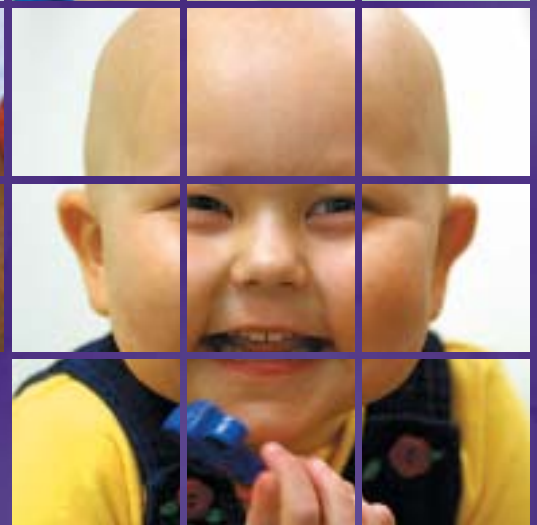
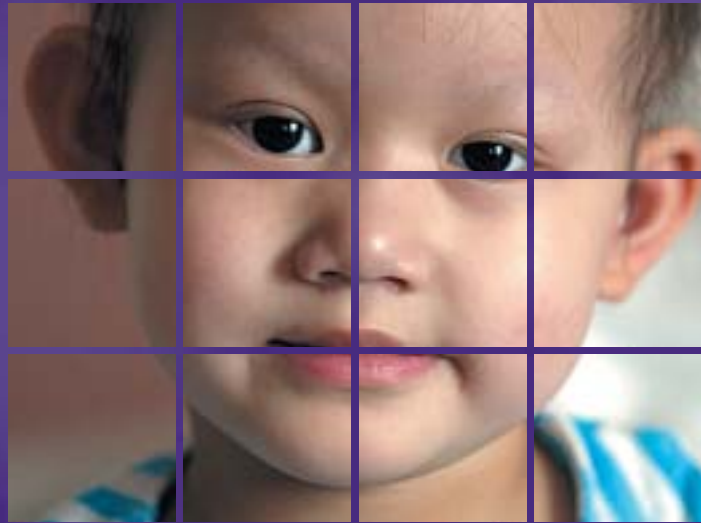


annual report

2002
2003

celebrating 20 years of caring, innovation and leadership



POGO

PEDIATRIC ONCOLOGY GROUP OF ONTARIO





**“POGO’S efforts
to provide
equivalent care
for children
across the province
have been amazing! It is
reassuring to know that
the care our kids receive is
of the highest standard.”**

*Susan Kuczynski,
parent of childhood cancer survivor,
Co-Chair of Ontario Parents Advocating
for Children with Cancer (OPACC)*

INTRODUCTION TO POGO

Each year, an increasing number of Ontario's children (now more than 2500) undergo treatment or require follow-up care for cancer. Investments of human and financial resources, and a high level of professional collaboration have resulted in a 75% overall survival rate for these children. However, survival can come at a high cost. Quality of life may be compromised as survivors and their families struggle with the physical, psychological and socio-economic impacts of the disease and its treatment. And, despite decades of remarkable progress, 25% of children newly diagnosed with cancer will not survive. In fact, cancer kills more of our children than any other disease: on average, 2 children die of malignant disease each week in this province.

Since its founding in 1983, the Pediatric Oncology Group of Ontario (POGO) has championed childhood cancer care and control. As the concordant voice of the childhood cancer community, POGO seeks to ensure access for all of Ontario's children to well coordinated, state-of-the-art diagnosis, treatment and required ancillary services. The organization is a collaboration of the five specialty pediatric oncology programs in Ontario - The Hospital for Sick Children (Toronto); Children's Hospital, Hamilton Health Sciences; Children's Hospital of Western Ontario (London); Kingston General Hospital; and Children's Hospital of Eastern Ontario (Ottawa) - along with a growing number of partners drawn from community hospitals, community services, other members of the health care sector, families of children who have, or have had cancer, corporate and private benefactors, and volunteers.

Strong partnerships with Ontario's Ministry of Health and Long-Term Care (MOHLTC) and the childhood cancer community, and an



unflinching collaboration among the POGO programs and professionals have led to many successes. Over the years, POGO has built a reputation for recommendations based on solid provincial data, scientific evidence and extensive clinical experience. Today, POGO is the official source of advice to the MOHLTC on pediatric cancer care and control, and the Ministry has assigned pediatric cancer Priority Program status, thus assuring separate planning and committed funding for the disease.

The joint efforts of POGO and its partner hospitals have created an environment in which the gaps in cancer care and control are identified, and a secure and appropriate flow of funds to treating hospitals may be negotiated with government, and continually adjusted to accommodate new treatments and new service demands.

Thanks to POGO, care for Ontario's children with cancer has been integrated into an exemplary, province-wide system supported by practice guidelines, professional education, accurate information and research. The POGO collaboration strives to improve quality of life during all phases of a child's cancer journey - from diagnosis to palliation, or from diagnosis to cure and beyond.

“Our government is committed to ensuring that the children of this province have access to the very best healthcare that's available...

This funding will ensure that newly diagnosed children with cancer have the care they need.”

*Tony Clement,
Minister of Health
and Long-Term Care,
in reference to Ministry
funding for pediatric cancer
announced in 2003,
catalyzed by POGO.*

A MESSAGE FROM THE PRESIDENT

Dr. Ronnie Barr



Dr. Ronnie Barr

Twenty years ago, in 1983, POGO was formed by a group of pediatric oncologists who recognized that Ontario lacked knowledge of the total picture of childhood cancer in the province, and that the institutions delivering care had no formal system of collaboration, communication, or standard-setting. Their vision was to ensure that Ontario had a coordinated childhood cancer system which provided all children with equal access to state-of-the-art care. Over time, POGO's membership expanded to include other disciplines, such as nursing, pharmacy and psychosocial specialties, ensuring that its work and the care of the children addressed all aspects of the childhood cancer experience.

