



IN 2 MONTHS, HE'LL BE DIAGNOSED
WITH CANCER...

IN 20 YEARS WE WILL STILL
BE HELPING HIM.

POGO

PEDIATRIC ONCOLOGY GROUP OF ONTARIO

How can you help a child when a monster really does emerge from the dark?

How do you confront this intrusion into the sunlit dreams of childhood and what comfort, what reassurance, can you offer when you yourself are filled with dread?

How do you tell your child that he or she has cancer?



CHILDHOOD CANCER

A LIFETIME JOURNEY

Some 4,000 families in Ontario are facing these questions at any given point in time. And while a cancer diagnosis comes as a shock at any age, when the patient is so young it seems incomprehensibly unfair.

The causes of cancer in children are largely unknown; but much can be done to deal with the disease and its late effects, which can be damaging in unanticipated ways.

Some aspects of the cancer journey are more obvious. A frightened and bewildered child. Anxious parents struggling to negotiate unfamiliar areas of a complex healthcare system. The physical and emotional pain, the sense of helplessness, of vulnerability. But these are not the only challenges.

A whole world of disruption—financial, psychological, educational and vocational—comes with childhood cancer. It is a world of which few of us are fully aware, unless we have to enter it ourselves.



Whereas imaginary monsters of childhood are quickly dispelled with the dawning of the day and forgotten in adult life, cancer in childhood is not so easily dismissed. Not only does it pose a very real, immediate danger, its effects can linger, a shadow that follows a child for their lifetime.

Every child who has encountered the challenges of cancer, every family who loves that child, needs a champion. A trusted guide who knows the way ahead. A friend who will comfort and sustain them. A hero who will act for them, encourage them and walk with them every step of the way.

Fortunately, that champion already exists.

Its name is POGO.



CHILDHOOD CANCER

A UNIQUE ALLIANCE

POGO—Pediatric Oncology Group of Ontario—is an incorporated, not-for-profit entity with charitable status, which developed from an unprecedented alliance of visionary leaders, experts, healthcare professionals, the Ontario government, parents and childhood cancer survivors. The unifying goal of these stakeholders: to deliver the right care, in the right place, at the right time to children in the province whose lives are touched by childhood cancer.

As the official source of advice to the Ontario Ministry of Health and Long-Term Care (Ministry), directly involved in writing healthcare policy, POGO has pioneered a unique whole-life approach to childhood cancer care. As a licensed charity, committed to championing the cause, POGO has identified, and continues to identify, key support programs that government cannot fund, and raises private dollars to deliver these programs.

In partnership with the pediatric cancer programs in five major hospitals in Ontario, as well as an ever-growing network of community hospitals and services across the province, the POGO collaboration ensures seamless, integrated support to children and families, not merely during treatment but throughout the entire cancer journey.

OUR PARTNERS IN CANCER CARE





POGO PARTNER HOSPITALS

The Hospital for Sick Children, Toronto
Children's Hospital, London Health Sciences Centre
McMaster Children's Hospital, Hamilton Health Sciences
Kingston General Hospital
Children's Hospital of Eastern Ontario, Ottawa



POGO AFTERCARE CLINICS

The Hospital for Sick Children, Toronto
Princess Margaret Cancer Centre, Toronto
Children's Hospital, London Health Sciences Centre
McMaster Children's Hospital, Hamilton Health Sciences
Southeastern Regional Cancer Centre at Kingston General Hospital
The Ottawa Regional Cancer Centre
Children's Hospital of Eastern Ontario, Ottawa




POGO SATELLITE SITES

Trillium Health Partners, Credit Valley Hospital, Mississauga
Orillia Soldiers' Memorial Hospital
Northeast Cancer Centre, Health Sciences North, Sudbury
Windsor Regional Hospital
Grand River Hospital, Kitchener-Waterloo
Rouge Valley Health System, Centenary Health Centre, Toronto East
Southlake Regional Health Centre, Newmarket



POGO PEDIATRIC INTERLINK COMMUNITY CANCER NURSES

The Hospital for Sick Children, Toronto
Children's Hospital, London Health Sciences Centre
McMaster Children's Hospital, Hamilton Health Sciences
Children's Hospital of Eastern Ontario, Ottawa
Northeast Cancer Centre, Health Sciences North, Sudbury



POGO's genesis was in 1983, when a group of leading oncologists assembled to envision a better system of care for Ontario's children. That consultation established a key premise: cancer in childhood is not merely a variant of adult oncology but a unique set of diseases, posing unique challenges, calling for specialized methods of treatment and requiring an understanding of the impacts of treatment on young developing bodies and minds.

