POGO
PEDIATRIC ONCOLOGY GROUP OF ONTARIO
FOR KIDS WITH CANCER
FOR NOW, FOR LIFE.

THE CHILDHOOD CANCER CARE PLAN:

A Roadmap for Ontario 2024-2029

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A Letter from Lauren and David

It is our pleasure to present the Childhood Cancer Care Plan: A Roadmap for Ontario, 2024–2029. We do so while reflecting on the driving force behind this work—a shared vision to achieve an excellent childhood cancer care system.

POGO led the development of this Plan in collaboration with a wide spectrum of partners, including those with lived experience. The process presented an opportunity to assess the current state of the childhood cancer care system and refine the path toward ensuring everyone affected by childhood cancer has access to the best care and support. The diversity of our population requires that we find opportunities to help ensure families receive the care and support that meet their individual needs and honour who and where they are. We are excited to work hand in hand with the childhood cancer care community, of which the POGO Board of Directors plays an important role, to implement this Plan over the next five years. Thank you to everyone who contributed to its development and to all who will help bring it to life!

A diagnosis of cancer in childhood is a life-changing experience. Treatment can last for many years, and health monitoring for survivors is of lifelong importance. Thanks to the leadership of healthcare professionals across many disciplines, Ontario has a coordinated childhood cancer care system that places children and families at the centre of care and provides support throughout their journey—not only to meet their physical health needs, but with programs to support their mental health, educational and financial needs as well.

Children are often diagnosed at tertiary centres with specialized childhood cancer programs and progress through treatment at these centres or, when circumstances are right, at specific local community hospitals with a POGO Satellite Clinic which allows them to stay close to home. POGO Interlink Nurses support transitions across hospital care settings and back home, considering the needs of families and siblings and, for patients returning to school, POGO Interlink Nurses are there, providing support to teachers and classmates. With increasing rates of survivorship (over 85% of children with a cancer diagnosis will survive), a multidisciplinary network of care providers support survivors. POGO AfterCare Clinic teams monitor for the late effects of cancer and its treatment, and counsellors in the POGO Transitions Program provide guidance and supports for survivors planning for post-secondary education or work opportunities.

Working to achieve the best childhood cancer care system is a shared responsibility. POGO, as the Ontario government's advisor on childhood cancer and the collective voice of the community, is proud to fulfill its role in the integrated network of care that is a hallmark of our province and a leader nationally. We believe our vision for this Plan can be achieved through collaboration with all partner hospitals engaged in the care of childhood cancer patients, survivors, and their families. The focused action of these stakeholders as well as allied health professionals, government and others, is required to ensure Ontario's childhood cancer care system remains among the best in the world. Our collective success will be measured, in part, by our joint commitment to implementing the goals and objectives in a way that improves the lives of young people with cancer, during their treatment and for years to come.

Lauren Ettin
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Medical Director & Chair
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Goals and Objectives at a Glance

Quality Care in the Most Appropriate Setting

1. Increase care closer to home by expanding the scope and reach of local Satellite Clinic and Interlink Nursing programs and services.
2. Provide evidence-based supportive care, including routine symptom screening, to reduce the negative impacts of cancer and its treatments.
3. Improve the experience for patients transitioning between pediatric and adult care settings whether for treatment or follow-up care.
4. Expand care for the needs of adolescents and young adults facing cancer.

Equitable Access to Psychosocial Care

1. Optimize and augment utilization of hospital and community-based resources to improve psychosocial care.
2. Advance palliative care models to meet the needs of children with cancer and their families.

Optimal Well-being of Childhood Cancer Survivors

1. Ensure all survivors are screened at AfterCare Clinics for late effects in accordance with best evidence and their unique needs.
2. Improve the availability of treatment histories for survivors and their care teams over time and across care settings.
3. Improve the continuity and sustainability of survivor care through greater integration with primary care.

Timely and Equitable Access to Evolving Diagnostics and Therapeutics

1. Contribute to reducing the time it takes for evidence-based interventions to be funded and available to children and youth.
2. Improve equity of access to collaborative clinical trials across Ontario's tertiary and satellite hospitals.

Data-driven Planning and Quality Improvement

1. Improve provincial data holdings to reflect advancing science and care models, new partnerships and opportunities to identify the needs of underserved populations.
2. Enhance reporting to enable the use of high quality, timely data for system planning, surveillance and quality improvement.