In 1994, the Ministry of Health and Long-Term Care (MOHLTC) invited POGO to identify gaps in service across Ontario and propose strategies to fill these. In response, the childhood cancer community - health care professionals, administrators, parents and survivors - mobilized under POGO's leadership to develop a strategic plan which became the blueprint for an enhanced provincial childhood cancer system.

Shortly thereafter, POGO was named the official advisor to Ontario's MOHLTC and pediatric cancer was designated a Priority Program.

POGO has striven to ensure that the pediatric cancer institutions across Ontario function as a seamless network, supported by the MOHLTC,

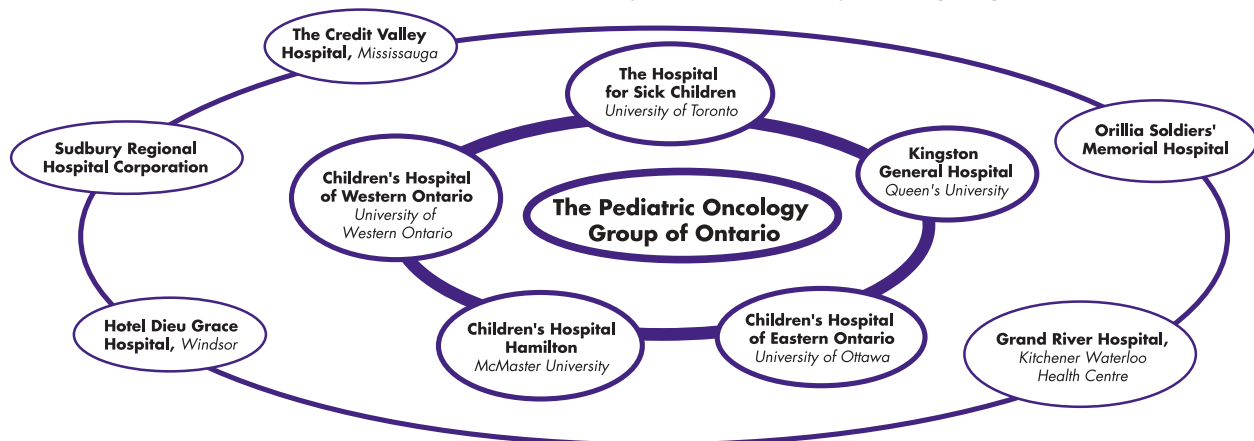
and that they adhere to practice standards and guidelines developed by expert representatives from their own ranks, under the umbrella and coordination of POGO.

In 2000, the POGO Chair in Childhood Cancer Control was established at the University of Toronto with the support of private sector donors. The incumbent of the POGO Chair, Dr. Mark Greenberg, concurrently works as POGO's Medical Director, enabling the organization to advance a range of consensus building, teaching and research activities and to ensure their translation into better care.

Today, POGO is on the brink of an exciting phase of growth which will advance its research agenda, add financial support for families, further consolidate childhood cancer services and, ultimately, necessitate increased private sector fundraising.

We are mobilized to make Ontario a model childhood cancer system, and through the sharing of POGO documents, data and expertise at the request of national and international organizations, to also benefit children and families beyond provincial borders.

Thanks to all of you who have played such an important role in POGO's past, and welcome to those who will be joining us on our continuing journey. We look forward to your ongoing support.



REPORT FROM THE EXECUTIVE DIRECTOR

Dr. Corin Greenberg

It is my pleasure to report on the activity undertaken by POGO during the fiscal year 2002/2003. During this time, POGO did much to advance the care of children with cancer in the areas of Care, Education and Research, through the development and maintenance of the provincial childhood cancer registry and database (POGONIS), and through the deployment of POGO models & guidelines in the service of other jurisdictions. Highlights of POGO activities during the past year include:

- **Advising the Ministry of Health and Long-Term Care (MOHLTC) on increased staffing requirements at pediatric oncology programs** across the province. As a result, the MOHLTC announced a further \$2.9 million per year for the five pediatric institutions - to help ensure that the care of children with cancer in this province continues to improve. Since 1998, and based on POGO advice, the MOHLTC has dedicated a total of \$51 million in new, operating funds for pediatric cancer physicians, nurses and allied health staff.
- **Taking on the administration and financial support of the Pediatric Oncology Financial Assistance Program (POFAP)**, which will help offset some of the immense burden of out-of-pocket costs faced by families of children with cancer (estimated to represent an average of approximately 1/3 of after tax income).
- **Securing dependable funding to allow the pediatric Interlink Community Cancer Nursing program to join other childhood cancer services under the POGO umbrella.** Interlink nurses help children with ongoing medical needs to reintegrate into the community during and after treatment.
- **Collaborating with the MOHLTC and the POGO programs to assess the impact of the Ministry's significant investment in childhood cancer since 1998**, e.g. changes in human resources; availability of a full spectrum of childhood cancer services; efficacy of service delivery; satisfaction among families and caregivers; and residual impediments to effective care delivery.
- **Expanding the activities of the POGO Research Unit (PRU)** and recruiting Madeline Riehl as Senior Associate, Research & Planning, to assist with the growth of POGO's research agenda. This will ensure that important research is undertaken to help secure the best possible outcomes and delivery systems for children with cancer in Ontario.

■ **Frequent consulting and advising regarding optimal models of health system delivery, at the request of organizations and institutions across Canada and internationally.** POGO is committed to sharing the wealth of expertise generated by the collaboration with jurisdictions beyond Ontario via presentations and sharing of strategic plans, methodologies and other documents.



Dr. Corin Greenberg

I am pleased to report that POGO is operating on a surplus basis. For the fiscal year ended March 31, 2003, the total income was \$4,366,740 with total expenses of \$3,600,859. The annual audit of POGO's financial statements is underway at press time, and these figures may change once the audit is completed. POGO's policy is to allocate a portion of any year-end surpluses against high-priority needs and programs approved by the POGO Board, and subject to Ministry of Health approval when concerning Ministry funds, while retaining a positive fund balance into the subsequent fiscal year. For detailed financial statements please contact Susan Grace in our office at 416-592-1232.

