Atlas of Childhood Cancer in Ontario

1985-2004

EDITORS:

Mark L. Greenberg
Heidi Barnett
Jack Williams

January 2015

POGO
PEDIATRIC ONCOLOGY GROUP OF ONTARIO

Published by the Pediatric Oncology Group of Ontario (POGO)

Pediatric Oncology Group of Ontario
480 University Avenue, Suite 1014
Toronto, Ontario M5G 1V2
info@pogo.ca

Canadian cataloging in publication data:

Atlas of Childhood Cancer in Ontario
Includes bibliographical references.
ISBN: (Print) **978-0-9939255-0-4**
ISBN: (Online) **978-0-9939255-1-1**

How to cite this publication:

The production of *Atlas of Childhood Cancer in Ontario* was a collaborative venture. Accordingly, to give credit to individual authors, please cite individual chapters and title, in addition to editors and book title.

For example: Pole JD, Greenberg ML, Sung L, Agha M, Riehl, M. Survival. In: Greenberg ML, Barnett H, Williams J, editors. Atlas of Childhood Cancer in Ontario. Toronto: Pediatric Oncology Group of Ontario; 2015.

This document is available at www.pogo.ca and www.ices.on.ca

Cover photos by Tynan Studio & Click Photography

PREFACE

When the concept of a provincial pediatric oncology group emerged in 1983 from discussions held in the attic of Ronald McDonald House in Toronto, the primary objective was deceptively simple: to ensure that every child with cancer in the vast Province of Ontario would have equal access to optimal care. Those of us present at that time had only a modest understanding of the challenges that lay ahead. Over the subsequent 3 decades, the Pediatric Oncology Group of Ontario (POGO) has grown into a sophisticated and highly professional organization with a $10 million annual budget, but the original objective has remained the cornerstone of our mission and vision, and the constant motivator to strive for that achievement.

Although we are justly proud of and enjoy the many fruits of our labours over more than 30 years, we have come to recognize the complexity inherent in the spectrum of cancer control in childhood and adolescence. This complexity has demanded investment in a broad array of endeavours that have contributed to the attainment of the principal goal, endeavours as disparate as these:

- The Pediatric Oncology Family Assistance Program and the Successful Academic and Vocational Training Initiative for cognitively challenged survivors
- The satellite clinic network in community hospitals and the aftercare system for comprehensive long-term follow up
- The research unit, with its distinctive focal "pillars" (epidemiology, health services, economics and survivorship/quality of life)
- POGO's networked information system (POGONIS) – one of the real jewels in our crown

Indeed, POGONIS facilitated the leadership role that POGO played in the national Childhood Cancer Surveillance and Control Program of the Public Health Agency of Canada, that program being co-chaired for a decade by two founding members of POGO.

All of these continuing activities have enjoyed the support of our major partner, the Ministry of Health and Long-Term Care (MOHLTC). At the request of the Ministry, and building on the first-ever needs assessment of Ontario's children with cancer and their families (undertaken by POGO in 1988), long-range plans for childhood cancer control were submitted in 1994 and 2005. It is small wonder that POGO became the MOHLTC's official source of advice on pediatric oncology in 1995. Spurred by the early development of staffing ratios, accepted by the Ministry and by other jurisdictions in Canada and beyond, and generating additional support for infrastructural development, POGO has catalyzed some $200 million into health care services and related activities devoted to the primary goal. Being headquartered within walking distance of the seat of provincial government has not hindered the journey to this success!

It is no accident that POGO's offices are located within the Discovery District of Canada's largest city. POGO's research unit is led by our medical director, who holds the endowed POGO Chair in Childhood Cancer Control at the University of Toronto. The unit sustains a fellowship program, seed funding and open operating grants with considerable support from the Canadian Cancer Society's Ontario Division. The work of the research unit is underpinned by the rich resource embedded in POGONIS. Moreover, after POGO incorporated as a not-for-profit entity and achieved charitable institutional status in 2003, it was accorded the designation of a “45.1 entity” under federal-provincial privacy legislation, allowing POGO to hold detailed health information on patients and linkage to administrative databases.

