

Turning
commitment into



Action

| Recommendations of the Delaware Advisory
Council on Cancer Incidence and Mortality |

APRIL 2002

We dedicate this report to all those
who have shared their stories—
both triumphant and tragic—with us.
Your indomitable spirit inspires us
to seek answers and effect change.



A Special Thank You

To our guest speakers:

We would like to express our appreciation to the following individuals who shared their stories with us. Your courage, spirit and drive to make a difference inspire us all:

Sterlin Beckwith
Brenda Billingsley
Jerry Broussard
Nellie Foster
Judy Lieberman
Shirley Moore
Mary Ellen Nantais
Rebecca Wolhar

To all the public attendees who shared their interest and insight.

To the presenters during council or subcommittee meetings who guided us with their experience and knowledge:

Jon Kerner, Ph.D.
National Cancer Institute
Paul Silverman, Dr.P.H.
Delaware Division of
Public Health
Lance Wallace, Ph.D.
Research Triangle Institute

To our nearly 200 participants in the Concept Mapping Project:

Thank you to all the people around Delaware—including survivors, family members who lost loved ones, professionals and scientists. Your ideas on cancer issues were invaluable. Your input helped lay the groundwork for our recommendations.

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“...Justin is gone but my promise to him rings in my ears, to find the answers to the questions he never wanted another parent to have to ask—‘why did my child get cancer and why did he have to die?’”

MARY ELLEN NANTAIS OF NEWARK WHOSE SON, JUSTIN, DIED OF CANCER IN 2000 AT AGE 19.



Inspiration to seek answers and develop a plan is all around us.

This is a report from the Delaware Advisory Council on Cancer Incidence and Mortality. It is much more than statistics and data. It represents the observations of our families, friends and neighbors whose lives have been touched by cancer. Their stories are part of our report to you. Some fought bravely and lost. Others have persevered and learned the meaning of the word courage. They represent the reason why our Council was formed by Governor Minner and the Delaware General Assembly in March 2001.

Our goal is obvious—to find methods to reduce cancer in our state.

We culled information from every area—from many experts—from any who would volunteer their personal experiences. We talked to more than 195 people who are living with the disease or have experienced its devastation. We coordinated brainstorming sessions. We solicited over 500 thoughts about the disease. We identified 118 solid ideas about controlling cancer in Delaware.

Our results—and a workable plan—are here for you to see.

A clear set of priorities was established by the Council. Six subcommittees got to work identifying recommendations. The work was reviewed and is here in this report. It's just a beginning. But it's our hope for the future.

EXECUTIVE SUMMARY

WHY IS CANCER IN DELAWARE SO IMPORTANT?

Cancer is always life changing for the people diagnosed, their families and loved ones. Cancer is the second leading cause of death in Delaware and every one of us is at risk of developing this dreaded disease. The cancer issues in Delaware are not new and they belong to each of us. The fact that so many of us are affected makes the need for meaningful action much more urgent.

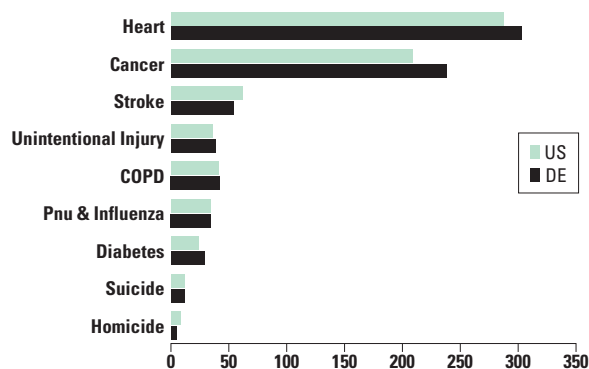
How much Cancer is there in Delaware?

In 1999, 3,786 Delawareans were diagnosed with cancer. 1,735 died.

Delaware's cancer rates are higher than the national average. This is true both for incidence (number of people diagnosed with cancer) and death rates. Cancer incidence rates peaked in Delaware and the nation in the early 1990s. Since then, rates have begun to decrease. Between 1994 and 1998, the cancer incidence rate in Delaware was 10% above the national average.

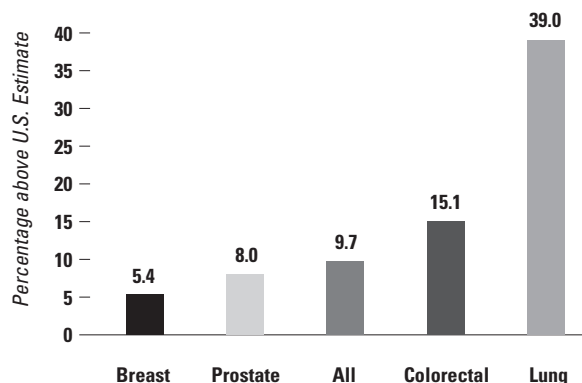
5-YEAR AVERAGE AGE, RACE, SEX ADJUSTED MORTALITY RATES PER 100,000, U.S. AND DELAWARE, 1994-1998

NOTE: 1999 data are provisional



Age, race, sex adjusted using 2000 U.S. population standard
 Delaware: Delaware Health Statistics Center, Delaware Division of Public Health
 U.S.: National Center for Health Statistics

