

Addressing the Burden of Cancer for the People of North Carolina

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The bad news. Cancer is now the leading cause of death in North Carolina.¹ More than 47 North Carolinians die each day from cancer,² and nearly 119 individuals a day will hear the words, “You’ve got cancer.”³ Considering the probability that more than 1 in 3 persons will be affected by cancer during their lifetime, it is clear that this is a disease that affects virtually all of us.⁴

The good news. A great deal is being done to address the burden associated with this disease. More than ever, North Carolina is actively engaged in prevention, early detection, and care programs, and stands ready to address the needs of the growing numbers of cancer survivors.

The North Carolina Paradox

There is a paradox in North Carolina, and it is reflected in statistics that describe cancer morbidity and mortality. North Carolina is the 10th largest state in the United States with a population of more than 9 million persons.⁵ It is home to several world-class public and private universities, an outstanding community college system, and many major corporations such as IBM, GlaxoSmithKline, and Quintiles. North Carolina has 43 cancer programs approved by the Commission on Cancer of the American College of Surgeons.⁶ The programs at Duke University, the University of North Carolina at Chapel Hill, and Wake Forest University are National Cancer Institute-designated cancer centers.⁷ Several North Carolina hospitals are among the top-rated cancer hospitals in the nation.⁸ Recently, many of these institutions came together for the first meeting of North Carolina’s cancer centers in Winston-Salem, which led to the creation of the North Carolina Cancer Centers’ Collaborative.

North Carolina is also home to a significant amount of cancer research. As of July 1, 2007, the American Cancer Society funded 41 projects for more than \$17 million.⁹ As of May 1, 2008, the National Cancer Institute funded 695 projects in the state.¹⁰ Additional research funding is also provided by nonprofit groups such as Komen for the Cure and The V Foundation for

Cancer Research, and an unknown amount is contributed by the private sector (eg, pharmaceutical industries and clinical research organizations). This research translates into advances and practices that prevent, detect, and treat cancer.

Yet despite these world-class cancer resources and a relatively low cancer incidence (45th lowest in the US), we are 16th in cancer mortality. These numbers should be closer together, and the gap between them reflects poor rates of early detection and early treatment.^{11,12} There are disparities in mortality rates for

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minority populations: death rates among minorities for colon/rectum cancer are 1.4 times higher than for whites, 1.5 times higher for breast cancer, and 3.2 times higher for prostate cancer.¹³ Low-income populations are also disproportionately burdened with cancer. Twenty-five percent of North Carolina counties have poverty rates greater than 18% and one-fifth of our counties are classified as persistent poverty counties.¹⁴ From 2000 to 2003, North Carolina had the third highest poverty rate increase in the United States.¹⁴ These are just some of the possible explanations for high cancer mortality in the state.

How can a state with superb resources also have such poor outcome statistics? What can and should be done?

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Cancer Prevention and Control Activities in North Carolina: Past and Present

From the mountains to the coast, our state has a rich tradition in cancer prevention and control with the involvement of many individuals and organizations. North Carolina is a national leader in both innovation and the adoption of best practices. This issue of the *North Carolina Medical Journal* provides the opportunity to examine the prevention and control activities that seek to reduce the burden of cancer on North Carolinians and which are a part of the new tradition of caring for the people in our state.

Any history of cancer prevention and control activities in North Carolina must acknowledge the significant contributions of the American Cancer Society and the North Carolina Medical Society. These 2 organizations inaugurated formal statewide cancer control efforts beginning in 1941 with the establishment of state headquarters for the Women's Field Army of the American Society for the Control of Cancer. In 1945, these 2 organizations collaborated to encourage the North Carolina General Assembly to pass House Bill 786, which created the Division of Cancer Control and State Tumor Registry within the State Board of Health. The State Tumor Registry is an important tool in tracking the extent of our cancer burden and measuring progress. Karen L. Knight, director of the North Carolina Central Cancer Registry, and her associates describe the efforts of this dedicated cadre of professionals throughout the state who work behind the scenes to collect and process detailed data on every diagnosed case of cancer.

There was early recognition that cancer diagnosis and treatment could be a financial hardship for North Carolina citizens. Thus, House Bill 786 created the North Carolina Cancer Assistance Fund.¹⁵ This is reported to be the first such cancer control program in the country.¹⁶ The North Carolina Cancer Assistance Fund is a \$2.4 million fund that helps pay for cancer diagnosis and treatment for indigent patients. Amy C. Denham and Janet Dail contribute a commentary about the Fund, how it can be accessed, and how has it been utilized to assist those in need.