2003 marks the 20th anniversary of the remarkable collaboration of concerned and committed health care professionals, parents, and childhood cancer survivors, known as POGO. At this milestone in our history, we embark on an era of growth and expansion of activity facilitated by private sector funding, with great expectations that it will increase POGO's capacity to continue to improve the care and quality of survival for the children of Ontario; to enhance professional education, disease surveillance and research; and to extend the impact of POGO innovations beyond Ontario's borders to assist in the development of pediatric oncology in other jurisdictions around the world. We thank all of you for the many ways in which you have supported POGO - through your work, your expertise, your charitable contributions - and look forward to moving forward in continued partnership.

MEASURES OF OUR SUCCESS

Objectives Set in 1988 and 1994 Strategic Plans	2002/2003 Activity In Support of Objective
To ensure government has expert advice to build a childhood cancer care system.	<ul style="list-style-type: none"> ■ Delivered presentations to policy makers on the POGO model for a comprehensive, integrated health service system ■ Conducted data collection, development and analysis to support decision making ■ Sustained rapid policy development capacity
To initiate an integrated, comprehensive provincial system of care.	<ul style="list-style-type: none"> ■ Completed and implemented standards and guidelines for the Provincial Pediatric Oncology Satellite Program and the AfterCare Program
To create and sustain a provincial database on childhood cancer (Pediatric Oncology Networked Information System – POGONIS)	<ul style="list-style-type: none"> ■ Provided data on childhood cancer to multiple researchers, academics, speakers and media ■ Expanded provincial database to include surveillance of late effects ■ Adapted POGONIS to facilitate printing of <i>Passport to Health</i> summaries which capture treatment history of survivors ■ Increased speed and efficiency of data transfer into POGONIS ■ Developed further expertise in innovative analyses and reporting
To achieve a major expansion of expert staff in all disciplines	<ul style="list-style-type: none"> ■ Phase III expansion proposed to and approved by MOHLTC leading to an additional \$2.9 million to POGO centres for increased staff. Since 1998, POGO has catalyzed more than \$51 million in operational funding into the system from MOHLTC to augment care of children at the five POGO affiliated sites. ■ Conducted Impact of Funding Assessment to evaluate impact of recent Ministry investment in childhood cancer. Significant improvements, including a 69% overall increase in funded staff positions, were demonstrated. ■ AfterCare clinic staffing requirement specified, funded and offered professional development ■ Staffing secured for two newly activated Provincial Pediatric Oncology Satellite Program sites ■ Expanded POGONIS support staff ■ Positions added to the central POGO coordinating office: Clinical Programs Coordinator and Senior Research Associate
To create a provincial system of AfterCare Clinics for survivors of all ages.	<ul style="list-style-type: none"> ■ AfterCare staff recruited, guidelines activated ■ Developed AfterCare database ■ Enabled extraction and printing of <i>Passport to Health</i> summaries for survivors ■ Initiated professional education and update programs for AfterCare professionals
To initiate supportive strategies for patients/families	<ul style="list-style-type: none"> ■ Assumed responsibility of POFAP (Pediatric Oncology Financial Assistance Program) to reimburse families for specified out-of-pocket costs arising when children with malignant disease and their caregiver(s) attend cancer treatment over a prolonged course of care. ■ Achieved substantially increased access for families to multidisciplinary caregivers – 69% overall ■ Created on-line database of SAVTI resources to support survivors leaving high school.
To increase opportunities for professional development and specialization in pediatric oncology	<ul style="list-style-type: none"> ■ Held 11th Symposium on Childhood Cancer, Care at the End of Life ■ Provided peer review and consultation through POGO's Provincial Research Committee ■ Offered specialized practice updates for POGO's Satellite and AfterCare Program staff ■ Provided mentoring for abstract development and poster presentation ■ Published POGO News, circulation >2000 several times a year
To create a POGO Research Unit (PRU)	<ul style="list-style-type: none"> ■ A 5 year Ministry funding commitment to PRU, scheduled to end March 2003 was extended by 1 year to March 2004. Over the 5 years, the PRU: <ul style="list-style-type: none"> • Stimulated and expedited studies in four major interest areas • Attracted 26 highly relevant research projects, submitted by 82 investigators, which resulted in 21 publications, manuscripts, posters and other forms of academic output and significant subsequent funding from other sources. ■ Recruited a Senior Associate, Research & Planning, to manage PRU
To transfer knowledge to professionals and interested public	<ul style="list-style-type: none"> ■ Provided accurate information on childhood cancer to academics, clinicians, researchers, media, parents, and other interested parties.

CARE

In 1988 and 1994, POGO created comprehensive childhood cancer strategy documents for submission to the Ministry of Health and Long-Term Care (MOHLTC). In 2002/2003 POGO furthered implementation of the framework recommended in these documents to enhance care of children with cancer through:

