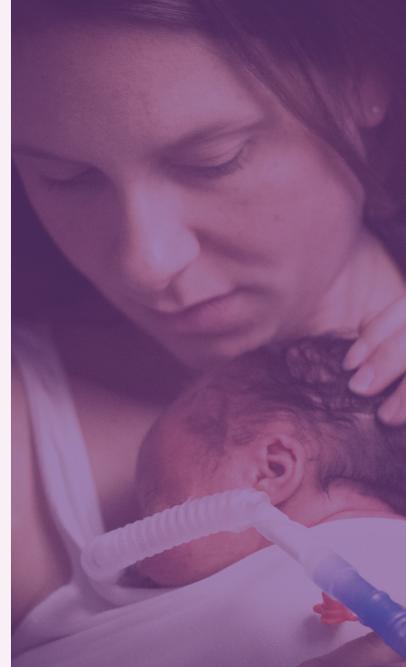


photo credit: Rebecca Thomas

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.

Our Focus Areas



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

~ Premie Parent

Thank you Friends

We are honored to work with these partners and sponsors. Their support is vital to our mission. We truly appreciate their interest in helping our organization thrive.

Sponsors

Abbvie
Astra Zeneca
Gluckstein Lawyers
Kiwanis Kingsway Humber
Medela
Pampers
Pampers Club
Prolacta Bioscience
Rotary Club Etobicoke
The Mathisen Family Foundation
WaterWipes

Special thanks to the students and staff of Our Lady of Sorrows Catholic School for their amazing fundraising efforts.

Partners

CANN (Canadian Association of Neonatal Nurses)
CNFUN (Canadian Neonatal Follow-up Network)
CNN (Canadian Neonatal 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)
Newborn Brain Society
PAHO (Pan American Health Organization)
SKIP (Solutions for Kids in Pain)

Contributors

Amaan Giga
Bright by Design Inc
MAS (Management Advisory Services)
Rebrandnew
University of Toronto, Mississauga

To all our individual donors, monthly donors, and families who fundraise for us, you can rest assured that your generous donation is being put to good use. We are so grateful to have you as part of our team!



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

CPBF  Canadian Premature Babies Foundation



canadianpreemies.org



@CanadianPremies



@CanadianPremie