Created in 1922 by the American College of Surgeons, the Commission on Cancer (CoC) is a consortium of professional organizations dedicated to improving survival and quality of life for cancer patients through standard-setting, prevention, research, education, and the monitoring of comprehensive quality care. Currently there are 43 approved cancer programs in North Carolina that are on the frontlines of providing care

and treatment. Frederick L. Greene, the national chair of the Commission, and 2 of his CoC colleagues discuss the approval process and how this process enhances the quality of cancer care in our state.

In 1957, the legislature created the Commission to Study the Cause and Control of Cancer and subsequently made it a permanent study commission in 1967. By 1991, a statewide Coalition for Cervical Cancer Control was created and a Study Commission on Cancer Prevention and Control was created in 1992. The previous study commission had become relatively inactive by this date and a new, revitalized effort was needed. During the 1993 North Carolina legislative session and following the recommendations of a legislative study commission, the North Carolina Advisory Committee on Cancer Coordination and Control was established to lead cancer prevention and control activities in the state. The Advisory Committee has 34 appointed or designated members,^a and the responsibilities of the Committee are:

- 1) To recommend to the secretary [of the Department of Health and Human Services] a plan for the statewide implementation of an interagency comprehensive coordinated cancer control program.
- 2) To identify and examine the limitations and problems associated with existing laws, regulations, programs, and services related to cancer control.
- 3) To examine the financing and access to cancer control services for North Carolina's citizens and advise the secretary on a coordinated and efficient use of resources.
- 4) To identify and review health promotion and disease prevention strategies relating to the leading causes of cancer mortality and morbidity.
- 5) To recommend standards for:
 - a. Oversight and development of cancer control services
 - b. Development and maintenance of interagency training and technical assistance in the provision of cancer control services
 - c. Program monitoring and data collection
 - d. Statewide evaluation of locally based cancer control programs
 - e. Coordination of funding sources for cancer control programs
 - f. Procedures for awarding grants to local agencies providing cancer control services¹⁸

a Members include the secretary or designee of the Department of Health and Human Services; 6 legislators; 4 cancer survivors; 4 members (1 each) from the Department of Health and Human Services, the Department of Environment and Natural Resources, the Department of Public Instruction, and the North Carolina Community College System; 4 members (1 each) from the cancer control programs at the University of North Carolina at Chapel Hill School of Medicine, the Wake Forest University Bowman Gray School of Medicine, the Duke University School of Medicine, and the East Carolina University School of Medicine; 1 oncology nurse from the North Carolina Nurses Association; 1 member of the Cancer Committee of the North Carolina Medical Society; 1 member of the Old North State Medical Society; 1 member of the American Cancer Society, North Carolina Division; 1 member of the North Carolina Hospital Association; 1 member of the North Carolina Association of Local Health Directors; 1 primary care physician licensed to practice medicine in North Carolina; 1 member of the American College of Surgeons; 1 member of the North Carolina Oncology Society; 1 member of the Association of North Carolina Cancer Registrars; 1 member of the Medical Directors of the North Carolina Association of Health Plans; and up to 4 additional members at large.¹⁹

The North Carolina Cancer Plan

In 1998, North Carolina was 1 of 5 states and 1 tribal health board to receive funding from the Centers for Disease Control and Prevention to pilot national comprehensive cancer control. A major outcome and achievement of this has been the publication and distribution of a revised North Carolina Cancer Plan. Lynn Erdman, Walter L. Shepherd, and Manzoor Choudry discuss this “blueprint” that has been developed to guide North Carolina’s statewide efforts. Abandoning the more traditional approach of 5-year plans, the North Carolina Advisory Committee on Cancer Coordination and Control has sought to create a “living plan” that has the ability to adapt as required.

In an effort to translate the North Carolina Cancer Plan into specific, local activities, 6 cancer regions have been developed with placement of field staff (1 program and 1 research) in each region. Staff conduct ongoing needs assessments; channel and coordinate research efforts; assist with development and coordination of resources; and communicate with regional and state-level agencies and organizations relative to regional needs.