These developments have contributed importantly to a longstanding undertaking: the creation of the *Atlas of Childhood Cancer in Ontario* that unfolds on the following pages. It paints a comprehensive picture over a considerable timeframe (up to 20 years) of an ever-changing landscape, yet another claim to distinction marking POGO as truly one of a kind in the worldwide community of pediatric oncology.

Ronald D. Barr

Dr. Ronald D. Barr, MB ChB, MD
FRCP (Glasg), FRCP (Lond), FACP, FRCPath, FRCPC, FRCPCH

Professor of Pediatrics, Pathology and Medicine
McMaster University and McMaster Children’s Hospital, Hamilton Health Sciences

Past President
POGO Board of Directors

TABLE OF CONTENTS

AUTHORS' AFFILIATIONS

Oussama Abla, MD
Staff Haematologist/Oncologist
Division of Hematology/Oncology
The Hospital for Sick Children

Associate Professor
Department of Paediatrics
University of Toronto

Mohammad Agha, PhD
Associate Scientist
Pediatric Oncology Group of Ontario

Adjunct Scientist
Institute for Clinical Evaluative Sciences

Assistant Professor
Dalla Lana School of Public Health
University of Toronto

Eric Bouffet, MD, FRCPC
Director, Neuro-Oncology Program
Neuro-Oncologist
Division of Haematology/Oncology
Garron Family Chair in Childhood Cancer Research
Senior Associate Scientist
Child Health Evaluative Sciences
SickKids Research Institute
The Hospital for Sick Children

Professor of Paediatrics
University of Toronto

Nicole Bradley, MHSc
Senior Health Care Analyst & Project Manager
Pediatric Oncology Group of Ontario

Bruna DiMonte, RN, BScN
Senior Database Administrator, Co-Privacy Officer
Pediatric Oncology Group of Ontario

J. Ted Gerstle, MD, FRCSC, FACS, FAAP
Attending Staff Surgeon
Director, Surgical Oncology Program
Division of General and Thoracic Surgery
Project Investigator
Cell Biology
SickKids Research Institute
The Hospital for Sick Children

Associate Professor of Surgery
Department of Surgery
University of Toronto

Surgical Director
Qatar New Children's Hospital Project, SickKids International

Ronald M. Grant, MD, FRCPC
Staff Oncologist
Division of Hematology/Oncology
The Hospital for Sick Children

Associate Professor
Department of Paediatrics
University of Toronto

Mark L. Greenberg, OC, MB, ChB, FRCPC
Senior Staff Oncologist
Division of Haematology/Oncology
The Hospital for Sick Children

Senior Adviser, Policy & Clinical Affairs
Pediatric Oncology Group of Ontario

Professor of Paediatrics & Surgery
Departments of Paediatrics & Surgery
University of Toronto

Corin M. Greenberg, PhD
Chief Executive Officer
Pediatric Oncology Group of Ontario

Paul J. Gibson, MD, FRCPC
Staff Physician
Paediatric Oncologist
Children's Hospital, London Health Sciences Centre

Assistant Professor
Paediatric Hematology/Oncology
Western University

Peter Gozdyra, MA
Medical Geographer
Institute for Clinical Evaluative Sciences

Jacqueline Halton, MD, FRCPC
Pediatric Hematologist/Oncologist
Division of Hematology/Oncology
Medical Director, Ambulatory Care
Children's Hospital of Eastern Ontario

Professor
Department of Pediatrics
University of Ottawa

Johann Hitzler, MD, FRCPC, FAAP
Staff Haematologist/Oncologist
Division of Haematology/Oncology
Head, Section Leukemia and Lymphoma
Division of Haematology/Oncology
Senior Scientist
Developmental & Stem Cell Biology
SickKids Research Institute
The Hospital for Sick Children

