7TH MARUZZA INTERNATIONAL CONGRESS ON PAEDIATRIC PALLIATIVE CARE

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Toward Improved Access:

Lessons from Four Decades of Paediatric Palliative Care in Canada



Image courtesy of Canada's Pediatric Palliative Care Alliance

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Canada's pediatric palliative care alliance
Care for every short life

IWK Health

TODAY, I WANT TO TELL YOU A STORY...

OR RATHER, I WANT TO TELL YOU ABOUT SOME OF THE *MANY* STORIES WE HEARD ABOUT THE PAST, PRESENT, AND FUTURE OF PAEDIATRIC PALLIATIVE CARE IN CANADA.

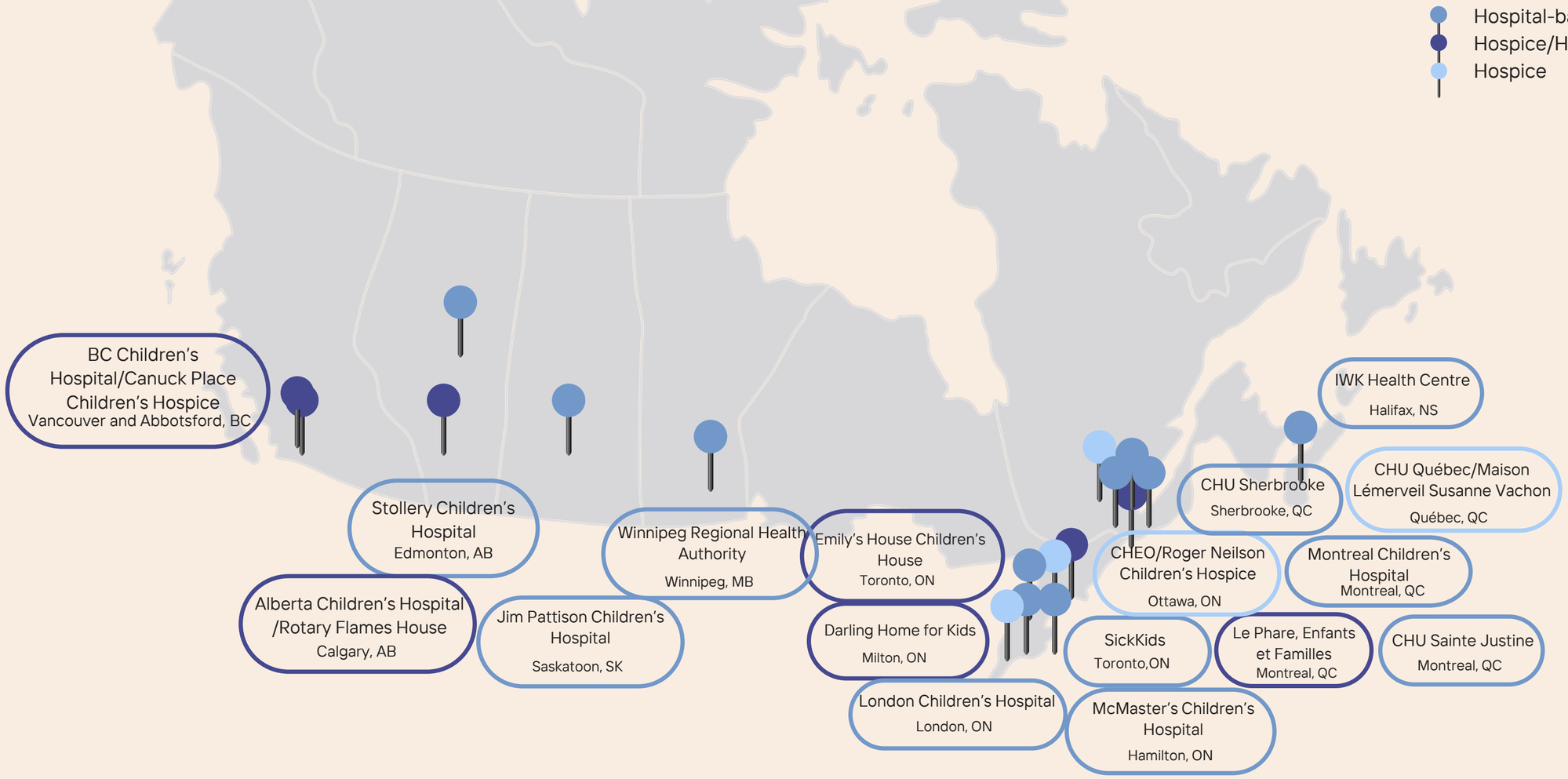






IT STARTS AS IT USUALLY DOES: WITH A COMING TOGETHER OF CURIOUS AND PASSIONATE PEOPLE.

PAEDIATRIC PALLIATIVE CARE IN CANADA



OUR STUDY AT A GLANCE

