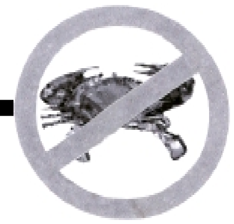

Cancer Control Legislation and Policy Milestones in North Carolina

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Cancer, the nation's second leading cause of death, is consistently ranked as one of the leading US public health problems. Development of cancer control policies on a national level began with President's Nixon's declaration of the national "War on Cancer" in 1971. As a result of that initiative, the National Cancer Institute (NCI) was asked to escalate cancer control efforts and to implement a process of distributing comprehensive cancer research centers nationwide. Duke University was among the first 12 NCI-designated comprehensive cancer center sites. Two decades later, in the early 1990s, the Centers for Disease Control and Prevention (CDC) received substantial appropriations to enhance breast and cervical cancer screening, and to establish a National Program of Cancer Registries.[1] At the time these national programs were starting up, the CDC began coordinating the establishment of cancer control programs in every state.

In 1995, North Carolina was in the second year of implementing its cancer control coalition, but cancer control efforts in many states were limited to "capacity building." Because a few states' funds were building "comprehensive" cancer control programs, the CDC developed a handbook, the *Blue-Print for Comprehensive Cancer Control*, to guide the organizing of state-based comprehensive cancer control programs.[2] Salient elements of these programs included (1) the presence of a statewide coalition for cancer control, and (2) the implementation of a statewide cancer control plan. This article represents our recollections of the events leading up to the passage of the pivotal legislation and some of the earlier activities related to the adoption of the first statewide cancer control plan in 1996. We present these observations on the occasion of the adoption and implementation of the second North Carolina Cancer Control Plan.

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Background

In 1933, the North Carolina Medical Society formed its Committee on Cancer. Later, in the early years after War World II, the American College of Surgeons began to promote the formation of cancer registries.[3] During the post-war years, over 30 states passed legislation establishing central cancer registries and, in many, state-based programs for cancer control. North Carolina was one of those states. In 1945, the General Assembly passed legislation (GS 130A; see Table) providing for cancer registration by the State Health Department and creating within the agency a program to "reduce the impact" of cancer on citizens. This legislation more or less languished for 40 years; funds were scanty and little was done; there were few active periods of cancer control policy development, except as related to breast and cervical cancer screening and the appropriation of funds to pay for indigent cancer care.

Cervical cancer screening brought two prominent forces onto the cancer control scene in NC: Dr. John Kernodle and the volunteers of the American Cancer Society, including Dr. Charles Spurr. Dr. Kernodle, a prominent gynecologist from Burlington, had been trained by Dr. George Papanicolou in the use of cervical cancer screening with the then innovative technique of exfoliate cytology (reading the microscopic appearance of cells 'shed' normally by the body). Dr. Kernodle brought the technique to North Carolina and, in concert with the American Cancer Society, lobbied to make this inexpensive screening procedure available to all women in the state. It should be noted that in the 1950s cervical cancer was the leading cause of cancer death among women, particularly economically disadvantaged women.

The Pap test brought a breakthrough in early detection, but it led to a new dilemma: how to find treatment for the poor women now diagnosed with cervical cancer. Hence the

Table. Cancer control-related legislative actions in North Carolina

Cancer-related legislation before 1990	
GS 130A-205	Established Cancer Control Program and administrative rules
GS 130A-206	Financial aid for cancer diagnosis and treatment
GS 130A-207	Designated cancer clinics
GS 130A-208	Established Central Cancer Registry; mandated reporting all new cases
Cancer-related legislation from 1993-4	
GS 58-50-155	Established standard and basic health-care plan coverage
GS 58-50-156	Coverage for prescribed drugs for cancer treatment
GS 58-51-57	Coverage for mammography and Pap smear screening
GS 58-51-58	Coverage for prostate specific antigen screening
GS 130A-33.50-51	Established Advisory Committee for Cancer Coordination and Control
Cancer-related legislation submitted in 1995-96	
S335	Appropriated funds for Central Cancer Registry
H218	Directed DEHNR use of appropriated funds (NCACCCC)
H439/S432	State employee health plan coverage of cancer screening
Cancer-related legislation submitted in 1997-98	
H62/H318/S255	Appropriated funds for Cancer Control Program
S1282	Added members to ACCCC
H813/S714	Coverage for reconstructive surgery
S1215	Funds for [cervical] cancer screening
H815/S701	Donations from taxes for breast cancer research
Cancer-related legislation submitted in 1999-2000	
S998	Changed membership terms for ACCCC
S273	Authorized charges for state-collected cancer reporting
S274	Appropriated funds for cancer control programs
S781	Insurance coverage for clinical trials
Cancer-related legislation submitted in 2001	
S72/H1312	Funds for pediatric cancer programs
S132	Insurance coverage for [colorectal] cancer screening
H566/S537	State matching funds for receipt of federal Medicaid breast and cervical cancer treatment coverage

