IMPACT REPORT

2019 - 2020



Canadian Premature Babies Foundation

Charity number: 801837287 RR0001



CPBF IMPACT REPORT 2019–2020: TOGETHER FOR BETTER OUTCOMES

As a parent-led charity, Canadian Premature Babies Foundation (CPBF) supports and educates families of babies born prematurely. We provide education, support, and advocacy for Canada's premature babies and their families.

Approximately 30,000 babies are born prematurely every year in Canada. Our goal is to build momentum by continuing to develop peer support programs, distribute helpful materials and resources to families and health care professionals, and investigate how we can better the lives and experiences of premature babies and their families.

TOGETHER, WE'RE CREATING A BRIGHTER FUTURE FOR ALL BABIES BORN PRETERM. THIS IS ONLY POSSIBLE WITH YOUR SUPPORT.

NICU parents & health care professionals: Family Integrated Care (FICare) Conference – February 2020, Calgary, AB





A MESSAGE FROM CPBF'S EXECUTIVE DIRECTOR

My personal journey has led me to do the work I do today. As a mother of a surviving twin born at 26 weeks' gestation, I understand firsthand the long-term impact of prematurity. While we celebrate the fact that our son Gabriel is alive and thriving, we also still deal with many medical appointments because Gabriel has cerebral palsy and a compromised immune system.

I've been leading CPBF since January 2019. Every day, I put my heart to work to support families who are now walking in my shoes. I needed so much encouragement, help, and education during my NICU days and beyond. I understand the value of peer-to-peer support, relevant and accurate information, and the availability of resources and outreach.

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 proposed by our board or identified by the families we serve. 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.

We have strengthened the organization and are positioning CPBF as the main source of information and support for Canadian families of premature babies. We have also aligned our organization to offer more strategic input on research nationally and internationally.

As the world has changed in the last six months, CPBF has kept pace, collaborating with health care professionals to offer real time peer support and mental health support online, and education sessions for families on Facebook Live. These new programs have been very successful and given us immense hospital and community visibility, which has in turn created new opportunities. Increasingly, clinicians are requesting our help to support families with education and resources, involve them in research studies, and invite them to participate in conferences and committees. Technology grants were awarded to eight hospitals across the country to keep families connected during the pandemic.

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.

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.

I look forward to working with all of you in 2021.

OCTOBER 2020

With gratitude,

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OUR REACH

facebook

sessions 40

PAGE FOLLOWERS 6312

VIEWS 26,000+

PARENTS REACHED ON FACEBOOK PAGE 81,000

Using Facebook Live as a platform, CPBF's twice-weekly sessions from March to July 2020 with experts, researchers, and parents achieved an international audience.



Thanks CPBF for creating this for us [parents]. This is very convenient as I can watch and learn while caring for my baby.

NICU Parent

On behalf of our staff and parents from our Saint John Regional Hospital NICU, we would like to thank you and CPBF for such a great project directed to parents, their families and staff. It has made our day to day care for our families and babies much easier! Well done!

Dr. Luis Monterrosa, neonatologist



OUR REACH

facebook
World Prematurity Day

ILLUMINATIONS ACROSS CANADA

23 IN 5

REACH 383,087

37,454

GRADUATION VIDEO VIEWS **225,000**

World Prematurity Day took place on November 17th, 2019. CPBF-FBPC plays a major role in raising awareness of World Prematurity Day across Canada, and partners with several organizations to promote nationwide programming. We also support the International Global Illumination Project, which has significant landmarks illuminate in purple to honour preemies, their families, and their caregivers.



In 2019, the national Illumination campaign of buildings and monuments across Canada was enjoyed by hundreds of thousands of people, as well as on CPBF's social media channels. To raise awareness, we were also pleased to present our first "graduation video", highlighting the journey of a premature baby from the NICU to discharge day (graduation).



HELP FOR PARENTS OF PREMATURE BABIES

Meeting the emerging mental health crisis brought on by the global pandemic, CPBF offered a pilot program of free online individual and group therapy for families in the NICU and for those who had been discharged within the last 12 months. Our pilot project helped 50 families, and our goal is to extend the COVIDCare program into 2021 to meet increasing demand.



Being able to open up about what I was struggling with and receiving support. Very thankful to receive free counselling support as I cannot afford to pay for private counselling.

Program Participant

The therapist was someone who knew what I was going through. She was kind and understanding and gave me some tools to work with to handle anxiety better. I wish more than two sessions were available.

Program Participant

PEER SUPPORT NETWORK

Our online peer support network has more than 2500 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.

REAL-TIME SUPPORT GROUP FOR NICU PARENTS

Offered once a week, this group is facilitated live online by a therapist who is also a preemie parent.

It's my favourite time of the week. I never miss it. I love listening to other people's stories and understanding I'm not alone. I learn something from someone every single time.

Parent group attendee

Recognizing the importance of peer support, from members' own experiences, ongoing identified needs and a scarcity of peer support in Canada, CPBF created a program for NICUs and community groups as well as families post discharge. These trained peer parents have become pivotal in providing support as parents struggle through the crisis of having had a preterm infant.

Marianne Bracht, RN

CPBF has been an invaluable resource for me as a parent with a preemie. The ability to connect with others going through the same situation, in an amazingly positive and supportive community, gave me the help I needed in a stressful time of life. With my little one growing up healthy, I'm so glad to be able to help other parents through their preemie journey.