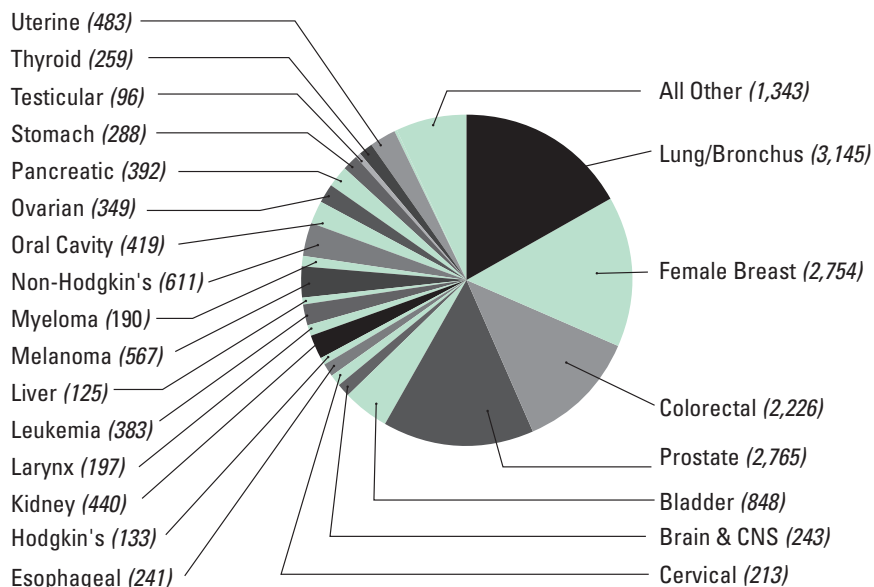
DELAWARE AGE-ADJUSTED INCIDENCE RATE PER 100,000 AS PERCENTAGE ABOVE U.S. ESTIMATE FOR 1994-1998



Delaware: Delaware Cancer Registry, Delaware Division of Public Health
 U.S.: Surveillance, Epidemiology and End Results (SEER) Program, National Cancer Institute

CANCER BY TYPE (NUMBER OF CASES), DELAWARE, 1995-1999

NOTE: 1999 Data are provisional



WHAT CAN BE DONE?

The reality is that cancer is a complex disease. We do not know all of the answers, but we have a wealth of information that can make a tremendous difference. If we commit to the recommendations in this report, here's what we can do:

Immediately

- Improve the quality of cancer care in Delaware and help people with cancer get the services they need
- Increase screening so that cancer is diagnosed earlier
- Pay for cancer treatment for the uninsured

Over the long term

- Decrease cancer incidence rates
- Decrease cancer death rates
- Make Delaware a model for quality cancer care and early detection
- Eliminate the differences in cancer rates between different races, genders and socioeconomic groups
- Learn more about who gets cancer and why

RECOMMENDATIONS OF THE DELAWARE ADVISORY COUNCIL ON CANCER INCIDENCE AND MORTALITY

This report contains 26 specific recommendations to lessen the cancer burden in Delaware. These recommendations are grouped into the following categories:

- Increase screening for and early detection of colorectal cancer
- Provide the highest quality of care for every Delawarean with cancer
- Pay for cancer treatment for the uninsured
- Provide reliable and useable cancer information
- Reduce the threat of cancer from the environment
- Increase our knowledge about cancer including environmental causes
- Reduce tobacco use and exposure
- Eliminate the unequal cancer burden affecting minorities and the poor

How much will it cost?

If fully adopted, our recommendations would cost approximately \$48.4 million over four years. The Council also advocates a \$0.50 increase in the tobacco excise tax and legislation allocating a portion of these funds to pay that cost, preferably designated to the Delaware Health Fund. In addition to funding all of our recommendations, this increase would result in 4,200 fewer Delaware children smoking, 1,300 Delaware children saved from a smoking death as an adult, and \$83.4 million dollars saved in long-term health care costs. (*Campaign for Tobacco-Free Kids 2001*)

Tobacco-Free Kids 2001)



“I had none of the risk factors for colon cancer and no known family history of the disease. At age 49, I awoke from surgery with a diagnosis of stage IV colon cancer, with metastases to the lymph nodes and liver. Delaware family doctors must learn to take the symptoms of colorectal cancer seriously, and in the case of women, gynecologists need to recommend colonoscopy as a standard screening method. High standards of colorectal cancer care and monitoring should be available to all patients, and health insurance companies and employers would do well to offer the highest standards of screening. Emotional support is just as important as the latest clinical advances.” | BRENDA BILLINGSLEY, WILMINGTON.

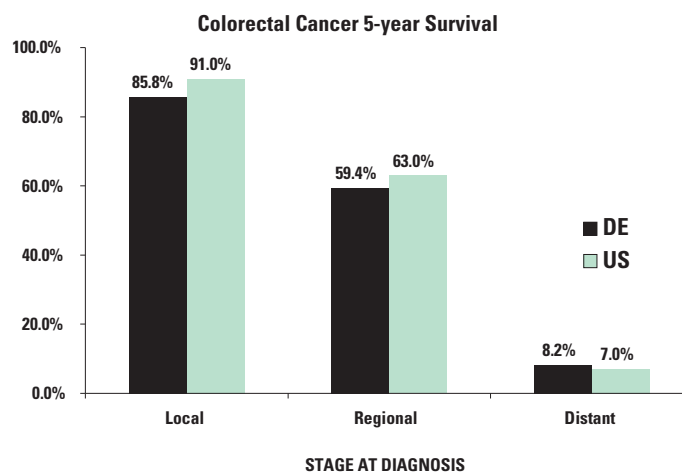
INCREASE SCREENING FOR AND EARLY DETECTION OF COLORECTAL CANCER

WHY?