Our study aimed to describe the evolution and current state of paediatric palliative care (PPC) in Canada, to help inform system planning.



Image courtesy of Canada's Pediatric Palliative Care Alliance



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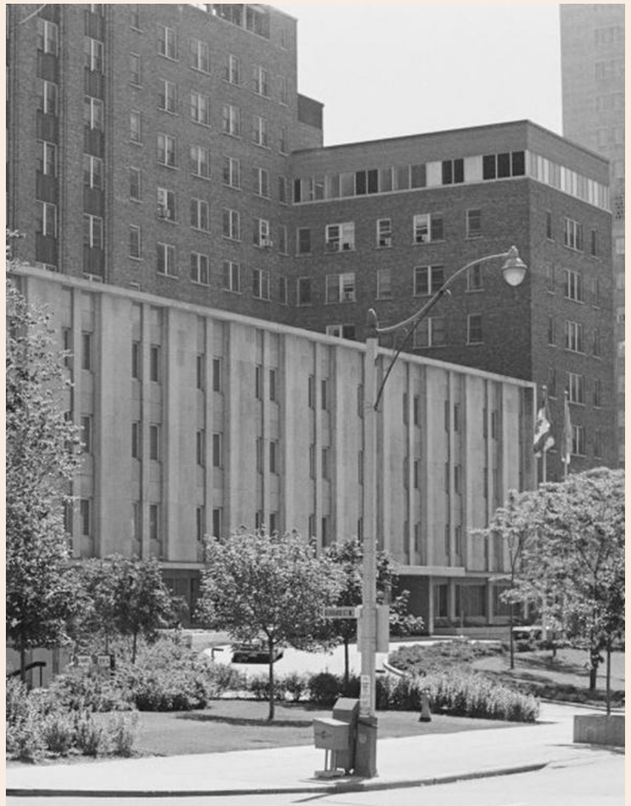
We performed **interviews** with program representatives, sent **surveys,** and performed a brief **document review** to capture any background information to position findings.

Throughout 2025, we spoke with **34 program representatives, representing all 17 specialized PPC programs** in Canada.

TODAY, I WANT TO SHARE THEIR STORIES IN 6 CHAPTERS.

(Bradshaw et al., 2017; Braun & Clarke, 2006, 2019; Clarke & Braun, 2017; Sandelowski, 2000)

CHAPTER 1



Toronto's SickKids hospital in 1970s. Home of SickKids Pediatric Advanced Care Team (Toronto). Photo by Toronto Digital Archives.

