CHAPTER 1. Advocacy

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ADVOCACY

Cancer is a personal, tangible, and powerful issue for millions of Americans and thousands of New Jerseyans. The disease has political, as well as medical, social, psychological, and economic facets. Every day legislators make decisions that impact the lives of current and future cancer patients, survivors, and their families.[1] To influence those decisions constructively, the *Comprehensive Cancer Control Plan for New Jersey* will continue to incorporate advocacy as a major strategy to promote beneficial policies, laws, and regulations for those affected by cancer.

Advocacy is the pursuit of influencing outcomes—including public policy and resource allocation decisions within political, economic, and social systems and institutions that directly affect people's lives.[2] The goal of advocacy for this *Plan* is to promote public policies at all levels of government that support cancer prevention and detection programs, provide access to care, and enhance quality of life for those affected by cancer.

While cancer issues are increasingly attracting attention on the legislative front, additional advocacy work remains to be done by the Task Force and its workgroups, subcommittees, and county-level Coalitions.[3] Through the implementation of the first five-year *Plan*, the Advocacy Ad Hoc Committee of the Task Force was instrumental in the passage of 35 bills pertaining to cancer in 2005. Legislative priorities in the cancer arena have and will continue to focus on advancing the *Plan* and ensuring that all residents have access to cancer education, screening, and quality cancer care. Specific advocacy goals, objectives, and strategies are also cited within each site-specific chapter of the *Plan*. However, the following overarching advocacy goals, objectives, and strategies reflect the most urgent and comprehensive actions needed to implement and sustain this ambitious state plan.

GOALS, OBJECTIVES, AND STRATEGIES

The recommendations of the Advocacy Ad Hoc Committee are summarized below:

- Develop *internal structure and funding* for cancer awareness, education, and early detection programs and access to care.
- Advocate for increased *access* to cancer care, prevention, early detection, and awareness programs.
- Advocate for reduced cancer-related *health disparities* among minorities and the medically underserved.

OVERALL GOAL	Promote public awareness of cancer prevention, early detection, and treatment in New Jersey.

INTERNAL STRUCTURE AND FUNDING FOR CANCER ADVOCACY

Our nation has made remarkable progress since the war against cancer began three decades ago. Some cancers have been cured, while others are being detected earlier and treated more effectively. The National Cancer Institute estimates that approximately 10.5 million Americans with a history of cancer were alive in January 2003.[4] In addition, the overall cancer death rate has been declining since 1992.[5] Yet there is a crisis of confidence in the capacity of our medical system to treat those with chronic and life-threatening illnesses such as cancer. Efforts to define quality care must underscore the fact that 41 million Americans are uninsured and many millions more are underinsured.[6]

To build and support the advocacy component of the *Plan* as outlined, the Advocacy Ad Hoc Committee recommends building an infrastructure to foster its successful implementation.

GOAL AD-1	To advocate for funding of and support for the *New Jersey Comprehensive Cancer Control Plan*, including cancer awareness, education, and early detection programs, as well as access to care.

Objective AD-1.1

To identify, engage, and involve interested public and private parties, institutions, and agencies to garner ongoing support of the *Plan*.

Strategies

AD-1.1.1 Build cancer advocacy capacity through recruitment of identified interested parties. Parties initially identified include, but are not limited to, media, legislators, insurers, pharmaceutical companies, healthcare professionals, corporations, state agencies, and other key decision-makers.

AD-1.1.2 Identify champion(s), e.g., patients and patients' families, to advocate on behalf of the *Plan*.

Objective AD-1.2

To educate legislative members and staff about the importance of funding cancer prevention and control programs.

Strategies

AD-1.2.1 Charge the Task Force on Cancer Prevention, Early Detection and Treatment to maintain an Advocacy Ad Hoc Committee, comprised of a representative from each of the Task Force workgroups, to address the legislative initiatives cited within each respective chapter of the *Plan*.

AD-1.2.2 Work with partner organizations and coalitions to build and continue support for cancer education, early detection, and access to care.

ADVOCACY FOR ACCESS TO CANCER CARE

In 1999, in accordance with its charge, the President's Cancer Panel reviewed the evolution of the National Cancer Program and considered how the nation should move forward to reduce the burden of the disease more rapidly. It was decided that the equal importance of the research and delivery components of the National Plan on Cancer be recognized; that the current barriers preventing quality cancer care from reaching people in all neighborhoods of the nation be removed; and that the unequal burden of cancer carried by the poor, ethnic minorities, and the underserved be relieved.[7] The complex issue of healthcare access encompasses many barriers, including inadequate health insurance coverage, insufficient cost reimbursement, inconvenient health center hours and locations, and a lack of efficient and affordable transportation for screening and treatment services.

For many in New Jersey and the U.S., lack of adequate health insurance is a significant impediment to access to healthcare, including both traditional and cutting-edge treatments, and to prevention or early detection tools that have long been accepted by the medical community. The percentage of New Jersey residents without health insurance has been increasing steadily over the last decade. In 2005, an estimated 1.3 million New Jersey residents lacked any kind of healthcare coverage, and many more

reported having inadequate health insurance.[8,9] As a result, the Advocacy Ad Hoc Committee has adopted a position of support for universal healthcare for all New Jersey residents and recommends adopting universal standards of care.

Access to needed services can also be adversely affected by unrealistic provider reimbursement practices.[10] Providers are often inadequately reimbursed for the cost of providing preventive services, such as counseling patients on tobacco cessation. Ensuring that providers are reimbursed at acceptable rates for cancer prevention, early detection, and treatment services would create incentives for providing these services.