Recent Cancer Control Efforts

In its 2007 session the North Carolina General Assembly did something remarkable by establishing the University Cancer Research Fund. The University of North Carolina at Chapel Hill School of Medicine and its Lineberger Comprehensive Cancer Center will receive \$25 million in FY 2007-2008—increasing to \$50 million per year beginning in 2009—to conduct cancer research and assure that the research is applied in communities in North Carolina and beyond. Michael S. O’Malley, associate director of the UNC Lineberger Comprehensive Cancer Center, and his colleagues provide an overview of the goals of the legislation and what it means to North Carolina and its citizens.

The UNC Lineberger Cancer Center has also been designated as a site for the development of a Lance Armstrong Foundation Survivorship Center of Excellence. Through successes in early detection and treatment, more individuals now survive cancer. It is estimated that there are more than 300 000 cancer survivors in North Carolina.^b However, cancer survivorship presents its own set of challenges and opportunities. Marci K. Campbell and colleagues comment on these challenges and discusses what is being done in North Carolina through outreach and awareness programs and the designation of a Lance Armstrong Foundation Survivorship Center of Excellence at the University of North Carolina at Chapel Hill. As an additional response to this need, there have been 2 statewide North Carolina Cancer Survivorship Summits with 600 participants each, held in Research Triangle Park and Winston-Salem.

^b North Carolina estimates were made by applying proportion of US survivors in 2003 to the total US population and then applying to NC population estimate. US figures obtained from the US National Cancer Institute. <http://www.cancer.gov/cancertopics/factsheet/NCI/NCI>. Published October 17, 2006. Accessed July 23, 2008. NC population data accessed at <http://www.osbm.state.nc.us/demog/ncusagr7.htm> on July 23, 2008.

“Diagnosed at age 3 (1984), had surgery in Iran to remove tumor in neck. Moved to US to have chemotherapy and radiation and have been in remission for 23 years.”

— *Scott
Non-Hodgkin’s Lymphoma*

For many people with cancer, participation in clinical trials may offer the best hope or be the last treatment option after other therapies have failed. John Feldmann and colleagues comment on the current status and distribution of cancer clinical trials in North Carolina. The authors present ways to promote greater awareness of, and enrollment in, clinical trials and ways to make trials more accessible. The first meeting to discuss the creation of a Web-based North Carolina Cancer Clinical Trials’ Clearinghouse took place recently in order to try to further these efforts.

Other North Carolina Efforts to Address Cancer

- Organizational meeting of the North Carolina Oncology Navigators’ Association (NCONA) to bring together those who are involved in cancer patient navigation activities.
- A statewide meeting, Conversations about Colorectal Cancer, held in Greensboro.
- Annual meeting of the National Black Leadership Initiative on Cancer, held in Durham.
- Creation of the North Carolina Lung Cancer Partnership.
- Development of working groups and/or reports on melanoma, childhood cancer, cancer in adolescents and young adults, survivorship, palliative care, clinical trials, colorectal cancer, prostate cancer, and hematological cancers.
- North Carolina’s Cancer Web Portal (www.nccancer.com). This Web site can assist patients and physicians as they face overwhelming amounts of information and resources when they initiate searches about cancer.

Although oral cancer does not make the top 10 list of cancer in North Carolina, it is a type of cancer that can be frequently prevented and easily detected. Valerie A. Murrah contributes a piece that discusses the extent of oral cancer in North Carolina—much of which can be prevented by changes in personal behaviors—and what is being done both to prevent occurrence and to provide treatment.

North Carolina has an impressive record in the adoption of legislation and policies that impact the lives of cancer patients;

however, there is still more to do. Marcus Plescia and Ashley Bell examine past policy initiatives and make recommendations for the future.