Colorectal cancer kills 170 Delawareans every year. Colorectal cancer can be cured if found early enough and is preventable in many cases. Unlike many other cancers, there are reliable and cost-effective tests for colorectal cancer to find it early. Yet tragically, too few Delawareans know about and take advantage of these life-saving tests.

COLORECTAL CANCER 5-YEAR SURVIVAL RATES BY STAGE OF DIAGNOSIS, U.S. AND DELAWARE, 1994-1998

(Delaware Cancer Registry, Delaware Division of Public Health; Centers for Disease Control and Prevention 1999)



ARE SOME OF US MORE LIKELY TO BE AFFECTED BY THIS THAN OTHERS?

In 1999, percent of Delawareans reporting ever having a colorectal cancer screening:

- White: 45.3%
- African American: 39.6%
- Hispanic: 19.0%

Rates of death due to colorectal cancer in Delaware were 59% higher among African Americans than among whites.

(Behavioral Risk Factor Surveillance Survey, Delaware Division of Public Health 1999; Delaware Cancer Registry, Delaware Division of Public Health)

WHAT CAN BE DONE?

- Screen 80% of Delawareans over 50 years of age in the next 5 years
- Create a comprehensive statewide colorectal cancer screening and advocacy program
- Reimburse for colorectal cancer screening of uninsured Delawareans age 50 and older
- Case manage every Delawarean with an abnormal colorectal cancer screening test

WHAT IF 80% of Delawareans age 50 and older received a colonoscopy and appropriate follow-up every 10 years...

THEN Delaware would have the lowest colorectal cancer death rate in the country, decreasing by more than 60%. *(National Center for Health Statistics; Ranshohoff and Sandler 2002; Colditz, 2000)*

THEN the gap in death rates between whites and minorities in Delaware would begin to close.



“After a pelvic sonogram, my internist and a radiologist showed me 20 tumors in my abdomen. I waited a week to be scheduled for surgery and another month for the procedure to take place. This was after I had had a complete physical three months before and was told I was in fine health. In Delaware, we need to update our diagnostic tools and recommend them to a patient, talk directly to the patient and educate them about alternatives. Sensitivity training should start at the front door.” | REBECCA WOLHAR, WILMINGTON.

PROVIDE THE HIGHEST QUALITY OF CARE FOR EVERY DELAWAREAN DIAGNOSED WITH CANCER

WHY?

The Council heard testimony from people with cancer. Their compelling stories detailed frustration with the overwhelming and fragmented health care system. A team approach that guides us on all levels, medically, emotionally and financially, can ease the burden and help us make informed choices. Every Delawarean also has the right to high-quality, compassionate health care that follows the latest cancer screening recommendations and treatment options. The difference can be a cancer found early and cured rather than one where delayed treatment leads to the cancer spreading and increasing the chance of death.

- Some cancer centers in the United States are taking a team approach to cancer care. In addition to oncologists and surgeons, the teams often include professionals like oncology nurses, case managers, social workers and dietitians.
- More than 600 cancer-related services are available throughout Delaware. The reality is many barriers hinder access to these resources. A case manager for every cancer patient would link patients and resources.
- Many Delawareans are already getting routine checkups. These visits must be used to encourage routine cancer screenings and promote prevention. A comprehensive evaluation of cancer screening practices will increase early detection.

Percent of Delawareans who have visited a doctor in the past year for a routine checkup

Age 45-54: 70.2%

Age 55-64: 86.2%

(Behavioral Risk Factor Surveillance Survey, Delaware Division of Public Health, 2000)

- On average, the cost of care in the first six months of treatment is 33% less when cancers are found in the early stage (in situ) instead of the late stage (distant). *(Eddy 1990; Taplin, Barlow et al. 1995; Penberthy, Retchin et al. 1999)*

“The practice that handled my case has many Medicaid patients, perhaps too many patients, I got lost in the shuffle. Delaware ranks very low in statistics for quality medical care. Perhaps there needs to be greater doctor accountability in cancer diagnoses or even a central reporting area with follow-up in every case.” | JUDY LIEBERMAN, DOVER.



ARE SOME OF US MORE LIKELY TO BE AFFECTED BY THIS THAN OTHERS?

- The rate at which people die from cancer in Delaware is consistently higher than the nation. This gap in cancer deaths can be attributed to the type of cancers, lack of screening and the need for improved access to state-of-the-art care.

WHAT CAN BE DONE?

The Council recognizes that quality of care issues at all levels of cancer care must be addressed on an ongoing basis and the recommendations that follow are first steps. It is the recommendation of the Advisory Council that the Permanent Council (see Implementation of Recommendations, page 66) have a Medical Committee, led by oncologists, to oversee implementation of these and future recommendations to make Delaware a model for cancer care. The committee will require administrative support and should include professionals in a range of disciplines addressing cancer care such as pediatrics, surgery, dietetics, palliative care and social work.

- Provide a care coordinator that is part of a statewide-integrated system to every person diagnosed with cancer in Delaware. Care coordinators will be culturally competent to overcome language, ethnicity and gender barriers.
- Assure insurance coverage for state-of-the-art cancer clinical trials.
- Institute centralized credentialing reviews of medical practices by third party payors that include cancer screening, prevention, early detection and treatment practices as well as ongoing provider education.
- Support training for physicians and other health care providers in symptom management and end-of-life care approaches.