The need for a seamless, province-wide approach had become glaringly apparent.

One member of the group, Dr. Mark Greenberg, proposed an invaluable first step: a registry and database to which specialists across the province could contribute. The group later engaged Dr. Corin Greenberg, an applied research psychologist and policy developer, to carry out a system-wide needs assessment. Working closely with the community to map the services and define the gaps, she began the work of drafting a blueprint for future activities.

In 1988, POGO delivered a comprehensive report, identifying gaps in the system, providing strategies for addressing these gaps, recommending mechanisms to coordinate the patchwork of existing services and proposing the collection of additional data on children and families to support future planning.

That plan, and a second one that followed in 1994, profoundly influenced provincial healthcare funding priorities, stimulated policy development and facilitated access to specialty pediatric oncology programs. In 1995, POGO became the Ministry's official source of advice on pediatric cancer care and control, and POGO's childhood cancer database, POGONIS, was transformed into a fully networked system that the Ministry and POGO could rely on for comprehensive, standardized information, and one that hospitals could use as a core information source about the children they served.

POGO's services grew to include the administration of two important networks of clinics: Satellite Clinics to enable families who live outside major city centres to receive certain components of care at community hospitals closer to home, and AfterCare Clinics to provide survivors with follow-up services focused on health promotion and monitoring for late effects.



POGO incorporated as a not-for-profit entity in 1997 and acquired charitable status in 2003, enabling the organization to seek private support for key programs and services that fall outside the scope of government funding. These include:

- POGO's financial assistance to families program, which supports families through the enormously financially challenging period of active treatment;
- Successful Academic and Vocational Transition Initiative (SAVTI), which addresses educational and employment issues for survivors with cognitive challenges;
- Professional development opportunities to ensure that Ontario's childhood cancer community remains best-in-class in the rapidly advancing field of pediatric oncology; and
- The POGO Research Unit, which conducts and supports research in a wide variety of disciplines, enhancing our understanding of childhood cancer's effects, and developing the next generation of pediatric cancer researchers. This work is underpinned and supported by the extraordinary data in POGONIS.

POGO's board comprises representatives from partner hospitals across the province, including their heads of pediatric oncology, nursing and behavioural oncology leaders. These leaders serve on POGO committees that identify gaps in the system, plan programs, write practice guidelines, advise the Ministry on its allocation of resources and design implementation plans. When POGO plans are funded, the pediatric oncology units across Ontario implement them in their childhood cancer programs province-wide.

It is to the transformational work of POGO that Ontario's healthcare system owes its current grasp of the full scope of the challenges presented by childhood cancer. Thanks to POGO, the Ministry identified pediatric cancer as a component of its cancer priority, ensuring separate planning and committed funding for this distinct area of oncology.



MILESTONES IN

POGO'S JOURNEY

POGO develops the first long-range, provincial plan for childhood cancer

POGO incorporates

1988

1997

1983

The POGO collaboration is formed

1995

POGO becomes the official advisor to the Ministry of Health and Long-Term Care

POGO's childhood cancer database is transformed into a networked information system, POGONIS

1998

The Provincial Pediatric Oncology Satellite Program is implemented

POGO's Research Unit is established

The POGO Chair in Childhood Cancer Control is endowed through private-sector fundraising

2000

The Successful Academic and Vocational Transition Initiative (SAVTI) is created

2002

2001

A system of AfterCare Clinics is implemented

2003

POGO receives charitable status
POGO assumes administration and funding of the financial assistance to families program

POGO assumes
administration of the
Pediatric Interlink
Community Cancer
Nurses Program

2005

KEYS to Succeed pilot
is launched

2014

2012

POGO publishes
*Money Matters: A Guide to
Financial Resources for Families
of Children with Cancer*

2015

Survivor Care Plan
is launched

POGO has contributed immensely to the field of pediatric oncology coordinating services; planning a system that will support the whole journey for the child, family and professional care providers; tracking prevalence and outcomes of treatment; asking important questions; developing policy and programs; and translating what is learned at each step into improvements and supports for children with cancer.