Childhood Cancers in Ontario

Childhood cancers strike during a critical phase of development, when children and adolescents are marking important physical, developmental, psychological, cognitive and social milestones. A diagnosis is a life-changing event for the patient, for parents, siblings, extended family, teachers and classmates—all are deeply impacted across many dimensions of their lives, be it work, school or home.

The types of cancers experienced by children are very different from adult cancers and often require intensive treatment modalities and subspecialty expertise only available in regional pediatric cancer programs. Thankfully, advances in childhood cancer care mean that many children, over 85%—with optimal access to modern treatment—will be cured and become long-term survivors. However, the impact of childhood cancer is often experienced long after treatment is finished; survivors require ongoing comprehensive preventive and supportive care to address potential late effects.

Long-range planning for the childhood cancer system is necessary to ensure resources are available to support patients, families and survivors as much as possible throughout their cancer journey.

Over 85% of children diagnosed with cancer in Ontario will survive.

There are over 4,500 families in Ontario with a child in cancer treatment or follow-up care each year.

Cancer remains the most common cause of disease-related deaths among children in Ontario aged 1 year or older.

There are approximately 500 children and youth diagnosed with cancer in a pediatric cancer program in Ontario each year.

There are over 20,000 childhood cancer survivors living in Ontario.

2 of every 3 childhood cancer survivors are at increased risk of at least one late effect due to their cancer or its treatment, including heart disease, second cancers and cognitive challenges.

About POGO

POGO champions childhood cancer care in part through collaboration with a multidisciplinary network of childhood cancer health professionals and hospital leadership. Thanks to the Ministry of Health and the generosity of donors, POGO's initiatives span the spectrum of care for survivors, families and healthcare providers:

- Six hospitals provide the POGO Interlink Nursing Program. As important members of the oncology care team, POGO Interlink Nurses deliver patient and family-centered care throughout the cancer journey—from hospital settings to homes, communities and schools.
- Eight POGO Pediatric Oncology Satellite Clinics in community hospitals manage more than 7,200 ambulatory care visits per year, bringing care closer to home for patients and families.
- Eight POGO AfterCare Clinics provide preventive health care and services to over 2,750 survivors of childhood cancer annually.
- Six POGO School and Work Transitions Counsellors assist childhood cancer survivors facing challenges in transitioning to post-secondary school and/or work settings because of their disease or treatment.
- 700 families, on average each year, benefit from the POGO Financial Assistance Program which helps relieve some of the financial burden associated with out-of-pocket costs for everyday expenses.
- 19 clinical practice guidelines have been developed and published in peer-reviewed journals through the internationally-recognized POGO Supportive Care and Guidelines Program.
- Four pediatric and adult oncology programs are collaborating with POGO and Ontario Health (Cancer Care Ontario) to develop services for adolescents and young adults (AYAs) with cancer.
- Developing guidance for healthcare providers in partnership with the Provincial Council for Maternal and Child Health (PCMCH), which focuses on managing the symptoms and palliative care needs of pediatric patients approaching end of life.
- Funding research which promotes multidisciplinary, multi-institutional health research activities that contribute to a better understanding of childhood cancer and its impacts, and improved outcomes for children with cancer and their families.
- Continuing education that provides a wide range of opportunities for healthcare professionals to enhance their knowledge and advance their practice to improve the delivery of care.

Developing the Plan

As the provincial government's advisor on childhood cancer, POGO has been leading the development of Ontario's childhood cancer care plans since 1988.

The Childhood Cancer Care Plan provides a roadmap for Ontario to deliver the best care for the best possible outcomes, meet current challenges and manage future demands. This Plan describes a path for working collaboratively to turn gaps and challenges into opportunities and actions that strengthen Ontario's childhood cancer system.

Consultations with pediatric oncology experts, childhood cancer survivors and families from across Ontario were undertaken by POGO in 2023. Over 100 individuals shaped the Plan which will guide collective actions to improve outcomes and the care experience.

These consultations confirmed that the directions set in the previous system plan have put us on the right path and that more work is needed in these areas moving forward. This Plan will build on progress to date, identify new opportunities to advance childhood cancer care, and strengthen partnerships to share knowledge, expertise and resources.

Goal 1: Quality Care in the Most Appropriate Setting

In Ontario, childhood cancers affect a small number of young people dispersed across a large geographic area, creating practical challenges for the equitable delivery of programs and services.

Parents describe the burden of travelling to treatment centres and unexpected out-of-pocket costs associated with time away from home as a tremendous source of distress. Locating care closer to home in satellite clinics in community hospitals reduces family burdens and frees up much-needed capacity in specialized tertiary programs, resulting in a positive impact for children, youth, their families and the care system itself. At the same time, improvements are needed in coordinating care between providers and locations to enhance the experience of a shared-care system for families.