**PROVIDE THE HIGHEST QUALITY OF CARE FOR EVERY
DELAWAREAN DIAGNOSED WITH CANCER** *(continued)*

WHAT IF every person diagnosed with cancer in Delaware had a qualified case manager to make sure they had access to all the services they needed...

THEN differences in the death rates between whites and minorities would decline

THEN many barriers to care could be eliminated

THEN the quality of life for people with cancer would be better

THEN treatment outcomes would improve

WHAT IF physicians improved their cancer screening practices...

THEN cancer screening rates would increase

THEN follow-up on abnormal results would improve

THEN cancers would be diagnosed and treated earlier

THEN cancer death rates would decrease



“I was in the Screening for Life program. They paid for my mammogram and biopsy but nothing else. My radiation bill alone was \$10,000. It’s like once you have cancer, they’ll tell you you have it and then you’re on your own. My husband also has cancer. I’m on disability and he’s on Social Security. There’s just no extra money for medical bills. This has been a financial tragedy for us. I don’t know what we’re going to do.” | SHIRLEY MOORE, WILMINGTON.

PAY FOR CANCER TREATMENT FOR THE UNINSURED

WHY?

We know that people who are uninsured often wait to get medical care. We also know that the later a cancer is found, the more difficult it can be to treat. If someone you love is diagnosed with cancer tomorrow, the last thing you should have to worry about is how to pay for medical care.

275 Delawareans without health insurance will be diagnosed with cancer this year. (*Delaware Cancer Registry, Delaware Division of Public Health; University of Delaware’s Center for Applied Demography and Survey Research 1994-1998*)

THE AVERAGE COST OF THE FIRST YEAR OF CANCER TREATMENT

Type of Cancer	Stage of Diagnosis	Average Cost for First Year of Treatment
Colorectal	Local	\$34,362
Colorectal	Distant	\$40,670
Breast	Local	\$20,348
Breast	Distant	\$34,396
Cervical	Local	\$30,304
Cervical	Distant	\$48,560

(Eddy 1990; Taplin, Barlow et al. 1995; Penberthy, Retchin et al. 1999)

WHAT CAN BE DONE?

Reimburse the cost of cancer treatment for every uninsured Delawarean diagnosed with cancer up until one year after diagnosis.



“I put off having my annual mammogram because we didn’t have insurance at the time. I was persuaded to get one through Screening for Life. I was just two months late for it, but it showed a mass in my breast that turned out to be cancer. If I had not had the mammogram, it would’ve probably been too late for me. It was an aggressive tumor.” | NELLIE FOSTER, DOVER.

PROVIDE RELIABLE AND USEABLE CANCER INFORMATION

WHY?

Cancer is a complex disease. New information about causes, early detection and treatment is available to us every day. We need to have reliable and useful information in order to make healthy choices. The decisions we make today will affect Delaware’s cancer rates in the future.

ARE SOME OF US MORE LIKELY TO BE AFFECTED BY THIS THAN OTHERS?

Minority populations are less likely to get routine cancer screening tests. As education and income levels decrease, cancer screening rates also decrease. Cancer-related public education is inadequate to ensure individuals are able to make informed lifestyle and cancer care decisions. Education efforts must be carefully targeted to communities where cancer prevention can make the most difference.

PROPORTION OF DIFFERENT GROUPS EVER SCREENED FOR CANCER*(Center on an Aging Society, 2000)*

	Prostate Cancer	Breast Cancer		Cervical Cancer	Colorectal Cancer			Skin Cancer
	Men 50+	Women 40+		Women 40+	Adults 50+			All Adults
<i>Screening Service</i>	<i>Exam (%)</i>	<i>Exam (%)</i>	<i>Mammogram (%)</i>	<i>Pap Test (%)</i>	<i>Blood Stool Test (%)</i>	<i>Digital Rectal Exam (%)</i>	<i>Proctoscopic Exam (%)</i>	<i>Exam (%)</i>
ALL GENDER	—	—	—	—	48	57	36	21
Male	84	—	—	—	48	63	41	20
Female	—	87	80	91	48	52	32	22
RACE								
White	86	88	81	92	49	59	37	23
Black	80	83	75	90	40	48	28	11
INCOME								
<\$20,000	80	79	71	86	42	49	30	16
\$55,000+	88	94	88	96	56	65	42	27
RESIDENCE								
Urban	86	87	81	91	50	58	37	22
Rural	78	86	78	92	42	54	33	19
MARITAL STATUS								
Married	86	89	82	94	50	61	38	23
Not Married	80	83	76	88	44	51	32	18

WHAT CAN BE DONE?

- Initiate and support statewide and district-level school health coordinating councils.
The statewide council will serve as a model, resource and funding vehicle for the district councils
- Form a statewide, permanent alliance to coordinate and promote public education on cancer
- Decrease our exposure to cancer causing chemicals or substances

“Justin was diagnosed with a malignant brain tumor in July of 1998, four weeks before he was to start his freshman year at Penn State. He died two years later. It seemed as though I was holding my infant son once again as I looked down at his face and half-closed eyes. I made a promise to him that we would find out what caused his cancer. That promise rings in my ears...to find the answers to questions he never wanted another parent to have to ask. Why did my child get cancer and why did he have to die?”