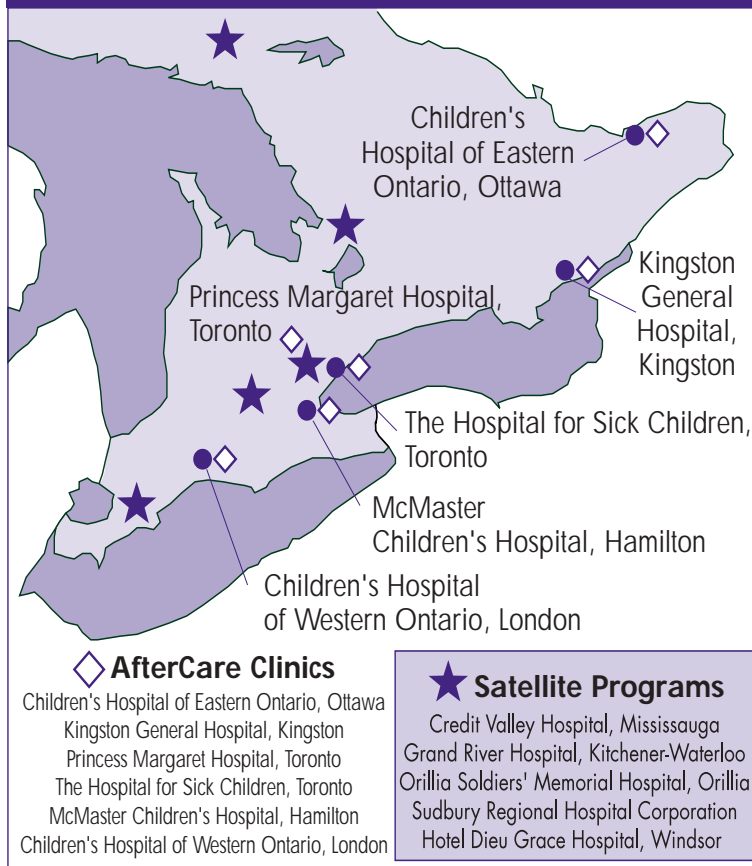
Standards & Guidelines

- updating the operating guidelines of the **Provincial Pediatric Oncology Satellite Program** which transfers aspects of children's care to community hospitals closer to their homes in order to minimize disruption for the patient and family, and to reduce pressure on understaffed hospitals.
- disseminating and implementing guidelines for **POGO AfterCare Clinics** which monitor and promote the health of survivors who often face late effects of their disease and treatment, and assure application of information relevant to care and research for future patients.
- updating POGO guidelines for the management of central venous lines - devices which facilitate the delivery of chemotherapy - to help reduce infection risk, thereby minimizing the trauma of treatment.
- developing guidelines for the safe handling of chemotherapy drugs - the work of POGO's Nursing Committee.

Patient & Family Resources

- undertaking the administration and more than 60% of the funding of **POFAP, the Pediatric Oncology Financial Assistance Program**, previously operated by the Canadian Cancer Society (CCS), Ontario Division. POFAP reimburses families for certain costs incurred when a child is in treatment, such as food, accommodation, and babysitting for siblings. Such costs can consume approximately one-third of a family's after-tax income. Until March 2006, POGO will provide funding in partnership with CCS. Thereafter, POGO will seek partnerships to raise funds to ensure POFAP's viability.
- creating **SAVTI, the Successful Academic and Vocational Transition Initiative**, to assist survivors with cognitive affects of their disease and treatment to transfer into post-secondary learning and/or work environments. The SAVTI blueprint was finalized and a pilot program implemented with George Brown College. SAVTI is expected to ultimately roll out across Ontario.

Our Partners in Cancer Care



Filling Service Gaps

- increasing the number of expert staff available in all pediatric cancer programs by catalyzing a further \$2.9 million in MOHLTC funding. The Ministry's decision to allocate more than \$51 million in operating funds to expand human resources since 1988, was based on recommendations emerging from POGO's 1994 strategic plan which identified persisting gaps in service and funding. It has led to a 69% overall increase in funded positions.
- addition of two new satellites - Credit Valley Hospital, Mississauga and Hotel Dieu Grace Hospital, Windsor - to the Provincial Pediatric Oncology Satellite Program.
- supporting the induction of staff, development of data gathering and overall implementation of the POGO AfterCare Clinics.
- securing MOHLTC funding for the pediatric program of Interlink Community Cancer Nurses who provide community nursing support, and integrating these services into the provincial planning of the pediatric cancer network.
- securing funding to implement a technical program, Easy Pax, to facilitate the exchange of clinical images among the pediatric cancer treatment facilities, to support treatment decisions, and reduce repeat imaging and testing.

EDUCATION

POGO Annual Multidisciplinary Symposium on Childhood Cancer - Care at the End of Life: The Multiple Dimensions

Session Topics Included:

- Ethical Issues in Pediatric Care at the End of Life
- The Physiology of Dying and Pharmacologic Management of Symptoms that Result
- Talking to Dying Children
- Communication, Children and Death in the Age of the Internet
- Adolescents and Decision-Making at the End of Life
- Pharmacologic Control of Complicated Pain at the End of Life
- The Impact of End of Life Care on Pediatric Oncology Professionals

POGO is committed to providing frequent opportunities for education that allow health care professionals to remain up-to-date in the rapidly advancing field of pediatric oncology, and to ensure that the care delivered to Ontario's children is both current and focused on caring for the whole child. POGO's educational events are dynamic, multidisciplinary learning opportunities at which experts assemble to identify and examine challenging issues of caring for children with malignant disease from multiple perspectives. They provide valuable opportunities for consultation and collaboration, and excite discussion that advances policy, program and practice innovation.

Highlights of POGO's educational programs during 2002/2003 are described below.

Multidisciplinary POGO Symposium

The 11th POGO Symposium on Childhood Cancer, Care at the End of Life: The Multiple Dimensions, took place in November 2002. Program topics appear in the sidebar. Several hundred multidisciplinary professionals in attendance gave the 2002 Symposium extremely high ratings as an effective source of new information for practice and of new ideas for research. Since funds for professional education have been scaled back at some institutions, bursaries were made available to each of the POGO partner centres to facilitate broad-based participation in this conference. The costs of the Symposium were offset, in part, by corporate sponsorship. A list of sponsors can be found on page 17.

Specialized Practice Updates

POGO held a specialized practice update for partners in the **Provincial Pediatric Oncology Satellite Program**. The pro-

gram was delivered in partnership with The Hospital for Sick Children's Bone Marrow Transplantation Unit (which also provided teaching faculty) and was chaired by POGO's Medical Director/the POGO Chair in Childhood Cancer Control. The event focused on Bone Marrow Transplantation (BMT) - Care and Management of Patients. Topics included Management of BMT Complications; Psychosocial Impacts of Transplantation; and Nutritional Needs in the Post-Transplant Patient.

Research Review and Consultation

Through POGO's Research Committee, conceptual, methodologic and analytic expertise and advice were made available to help refine research proposals, academic abstracts and posters. POGO's work in this regard supports the development of research skills, augments the capability of disciplines less familiar with research methodology to pursue research questions, and facilitates multidisciplinary research collaborations.