Associate Professor
Department of Paediatrics
University of Toronto

David Hodgson, MD, MPH, FRCPC
Staff Radiation Oncologist
Princess Margaret Hospital Cancer Centre

Associate Professor
Department of Radiation Oncology
University of Toronto

Meredith Irwin, MD
Section Head and Staff Oncologist
Solid Tumour Section, Division of Haematology/Oncology
Associate Chair (Research), Paediatrics
Senior Scientist
Cell Biology
SickKids Research Institute
The Hospital for Sick Children

Professor
Departments of Paediatrics & Medical Biophysics
Institute of Medical Sciences
University of Toronto

Donna Johnston, MD, FRCPC, FAAP
Chief
Division of Hematology/Oncology
Clinical Investigator
CHEO Research Institute
Children's Hospital of Eastern Ontario

Associate Professor
Department of Pediatrics
University of Ottawa

Daniel Keene, MD, MA, FRCPC
Staff Neurologist
Children's Hospital of Eastern Ontario

Associate Professor
Department of Pediatrics
University of Ottawa

Paul C. Nathan, MD, MSc, FRCPC
Director, AfterCare Program
Division of Haematology/Oncology
The Hospital for Sick Children

Associate Professor
Departments of Paediatrics & Institute of Health Policy,
Management and Evaluation
University of Toronto

Jason D. Pole, PhD
Scientist
Pediatric Oncology Group of Ontario

Adjunct Scientist
SickKids Research Institute
The Hospital for Sick Children

Adjunct Scientist
Institute for Clinical Evaluative Sciences

Assistant Professor
Dalla Lana School of Public Health
University of Toronto

Carol Portwine, MD, FRCPC, PhD
Associate Professor
Department of Pediatrics, Division of Hematology/Oncology
McMaster University

Mariana Pradier Silva, MD, FRCPC
Head
Division of Paediatric Haematology/Oncology
Kingston General Hospital

Professor
Department of Pediatrics
Queen’s University

Raveena Ramphal, MBChB, FRACP, MPH
Pediatric Hematologist Oncologist
Division of Hematology/Oncology
Children’s Hospital of Eastern Ontario

Associate Professor
Department of Pediatrics
University of Ottawa

Madeline Riehl, MHSc
Senior Associate, Research & Planning, Co-Privacy Officer
Pediatric Oncology Group of Ontario

Lillian Sung, MD, PhD, FRCPC
Staff Physician
Department of Haematology/Oncology
Scientist
Child Health Evaluative Sciences
SickKids Research Institute
The Hospital for Sick Children

Associate Professor
Department of Paediatrics
University of Toronto

Sheila Weitzman, MB, BCh, FCPSA, FRCPC
Senior Staff Oncologist
Division of Haematology/Oncology
The Hospital for Sick Children

Professor
Department of Paediatrics
University of Toronto

Jack Williams, PhD, FCES
Scientist Emeritus
Institute for Clinical Evaluative Science

Scientist Emeritus
Clinical Epidemiology
Sunnybrook Health Sciences Centre

ACKNOWLEDGEMENTS

The authors wish to thank the following individuals and organizations for their contributions to the success of this project. We apologize for any inadvertent omissions.

Ministry of Health and Long-Term Care

POGO gratefully acknowledges funding support from the Ontario Ministry of Health and Long-Term Care. The views expressed in this publication are those of POGO and do not necessarily reflect those of the Province of Ontario.