MARY ELLEN NANTAS OF NEWARK WHOSE SON, JUSTIN, DIED OF CANCER IN 2000 AT AGE 19.



REDUCE THE THREAT OF CANCER FROM THE ENVIRONMENT

WHY?

Exposure to cancer causing substances can occur anywhere in our daily environment including our home, our workplace, during our commutes, the buildings we enter and where we spend time outside. If we know more about our environment, we can make healthy decisions and good policies. To guide us, it is also important that we collect data to have a better understanding of environmental links to cancer.

WHAT CAN BE DONE?

The Council recognizes that carcinogens can be present in the air we breathe, the water we drink, the food we eat, things that touch our skin and many other places. The decision to address the following issues on a limited basis was based on the amount of reliable information that is available and the potential to effect a change in exposure levels. It is the recommendation of the Advisory Council that the Permanent Council have an environmental committee to oversee implementation of these recommendations and that carcinogens from water, food and other sources be included in future recommendations on a more comprehensive basis.

- Reduce exposure to carcinogenic substances in the ambient environment
- Coordinate with federal OSHA to reduce workplace carcinogenic risk and exposure
- Reduce exposure to carcinogens in the indoor environment

INCREASE OUR KNOWLEDGE ABOUT CANCER INCLUDING ENVIRONMENTAL CAUSES

WHY?

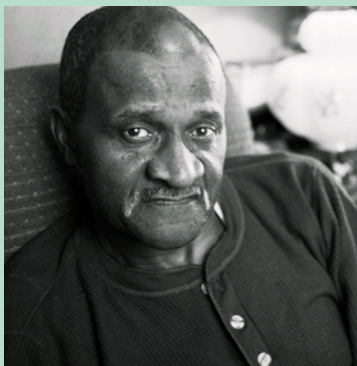
If we are to make sound decisions about controlling cancer in Delaware we must have reliable and complete information. Data can tell us about what we are doing well and where improvements are necessary. Even though we are a state with one of the most complete cancer registries in the nation, there are still improvements to be made. Collecting data is only the beginning—it is meaningless if we don't use it to target our efforts and use information to make real and lasting change.

ARE SOME OF US MORE LIKELY TO BE AFFECTED BY THIS THAN OTHERS?

Without data and information, there would be no way of demonstrating that there are some of us more affected by cancer than others. While we often think of these differences in terms of race and ethnicity, we also know that a heavier burden falls on those of us with lower incomes, less education and no health insurance.

WHAT CAN BE DONE?

- Estimate the number of cancers that can be prevented and the number of deaths that can be avoided by primary prevention and early detection. Prioritize our common and preventable cancers
- Improve the collection and reporting of cancer incidence and mortality data
- Conduct a survey to examine the importance of past exposure to today's cancer rates



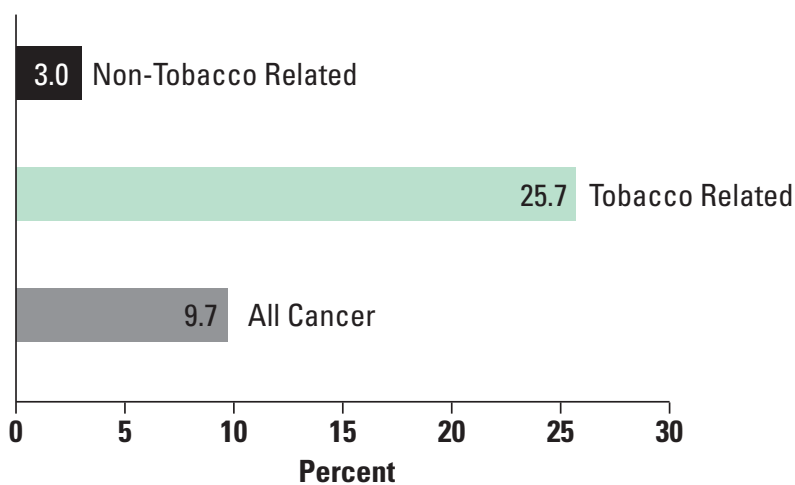
“I smoked for 40 years or more. I never had any problems. Then last May, I had a pain in my shoulder. When my doctor told me to have it X-rayed, they discovered a spot on my lung. It was a total shock. They took a piece of my lung in July.” | STERLIN BECKWITH, GEORGETOWN.

REDUCE TOBACCO USE AND EXPOSURE

WHY?

Tobacco-related cancers account for more than one third of all the cancers in Delaware. Delawareans smoke at a higher rate than people in 22 other states. Tobacco smoke affects smokers and non-smokers and cancer is only one of many health problems caused by tobacco. Delaware has recently increased its tobacco control spending by more than five times, but there are still actions we can take that will help protect us from the effects of tobacco.

**PERCENTAGE INCREASE OF DELAWARE CANCER
AGE-ADJUSTED INCIDENCE VS. U.S. ESTIMATE, 1994-1998**



Tobacco related cancers: lung, bladder, larynx, esophageal, kidney, pancreas, oral, cervix.