NICU Parent

PAMPERS CONNECTIVITY GRANT

Awarded to:

MONTREAL CHILDREN'S HOSPITAL BRAMPTON CIVIC HOSPITAL TRILLIUM HEALTH PARTNERS CHILDREN'S HOSPITAL OF EASTERN ONTARIO VICTORIA GENERAL HOSPITAL MOUNT SINAI HOSPITAL CHU DE QUÉBEC UNIVERSITÉ LAVAL HOSPITALS OF REGINA FOUNDATION

Facilitated by the CPFB, this grant creates connection between families and their hospitalized babies when a parent, siblings, or extended family members cannot be present. Awarded to eight hospital NICUs across Canada, it helps hospitals purchase technology, enabling families to stay connected during and beyond the pandemic.



"In these unprecedented times, bonding and connecting is more crucial than ever. The funding will help families connect with their newborns during the NICU team interactions, and will allow the babies to hear the voices of their parents via recording."

Renée Vézina, President, Montreal Children's Hospital Foundation



EFCNI 2020 AWARD RECIPIENT

Canadian Premature Babies Foundation (CPBF/FBPC)

CPBF is very proud of executive director Fabiana Bacchini, recipient of a European Foundation for the Care of Newborn Infants (EFCNI) Award for the amazing work our organization is doing in Canada. Since CPBF was founded in 2012, we have maintained a close relationship with EFCNI, sharing information and resources.

TOGETHER, WE'RE CREATING A BRIGHTER FUTURE FOR ALL BABIES BORN PRETERM. THIS IS ONLY POSSIBLE WITH YOUR SUPPORT.

Left to right: Silke Mader, Nicole Thiele, Fabiana Bacchini and Aurelia Abenstein



KEY COLLABORATIONS



"CPBF has been a true partner and a guiding force behind the International FICare movement, promoting the engagement of parents in the care of their infants in the NICU by providing education and peer support to those parents and highlighting the benefits of FICare in national and international forums."

Dr. Karel O'Brien, Associate Professor and Staff Neonatologist, Mount Sinai Hospital

CPBF collaborated with the International FICare (Family Integrated Care) Steering Committee to bring parent-partners from across Canada to FICare's national conferences in 2019 and 2020. Since the onset of COVID-19, CPBF has worked with the FICare team to create a position statement and recommendations to keep parents and babies together in the NICU even during the pandemic.

GLANCE

CPBF has joined the Global Alliance for the Newborn Care (GLANCE) to advance standards of care worldwide, advocating with 150 organizations on the ZERO Separation campaign to keep babies and parents together during the pandemic and beyond. In 2019, our executive director Fabiana Bacchini was part of the founding committee of GLANCE.

The Canadian Neonatal Network and the Canadian Preterm Birth Network strongly support collaborations with the CPBF in issues related to advocacy for parents and families of neonates admitted to NICUs. The values of parental involvement in the NICUs have been validated in CNN studies. We will continue to support this direct relationship and to further explore opportunities for parents to take part in our continuous nationwide quality improvement program ("Evidence-Based Practice for Improving Quality" or "EPIQ") and research program so that we can together improve outcomes of preterm infants nationally and internationally."

Dr. Prakesh Shah, Director of CNN and Pediatrician-in-Chief, Mount Sinai Hospital



CPBF is collaborating with EPIQ (Evidence-Based Practice for Improving Quality) and the CNN (Canadian Neonatal Network) to educate families and health care professionals about how to engage families in quality improvement projects to improve outcomes for babies and families. Parents who volunteer or work in NICUs as parent partners need a voice at the table and the opportunity to co-design projects. Only in the past two years have parents been invited to participate, along with clinicians, and share the parent perspective.

HIGHLIGHTS

RESEARCH



Across Canada, CPBF fosters a culture of engaging parents of babies born preterm 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.

NEW CPBF WEBSITE



Our new site features updated evidence-based educational materials for families and health care professionals. The website had 24,000 visits and 18,000 unique visitors from September 2019 to August 2020.

CANN 2019 PRE-CONFERENCE WORKSHOP



CPBF hosted a session bringing parents, nurses, and other health care professionals together to share the latest research, knowledge, and experiences in the NICU.

WITH YOU IN THE NICU PODCAST SERIES



This new CFPB podcast was created for mothers pumping breastmilk.
Episodes garner approximately 210 listens each, above average in the podcast world!

HIGHLIGHTS

NATIONAL SURVEY



The Understanding Parents' **Knowledge of Common** Winter Illnesses and Respiratory Syncytial Virus (RSV) Survey was undertaken by CPBF and Préma-Québec to identify gaps in NICU parents' understanding of the impact of RSV. 691 parents participated in the survey (108 French, 583 English). CPBF will launch a full report on October 28, 2020, on the data as well as recommendations for health care professionals on how to educate families in the NICU and post-discharge on RSV and other winter illnesses.

FUNDING FOR PEER SUPPORT PROGRAMS



hospitals and three community organizations with funding to organize and facilitate peer support programs. Participating parents enjoy refreshments, craft time, conversations, and a safe and welcoming place to turn while inside and outside the NICU. CPBF has trained more than 150 "NICU graduate parents" (or mentor parents) across Canada to provide peer support.

MISSION

To support and educate Canadian families every step of the way – before, during, and after their NICU stays.

A brighter future for all premature babies and those who care for them.

VISION

OUR STRATEGIC GOALS

- Partnerships: Work collaboratively with key stakeholders to improve knowledge, resource sharing, and support for families in NICU and discharged to home.
- Families: Improve access to support for families, particularly peer support, by providing online, real-time support groups and individual therapy via our COVIDCare Program.
- Financial resource development: Achieve sustainability through expanding our donor network and applying for new grants.
- Governance: Recruit new directors to the Board, and build scientific advisory and a family advisory committee.
- Operations: Build operational capacity.

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

& PARTNERS

Our Sponsors

















Grants



General Mills Foundation Hometown Grantmaking Program







The Sandbox Project



Kingsway Humber Kiwanis

Collaboration













International Collaboration