initiative led by Dr. Kernodle of Duke University Medical Center and Dr. Spurr of Bowman-Gray Medical School. With legislative appropriations from the NC General Assembly, a series of eight cancer clinics were established at regionally distributed hospitals. These clinics provided care for indigent cancer patients.

Over the years, the state health department's cervical cancer screening and cancer care for the indigent programs have waxed and waned, but they have always remained functional to some degree. The extensive cytology program at the State Laboratory is an outgrowth of the efforts led by Dr. Kernodle and his colleagues to provide reading of the Pap smears produced at the county health departments. Training programs for laboratory technicians are another 'spin-off' of these efforts.

Dr. Spurr championed another cause pertinent to cancer control. The treatment of cancer patients was evolving rapidly in the 1960s and 70s. The emergence of chemotherapy and recognition of the importance of scientific clinical trials of treatment regimens underscored the need for high quality data collection on cancer patients, and for information on the outcomes of cancer care—activities associated with cancer registries. In the 1970s, the staff of the NC Cancer Control program (the group that dispenses the funds that provide care for indigent patients and for the operation of cancer clinics) began promoting cancer registries in funded hospitals. At the same time, surgeons were getting similar recommendations from the American College of Surgeons.

In 1975, a National Tumor Registrars Association was founded, and one year later, a North Carolina chapter was established under the leadership of Ms. Luna Woods of Duke University. Over the next decade, as the state's large hospital cancer databases were being developed, support grew for pooling the data in a central cancer registry.[3] In 1986, Dr. Spurr, the NC Medical Society, and the American Cancer Society had made it a priority to have the legislature underwrite a North Carolina Central Cancer Registry. In 1988, state appropriations were received and the current Central Cancer Registry [CCR] was begun[4] (see the article by Cooper et al on page 308).

The Advisory Committee for Cancer Control and Coordination

As data came in to the CCR, a variety of high-risk patterns became apparent. Among the more distressing findings were age and race disparities in cervical cancer incidence and mortality. In 1991, Dr. Kernodle led a coalition of the American Cancer Society, NC Equity, and several women's organizations to push legislative funding of a statewide task force to evaluate cervical cancer control within the state. That statewide coalition, chaired by Dr. Kernodle, funded by two-year appropriations, made a report to the Legislature that included several population-specific recommendations such as greater cervical cancer screening of older women and the formation of a statewide committee to coordinate cancer control activities in the state.

Drs. Kernodle and Spurr and many of their colleagues saw the need to coordinate cancer control efforts to the optimal benefit of the state's citizens. A cervical cancer task force was formed to bring together leaders from the cancer control programs active in North Carolina in the early 1990s. The benefits were many: there was the American Cancer Society working alongside large community hospitals and medical schools; there were federally funded cancer control activities at the state's three NCI-designated Comprehensive Cancer Centers; there was CDC funding for breast and cervical cancer screening by the state health department.

In 1993, the creation of a "commission" to coordinate cancer control in NC led the cancer legislative agenda. The result was the North Carolina Advisory Committee for Cancer Control and Coordination [NCACCCC]. The Committee comprised representatives from the state's medical schools, cancer centers, professional societies, businesses, the lay public (specified as cancer survivors), and six elected legislators (three from each house). This design conformed exactly to the national "blue print" strategy for comprehensive cancer control. The new organization convened for the first time in January 1994, and four subcommittees were formed: Prevention, Early Detection, Care and Legislation/Education.