(Delaware: Delaware Cancer Registry, Delaware Division of Public Health; U.S.: Surveillance, Epidemiology and End Results (SEER) Program, National Cancer Institute)

- If not for lung cancer, the overall cancer death rate in the United States would have declined by 14% since 1950. Instead, it has increased 22%. *(Surveillance, Epidemiology and End Results (SEER) Program, National Cancer Institute)*
- The death rate from lung cancer has increased only slightly overall, but is increasing more rapidly among women. In recent years, lung has surpassed breast as the leading cause of cancer death among women. *(National Center for Health Statistics)*
- Delaware has the 32nd lowest cigarette tax in the nation. *(Campaign for Tobacco-Free Kids 2001)*

WHAT CAN BE DONE?

- At a minimum, fund comprehensive statewide tobacco control activities at \$8.6 million (CDC recommended minimum.)
- Strengthen, expand and enforce Delaware's Clean Indoor air Act to include public places and workspace environments
- Strongly endorse, coordinate and implement the action plan recommendations presented in "A Plan for A Tobacco-Free Delaware"
- Expand and sustain a comprehensive public awareness campaign on the health risks of tobacco use and support resources available to help quit smoking
- Increase the Delaware excise tax on tobacco products to \$0.74 and seek to identify other potential funding sources to support tobacco and cancer control efforts
- Catalog all tobacco control activities in Delaware and develop and disseminate a comprehensive public resource guide

WHAT IF 30 years ago, no one in Delaware smoked...

THEN instead of our lung cancer incidence rate today being 10% above the national estimate, it would be 12% below the national estimate. *(Delaware Cancer Registry, Delaware Division of Public Health; Surveillance, Epidemiology and End Results (SEER Program)*

WHAT IF Delaware's excise tax on tobacco products were increased by \$0.50 per pack...
THEN

4,200 fewer Delaware kids would start smoking

1,300 Delaware kids would be saved from a smoking death as an adult

4,000 fewer Delaware adults would smoke

\$83.4 million in long-term health care costs would be saved

\$49 dollars each year in revenue would be generated *(Source: Campaign for Tobacco-Free Kids, 2001)*

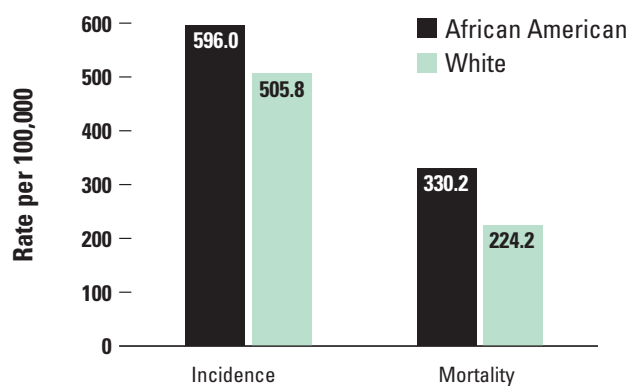


ELIMINATE UNEQUAL CANCER BURDEN

WHY?

Our race, ethnicity, gender, where we live, income and whether we have insurance affect our chances of getting cancer, how early it is diagnosed and whether we live or die.

DELAWARE FIVE YEAR RACE-ADJUSTED INCIDENCE AND MORTALITY RATES PER 100,000, 1995-1999



Delaware: Delaware Cancer Registry, Delaware Division of Public Health; U.S.: Surveillance, Epidemiology and End Results (SEER) Program, National Cancer Institute.

Delaware Health Statistics Center, Delaware Division of Public Health; National Center for Health Statistics.

Note: 1999 incidence data are provisional.

Rates are age-adjusted to 2000 U.S. standard population.

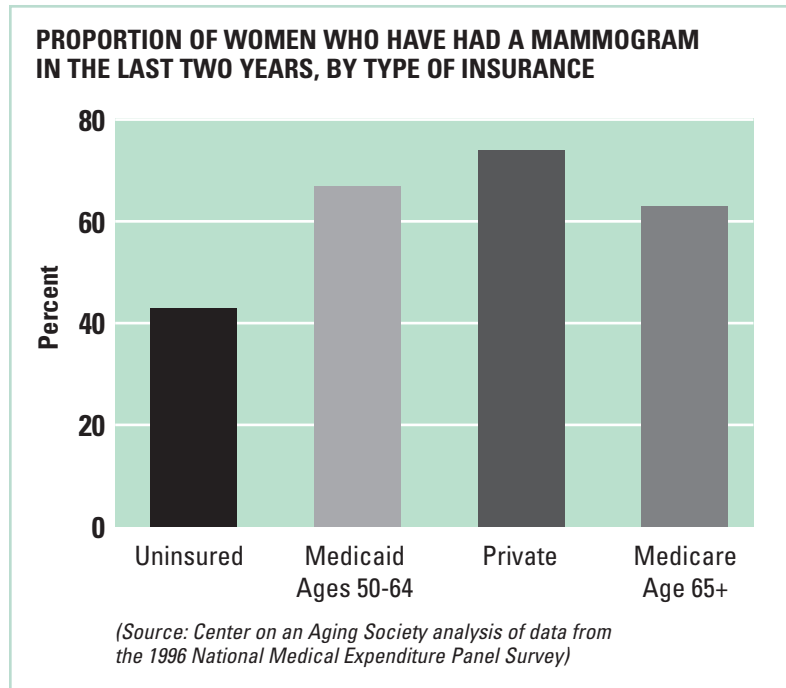
- White residents are more likely to have cancer diagnosed at an earlier stage than are African American residents (49% diagnosed in early stages for white, 43% for AA).