POGO News

POGO periodically publishes a newsletter circulated to over 2000 professionals and other stakeholders across Canada, the USA and internationally. POGO News summarizes new advances; analyzes the implication of new policies and legislation; provides a summary of upcoming conferences; reviews relevant, recent publications; and provides updates on the activities of POGO programs and POGO's standing committees. A 2002/2003 newsletter focusing on Adolescent and Young Adult Oncology generated so much interest that the topic was selected as the focus of the 2003 Symposium.

RESEARCH

The **POGO Research Unit (PRU)** was initiated in 1998, with a mandate to focus on research that contributes to a better understanding of childhood cancer control and improved outcomes for children with cancer and their families.

The Ministry of Health and Long-Term Care (MOHLTC) funded the PRU initially; by 2002/2003, POGO was committed to increasing its research capacity. To this end, staff has been hired to develop and implement research activities and to augment partnerships with other researchers and institutions. Moving forward, the PRU will seek funding support from the private sector and granting agencies, in addition to the MOHLTC.

To fulfill its mission, the PRU is guided by the following goals as they pertain to pediatric oncology:

- To document and understand province-wide patterns and trends;
- To carry out health services research relevant to policy;
- To investigate physical, behavioural and societal outcomes of the disease and treatment;
- To generate and evaluate strategies intended to continually improve the quantity and quality of survival in childhood cancer;
- To encourage improved communication and implementation of knowledge, resulting in more informed policy development;
- To create a research staff responsive to investigators seeking advice, consultation and expertise in research design and development;
- To promote linkages between health care services, providers and decision-makers.

The POGO Research Unit will initiate, coordinate, facilitate, conduct and educate in the realm of research across the entire

range of cancer control components in childhood. POGO is uniquely able to carry out such research because of its access to an entire population, the breadth of disciplines it encompasses, and its unique database - **POGONIS (the Pediatric Oncology Group of Ontario Networked Information System)**. The PRU will promote research that is complementary to that of its partner hospitals and existing research institutes within the following general categories:

Demographic studies will examine environmental and molecular interactions, especially relating to those cancers of increasing incidence in childhood.

Evaluation of clinical practice and health intervention studies that will review components of the disease, its treatment, and system and sociologic determinants of clinical outcomes.

Health economics and quality of life investigations will focus on application of existing methodologies for estimation of the costs and effectiveness of therapy, and the measurement of quality of life and the burden of illness.

Status of survivors projects will evaluate health outcomes and identify and study interventions intended to alter long-term health status, including preventive strategies and health promotion interventions.

The years ahead will see significant growth in scope and activity for the PRU. A fully operational POGO Research Unit will generate investigations that pave the way for continued advances in the care of children with cancer and further define strategies for optimizing the quality of life of survivors. Scientists and staff will increase in number and an educational Research Fellowship Program will pave the way for three Research Fellows to join the PRU in 2004.

Studies active through 2002/2003 with various partners and collaborations, are described below:

Projection of Future Demand for Pediatric Cancer Services and a Determination of the Staffing Funding Required - To anticipate and ready the system for future service demand, POGO researchers analyzed data to determine patterns and trends in childhood cancer incidence, future demand and staffing levels. The implications were presented to the MOHLTC and, most recently, resulted in a further allocation of \$2.9 million to the POGO centres in accordance with staff-to-patient ratios determined by POGO for multidisciplinary staff teams.

Exploration of the Risk Factors for Childhood Cancer - Several investigations examined environmental exposure and the child's genetic ability to permit or obstruct the development of malignancies. One important study looked at the impact of universal dietary folic acid supplementation on the epidemiology of Neuroblastoma. The results of a study on Osteosarcoma, genetic makeup and specific viral exposure were published, with further funding catalyzed to continue this line of enquiry.

An Investigation of the Pediatric Oncology Nursing Workforce - POGO nurse researchers from the five POGO centres examined nursing
(continued on page 10)

PROVINCIAL CHILDHOOD CANCER REGISTRY AND DATABASE

“The PRU (POGO Research Unit) has proven to be an effective mechanism to facilitate the development and conduct of innovative studies that require the infrastructure of a dedicated pediatric oncology research group. The comprehensive nature of the POGONIS database facilitates multi-disciplinary population as well as cohort-based research in the field that cannot otherwise be achieved. Expansion of the current infrastructure, as well as in-house expertise and capacity of the PRU will significantly augment the research agenda. Furthermore, initiation of a POGO fellowship will address the ongoing need to support and nurture a generation of young and enthusiastic investigators in the field of pediatric cancer control research.”

*David Malkin, Senior Scientist,
Cancer Research Program,
The Hospital for Sick Children*

POGO has built and maintains **POGONIS (Pediatric Oncology Group of Ontario Networked Information System)**, a database and registry capturing selective, standardized data on all childhood cancer cases in the province of Ontario.

The purpose of POGONIS is to monitor:

- the incidence and prevalence of cancer in childhood;
- demand for care;
- the nature and specifics of treatment;
- patient outcomes; and
- long-term effects of childhood cancer and its treatment.

Coupled with the knowledge capital represented within POGO's Board, staff, and standing committees, POGONIS is the cornerstone of expert advice and planning for the province. It is a unique source of reliable validated data that is the basis for:

- precise estimates of the incidence of childhood cancer in the province;
- planning new programs and ensuring that decisions about where to locate these are well informed;
- provision of data for multiple research projects;
- population-based research on the POGONIS data itself;
- accurate projections of the number of children to be treated in the future;

- forecasting the number of staff required; and
- a clear understanding of where the children live in relation to where they are treated, in order to facilitate the strategic location of treatment facilities.

POGO has taken a number of steps recently to ensure further development and enhancement of POGONIS. For example:

- POGONIS has been structured to enable local data query by POGO partner hospitals, in order to facilitate its use by personnel in the institutions delivering pediatric cancer care.
 - POGONIS has been expanded to accommodate the tracking of late effects and AfterCare services.
 - POGO has undertaken to fund and train data managers and otherwise support the collection of information on survivors diagnosed prior to 1995 in order to create a *Passport to Health* for each survivor. The *Passport to Health* was designed by POGO to contain information critical to the ongoing care of survivors, and to be carried by survivors.
- Into 2003/2004, POGO will continue to provide financial assistance for POGONIS data management, and will provide ongoing training and professional development for POGO data managers.