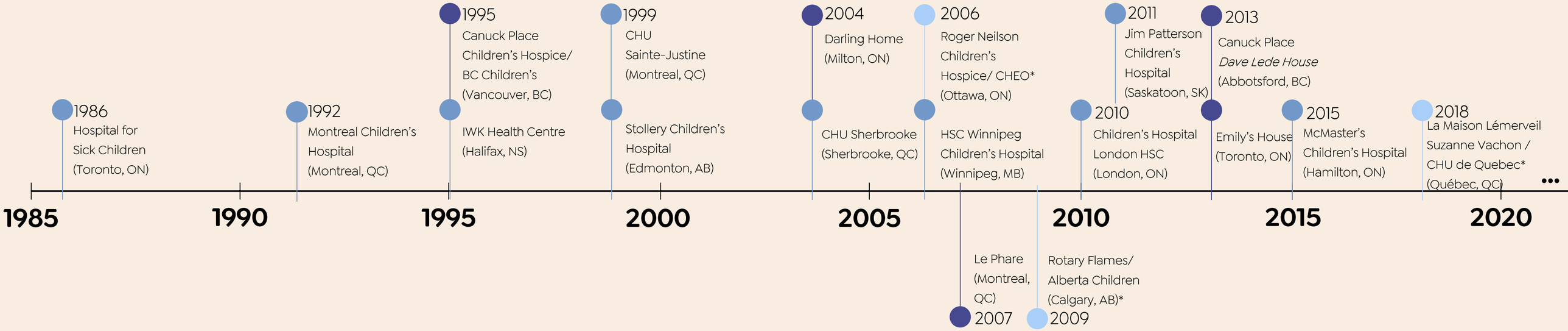
The origins of many PPC programs in Canada were grounded in community vision and grassroots action.

Families and clinicians were amongst some of the earliest advocates, pushing for specialized services and recognizing the need for appropriate care for children likely to die before adulthood.

CHILDREN'S HOSPICES TOLD PARALLEL STORIES OF COMMUNITY-DRIVEN FOUNDATIONS.



Glen Brae Manor. Home of Canuck Place Children's Hospice (Vancouver). Photo from Canuck Place Children's Hospice.



*Hospital program preceded the hospice opening

[The program founders,] they had to fight for everything. It was **always a fight**.

PARTICIPANT 9

...and today, it is still a fight.

CHAPTER 2



Image courtesy from Canuck Place Children's Hospice.

ADVOCACY

LEGITIMIZING THE LEGITIMATE

The ongoing burden of defining, explaining, and advocating for PPC.

CHAPTER 3



Image courtesy of Canada's Pediatric Palliative Care Alliance.

SUSTAINABILITY

FIGHTING FOR SUSTAINABILITY

Funding precarity and workforce challenges threaten the stability and growth of programs.

CHAPTER 4



Image courtesy of Canada's Pediatric Palliative Care Alliance.

GEOGRAPHY

GEOGRAPHIES OF CARE

Caring for children and families across vast distances and unevenly distributed services.

CHAPTER 5



Image courtesy of Canada's Pediatric Palliative Care Alliance

Hospices could act as centres of expertise, spaces that bring families, clinicians, and community partners together, and visible embodiments of what PPC can and should offer.