Note: 1999 data are provisional (Delaware Health Statistics Center, Delaware Division of Public Health)

- Residents in Sussex County are less likely to have cancer diagnosed at an earlier stage than are residents in Kent County and New Castle County.

Note: 1995-1999; 1999 data are provisional (Delaware Health Statistics Center, Delaware Division of Public Health)

How Insurance Status Affects Screening Rates



WHAT CAN BE DONE?

Some Delawareans are more likely to get and die from cancer and the differences are often astounding. The Council recognized this as a significant problem and put special emphasis on ways to eliminate these differences. While the following recommendation is the only one that specifically targets this problem, it is also an integral part of nearly every other recommendation in this report. Efforts must be made on all levels to realize change.

- Compile and analyze existing data on health disparities and cancer into a report and inform through a public education campaign



“The recommendations of this Council will be a powerful force for change. We know what needs to be done, who should do it and where we go from here. Delaware has the opportunity to take action and make positive changes in the lives of all its citizens.”

WILLIAM W. BOWSER, ESQUIRE, OF WILMINGTON, DE, COUNCIL CHAIR WHOSE SON, MICHAEL, IS A LEUKEMIA SURVIVOR.

IMPLEMENTATION OF RECOMMENDATIONS

WHY?

The recommendations provided in this report provide a blueprint for action. If implemented, fewer people will die from cancer in Delaware, more people will get quality cancer care, and eventually fewer people will get cancer. However, none of this will happen unless the state institutionalizes a process to continue the work of the Council.

WHAT CAN BE DONE?

- Create and maintain a Permanent Council, managed by a neutral party, that reports directly to the Governor to oversee implementation of the recommendations and comprehensive cancer control planning. The Council should have medical, environmental, research, policy and education committees that continually evaluate and work to improve cancer care and cancer-related issues in Delaware.
- Develop and implement a state cancer control and prevention plan. The plan should be based on CDC guidelines and involve multiple stakeholders with assigned responsibilities.

FULL COUNCIL RECOMMENDATIONS

ADVISORY COUNCIL ON CANCER



COLORECTAL CANCER

“I had none of the risk factors for colon cancer and no known family history of the disease. At age 49, I awoke from surgery with a diagnosis of stage IV colon cancer, with metastases to the lymph nodes and liver. Delaware family doctors must learn to take the symptoms of colorectal cancer seriously, and in the case of women, gynecologists need to recommend colonoscopy as a standard screening method. High standards of colorectal cancer care and monitoring should be available to all patients, and health insurance companies and employers would do well to offer the highest standards of screening. Emotional support is just as important as the latest clinical advances.” | BRENDA BILLINGSLEY, WILMINGTON.

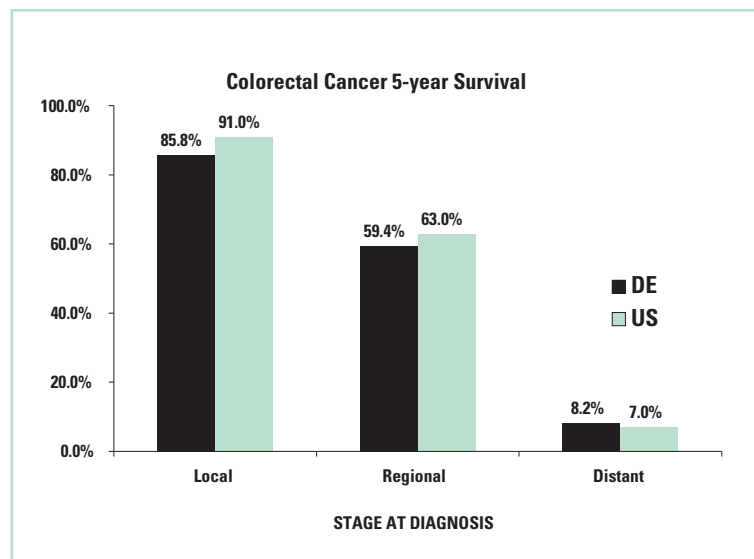
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COLORECTAL CANCER 5-YEAR SURVIVAL RATES BY STAGE OF DIAGNOSIS, U.S. AND DELAWARE, 1994-1998

(Delaware Cancer Registry, Delaware Division of Public Health; Centers for Disease Control and Prevention 1999)



ARE SOME OF US MORE LIKELY TO BE AFFECTED BY THIS THAN OTHERS?

In 1999, percent of Delawareans reporting ever having a colorectal cancer screening:

- White: 45.3%
- African American: 39.6%
- Hispanic: 19.0%

Rates of death due to colorectal cancer in Delaware were 59% higher among African Americans than among whites.