STAGES IN THE JOURNEY

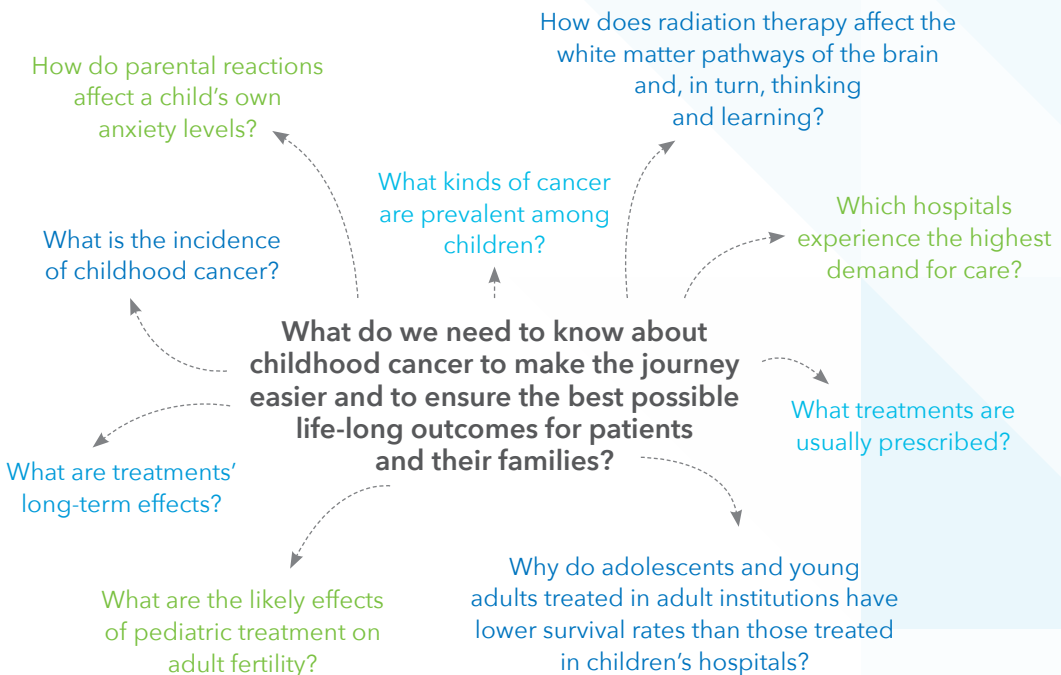
UNDERLYING CARE: TRANSFORMATIVE RESEARCH

For a family, it begins with diagnosis. It is usually then they first become aware of POGO.

As children and parents struggle to absorb the shock of the word “cancer,” the path before them seems dark and terrifying. But no child, no parent, need set out on this journey alone; POGO has explored and charted the territory ahead.

From its inception, POGO has posed a fundamental question: what do we need to know about childhood cancer to make the journey easier and to ensure the best possible life-long outcomes for patients and their families?

Answering that question requires asking many more.




Since the early 1980s, POGO has been gathering and analyzing information on pediatric cancer cases in Ontario. The fruit of this labour—and a cornerstone for all of POGO’s work—is a unique childhood cancer database called POGONIS: the Pediatric Oncology Group of Ontario Networked Information System.

Unmatched by any other in the world, POGO’s database contains more than 30 years of standardized and comprehensive information on diagnosis, treatment, complications and long-term outcomes. This data is collected at the source—in the treating hospitals, by data managers trained by POGO. POGO does not have to rely on incomplete or inaccurate data, or on data self-reported by patients.