In addition to cancer diagnosis and treatment, children and youth require access to effective supportive care interventions to help prevent and relieve adverse effects—such as infections, vomiting, fatigue, anxiety and depression. Optimal supportive care is informed by each patient's experience through routine symptom screening. Implementation of symptom screening and evidence-based supportive care interventions in centres across Ontario will help ensure equitable access to quality care and improve outcomes.

For adolescents and young adults (AYAs) between the ages of 15 and 39 years, a cancer diagnosis comes at a time when young people are completing education, launching careers, forming social/emotional relationships and planning for the future. The nature of cancer in this age group and implications of treatment mean that the childhood and adult cancer systems must work collaboratively to address the unique medical and psychosocial needs of AYAs with cancer.

Objectives

1. Increase care closer to home by expanding the scope and reach of local Satellite Clinic and Interlink Nursing programs and services in the community.
2. Provide evidence-based supportive care, including routine symptom screening, to reduce the negative impacts of cancer and its treatments.
3. Improve the experience for patients transitioning between pediatric and adult care settings whether for treatment or follow-up care.
4. Expand care designed for the specific needs of adolescents and young adults facing cancer.

> “Imagine, instead of your child's week being filled with school, daycare, sports, playdates, or even just playing at home and cuddling on the couch, your week is filled with chemotherapy, radiation, blood transfusions, blood work, checkups, follow-ups, emergency visits and hospital admissions. Now, imagine driving your child to Toronto for all of the above. This is the reality for local families whose child is diagnosed with cancer.
>
> Now, imagine that family can do all the above closer to home, or at least sometimes. Because of the team at our satellite clinic, battling cancer and undergoing chemotherapy close to home was our reality most days. The team became our support system, family and friends. They have ensured that our childhood cancer warriors receive not only quality care but also quality of life.”
>
> *-Parent, Peterborough*

Goal 2:
Equitable Access to Psychosocial Care

Cancer in children, adolescents and young adults places significant stress on a family and can affect the mental health of the patient, parents and siblings. Psychosocial care for childhood cancer patients and their families—including support for social, emotional, mental health and financial needs—is recognized as an essential component of supportive care. Opportunities exist to improve outcomes and care experiences for patients and families using standardized psychosocial screening tools and evidence-based interventions.

Practical solutions are also needed to ensure appropriately trained health human resources are available and equipped to provide psychosocial support in palliative care and, where needed, end-of-life and bereavement care for patients and families dealing with childhood cancer. While the focus on pediatric palliative care for this population has increased, partnership efforts must continue to improve access to educational opportunities and resources that inform and support practitioners.

Access to psychosocial care varies based on geography, financial circumstances and other social determinants. Hospital mental health services have limited capacity and are often not available to survivors or families. Access to professional mental health services in the community is variable and often costly. Action is being taken to implement a range of community-based mental health programs and services that can benefit childhood cancer patients, as well as to increase awareness and streamline referrals for mental health care.

Objectives

1. Optimize and augment utilization of hospital and community-based resources to improve psychosocial care.
2. Advance palliative care models to meet the needs of children with cancer and their families.

> “No matter what the outcome, cancer diagnosis and treatment take an enormous psychosocial toll on children and their families. While attention to the psychosocial impacts of childhood cancer diagnosis and treatment has increased in both clinical and research spheres in recent years, there is a pressing need for more knowledge and resources to support the implementation of evidence-based psychosocial interventions and programs of care for children, caregivers and siblings throughout their diagnostic and treatment odysseys, including among survivors. Better understanding of the psychosocial implications of emerging approaches to care are required to ensure that new directions in cancer care for children are designed to support the psychosocial flourishing of children and their families.”
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> *-Pediatric Oncologist*

Goal 3:
Optimal Well-being of Childhood Cancer Survivors

Childhood cancer and its treatment have significant and long-term health consequences. Consequently, there is no “one size fits all” approach to aftercare, and, more than ever, optimizing survivor health care requires collaboration between childhood cancer programs and community resources.

Both caregivers and survivors advise that treatment histories and follow-up care plans are critical elements of shared care that help ensure appropriate care no matter where it is delivered. Access to appropriate screening tests is a critical component to maintaining survivor health. And connecting a childhood cancer survivor with a primary care provider in their community, one who is prepared to support their ongoing needs, is a crucial step which can be supported by additional outreach to these professionals, and the development of tailored informational materials and care plans. By offering these, survivors will be empowered with the information they need and the ability to share that information with care providers of their choice who, in turn, will have the right information to provide the right care.

