

TABLE OF CONTENTS

FOREWORD	vi-vii
John E. Niederhuber, Gregory Reaman, Barry Anderson, Karen Albritton	
CHAPTER CONTRIBUTORS	viii
CHAPTER 1 — INTRODUCTION	1
Archie Bleyer, Aaron Viny, Ronald Barr	
CHAPTER 2 — METHODS	15
Archie Bleyer, Maha Hag-Alshiekh, Bradley Pollock, Lynn Ries	
CHAPTER 3 — LYMPHOMAS AND RETICULOENDOTHELIAL NEOPLASMS	25
Maura O’Leary, Jan Sheaffer, Frank Keller, Xiao-Ou Shu, Bruce Cheson	
CHAPTER 4 — LEUKEMIAS	39
Leonard Mattano Jr., James Nachman, Julie Ross, Wendy Stock	
CHAPTER 5 — MALIGNANT MELANOMA	53
Cynthia Herzog, Alberto Pappo, Melissa Bondy, Archie Bleyer, John Kirkwood	
CHAPTER 6 — CENTRAL NERVOUS SYSTEM CANCER	65
Anne Bendel, Orren Beaty III, Krystal Bottom, Greta Bunin, Margaret Wrench	
CHAPTER 7 — SOFT TISSUE SARCOMAS	81
Jacqueline Casillas, Julie Ross, Mary Louise Keohan, Archie Bleyer, Marcio Malogolowkin	
CHAPTER 8 — MALIGNANT BONE TUMORS	97
Leo Mascarenhas, Stuart Siegel, Logan Spector, Carola Arndt, Dominic Femino, Marcio Malogolowkin	
CHAPTER 9 — BREAST CANCER	111
Krystal Bottom, Maura O’Leary, Jan Sheaffer, Marianne Phillips, Xiao-Ou Shu, Banu Arun	

CHAPTER 10 — COLON AND RECTAL CANCER	123
Sheri Spunt, Wayne Furman, Michael La Quaglia, Melissa Bondy, Richard Goldberg	
CHAPTER 11 — LIVER AND INTRAHEPATIC BILE DUCT CANCERS	135
Marcio Malogolowkin, Logan Spector, Yuman Fong	
CHAPTER 12 — THYROID CANCER	143
Steven Waguespack, Sam Wells, Julie Ross, Archie Bleyer	
CHAPTER 13 — MALE GENITAL TRACT CANCER	155
Robert Fallon, Andrew Olshan, Scott Saxman	
CHAPTER 14 — FEMALE GENITAL TRACT CANCER	163
Maura O’Leary, Jan Sheaffer, Jerry Finklestein, Andrew Olshan, Jubilee Brown	
CHAPTER 15 — HIGHLIGHTS AND CHALLENGES	173
Archie Bleyer, Ronald Barr	
APPENDIX I — RESOURCES	191
Jan Sheaffer, Carmina Valle	
APPENDIX II — INTERNATIONAL CLASSIFICATION OF CHILDHOOD CANCER	198
INDEX	200

LETTER FROM THE DEPUTY DIRECTOR OF THE NATIONAL CANCER INSTITUTE

Cancer, we have come to learn, is principally a disease of aging. Its likelihood increases as we get older, in part because *cancer does not occur at a precise moment in time, but rather is a process which can take many years to develop*. We also know that cancer's process is, at times, a very brief one, striking young children—the most defenseless among us.

But there is one group that oftentimes gets lost in our healthcare system: young adults. Poised between adolescence and adulthood, these young adults are—as an age group—experiencing distinct physical changes as well as unique emotional hurdles. When the burden of cancer is added, it becomes part of this extraordinary and challenging time in their growth and development. Historically, though, little attention and few resources have been devoted to studying the incidence, biology, and treatment outcomes in this age group. The National Cancer Institute (NCI) is trying to change that fact.

In 2006 the NCI, in collaboration with the Lance Armstrong Foundation, is conducting a yearlong evaluation of the issues facing older adolescents and young adults with cancer. This Progress Review Group hopes to identify and prioritize the scientific, medical, and psychosocial barriers facing adolescent and young adult cancer patients and to develop strategies to improve their outcomes.

Likewise, with the establishment of the Adolescent and Young Adult Committee of the NCI-funded Children's Oncology Group (COG), research and education for and about young people will move forward a more-rapid pace.

This monograph is the first to collect detailed information about cancer incidence and outcomes in adolescents and young adults. It would not have been possible without the many institutions participating in the COG and adult treatment consortiums, or without the extensive data collection efforts of the NCI's Surveillance Epidemiology and End-Results (SEER) program.