Designated one of just four 45.1 entities under Ontario’s Personal Health Information Protection Act, POGO can ask questions, access data and launch invaluable research. For example, POGO can link its childhood cancer database to large administrative databases enabling analysis of healthcare utilization long term. This kind of analysis means POGO is uniquely positioned to help the Ministry and hospitals make informed decisions about the planning and delivery of care, and to make policy recommendations and other service delivery decisions.

Knowing, for instance, how many children are diagnosed and treated in each hospital in the network, enables POGO to ensure that the healthcare team has the right mix of oncologists, nurses, social workers, pharmacists and other experts to meet the need. That same knowledge informs POGO’s decisions on where to establish its Satellite Clinics, and helps POGO to understand the health service utilization patterns of children with cancer compared with their peers.



Health services research is one of four pillars of research that POGO's database supports. Established in 1998, the POGO Research Unit (PRU) focuses on investigations of the trajectories of human lives, whereas clinical trials and other forms of biomedical research fall under the domain of other organizations, including POGO's partner hospitals. The PRU focuses on health economics; patterns and outcomes of cancer in childhood; and the impact of cancer and its treatment, on child development and on the well-being of families.

Conducted across many different disciplines, population-based research can be as transformative as biomedical research—and often leads far more swiftly to action, translating more immediately into improved care and better outcomes.

Some of this work is done by POGO's staff researchers. POGO also provides fellowships and seed funding for independent researchers whose projects are identified as meriting further support. The range of potential avenues of discovery—each with the potential to lead to others—is virtually limitless.

SEED GRANTS
KNOWLEDGE TRANSFER
METHODODOLOGY
SURVIVOR STATUS
QUALITY OF LIFE INTERVENTIONS
HEALTH SERVICES
POGONIS
TECHNOLOGY
INVESTIGATION
ANALYSIS
POGO
RESEARCH
UNIT
ECONOMICS
TECHNOLOGY
DATABASE
BENEFIT
COST
HEALTH OUTCOMES
FELLOWS
QUALITY OF LIFE
POPULATION-BASED
RESEARCH
INCIDENCE
ANALYSIS

*The benefits of the knowledge PDGD has
amassed are of global significance.*

Knowledge gained in this province—knowledge that will inform
the development of healthcare policy and practice—will ease
the journey for families around the world.

The greatest fear of all is fear of the unknown. Knowledge
helps us confront that fear and prepare us for the future.

STAGES IN THE JOURNEY

THE DIAGNOSIS

When cancer is suspected, a local hospital will generally refer the patient to a pediatric cancer program in one of five major hospitals in Ontario. The most common childhood cancer is leukemia, followed by cancers of the brain, bones, kidneys, adrenal glands, lymph nodes, soft tissues and eyes.

Upon diagnosis, a POGO Interlink Nurse is assigned to the case. POGO Interlink Nurses provide support throughout the illness. They explain the diagnosis to the child, in easily understandable terms, and help the parents come to terms with it. They help families navigate the complexities of the healthcare system, put them in touch with the services and resources available to them in their communities and help set up their homes to accommodate the child's new needs.

They may visit the child's school to explain to the staff and other students what is happening and what to expect. As experienced cancer nurses, they can also provide childhood cancer education to nurses in the patient's community.





400

*There are approximately 400 children
diagnosed in this province each year.*

STAGES IN THE JOURNEY

TREATMENT

In addition to the emotional stress that comes with a cancer diagnosis, many families face tremendous logistical and financial challenges during their child's treatment.

Distance, for instance, can become a major obstacle. Treatment, which often lasts as long as three years, requires repeated and extended visits to a major pediatric cancer program. Since there are only five such programs in Ontario, many families live far from their source of care and must undertake long trips, made more arduous by the nausea experienced by many children following treatment. Often these families need overnight lodging to support treatment sessions.

Suddenly, families face a dizzying array of unanticipated travel expenses:



TRANSPORTATION



ACCOMMODATION



MEALS




CHILD CARE FOR SIBLINGS



HOSPITAL PARKING

The cumulative cost of out-of-town treatment, added to that of any medications not covered by the Ontario Health Insurance Plan, can be financially crippling. Without assistance, families may never fully recover financially.