Editorial Committee

Mark L. Greenberg (Chair)
Mohammad Agha
Ronald D. Barr
Bruna DiMonte
Corin M. Greenberg
Jacqueline Halton
Eleanor Hendershot
Lawrence Jardine
Jason D. Pole
Mariana Pradier Silva
Madeline Riehl
Sheila Weitzman

Project Manager

Heidi Barnett
Pediatric Oncology Group of Ontario

Administrative Support

Helen Craig
Pediatric Oncology Group of Ontario

Editorial Assistance

Elena Pasko

POGONIS Data Support

Bruna DiMonte
Sibel Yardimoglu
Husein Patel
Pediatric Oncology Group of Ontario

POGONIS Data Managers

The Hospital for Sick Children
Children’s Hospital of Eastern Ontario
Children’s Hospital, London Health Sciences
Kingston General Hospital
Hamilton Health Sciences

Additional Data Sources

Institute for Clinical Evaluative Sciences
Cancer Care Ontario

Medical Geographer

Peter Gozdyra
Institute for Clinical Evaluative Sciences

Graphic Design

Michael Betteridge, Cheryl James

Copy Editor

Donna Dawson, CPE

Proofreading

Janice Dyer, CPE

Printing

Exodus Graphics Corp.

ABOUT THE ORGANIZATIONS INVOLVED IN THIS ATLAS

POGO
PEDIATRIC ONCOLOGY GROUP OF ONTARIO

ICES

POGO

Pediatric Oncology Group of Ontario (POGO) is the official source of advice on childhood cancer to the Ministry of Health and Long-Term Care; a trusted source of information among colleagues, parents, survivors and the public; and the long-standing leader of a collaboration among 5 academic pediatric oncology programs and other stakeholders. The result is a highly integrated childhood cancer system that delivers equitable care, accessible to families living across Ontario's vast geography.

Informed by POGO's unique database, expert analyses and the input of thought leaders, POGO delivers advice, recommendations and strategies; ensures implementation of solutions; and provides ongoing support and updates for childhood cancer programs. Together, these contributions ensure the evolution of the childhood cancer care system in response to constantly changing demands. POGO's programs have been deployed nationally and internationally and its work is published in peer-reviewed journals.

POGO collaborators include policy experts, researchers, epidemiologists, pediatric oncology clinical leaders, parents, childhood cancer survivors, Ministry and other stakeholders.

POGO receives core funding from the Ministry of Health and Long-Term Care. An engaged and supportive donor base provides additional funding for POGO research and family shield services, and granting agencies support the work of a focused POGO Research Unit.

ICES

The Institute for Clinical Evaluative Sciences (ICES) leads cutting-edge studies that evaluate health care delivery and outcomes. This research results in an evidence base that is published as atlases, investigative reports and peer-reviewed papers, and is used to guide decision-making and inform changes in health care policy and delivery.

ICES researchers, many of whom are practicing clinicians, have access to a vast array of Ontario's health-related data, including population-based health surveys, anonymous patient records and clinical and administrative databases. ICES is recognized as an international leader in maintaining the privacy and security of health information.

ICES receives core funding from the Ontario Ministry of Health and Long-Term Care. In addition, ICES scientists compete for peer-reviewed grants from federal funding agencies, such as the Canadian Institutes of Health Research, and receive project-specific funding from provincial and national organizations. The knowledge that arises from this research is always produced independent of the funding bodies, which is critical to ICES' reputation as a trusted, impartial source of high-quality health and health services research and evidence.

