

Our Database: POGONIS

The childhood cancer data within POGONIS supports POGO and its partners in planning for childhood cancer control in Ontario, and is a valuable resource for the research activities it supports.

The POGONIS database contains the following health information for each child diagnosed with cancer in Ontario since 1985:

- Demographic information (e.g., full name, address, postal code, date of birth, sex, health card number);
- Diagnosis information (e.g., cancer type, date of diagnosis, histology information);
- Treatment information (e.g., type of treatment, dose, date, place); and
- Death information (e.g., date of death, cause, location).

POGO collects information from the five tertiary pediatric hospitals in Ontario, the six formal POGO Satellite and from seven pediatric and adult AfterCare Programs affiliated with the tertiary pediatric hospitals. Designated staff at these centres transmit information by private, secured electronic data lines.

POGONIS is designed to monitor:

- The incidence and prevalence of childhood cancer
- The demand for care and workload of pediatric oncology programs
- The nature and specifics of treatment
- Patient outcomes and long-term effects of childhood cancer and its treatment



Questions and/or concerns regarding privacy and security at POGO may be directed to:

Ms Bruna DiMonte
Database Administrator,
Research Assistant &
Co-Privacy Officer
bdimonte@pogo.ca

Madeline Riehl
Senior Associate:
Research and Planning &
Co-Privacy Officer
mriehl@pogo.ca



Where caring is the best medicine
for kids with cancer.

480 University Avenue
Toronto, ON M5G 1V2
Phone: 416.592.1232
Fax: 416.592.1285
www.pogo.ca

Pediatric Oncology Group of Ontario

Privacy Statement



Zippering up for security:

*Committed to ensuring privacy
and security of personal health
information*

What is POGO?

The Pediatric Oncology Group of Ontario (POGO) is a non-profit charitable collaboration, established in 1983 by the five pediatric tertiary institutions in Ontario to provide a voice for children's cancer control and treatment. POGO plans provincial pediatric oncology needs, coordinates the allocation of funding across the province, maintains the provincial pediatric oncology database (POGONIS) and conducts research focusing on childhood cancer. In 1995, POGO received the official designation of Adviser to the Ontario Ministry of Health and Long-Term Care (MOHLTC) regarding childhood cancer care and control.

How our collaboration has made a difference

Some examples of how our collaboration has made a difference:

- Exploration of the Risk Factor of Childhood Cancer - one study examined the impact of universal dietary folic acid supplementation on the epidemiology of Neuroblastoma (nervous system tumour).

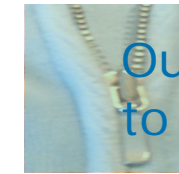
The findings suggest that food enriched with folic acid has resulted in a 60% reduction in the incidence of this type of tumour, implying that the incidence of this particular childhood cancer can be modified through maternal diet.

- Incidence Projections - the examination of the number of childhood cancer cases and types diagnosed from 1985 to 1997 established updated projections of cases to 2005. This analysis facilitated planning for future pediatric cancer services and analysis of staffing needs. Based on this information, since 1998, the Ministry of Health and Long-Term Care has dedicated a total allocation of \$51 million in new operating funds for pediatric cancer physicians, nurses, and allied health staff.

- Quality of Life Studies - several studies have been undertaken to investigate the impact of specific diagnoses and treatment on the physical and psychosocial outcomes of patients. These studies, some of which are ongoing, permit researchers and clinicians to re-evaluate current treatment approaches and identify interventions to moderate the factors which impair future quality of life.

- Creation and support of a provincial system of AfterCare (long term follow-up clinics) for survivors of all ages.

- Creation and support of a provincial Satellite Care system whereby pediatric oncology patients receive a portion of their care closer to home.



Our commitment to privacy

POGO's Privacy Code is based on the ten Principles of the Canadian Standards Association Model Privacy Code for the protection of personal health information found in Canada's federal privacy legislation. Among these principles, is our commitment to:

- Accountability: POGO is responsible for all data held in its possession or custody and designates individuals who are accountable for compliance with specific principles.

- Openness: Information about our privacy policy and practices is available in both printed format and on our website www.pogo.ca.

- Challenging compliance: Individuals have a right to know which data sources POGO uses for research and analysis, and can be referred to the organization that collects their data, for additional information.

- Safeguards: POGO protects all personal health information within its custody and considers it to be highly sensitive. The safeguards POGO has put in place include physical, organizational and technological measures. For example: a locked facility with tracked card access; internal/external video monitoring of POGO; confidentiality agreements signed by all employees, researchers and individuals affiliated with POGO; the use of firewalls, passwords, encryption and anonymization of data; and virtual privacy network.