The National Cancer Institute has challenged the United States to a goal: eliminate the suffering and death due to cancer by the year 2015. If we are to make that goal a reality, we must enhance the lives of all patients, whether they are young, old, or precariously positioned in between.



John E. Niederhuber, M.D.

LETTER FROM THE CHAIRMAN OF CHILDREN'S ONCOLOGY GROUP

Supported by the National Cancer Institute, the Children's Oncology Group (COG) designs and conducts clinical trials, correlative laboratory research and epidemiology studies of cancer in infants, children and adolescents. More than 200 member institutions in the U.S., Canada, Europe, Australia and New Zealand participate in these clinical trials, as we strive to improve survival rates and lessen the late effects of cancer treatment in this population. Older adolescent and young adult participation in our clinical trials is significantly lower than that of younger patients, and parallels the relatively worse treatment outcomes for each cancer type in this population.

The Adolescent and Young Adult Committee of COG was formed to focus research attention on this group, develop treatment protocols aimed at this population, increase participation in clinical trials by this population, and ultimately improve survival rates for older adolescents and young adults.

The following chapters highlight the initial efforts of this Committee in addressing the scope of the problem of adolescent and young adult under-representation in clinical trials and offer evidence that such a discrepancy may partially explain outcome differences. In addition, these chapters present information about biologic differences between specific cancer subtypes most common in younger children and those exhibited by the same cancers in adolescents and young adults, and offer plausible explanations for outcome differences as well as potential treatment strategies. The continued progress of these activities is a high priority of the COG and is expected to be the focus of future publication efforts.



Gregory H. Reaman, M.D.

LETTER FROM THE CANCER THERAPY AND EVALUATION PROGRAM OF THE NATIONAL CANCER INSTITUTE

Older adolescents and young adults with cancer are now the focus of national and international research investigating the tumor biology, treatment access, treatment compliance and psychosocial issues unique to this select age group of cancer patient. These investigations are being undertaken in an attempt to improve treatment regimens and boost the survival rates and quality of life for these young patients. I have the privilege to co-Chair, along with Drs. Karen Albritton and Michael Caligiuri, the *Progress Review Group (PRG) in Adolescent and Young Adult Oncology*, a year-long evaluation of the issues facing older adolescents and young adults with cancer, and co-sponsored by the National Cancer Institute and the Lance Armstrong Foundation. The *PRG* evaluation will bring critical attention to the specific needs of those with cancer in this age group.

This monograph was developed to gather population-based incidence, mortality, and survival data specific to cancers that occur in the AYA population, along with epidemiological data and risk factors for the development of age-specific cancers. This monograph uses both the International Classification of Childhood Cancer and the International Classification of Diseases-Oncology because cancers occurring in this age group span the pediatric-to-adult spectrum of diseases. We believe this monograph will help educate medical providers and the public about cancer incidence and survival in this age group, and provide the impetus for further research to improve the survival and the quality of life of these young people.



Barry Anderson, MD, PhD

LETTER FROM THE CHAIR OF THE CHILDREN'S ONCOLOGY GROUP ADOLESCENT AND YOUNG ADULT COMMITTEE

The primary goal of the Adolescent and Young Adult Committee of the Children's Oncology Group is to increase, through research and awareness, the knowledge about cancer in teenagers and young adults. We firmly believe this knowledge will improve the survival and quality of survival of a population that has not seen the same improvements as younger or older cancer patients. Through age-specific therapeutic studies of the cancers that occur in this age group, descriptive and interventional studies to decrease the burden of cancer, and studies to understand the processes of health access for this population, our committee strives to advance the emerging science of adolescent and young adult oncology.

Since the inception of the Adolescent and Young Adult Committee, we have sought to raise awareness through numerous publications about cancer treatment and outcomes in this age group. The publication of the Adolescent and Young Adult Cancer Monograph has been a long-term goal of the Committee. Until now, the incidence and survival rates of cancer occurring in adolescents and young adults in the United States has been unknown—another “gap” between the fields of pediatric and adult oncology. No longer.

We are hopeful that this monograph will be a valuable resource for those working with these patients, and a tool in the development of cancer research dedicated to this age group, including the deliberations of the upcoming Adolescent and Young Adult Oncology Progress Review Group.

We are grateful to the young people for their participation in clinical trials, for their willingness to advocate for improvements in cancer care, and their courage in living life to the fullest.



Karen Albritton, MD