Objectives

1. Ensure all survivors are screened at AfterCare Clinics for late effects in accordance with best evidence and their unique needs.
2. Improve the availability of treatment histories for survivors and their care teams over time and across care settings.
3. Improve the continuity and sustainability of survivor care through greater integration with primary care.

> “
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> When I turned 18, I graduated from the all-encompassing children’s hospital system, with its seamless management and coordination between departments, to the adult system. While I have three new doctors spread across the city, luckily for me, and every childhood cancer survivor in Ontario, all of my follow-up care is still coordinated through an aftercare clinic.
>
> So, when my cardiologist wanted to change my medication, my healthcare team was able to determine that it wouldn’t do any damage based on the treatment I had as a child. And when my internist wanted to do an exploratory procedure, my aftercare team again intervened noting it could do more damage than good with the scar tissue that was built up over many surgeries.”
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> *-Childhood Cancer Survivor*

Goal 4:
Timely and Equitable Access to Evolving Diagnostics and Therapeutics

Over the past 30 years, childhood cancer has shown near continuous improvement in survival outcome. These gains have resulted from better biologic characterization of childhood cancers, improved imaging, more effective cancer treatment and improved supportive care. In the past five years, drugs that were seen as “new and promising” have now moved to standard of care.

In pediatric oncology, there continues to be challenges in receiving Health Canada approval and universal funding for new treatments for a variety of reasons. These challenges add to existing barriers to evidence-based funding of drugs, both Health Canada approved and not, creating the potential for inequitable access to care across the province.

The childhood cancer community aims to work together to lessen the time from when an evidence-supported therapy is recognized and is both accessible and reimbursed in Ontario. This will require innovative approaches and partnerships between clinicians, POGO, health technology assessment bodies and funders. At the same time, we will work to increase access to collaborative clinical trials, such that children with cancer can receive the most up-to-date care regardless of where they live in the province or their financial circumstances.

Objectives

1. Contribute to reducing the time it takes for evidence-based interventions to be funded and available to children and youth.
2. Improve equity of access to collaborative clinical trials across Ontario’s tertiary and satellite hospitals.

> “I am thankful for the many opportunities I have had to be involved with POGO's initiatives and committees...some of which have led to chemotherapy drugs being more accessible to our patients, as well as more resources at our hospitals to serve our patients.”
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> *-Healthcare Provider*

Goal 5: Data-driven Planning and Quality Improvement

Accessible data collected in a reliable and timely manner are foundational to health system planning and service delivery. Over the past four decades, POGO has enhanced its data repository on childhood cancer in Ontario with specialized data holdings that collect information from the point of diagnosis to active treatment and outcomes, to late effects and long-term follow-up care in survivorship. The POGO Networked Information System (POGONIS), POGO's main childhood cancer database and active registry, increases the value of the data POGO holds through its ability to link with other repositories maintained both by POGO and our partners such as the Ontario Cancer Registry (OCR) and the Institute for Clinical Evaluative Sciences (ICES), among others.

New data sources and partners in data collection are emerging that will expand the utility of POGONIS in driving an effective childhood cancer system. In addition, hospitals and POGO aim to work collaboratively to improve data quality and provide timely access to their data in formats that meet each hospital's analytic and program planning needs. Enhanced public reporting will benefit service providers, researchers, patients and families by contributing to a generation of new research and expanding awareness regarding the impacts of childhood cancer.

> “The childhood cancer registry POGONIS, is an unparalleled resource for pediatric cancer research. The results of projects generated from this registry will have immediate and lasting impact on the care of Ontario's children with cancer, as well as that of children around the globe—both those who are newly diagnosed and the growing population of long-term survivors.”
>
> *-Researcher*

Objectives

1. Improve provincial data holdings to reflect advancing science and care models, new partnerships and opportunities to identify the needs of underserved populations.
2. Enhance reporting to enable the use of high quality, timely data for system planning, surveillance and quality improvement.

Plan Champions and Enablers

The Childhood Cancer Care Plan identifies opportunities for a wide group of stakeholders to champion childhood cancer care and drive Ontario's childhood cancer system to deliver the best possible care and outcomes, and to meet current and future challenges. Enduring partnerships, underpinned by resources and capacity, are critical to effective implementation of the five-year Plan. POGO will work with government, the network of pediatric cancer programs in tertiary and community hospitals, and other partner organizations to individually and collectively implement Plan goals and objectives to benefit patients, families and survivors of childhood cancer.