(continued from page 9)
turnover levels and educational needs, and identified strategies to prevent nursing shortages. A follow-up study focusing on education, work experience and employment status of the nursing workforce will be conducted through 2003/2004, and should enable

POGO to continue to address challenges related to nursing turnover and retention.

A Series of Studies Probing Quality of Life of Survivors - Several studies have been undertaken to investigate the impact of specific diagnoses and treatment on the physical and psychosocial out-

comes 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 later quality of survival. Several different types of cancer and treatments are included in this grouping.



DEPLOYMENT OF POGO KNOWLEDGE CAPITAL IN THE SERVICE OF OTHER JURISDICTIONS

The POGO model of collaborative decision making has been utilized by government and other agencies as a template for policy development and the organization of health services. POGO is regularly called upon to consult with health planners on the development of health care delivery models in Canada and around the world.

Examples of POGO's consultation to other jurisdictions through 2002/2003 are listed below:

In Canada

- POGO's Medical Director/the POGO Chair in Childhood Cancer Control led a workshop for the British Columbia Cancer Control Agency and Women and Children's Hospital of British Columbia on the development of regionalized childhood cancer services.
- The POGO model for the development of AfterCare services has been used as a template in Atlantic Canada, Quebec and British Columbia.
- POGO consulted and presented information to Ontario's Specialized Pediatric Coordinating Council on the development and maintenance of a vital, tiered, coordinated and integrated health care service delivery system, using the POGO model of care delivery as a "best-in-class" example.
- POGO's Medical Director/POGO Chair in Childhood Cancer Control consulted and presented to the Gynecological Oncology Group of Ontario on the development of an integrated provincial system of cancer care and control.
- The Medical Director/POGO Chair participated in Toronto's Ian Anderson Program Workshop on the development of teaching modules addressing principles and policies in palliative care.

Internationally

- By invitation of the Institute of Medicine of the National Academy of Sciences of the United States, POGO's Medical Director/POGO Chair in Childhood Cancer Control addressed the Institute on the development and organization of a system for the care of survivors of childhood cancer, and participated in the development of their report on this issue. The report will cite POGO as an exemplary model.
- POGO accepted an invitation to participate in an international outreach program in Central America (the "Central American Pediatric Oncology Research Infrastructure (CAPRI)" initiative) in partnership with St. Jude Children's Research Hospital, the Monza International School of Pediatric Hematology/Oncology and the Central American consortium of pediatric cancer institutions, AHOPCA.

“POGO has been a catalyst for life beyond the cure and survivors' special needs.”

*Jill & Andrew Sprawson,
childhood cancer survivors
and founders
of Rebounders Canada*



A MESSAGE FROM THE POGO CHAIR IN CHILDHOOD CANCER CONTROL AND MEDICAL DIRECTOR

Dr. Mark Greenberg



Dr. Mark Greenberg

“The work of the POGO Chair in Childhood Cancer Control has had a great impact on the university and the medical research community, but more importantly, on the families it was always intended to serve.”

Jon S. Dellandrea
VP and Chief Advancement
Officer, University of Toronto

It has been my privilege, in my dual capacity as POGO Chair in Childhood Cancer Control and POGO's Medical Director, to continue my work, in collaboration with Ontario's leaders in childhood cancer control, to enhance the care of those afflicted with childhood cancer. Over the past year, we have made significant inroads into realizing our vision of a cutting edge care delivery system that uses precious resources effectively. The childhood cancer care community remains committed to working together to advance care, research, education and knowledge transfer in Ontario, Canada and across the globe.

To this end, I have been involved in a wide range of activities during 2002/2003. These are detailed below:

CARE

Standards & Guidelines: My role during the past year was to provide leadership and consultation on the following projects:

- Update and refinements of the **Provincial Pediatric Oncology Satellite Program** and the guidelines that define it;
- Update of the guidelines of the management of central venous lines;
- Consultation regarding the POGO guidelines for safe handling of chemotherapeutic agents;
- Development of guidelines for the delivery of care to survivors of childhood cancer through the **POGO AfterCare clinics**.

Filling Service Gaps: In my dual role, I am responsible for ensuring that gaps in service delivery are identified and filled. Examples of such activity include:

- Advocacy with the Federal Government for the continued funding of the national Childhood Cancer Surveillance and Control Program of Health Canada;
- Consultation with the Assistive Devices Program of the Ministry of Health and Long-

term Care (MOHLTC), regarding the provision of nutritional support and assistive devices to the childhood cancer population;

- Reporting the results of the POGO “needs and gaps study” completed this year in which I played a major role in the design, analysis and interpretation of the implications for funding;
- Playing a lead role in the development of **SAVTI**, the vocational transitions program for congenitally affected survivors of childhood cancer. This program was conceived from clinical experience, developed in concert with multi-disciplinary partners from the health and education sectors, and is currently being operationalized.

EDUCATION

During 2002/2003, I was pleased to coordinate, convene and otherwise participate in several educational endeavours. My involvement in some of these endeavours is detailed below:

- I organised and chaired the very successful 2002 annual **POGO Multidisciplinary Symposium** on “Care at the End of Life: The Multiple Dimensions”;
- I chaired and organised the Pediatric Oncology Satellite Education Day and Round Table 2002, focusing on Bone Marrow Transplantation (BMT) - treatment advances and post-BMT care;
- I helped in the organization and planning of the first AfterCare Education Day;
- I participated in the planning and production of POGO News and acted as editor of selected issues;
- I delivered many lectures and addresses to professional peer groups;
- I addressed the Institute of Medicine of the National Academy of Sciences in Washington, DC on the organization of care for survivors of childhood cancer.