North Carolina presents a paradox in cancer care: the state has invested substantial efforts to control and treat cancer, but we continue to have unacceptably high rates of the disease and we have a way to go in getting people with cancer the best care we can provide. The elements to reach the goal of minimizing the burden of cancer are reachable and we have begun to put

the pieces into place to achieve that outcome. What we need to do is make sure those pieces fit together well and that we understand that this is a long-term battle that requires a continued and coordinated effort from all of us involved in the effort. North Carolina can become the shining beacon in the fight against cancer, leading the way in protecting our people from the disease, treating it effectively when it occurs, and supporting survivors by helping them to lead full and productive lives. **NCMJ**

REFERENCES

- 1 Schriber C. Cancer replaces heart disease as leading cause of death in NC [press release]. Raleigh, NC: State of North Carolina, Dept of Human Resources; November 19, 2007.
- 2 State Center for Health Statistics, Division of Public Health. North Carolina Vital Statistics 2006, Volume 2: Leading Causes of Death. Raleigh, NC: State of North Carolina, Dept of Human Resources; 2007.
- 3 2005 Cancer incidence rates by race, North Carolina. NC Central Cancer Registry Web site. <http://www.schs.state.nc.us/SCHS/CCR/incidence/2005/race.pdf>. Published March 2008. Accessed April 21, 2008.
- 4 Hewitt M, Greenfield S, Stovall E, eds.; Committee on Cancer Survivorship: Improving Care and Quality of Life, National Cancer Policy Board. *From Cancer Patient to Cancer Survivor: Lost in Transition*. Washington, DC: National Academies Press; 2006.
- 5 Population Estimates and Projections, 2007. North Carolina Office of State Budget and Management Web site. <http://demog.state.nc.us/> Accessed April 21, 2008
- 6 Approved Cancer Programs. American College of Surgeons Commission on Cancer Web site. http://web.facs.org/cpm/CPMApprovedHospitals_Result.cfm. Accessed April 27, 2008
- 7 NCI-Designated Cancer Centers. National Cancer Institute Web site. http://cancercenters.cancer.gov/cancer_centers/cancer-centers-list.html#NC. Accessed April 27, 2008
- 8 *US News & World Report*. Best Hospitals 2007 Specialty Search: Cancer. <http://health.usnews.com/usnews/health/best-hospitals/search.php?spec=ihqcanc>. Accessed April 27, 2008
- 9 Extramural Grants in Effect on 7/1/2007. American Cancer Society Web site. <http://www.cancer.org/downloads/RES/NC.pdf>. Accessed May 1, 2008
- 10 Cancer Research Portfolio. National Cancer Institute Web site. <http://researchportfolio.cancer.gov/projectlist.jsp?result=true&srSearchID=313429>. Accessed May 1, 2008
- 11 State Health Facts. Age-Adjusted Invasive Cancer Incidence Rate per 100,000 Population, 2003. Kaiser Family Foundation Web site. <http://www.statehealthfacts.org/comparemaptable.jsp?ind=64&cat=2&sub=21&yr=13&typ=3&o=a&sort=n>. Accessed May 1, 2008
- 12 State Health Facts. Age-Adjusted Invasive Cancer Mortality Rate per 100,000 Population, 2004. Kaiser Family Foundation Web site. <http://www.statehealthfacts.org/comparemaptable.jsp?ind=67&cat=2&sub=21&yr=14&typ=3&sort=n&o=d>. Accessed May 1, 2008
- 13 2006 cancer mortality rates by race, North Carolina. NC Central Cancer Registry Web site. <http://www.schs.state.nc.us/SCHS/CCR/mort2006r.pdf>. Published March 2008. Accessed July 23, 2008.
- 14 Poverty in North Carolina. North Carolina Rural Economic Development Center, Inc. Web site. http://www.ncruralcenter.org/databank/trendpage_Poverty.asp. Accessed April 27, 2008
- 15 McPherson H. Second North Carolina History of the American Cancer Society. Raleigh, NC: The North Carolina Division, American Cancer Society, Inc.; 1976.
- 16 Stone-Wiggins B, Porterfield D. The North Carolina Cancer Control Program. *NC Med J*. 2001;62(5):248-251.
- 17 Advisory Committee on Cancer Coordination and Control. The North Carolina Cancer Control Plan, 2001-2006. Raleigh, NC: NC Advisory Committee on Cancer Coordination and Control; 2001.
- 18 G.S.130A-33.51 Advisory Committee on Cancer Coordination and Control; responsibilities. http://www.ncleg.net/EnactedLegislation/Statutes/HTML/BySection/Chapter_130A/GS_130A-33.51.html. Accessed April 21, 2008.
- 19 G.S.130A-33.50 Advisory Committee on Cancer Coordination and Control. http://www.ncleg.net/EnactedLegislation/Statutes/HTML/BySection/Chapter_130A/GS_130A-33.50.html. Accessed April 21, 2008.