The already challenging feat of nurturing a child while fulfilling employment and other obligations becomes vastly more difficult to accomplish. If a parent has to give up work to become the child's primary caregiver, then that source of family income is sacrificed at the very time when it is needed most.



Almost **65%** of children diagnosed with cancer are under the age of four

Their parents tend to be young and not yet well established financially. The financial burden can be devastating. POGO studies have shown that, on average, a family can lose a third of its after-tax income when there is a child in treatment.

POGO provides complementary solutions to these challenges: care closer to home through the Provincial Pediatric Oncology Satellite Program, and financial support through the POGO Financial Assistance Program.

In its original analysis of existing approaches to pediatric cancer care in Ontario, POGO realized that not all components of treatment required visits to major treating facilities. The concept of POGO's Satellite Clinics was born.

Aided by information housed in its database, POGO carefully selects the locations for these clinics and creates operational standards and guidelines. POGO remains an important resource linking healthcare teams at the five pediatric cancer programs in Ontario with those at the Satellite Clinic, monitoring Satellite activity, providing regular professional development opportunities for staff and evaluating the program to improve service delivery.

Long-distance trips cannot be eliminated altogether. But providing components of care closer to home vastly reduces families' overall levels of stress; disruption of work and school attendance; expense; and reduces the substantial demand for hospital beds in the pediatric cancer programs. To date, POGO has created seven Satellite locations across Ontario: Mississauga, Kitchener-Waterloo, Orillia, Sudbury, Windsor, Scarborough and Newmarket.

Meanwhile, POGO's Financial Assistance Program helps ease the economic burden from the beginning, before it becomes unmanageable. Available to all Ontario families who need it while their child is in active cancer treatment, the program provides a stipend for food, accommodation and child care for siblings. POGO will, for instance, help meet the cost of staying at a Ronald McDonald House (RMH); and has hotel partners that provide free rooms when the RMH option is unavailable.



Of all POGO's charitable services, the Financial Assistance Program is the program used by the greatest number of families. It is funded entirely by private donations.



STAGES IN THE JOURNEY

SURVIVOR CARE

More than 82% of children diagnosed with cancer will survive. But even when they hear the best of all possible news, that they are now cancer-free, their journey is far from over, because young children are particularly vulnerable to the late effects of cancer treatment. As many as 60% of survivors will experience ensuing complications. The survivor of childhood cancer requires far more than the usual extent of health monitoring.

Radiation treatment in childhood, for instance, while arresting the malignancy and preserving life, can lead to infertility or breast cancer in adulthood. The onset of late-effect breast cancer usually occurs under the age of 35—much earlier than the age at which screening would normally be carried out.

Other physical effects can include poor muscle and bone development, respiratory and dental health issues, thyroid damage, cardiac problems and impairments to vision or hearing.

In addition, some cancers, such as brain tumours, require radiation treatment to the head, and others involve chemotherapy that crosses the blood-brain barrier. These can cause such late effects as increased forgetfulness, persistent fatigue and cognitive impairment, resulting in learning difficulties that can affect the child's success at school. Compounding the academic disadvantages already caused by time lost during treatment, this can in turn damage a young person's career prospects. Some survivors fall prey to depression and have difficulty forming social and personal relationships. Many find it difficult or impossible to realize their career aspirations, achieve personal and financial independence, or fully integrate into society.

On this stage of the journey, too, POGO is their champion.

Beginning two years after treatment is completed, survivors are monitored in POGO's network of AfterCare Clinics. Until the age of 18, these AfterCare Clinics take place in the pediatric cancer programs. The risk of late effects, of varying degrees, is a life-long reality and so, the POGO network continues to follow survivors throughout their adult life in a POGO partner adult cancer institution.





60%

As many as 60% of survivors will face late effects due to their cancer and/or its treatment.

There are seven POGO AfterCare Clinics, in five cities: Toronto, Hamilton, Kingston, Ottawa and London. The clinics are staffed by hospital personnel knowledgeable about oncology and about survivorship issues. The care they provide is tailored to each survivor's medical profile and specific needs. Knowing the original diagnosis and the treatment that was delivered, AfterCare staff can ensure that survivors are fully informed about issues relating to their future health—and can monitor them for the first signs of late effects.