The original six legislative members of the ACCCC, Senators Ollie Harris, John Codington and Fountain Odom, and Representatives Walter Dickson, James Bowman, and Tom Wright, were determined to name their subcommittee "Legislation and Education." Legislation was a clear focus for the group, but they decided that the members of the General Assembly needed meaningful education because of the considerable complexity the Committee members saw in the process of cancer control.

As the first cancer control plan was being developed, the Legislative and Education Subcommittee sponsored six regional education seminars to promote grass-roots recognition of cancer control programs and to connect motivated citizens with their local elected officials. Next, the Subcommittee held an educational forum at the General Assembly to introduce legislators to the breadth and complexity of cancer control. At a luncheon seminar, prominent speakers from the state's medical schools emphasized the merits of early detection, and the need for public education about cancer risk and healthy behaviors like nutrition, and cancer screening.

The Current Perspective

Among the earliest legislative efforts of the Advisory Committee were expansion of the CCR so that it could collect

details of cancer treatment, and obtaining funds with which to implement the directives given the Advisory Committee (See 1995 and 1996 bills in theTable). In 1996, when the first NC Cancer Control plan was unveiled, the Legislation and Education Subcommittee organized a luncheon seminar for legislators. It focused on access to state-of-the-art cancer care, and the great potential for surviving cancer. Legislators heard presentations from cancer survivors, national spokespersons, and legislative leaders, each acknowledging the milestone represented by North Carolina's cancer control plan.

The first cancer control plan described a five-year timetable (1996-2001) for coordinating disease control efforts of immense diversity (public education, professional training, disease screening, promotion of participation in clinical trials). Many local organizations pledged to promote and implement these activities. The prodigious accomplishments made under this plan were described to the legislature at the end of the 2001 session, coincident with the unveiling of the second statewide plan for calendar years 2001 to 2006.

During the five-year period covered by the first cancer control plan, North Carolina received federal funds for implementation of its comprehensive cancer control plan. Money was devoted to education about skin cancer risk, promotion of early cancer detection, screening for colorectal cancer, and for data analyses of high-risk populations. The North Carolina Cancer Control plan was touted nationally as a model.

Over the years, the Legislative and Education Subcommittee has had a number of different members, and it has undertaken several different initiatives, but its unswerving dedication to providing cancer care for specific populations and access to state-of-the-art care for all has remained. The promotion of cancer care has led to introduction of legislation related to insurance coverage for clinical trials, the most "cutting-edge" care available (that legislation is pending). Protecting patients' rights has become a prominent issue because insurance companies may now want to use genetic markers to identify (and discriminate against) patients at high risk of cancer.

Now we are in a time of fiscal challenge, and once again we face the issue of assuring care for all women found to have early cervical cancer—and also breast cancer. The national program for breast and cervical cancer screening has recognized the need to provide care for the indigent patients identified by early cancer detection programs. Federal Medicare funding has been authorized for these women, but it requires a 3:1 state match. As the Table shows, appropriation of matching funds led the legislative priorities for this past session.

As the 21st century starts, a *National Dialogue on Cancer* has begun to promote policies and legislation for cancer control. Prominent among this group's recommendations is a program of coordinated education for state legislators. And as the new century begins, North Carolina implements its second statewide plan for cancer control; the new five-year period will, we hope, bring us one step closer to reducing cancer-related morbidity and mortality in this state.

Acknowledgment: The members of the Legislative and Education Subcommittee of the North Carolina Advisory Committee for Cancer Coordination and Control made the accomplishments outlined in this paper possible through their unswerving devotion to cancer control in North Carolina. We appreciate their personal sacrifices and the dedication that achieved these milestones: Representative Martha Alexander, Senator Robert Carpenter, Senator John Codington, Representative W.W. 'Dub' Dickson, Representative Zeno Edwards, Senator Ollie Harris, Representative Julia Howard, Senator William Martin, Senator Fountain Odom; Representative Thomas Wright and many supportive members from both houses of the General Assembly.

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