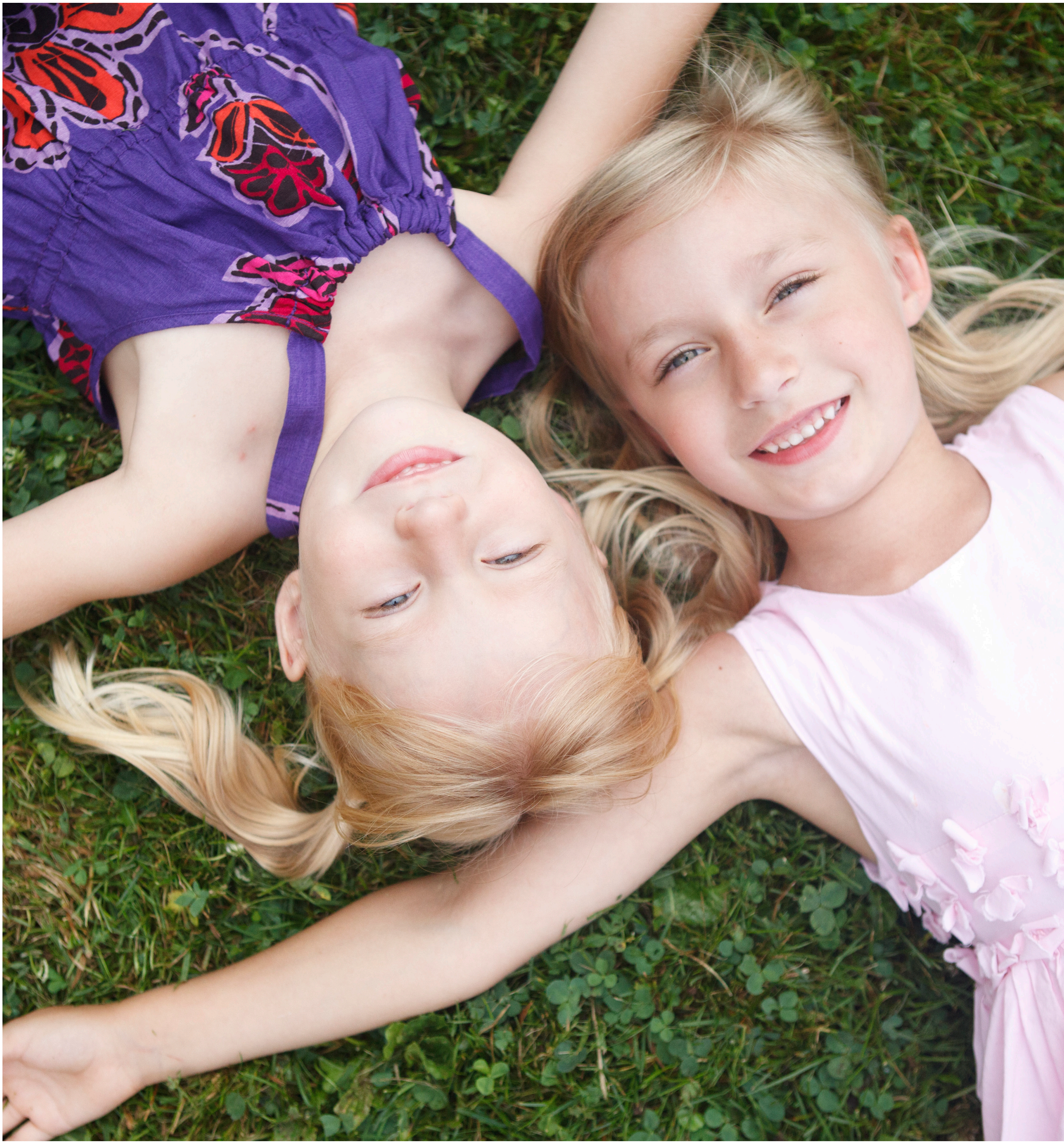

Photo by Tynan Studio

1

Introduction

Introduction

Childhood cancer is a rare disease, but one with enormous implications for the child, the family and the health care system. In our Ontario and Canadian jurisdictions, childhood cancer (defined as cancer occurring in the 0–14 year age range) constitutes less than one half of 1 percent of new cases of cancer.[1] Because it is rare, it is not often described in detail, and because it is perceived to have a small impact on health care systems, it garners little attention from policy- and decision-makers. Childhood cancer, however, has a double impact on the health care system. It contributes the largest number of disease related deaths in this age group, while simultaneously contributing among the largest numbers of years of life saved by cancer treatment in all age groups. The management of childhood cancer is complex, intensive and costly. This care is delivered primarily in tertiary care institutions and thus has significant incremental social and financial impact on families who reside outside of large cities.