If evidence of cognitive impairment appears, POGO offers a further dimension of care. In such a case, the clinic will refer the survivor to the counselling services provided by POGO's Successful Academic Vocational Transition Initiative, or SAVTI.

SAVTI is an unprecedented, made-in-Ontario POGO program that helps young cancer survivors make the transition from high school to college, university or into a career path.

Working one-on-one with survivors, POGO's trained counsellors use the information provided by neuropsychologists to help their clients develop realistic education and employment goals; select tools and strategies for managing school work; improve their problem-solving and self-advocacy skills; and connect with relevant services and resources within colleges, universities or the community.

Counsellors also help schools and post-secondary institutions achieve the flexibility that will offer survivors the opportunities to reach their maximum potential. The degree of accommodation sought varies according to the challenges in each case—it might be as simple as being granted extra time to complete assignments or tests, or taking a test orally rather than writing it.

It is a tribute to the program's success that it is now being emulated by other organizations in Canada and the U.S.

It is important that survivors of childhood cancer are able to understand and manage the unique issues they face. To this end, POGO organizes conferences and brings in experts to address such topics as screening and prevention, emotional health after cancer, fertility, assistive technology for individuals with cognitive challenges, health insurance and more.



3,000

Currently in Ontario, nearly 3,000 survivors struggle with late effects, including cognitive challenges

POGO's SAVTI program intervenes at one of the most critical stages in the patient's journey: the already daunting leap from the familiar environment of high school to the worlds of post-secondary education or employment. Thanks to POGO's work in this area, young cancer survivors may look forward to optimizing their possibility of becoming independent, productive participants in the global economy.

KNOWLEDGE TRANSFER

LEARNING AND DEVELOPMENT

Continuing evolution is vital. POGO recognizes that because pediatric oncology is a rapidly advancing field, constantly developing new diagnostic tools, therapeutic strategies and technologies, it is essential that POGO's healthcare professionals be at the forefront of that progress. POGO ensures that professionals, as well as survivors and their families, are kept up to date with the current state of knowledge.

Investment in professional development and educational activities is a major priority, which POGO addresses through its Education Program.

