



The Rhode Island Cancer Council

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Although Rhode Island's cancer incidence rate is not above the national average for an aging population in an urban industrial state in the Northeast, the number of deaths from cancer in Rhode Island exceeds the national average. Even with the state's excellent hospitals and educational facilities, coupled with a large corps of dedicated physicians, Rhode Island has a significant cancer problem. Based on the rule that "all politics is local," programs to improve the well being of Rhode Islanders must be local.

The Rhode Island Cancer Council was established to encourage cooperative, comprehensive and complementary planning among the public, private and volunteer sectors of the State by maintaining an integrated information network of resources for all to use. The Council became operational in May 1999; the Governor, the Senate Majority Leader, and the Speaker of the House of Representatives appointed the nine members to the Board, chosen for their leadership in oncology and in the community (Table I). [The national plan, "Conquering Cancer," calls for the establishment of comprehensive State-based cancer action plans in collaboration with all experts in the region - See "Cancer in the New Millennium," this issue].

In conjunction with the Department of Health, the Rhode Island Cancer Council has the responsibility to keep the Cancer Plan for the State of Rhode Island current and broadly applicable for all residents.

As one of our first tasks we re-examined the treatment algorithm for breast cancer. A panel of experts addressed the issue of screening and diagnosis. Another panel developed treatment guidelines. A third panel is addressing supportive care and quality of life. [This responds to the

recommendation of the NCLAC (Table II, Goal 10).] The cooperation and collegiality of the participants in developing the algorithm for breast care is encouraging and bodes well for its incorporation into medical practice in the State. Although mammography utilization in Rhode Island is above the national average, our death rate is 10% above the national average.

Colorectal cancer is the second leading cause of cancer deaths after lung cancer. Our death rate is 34% higher than the national average for men and 21% higher for women. Although early detection by regular screening can reduce our death rate, fewer than 50% of the population over the age of 50 have ever been screened for colorectal cancer. We recently surveyed two groups: the sixty-two gastroenterologists and surgeons who perform colonoscopy, and over 120 primary care physicians. The data point to a good deal of uniformity on screening guidelines across the specialists and the primary care physicians. [See "Colorectal Screening," this issue.]

The Council has embarked upon a broad public and professional education program. To reduce cancer deaths in Rhode Island, we must remove barriers to Rhode Island's state-of-the-art cancer programs. The Council maintains an integrated information network of resources. Our website, www.ricancercouncil.org, provides cancer-related information for Rhode Island, much of which is not available anywhere else (Table II).

Each month the Rhode Island Cancer Council provides a health column for an e-magazine, www.findri.com. Shortened versions of these columns are distributed to the churches, synagogues and mosques in Rhode Island for inclusion in their monthly bulletins.

The Rhode Island Cancer Council maintains a Cancer Forum (message board) on the Internet. In addition, the Council receives inquiries by telephone. Frequently people ask for assistance with the cost of medications. We relay information on the Drug Assistance Program at the University of Rhode Island and state programs. When appropriate we recommend clinical trials, referring callers back to their oncologists to discuss the appro-

TABLE I

**Members of The Rhode Island Cancer Council
(for biosketches, see www.ricancercouncil.org)**

- Paul Calabresi, MD, MACP** - Medical Oncologist, Chairman
- The Honorable J. Joseph Garrahy** - Former Governor of Rhode Island
- Arvin S. Glicksman, MD, FACR** - Radiation Oncologist, Executive Director
- Laura Hilderley, RN, MS** - Nurse Oncologist
- Louis Luzzi, PhD** - Dean, School of Pharmacy, University of Rhode Island
- Marlene McCarthy** - Breast Cancer Activist
- Charles McDonald, MD** - Dermatologist
- Patricia M. Nolan, MD, MPH** - Director, Department of Health
- The Honorable George Panichas** - Former Member of the State Legislature, Treasurer

TABLE II
Cancer Resources in Rhode Island
 (available on www.ricancercouncil.org)

- Oncologists:**
 - Subspecialties
 - Geographic Area
- Mammography Centers:**
 - Geographic Area
 - Handicap Accessibility
 - Hours of Operation
 - Languages Spoken
- Support Groups:**
 - Disease Specific
 - Geographic Area
- Clinical Trials:**
 - Disease Site
 - Stage of Disease
 - Principal Investigator
 - Contact Information
- Smoking Cessation Programs:**
 - Geographic Area

priateness of their participation. Health insurers in Rhode Island cover the costs associated with Phase II, III, and IV clinical trials, as well as the costs of drugs used off-label.

The Rhode Island Cancer Council has developed free printed "Fact Sheets" on the most prevalent cancers and brochures on screening guidelines. (Table III)

Following up on Resolution 2000-H-6942 of the House of Representatives, the Rhode Island Cancer Council has contacted every city and town in Rhode Island, making our services available to develop cancer awareness programs. To date, Pawtucket, Foster, Warren, Warwick, Cranston, Tiverton, and Cumberland have responded; program development is in progress.

The Council has produced thirty-second information spots, shown on cable television, as well as on the wide screen in the Food Court at the Warwick Mall. The Council broadcasts radio spots on most of the popular stations. Frequently, the Council places cancer-related announcements in local newspapers.

Initially the Legislature asked the Council to catalogue all laws and resolutions in Rhode Island relating to the detection and/or treatment of cancer. We have completed this task. The Secretary of State now has a new category "cancer."