RESEARCH

My role as Medical Director/POGO Chair involves me in the activities of the **POGO Research Unit (PRU)**. For example, in 2002/2003:

- I assumed a lead role in the establishment of this population-focused research unit, including the initiation and fostering of research directions, the recruiting of personnel, and the creation of linkages with potential partner organizations including Cancer Care Ontario; CIHR Institute of Human Development, Child and Youth; the Centre for Nursing Research; and others;
- I was involved in the submission of several grant proposals to granting agencies, including a study of delay in access to treatment and a study of the role of electronic technology in facilitating clinical trials;
- I have been involved in the publication of several abstracts and manuscripts crossing the spectrum of childhood cancer control;
- I participated in the design, execution and interpretation of POGO's Impact of Funding Assessment, examining the impact of increased MOHLTC funding on the pediatric cancer care system.

PROVINCIAL CHILDHOOD CANCER REGISTRY AND DATABASE

In 2002/2003, I led the expansion of the POGONIS database to accommodate a combined clinical and research component focused on long-term survivors. In addition, the data structure and organization were reviewed and updated.

DEPLOYMENT OF POGO KNOWLEDGE CAPITAL IN THE SERVICE OF OTHER JURISDICTIONS

I have accepted numerous invitations, extended to me this past year, to share the POGO model of collaboration, discuss innovative program delivery mechanisms, and the POGO standards and guidelines we have developed. I have made presentations, lead workshops, participated in symposia and



A POGO fundraiser

think tanks, and co-chaired, along with POGO's President, the Canadian Childhood Cancer Surveillance and Control Program. These undertakings are detailed elsewhere in this report. In aggregate, they have afforded the opportunity for POGO to influence health care thinking and policy development, both directly relevant to childhood cancer control, the wider childhood health care domains, and other aspects of health care at the local, provincial, national and international levels.

The year ahead promises much exciting activity, with new and expanded roles for POGO. Further development of clinical, research and educational programs is already underway. The focus of POGO continues to be the global wellbeing of the children and their families, and the initiatives currently on the drawing board and under development will enhance the care of children with cancer and the quality of life for them and their families.

Thank you to all of you who, by supporting the funding of the POGO Chair in Childhood Cancer Control, have recognized the importance of research and education to the precious children whose lives are affected by cancer.

“Our daughter, Erica, was diagnosed with Leukemia two years ago.

The treatment and care she has received throughout her chemotherapy has been at the highest standard a parent could expect. Erica's safety, comfort, and long term health are a top priority, thanks to the work of POGO and their partnership with her treating hospital.”

*Lynne and Ian Cleghorn,
parents*

A MESSAGE FROM POGO'S FUNDRAISING COMMITTEE CHAIR

Tony Melman



Tony Melman

“The leadership demonstrated by POGO through their initiatives, and their commitment to fundraising through events that put a human face on pediatric cancer and the families that deal with those issues on a daily basis, is outstanding.”

*Dr. David Naylor
Dean of the Faculty
of Medicine,
University of Toronto*

Congratulations to POGO and the community of pediatric health care providers, patients, and families on the 20th Anniversary of POGO. I applaud all of you who have helped advance the care of children with cancer in this province. I look forward to supporting your efforts as POGO embarks on an era of increased activity and contribution to success in the field of childhood cancer, facilitated by increased private sector fundraising.

It is my pleasure to report on our fundraising activities in 2002/2003. Special events this past year included the 2nd annual Family Fun Day at Camp Green Acres. This event, presented by TD Commercial, raised nearly \$25,000 for the POGO Chair. (A complete list of sponsors can be found on page 17.) POGO also benefited from third-party events during 2002/2003, including the Golf Town annual golf tournament, the Cedervale Family Fun Day and the Canadian International Marathon. In addition, Charles Coffey of RBC Financial Group, hosted a dinner to celebrate POGO's 20th anniversary, and to help raise awareness of our organization.

Corporate sponsorships helped offset the costs of the 11th POGO Multidisciplinary Symposium, "Care at the End of Life: The Multiple Dimensions". The generous sponsors who made this event possible are listed on page 17.

By the end of the 2001/2002 fiscal year, we had raised a total of approximately \$2.7 million for the POGO Chair, the primary focus of our fundraising activity in that year. I am pleased to inform you that as of March 31 2003, we have raised \$3.8 million and expect to reach our \$4 million goal by the end of calendar 2003. As an indication of my family's commitment to POGO, we have decided to

make an additional donation to fully fund the shortfall. Thus, I am pleased to advise you that the campaign for the Chair endowment is now complete.

I am also pleased to report that, in anticipation of POGO becoming a charitable entity, I have made a donation of a unique and rare collection of vintage guitars and amplifiers valued at over \$5 million. This collection, which was made through the Toronto Community Foundation, will be sold and will thereby provide the capital and income to underpin POGO's charitable activity.

Our fall 2003 campaign will be the first step in fundraising for other critical POGO programs, such as activity of the POGO Research Unit (PRU) and POFAP, the financial assistance program for families with children in treatment.

On behalf of the POGO community, I wish to extend my thanks to all of you who have shown such generous support during the past year. The years ahead will bring many exciting developments and advancements on behalf of Ontario's young cancer patients and their families. We will continue to rely on you to help ensure that children with cancer in Ontario are given the best chance possible to survive and to enjoy an optimal quality of life.