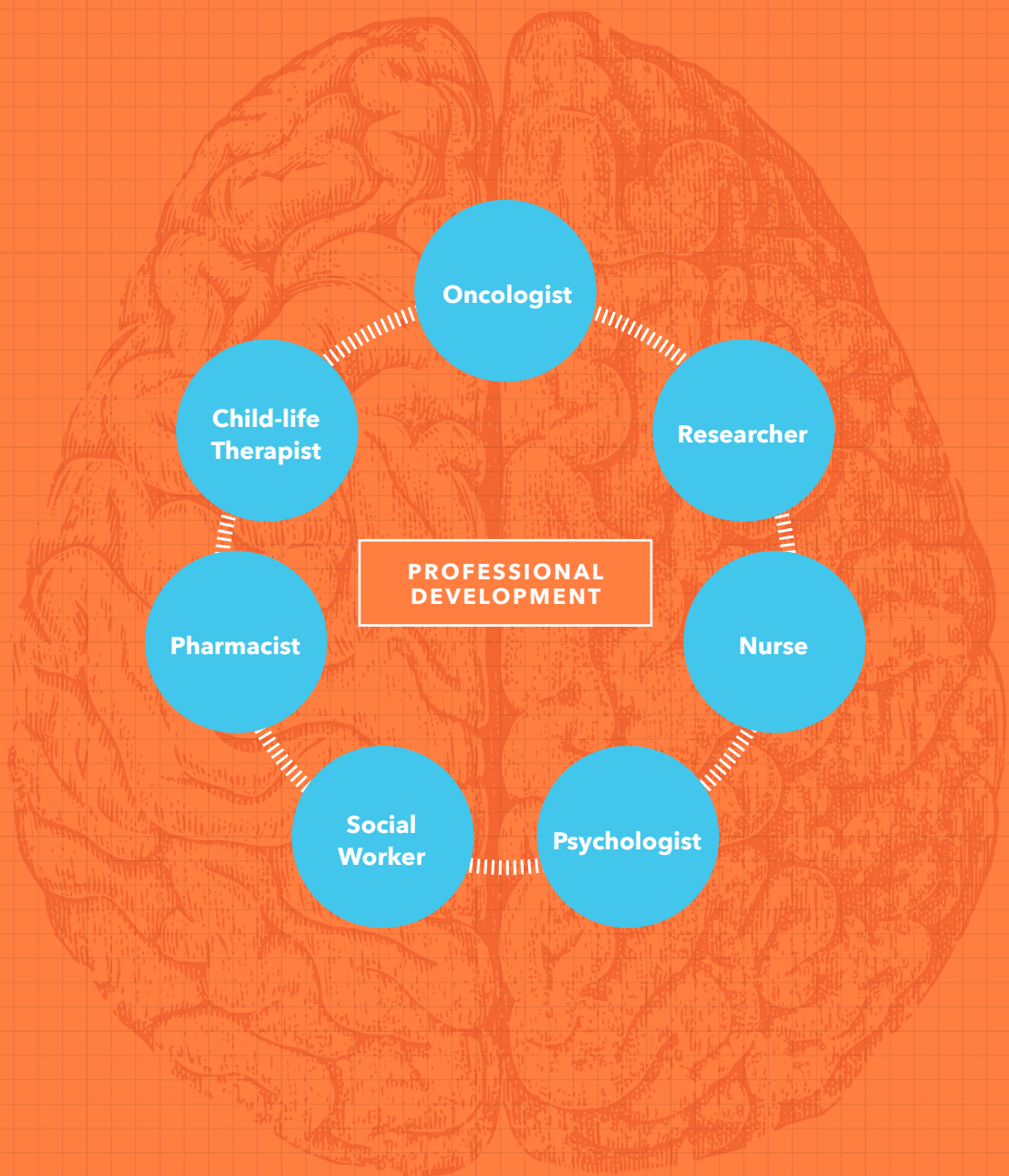
Among other development opportunities, this Program includes an annual symposium for professionals in a wide range of pediatric oncology disciplines. Some 300 delegates are drawn to this unique annual update, not only from across Ontario and Canada, but also from the United States, Central America and the United Kingdom.

Each symposium has a specific theme and is leading edge and multi-disciplinary in its focus. In past years, topics have included evolving genetics of cancer, pediatric brain tumours, cancer in infants, survivorship and innovations in pediatric oncology. In addition to providing an excellent opportunity for networking, consultation and discussion, these symposia have inspired new research collaborations between geographically dispersed colleagues.

POGO also provides the staff in its Satellite and AfterCare Clinics with regular education days to ensure that they are up-to-date in key areas. Healthcare and education professionals who work with survivors in POGO's SAVTI program receive similar learning opportunities.



In addition, each September POGO sponsors Childhood Cancer Awareness Month activities across the province to raise public awareness about pediatric cancer and its far-reaching impacts.



Interdisciplinary Team

THE ROAD AHEAD

POGO's programs and services that are part of direct patient care—such as its Interlink Nurses and Satellite and AfterCare Clinics—are funded by the Ministry. But many POGO programs that support families through the journey depend entirely on private philanthropy.

Without the generosity of private donors, POGO could not offer the financial assistance that provides so many families with relief during the most difficult time in their lives.

POGO could not help young survivors find their feet again as they struggle to complete their education and embark on careers.

POGO could not provide professional development opportunities for the doctors, nurses, neuro- and clinical psychologists and other specialists on whom families rely to save their children's lives. Nor could POGO provide families and children with the educational resources that will help them for the remainder of their lives.

And POGO could not conduct research that leads to improved care and better outcomes for kids with cancer in Ontario and around the world.

But it is clear now, as it was 30 years ago, that a change needs to take place. To properly meet the needs of today, and those of the future, POGO must dramatically transform its charitable revenue stream.

But we can't do it alone.



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