Plan Champions

Patients, Families and Survivors

Integrating experiences and perspectives of all persons with lived experience of childhood cancer is essential to ensure the evolving childhood cancer system meets their needs and expectations for culturally-sensitive, safe and respectful care at all stages of the cancer journey. Successful implementation of the Childhood Cancer Care Plan will depend on patients, families and survivors as authentic partners in design and execution of action plans, reviewing data and information, and providing advice and guidance for an effective patient- and family-centred system of cancer care.

Partnerships, Collaborations and Clinical Engagement

The Plan's adoption over the next five years will be facilitated by the ongoing engagement and collaboration with partner tertiary and community hospitals that deliver care directly to patients and families and that manage POGO programs at their sites. At its core, this Plan propels the evolution of childhood cancer care in Ontario, to which the work of these hospitals, their leaders and teams are fundamental and integral to advancing the delivery of childhood cancer care. Members of the POGO Board of Directors who lead specialized childhood cancer programs at their institutions and others who are members of the cancer community will be especially instrumental in helping to champion the goals and objectives of this Plan.

Building on partnerships across the wider pediatric oncology network—such as with government, Ontario Health (Cancer Care Ontario), the Provincial Council for Maternal and Child Health (PCMCH) and other provincial entities and national organizations, e.g., the Cancer in Young People in Canada (CYP-C) registry—will continue to be of focus. The expertise and voice that emerges through partnership is unparalleled. We must continually combine efforts and forge alliances to articulate mutual responsibilities, share data and resources, engage in creative thinking and evidence-informed discussion, and move forward through execution.

Plan Enablers

Health Human Resources

Building strong multidisciplinary teams is crucial to deliver comprehensive care and address the diverse needs of children and families. The right mix of health human resources (HHR) can better safeguard that each patient and family receive timely, appropriate treatment and experience better continuity of care, which enhances resilience in childhood cancer patients and their families. Collaboration is needed between government, POGO, hospitals and community partners to ensure system investments address HHR needs.

Education and Training

The best possible outcomes for patients and families can only happen when their providers have opportunities to participate in education, skills development, training and networking activities. Forums for presentation of new research and information, and sharing of lessons learned, are essential for providing insights and developing new knowledge in the evolving area of childhood cancer care and control.

Providing a range of opportunities for persons with lived experience to share their stories with health professionals remains a key objective for POGO's educational initiatives. POGO will continue to coordinate and ensure childhood cancer expertise leads the development and delivery of relevant training and education programs.

Clinical Practice Guidelines

Clinical practice guidelines translate research evidence into specific recommendations using rigorous methods and careful deliberation. This work is undertaken by multidisciplinary panels composed of clinical and methodologic experts, and persons with lived experience. Across medical specialties, treatment according to guidelines has been shown to improve outcomes. The POGO Supportive Care and Guidelines Program provides healthcare professionals in Ontario, and worldwide, with the best-known options for preventing and relieving the negative effects of childhood cancer and its treatment.

Data and Information

An effective childhood cancer system requires that data be collected, evaluated and translated into effective and sustainable policies and initiatives. Working with pediatric oncology networks and other healthcare partners, POGO will continue to prioritize evaluation of program impacts on patient outcomes and care experiences and apply evidence-based findings to meet needs and improve quality of life for patients, families and survivors.

Donor Support

Community support helps to provide important services consistent with the goals of this Plan, including financial assistance to offset the out-of-pocket costs families incur; personalized educational and employment counselling when survivors need this support in their final years of high school; and essential research that is needed to improve physical and mental health outcomes for patients, families and survivors of childhood cancer.

Acknowledgements

POGO gratefully acknowledges funding support from the Ontario Ministry of Health. As advisor to the Ontario government on childhood cancer, POGO is responsible for producing long-range plans for the childhood cancer system. Ontario is the only province/territory to have a documented system plan for childhood cancer. With deep gratitude, we acknowledge the important contributions of the many healthcare professionals, researchers, administrators, and their institutions, as well as patients, parents and survivors of childhood cancer who generously gave their time and expertise to the development of this Plan. We are deeply grateful to POGO staff and the Board of Directors for their unwavering commitment to excellence across all POGO programs and for their contributions to the Childhood Cancer Care Plan: A Roadmap for Ontario, 2024–2029.

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