Although a lack of insurance and prohibitive costs are the primary reasons cited for low cancer screening rates, transportation has been identified as another significant barrier. According to a report by the New Jersey Department of Health and Senior Services, healthcare services may not be located in places that are easily accessible, particularly to those who lack private transportation.[11] In a study of access to primary care in New Jersey, it was found that "transportation options are often limited for people living in rural settings, seniors, and those with disabilities and diseases. Some options provide only one-way transportation, and cab fare is viewed as prohibitively expensive."[12] In metropolitan areas, which offer more extensive public transportation systems, schedules and route maps can be confusing to consumers with limited knowledge of such systems. Furthermore, schedules and route maps may not be widely available to the general public. In less urban areas, lack of centralized, efficient public transportation forces vulnerable populations to rely on community resources to meet transportation needs. However, the private sector is often overwhelmed and unable to keep pace with demand.[12]

While there are organizations throughout the state that provide free transportation services to patients undergoing cancer treatment, these programs are not without their limitations. Transportation programs are often operated at the local or county level and are unable to transport patients outside the service area. In many cases, the demand for transportation exceeds the capacity of a program to provide adequate services.

GOAL AD-2

To advocate for increased access to quality cancer care, prevention, early detection, and awareness programs.

Objective AD-2.1

To advocate for providing to all New Jerseyans adequate health insurance coverage relating to cancer prevention and control.

Strategies

AD-2.1.1 Assess current New Jersey insurance coverage for cancer prevention, detection, and treatment to identify gaps.

AD-2.1.2 Educate legislators and insurance companies on identified gaps in cancer coverage.

AD-2.1.3 Monitor emerging issues related to adequate health insurance for cancer care and identify those issues for possible position development, e.g., undocumented citizen healthcare.

Objective AD-2.2

To ensure that cancer patients have access to quality prevention and cancer care, including both current therapies and treatments provided through high-quality, peer-review clinical trials.

Strategies

AD-2.2.1 Assess and/or review current and pending cancer-related legislation.

AD-2.2.2 Advise legislative members and staff of identified cancer-related needs.

AD-2.2.3 Continue to make policy-makers aware of data on cancer-related issues such as reimbursement.

AD-2.2.4 Advocate for improved transportation in order to increase access to cancer care and screening in New Jersey.

Objective AD-2.3

To create a state-level service that would provide a centralized resource for cancer information.

Strategies

AD-2.3.1 Evaluate current cancer resource information systems.

AD-2.3.2 Support and cooperate with the appropriate governmental body to develop a state-level cancer resource information system service.

AD-2.3.3 Advocate for funding of a centralized cancer resource information system in New Jersey.

Advocacy to Reduce Disparities—The Unequal Burden of Cancer

In order for a comprehensive health agenda to be truly effective in reducing cancer incidence and mortality, it must address all populations. We cannot address the differences in the burden of cancer for minority, poor, and medically underserved populations without creative interventions to overcome the barriers to care that threaten our ability to effectively reach and serve these populations.

Cancer among Minorities

Overall, black men in New Jersey and the U.S. are more likely to develop and die from cancer than persons of any other racial and ethnic group. (See Burden of Cancer in New Jersey chapter for additional information.) For the years 1998 through 2003, the U.S. incidence rates for all cancer sites were highest among blacks, followed by whites, Hispanics, Asian/Pacific Islanders, and American Indians/Alaska Natives. U.S. mortality rates during 1998 through 2003 were also highest among blacks, followed by whites, Hispanics, American Indians/Alaska Natives, and Asian/Pacific Islanders.[5] Despite the high rates of incidence from all cancers combined from 1992–1998, rates among blacks, Hispanics, and whites decreased, while remaining relatively stable among American Indians/Alaska Natives and Asian/Pacific Islanders. Similarly, mortality rates for all cancer sites decreased annually among blacks, Asian/Pacific Islanders, whites, and Hispanics, while leveling off among American Indians/Alaska Natives.[4,5] Many disparities among cancer sites also exist and are detailed in the site-specific chapters of the *Plan*.

These disparities must be addressed as part of any comprehensive cancer control plan.

Population Demographics Adding to the Cancer Burden

Cancer can strike at any age, but approximately 77% of all cancers are diagnosed at ages 55 and older.[4] The American population is graying, with a growing percentage of people now in their 60s and older. With the oncoming retirement of the Baby Boomers, the number of Americans over age 65 will double in the next 30 years. At current rates, the number of new cancer cases will rise dramatically, causing cancer to surpass heart disease as the nation's leading killer.[10] A higher percentage of retirement-age New Jerseyans have cancer and die of it than in the nation as a whole. Among those aged 65 and older, the cancer rate is 13% higher among men, 12% higher among women, as compared to the national average.[13]

GOAL AD-3	To reduce cancer-related health disparities among racial and ethnic minority populations, seniors, and the medically underserved.

Objective AD-3.1

To advocate for a healthcare system that provides cancer services that address the psychosocial, economic, physical, and educational needs of the patient in a culturally sensitive and linguistically appropriate manner.

Strategies

AD-3.1.1 Advocate for required quality improvement standards for cancer screening, diagnostic tests, treatment, rehabilitation, and palliation services and therapies that would be available and cost effective for all underserved and seniors.

AD-3.1.2 Advocate for organized healthcare systems that reduce fragmentation of available cancer services.

AD-3.1.3 Advocate for funding toward increased numbers of knowledgeable and competent navigators for cancer patients and families to help access and navigate the healthcare system.

AD-3.1.4 Collaborate with other interested stakeholders to integrate existing initiatives addressing health disparities.

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