"IT'S REALLY THE HUMANITY AND THE CONNECTION THAT'S THERE"
-PARTICIPANT 17

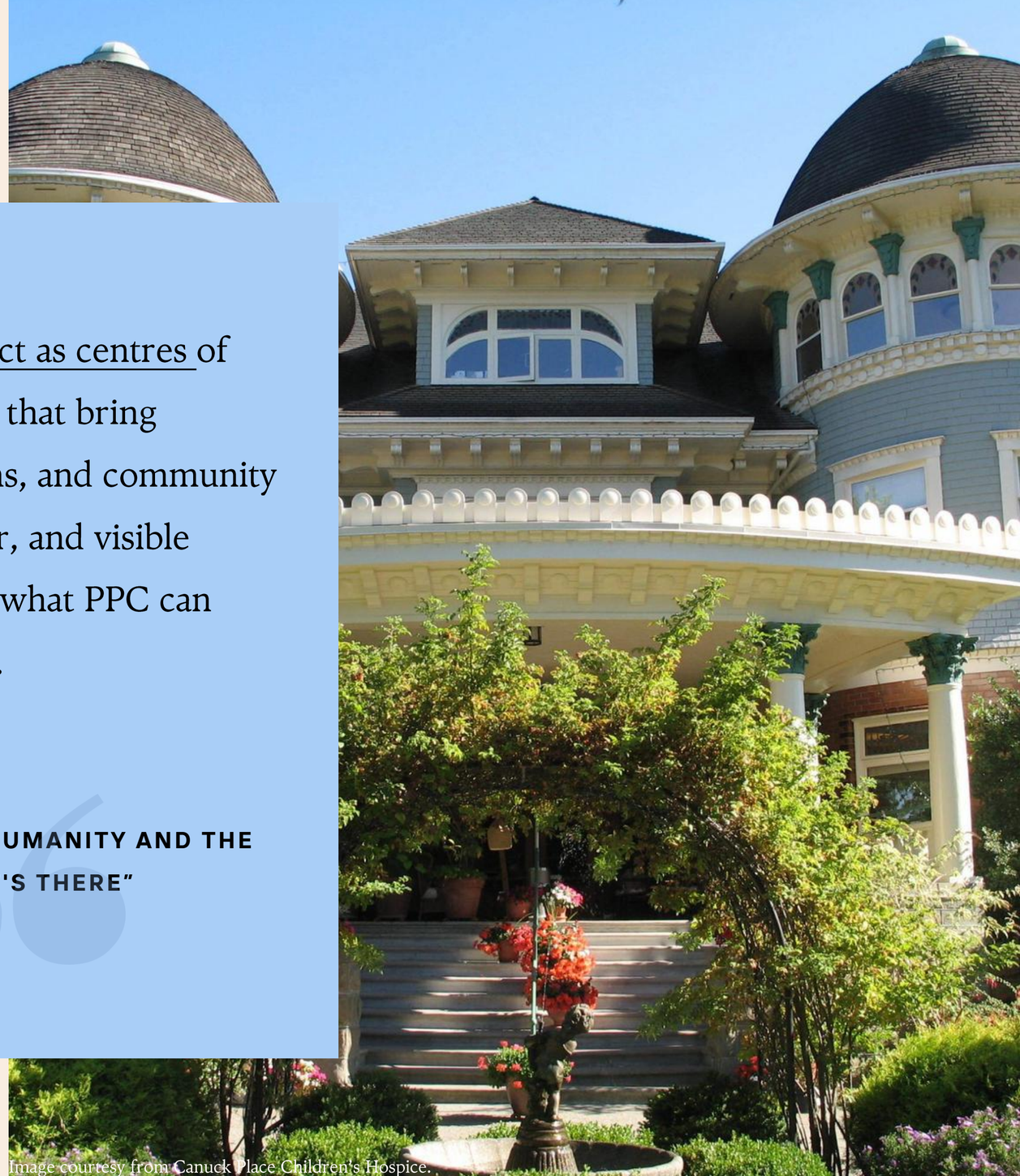


Image courtesy from Canuck Place Children's Hospice.



Image courtesy of Canada's Pediatric Palliative Care Alliance.

CHAPTER 6

Strengthening a Shared Future

CAPACITY BUILDING THROUGH EDUCATION AND COLLABORATION

"I think we have to figure out how to do the most within our current means and leverage that better. And I'd love to see that be data driven. And I'd love to see some sort of trans-Canada collaboration [...] and have what community services are available, equitably distributed."

-Participant 2

EPILOGUE

Throughout this study, participants described longstanding and remediable challenges, the likes of which should no longer characterize the field.

At the same time, they appeared to highlight meaningful momentum in emerging collaborations and growing recognition that access to high-quality PPC across the country is imperative for everyone.

Image courtesy of Canada's Pediatric Palliative Care Alliance

Thank you!

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Read our publication:

Learn more about the history of PPC in Canada:

Canada's pediatric palliative care alliance

Care for every short life



Image courtesy of Canada's Pediatric Palliative Care Alliance.

REFERENCES

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