Last fall the Council sponsored a public information forum, "Successful Survivorship After Cancer." Dr. Julia Rowland, Director of the Office of Survivorship at the National Cancer Institute, was the keynote speaker. Over 150 individuals attended. Another public forum in conjunction with the Oncology Nurses Society on Quality of Life issues associated with end-of-life was held in spring of 2001, again drawing an audience of over 150. In the fall, a public forum on complementary care was held, a joint effort with the Rhode Island Chapter of the Leukemia and

Lymphoma Society and The Rhode Island Breast Cancer Coalition. The Council will repeat this program in different parts of the State.

Last year the Council renewed the Waterman Dialogue lectureships in conjunction with the American Cancer Society. Dr. Judah Folkman and Dr. James F. Holland spoke on "Cancer Treatment for the 21st Century." The Council will continue the Waterman Dialogue, bringing experts to Rhode Island. The Council has also sponsored lectures by visiting professors on bladder cancer, prostate and other urological cancers, and breast cancer.

The Rhode Island Cancer Council encourages new research programs. Last year the newly-formed Transition Support Grant Program, awarded four grants (each approximately \$15,000) to individuals who were in the process of applying for funds from national agencies but required support to enhance their competitiveness in the national pool. Three of the four were successful for a total of approximately \$6,000,000 in research funds coming into Rhode Island. The fourth grant is under review. This year the Council hopes again to fund four or five promising projects.

Last year the Council held a roundtable on "Women's Issues in Cancer," bringing together twelve community leaders in this field. Copies of this report are available from the Council office.

The NCLAC report stresses the importance of implementing a National Cancer Prevention Initiative that eliminates tobacco use, increases physical activity, and improves nutrition (Table II, Goal 12). The Rhode Island Cancer Council has been an active participant in the tobacco wars as a member of the Rhode Island Tobacco Leadership Coa-

TABLE III
Cancer Fact Sheets and Resource Brochures
 (available on www.ricancercouncil.org and in printed form)

- Cancer Fact Sheets:**
 - Bladder Cancer
 - Breast Cancer
 - Cervical Cancer
 - Chemotherapy
 - Colorectal Cancer
 - Head & Neck Cancer
 - Hodgkin's Disease
 - Lung Cancer
 - Ovarian Cancer
 - Melanoma
 - Prostate Cancer
 - Stomach (Gastric) Cancer
 - Testicular Cancer
- Resource Brochures:**
 - Breast Prostheses
 - Cancer Screening Guidelines
 - Smoking Cessation Programs
 - Support Groups
 - Wigs

lition, a group representing essentially all of the organizations and programs working to reduce tobacco use in the State. The Coalition will launch a major advertising campaign to reduce tobacco use in Rhode Island.

The Rhode Island Cancer Council has undertaken a study of tobacco use on the campuses of the eleven colleges and universities in the State. We developed a questionnaire based, in large part, on the published Centers for Disease Control and Prevention (CDC) questionnaire, modified with questions concerning readiness to quit for current smokers. In the first year, this was administered to approximately 100 freshmen at each campus. Students have also been offered the opportunity to participate in focus groups concerning tobacco use. Referrals to smoking cessation programs are available. Of particular importance has been information from Focus Groups held on three campuses last year, giving us unusual insights to students' attitudes and influences. The questionnaire to the second group of freshmen have been distributed on the various campuses throughout the State and some of this year's data have already come in for collation.

This population is the fastest growing tobacco users. It had been generally accepted that children who did not start smoking by the age of 18 would probably never be addicted to tobacco; however, since the tobacco settlement, tobacco companies have targeted their media campaigns on 18 year-olds. Accordingly, we are seeing a rise in smoking among college students. Our program is designed to understand how students balance the pressures from the tobacco industry and from the various public health anti-tobacco campaigns. This program will yield information concerning attitude, about pressures coming from multiple sources. Importantly, the Behavioral Study Group of The Miriam Hospital/Brown University provides an intervention component.

"Conquering Cancer" urges a National Cancer Screening Initiative to increase substantially the early detection of cancer (Goal 9). The State of Rhode Island has been involved in screening programs for some time and has published a "Guide to Cancer Screening." In addition the Council has initiated a mammography program for early detection of breast cancer.

Annual screening mammograms are provided to all insured women in Rhode Island and are covered by Medicare for women over 65. For women without health insurance, the Department of Health has received funds from the Centers for Disease Control and Prevention to support mammograms for underinsured and uninsured women between the ages of 50 and 64. The program, working through the Community Health Centers, provides for outreach to the at-risk population. In addition, the program provides medical attention for

women with positive mammograms. This includes a biopsy of the suspicious area of the breast and a pathological analysis leading to a diagnosis. If cancer is detected, a network of providers is prevailed upon so that necessary surgery, medical oncology, radiation oncology, and psychosocial support are available. This program is not available to women below the age of 50 under the CDC grant. However, the State Legislature enacted legislation last year that established a comparable program for women between the ages 40 to 49. The State Health Department uses the existing network by extending the age eligibility. The Rhode Island Cancer Council funds this program under the legislation as passed. In the first six months of the fiscal year, 154 women have been screened. Since this program is now established by law, it will continue to provide services for women between the ages of 40 and 49 in future years.

Since its inception the Council has emphasized providing information in a timely and usable way to the public. It has developed programs with the assistance of a broad array of recognized leaders of oncology, and it has found strong support from many civic-minded public leaders without whom we could not have moved so rapidly to establish our programs. We believe that in this environment we can achieve our goal to diminish the burden of cancer in Rhode Island and improve cancer literacy throughout the State. The Council can also serve as a model for other community cancer programs as envisioned by the National Cancer Legislation Advisory Committee.

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