Childhood cancer treatment is one of the big success stories of contemporary medicine, with survival rates escalating dramatically over the last decades of the 20TH century. But because of the intensity of the treatment, the young age of many of the families and the uncertain outcome of treatment in terms of both survival and potential effects of treatment, the influence of the diagnosis and treatment of childhood cancer on families is disproportionately severe.

The impact on the health care system is similarly significant, and the funding necessary to support appropriate diagnostic, therapeutic and rehabilitation interventions is substantial. Over the past few decades, it has become apparent that the need for resources and funding does not end when treatment ends. The late effects of treatment for childhood cancer are significant for a proportion of survivors.

This Atlas encompasses a 20 year timeframe, from January 1985 to December 2004. Much change occurred over this period in the format of treatment, the use of different modalities of therapy and with the introduction of routine use of hematopoietic stem cell transplantation. During this period, more systematic organization of childhood cancer services has been achieved and thus systematic data were attainable. It is recognized that practice has changed further since the end of the study period; those changes will be the subject of a subsequent analysis. Nevertheless, the mature data for this cohort and the analytic approach used provide a substantive insight into the patterns of incidence and survival and their relationship to health care utilization.

Why Do We Need an Atlas of Childhood Cancer?

Most publications addressing childhood cancer report the results of patients treated on clinical trials. Planned, successive clinical trials, each predicated on the results of a prior trial, are the principal reason for the dramatic improvement in survival in this population. However, they capture only that proportion of the population for whom a trial is open, who are eligible for that particular trial and whose parents consent to trial participation. Additionally, the endpoints of clinical trials most often do not encompass post treatment events. Thus the larger picture of childhood cancer in terms of health services and health policy is obscured.

Ontario is fortunate to have a database that has, since 1985, actively recorded comprehensive data on all children treated in the 5 tertiary centres offering childhood cancer care. These data have created a natural population-based cohort, with data spanning demographic, diagnostic, treatment and outcome information. In addition, the Pediatric Oncology Group of Ontario (POGO) was accorded special status under the Personal Health Information Protection Act that permits it to link its database to a variety of administrative and registry databases, enabling certainty with respect to long term outcomes and access to health service utilization information.

Thus a comprehensive view of incidence, survival and health service use became possible, and it forms the backbone of this Atlas – describing for the first time in detail the scope of childhood cancer and the implications of a population-based childhood cancer cohort on our publically funded single payer health care system.

The Structure of This Atlas

The first 5 chapters describe the sources of data, the incidence of childhood cancer over the 20 year time span encompassed in the Atlas, the survival patterns over that period and the health service utilization patterns over time for the cohort as a whole and for subsets of patients. These chapters focus on the entire childhood cancer cohort.

The next 5 chapters address data on the 5 most numerous cancers as classified in the International Classification of Childhood Cancer (2005). These chapters set the Ontario experience in the context of world literature of similar scope. Leukemia is numerically the largest group, and along with lymphoma, is the category that most typically does not use surgery as one of the primary therapeutic modalities. Central nervous system tumours are the second most numerous group and over time have come to use all 3 therapeutic modalities – surgery, chemotherapy and radiation therapy. The non–CNS solid tumour group encompass 2 categories for which sample size is sufficient to identify trends in incidence, treatment and outcome. The rarity of childhood cancer is reflected in the relatively small numbers assembled over 20 years in the most populous province in Canada.

It is our hope that this volume will stimulate discussion, debate, policy consideration and, above all, more research from epidemiologists, clinicians, policy-makers, administrators and economists – all in the interests of improving both the understanding of childhood cancer and the policy and health care system in which it is managed.

---

[1] Canadian Cancer Society/National Cancer Institute of Canada. Canadian cancer statistics 2008. Toronto: The Society; 2008.