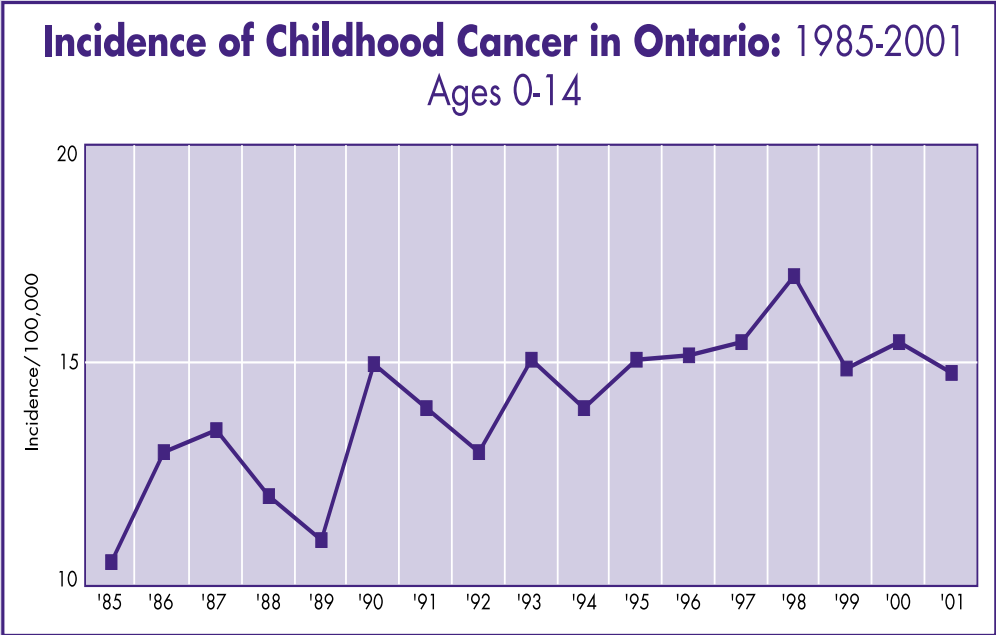
UNIVERSITY OF TORONTO
 POGO CHAIR IN CHILDHOOD CANCER CONTROL
 (Established at December 7, 1999)

STATEMENT OF ENDOWMENT FUND
 For the Year Ended April 30, 2003 (with comparative figures for the year ended April 30, 2002)

	2002-03	2001-02
	\$	\$
Book value of endowment		
Balance, beginning of the year	2,741,881.85	2,215,403.49
Donations (additions)	785,914.04	526,031.36
University matching	-	447.00
Balance, end of the year	<u>3,527,795.89</u>	<u>2,741,881.85</u>
Market value of endowment	<u>2,883,241.89</u>	<u>2,482,992.92</u>

FACTS ABOUT CHILDHOOD CANCER

- Cancer is the leading disease-related cause of death in Ontario children. About 100 Ontario children succumb to cancer every year.
- Between 1987 and 2000, pediatric cancer cases have risen 16 per cent, due to the growth in Ontario's population, and an absolute increase in the incidence of certain cancer types.
- Treatment of childhood cancers are typically intense, causing severe illness and complications, and in some cases resulting in long-term medical consequences.
- The psychological and social impact of childhood cancer can be significant. It may include problems of coping and adjustment of patient, siblings and parents, lapsed school achievement, learning deficits, and financial distress of the family.
- Survivorship in the pediatric population has improved across all diagnoses during the past 20 years. It is now 75 percent.
- By the year 2010, it is estimated that one out of every 400 young adults (aged 15 to 45) will be a survivor of childhood cancer.



THANK YOU

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TIMELINE OF POGO MILESTONES

1983

- The POGO collaboration is conceived, when Dr. Alvin Zipursky assembles pediatric oncology medical leaders in the province.
- Dr. Mark Greenberg proposes a standardized, provincial registry and database on childhood cancer and all medical directors agree to contribute. This is the forerunner of POGONIS (Pediatric Oncology Group of Ontario Networked Information System).

1987

- Dr. Corin Greenberg recruited to carry out a needs study and develop a blueprint for activity, in collaboration with the POGO professional community.
- First POGO Conference, held in Ottawa.

1988

- White paper on childhood cancer presented at second POGO Conference, in London.
- POGO Central office operation created with 2 part time positions.

1991

- Dr. Mark Greenberg takes office as President of POGO, which he holds until 2000.

1994

- POGO creates first Pediatric Oncology Nursing Program, a priority identified by the POGO Nursing Committee. The curriculum is adopted by McMaster School of Nursing in Hamilton.
- POGO holds a FORUM on childhood cancer, bringing all stakeholders in the childhood cancer community together. The event is planned and hosted with Candlelighters Canada.
- At the invitation of Ontario's Ministry of Health and Long-term Care (MOHLTC), POGO creates Provincial Pediatric Oncology Working Group and submits a comprehensive plan for development of an integrated childhood cancer network, identifying gaps in the childhood cancer care system and outlining a vision for the future.

1995

- POGO becomes Official Adviser to Ontario's MOHLTC on pediatric cancer care and control.
- Childhood cancer is designated a Priority Program by the MOHLTC.
- POGO's database is transformed into a networked information system, POGONIS, which will collect standardized, reliable and provincial data on childhood cancer in Ontario.

1998

- POGO implements the Provincial Pediatric Oncology Satellite Program to bring certain aspects of care closer to the patients' home.
- POGO's Research Unit (PRU) is established.
- First POGO Resource Guide published and distributed

1999

- POGO is successful in securing \$ 7.2 million in operating funds for expansion of childhood cancer staff.
- POGO endows the POGO Chair in Childhood Cancer Control and enters into private sector fundraising.

2000

- Dr. Mark Greenberg selected as incumbent POGO Chair in Childhood Cancer Control.
- POGO secures \$3.7 million in operating funds for a second major expansion of childhood cancer staff.
- Dr. Ronnie Barr takes office as POGO's President.

2001

- A system of AfterCare clinics, first proposed to MOHLTC in 1994, is implemented, a provincial blueprint adopted and *Passports to Health* designed, which summarize survivors' medical history.
- POGO Resource guide made available on the POGO website.

2002

- Successful Academic and Vocational Transition Initiative (SAVTI) is created by POGO and launched in partnership with George Brown College.
- POGO secures funding for pediatric Interlink Community Cancer Nurses.

2003

- POGO is successful in securing \$2.9 million in operating funds for childhood cancer for further expansion of care giver staff.
- POGONIS expanded to include the tracking of late effects and AfterCare services.
- POGO Office Staff numbers 13 (compared to 4 in 1999).
- POGO assumes administration and funding of Pediatric Oncology Financial Assistance Plan (POFAP), in a 3.5 year partnership with Canadian Cancer Society, Ontario Division.

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POGO

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