(Behavioral Risk Factor Surveillance Survey, Delaware Division of Public Health, 1999; Delaware Cancer Registry, Delaware Division of Public Health)

Create a comprehensive statewide colorectal cancer screening and advocacy program

The following specific tasks and activities should be included:

<i>TASK/ACTIVITY</i>	<i>RESPONSIBLE PARTY</i>	<i>TIMEFRAME</i>	<i>COSTS</i>	<i>POTENTIAL SOURCES</i>
1. Outreach to the six major health systems (Nanticoke, Beebe, Bayhealth, Christiana Care, Veterans Hospital and St. Francis) to participate in a comprehensive, community-focused colorectal cancer screening and advocacy program (may be Request For Proposal)	Delaware Healthcare Association, DHSS	Year 1	None	
2. Develop an evaluation plan	DHSS	Year 1 and ongoing	\$50,000	Delaware Health Fund, Proposed tobacco excise tax, existing resources
3. Hire project screening advocates	Health systems	Year 2	\$250,000 annually	Same as above
4. Market project and services	DHSS, Health systems	Year 2 and ongoing	\$100,000	Same as above
5. Project start up	All	Year 2	\$125,000	Same as above
6. Operational support	DHSS	Year 1 and ongoing	\$25,000 annually	Same as above

Points to note:

- Each program will include at least one full-time professional position of “Project Screening Advocate” housed within the hospital system. The advocate works with communities and organizations within the surrounding area to develop and oversee the program according to the specific needs of each.
- The advocate will be responsible for providing culturally sensitive outreach and recruitment, assuring screening access and scheduling, monitoring screening compliance, and assuring prompt clinical evaluation and follow-up to positive testing.

Reimburse for colorectal cancer screening of uninsured Delawareans age 50 and older*The following specific tasks and activities should be included:*

<i>TASK/ACTIVITY</i>	<i>RESPONSIBLE PARTY</i>	<i>TIMEFRAME</i>	<i>COSTS</i>	<i>POTENTIAL SOURCES</i>
1. Establish a \$1.5 million annual allocation to colorectal cancer screening for the uninsured	General Assembly, Executive Branch	Year 1	None	Proposed tobacco excise tax
2. Establish a system for billing and payment for colorectal cancer screenings whereby funds would be paid directly to health providers for reimbursable services based on Medicare rates	DHSS	Year 1	Dependent on system developed	Proposed tobacco excise tax
3. Provide colorectal cancer screening for uninsured Delawareans age 50 and older that includes a comprehensive monitoring and evaluation program	Dependent on system developed	Year 2 and ongoing	\$1.5 million annually	Proposed tobacco excise tax
4. Revise allocation based on actual costs and projections	General Assembly	Annually	None	

Points to Note:

- Population age 50-64 = 111,507
- Population uninsured age 50-64 = 18,220 based on estimates from the University of Delaware's Center for Applied Demography and Survey Research, Delaware Demographic Database, 1994-1998 average uninsured population
- Screening = 1 colonoscopy every ten years
- Estimated cost per screen = \$500
- Assumes 80% compliance, all screenings done in next 5 years
- Cost estimates do not include changes in infrastructure

Case manage every Delawarean with an abnormal colorectal cancer screening test.*The following specific tasks and activities should be included:*

<i>TASK/ACTIVITY</i>	<i>RESPONSIBLE PARTY</i>	<i>TIMEFRAME</i>	<i>COSTS</i>	<i>POTENTIAL SOURCES</i>
1. Establish a \$900,000 annual allocation for case management of Delawareans with abnormal colorectal cancer screening results	General Assembly, Executive Branch	Year 1	None	Proposed tobacco excise tax
2. Establish a system for case managing every Delawarean with an abnormal colorectal cancer screening using current systems as models that include a comprehensive monitoring and evaluation system	DHSS	Year 1	To be determined	Proposed tobacco excise tax
3. Begin case management system	Dependent on system developed	Year 2 and ongoing	\$900,000 annually	Proposed tobacco excise tax
4. Revise allocation based on actual costs and projections	General Assembly	Annually	None	

WHAT IF THEN

80% of Delawareans age 50 and older received a colonoscopy and appropriate follow-up every 10 years?

Delaware would have the lowest colorectal cancer death rate in the country, decreasing by more than 60%.

(National Center for Health Statistics; Ransohoff and Sandler 2002; Colditz 2000)

The gap in death rates between whites and minorities in Delaware would begin to close.

PROVIDING THE HIGHEST
QUALITY OF HEALTH CARE

“After a pelvic sonogram, my internist and a radiologist showed me 20 tumors in my abdomen. I waited a week to be scheduled for surgery and another month for the procedure to take place. This was after I had had a complete physical three months before and was told I was in fine health. In Delaware, we need to update our diagnostic tools and recommend them to a patient, talk directly to the patient and educate them about alternatives. Sensitivity training should start at the front door.” | REBECCA WOLHAR, WILMINGTON.



PROVIDE THE HIGHEST QUALITY OF CARE FOR EVERY DELAWAREAN DIAGNOSED WITH CANCER

WHY?

The Council heard testimony from people with cancer. Their compelling stories detailed frustration with the overwhelming and fragmented health care system. A team approach that guides us on all levels, medically, emotionally and financially, can ease the burden and help us make informed choices. Every Delawarean also has the right to high-quality, compassionate health care that follows the latest cancer screening recommendations and treatment options. The difference can be a cancer found early and cured rather than one where delayed treatment leads to the cancer spreading and increasing the chance of death.

- Some cancer centers in the United States are taking a team approach to cancer care. In addition to oncologists and surgeons, the teams often include professionals like oncology nurses, case managers, social workers and dieticians.
- More than 600 cancer-related services are available throughout Delaware. The reality is many barriers hinder access to these resources. A case manager for every cancer patient would link patients and resources.
- Many Delawareans are already getting routine checkups. These visits must be used to encourage routine cancer screenings and promote prevention. A comprehensive evaluation of cancer screening practices will increase early detection.

Percent of Delawareans who have visited a doctor in the past year for a routine checkup

Age 45-54: 70.2%

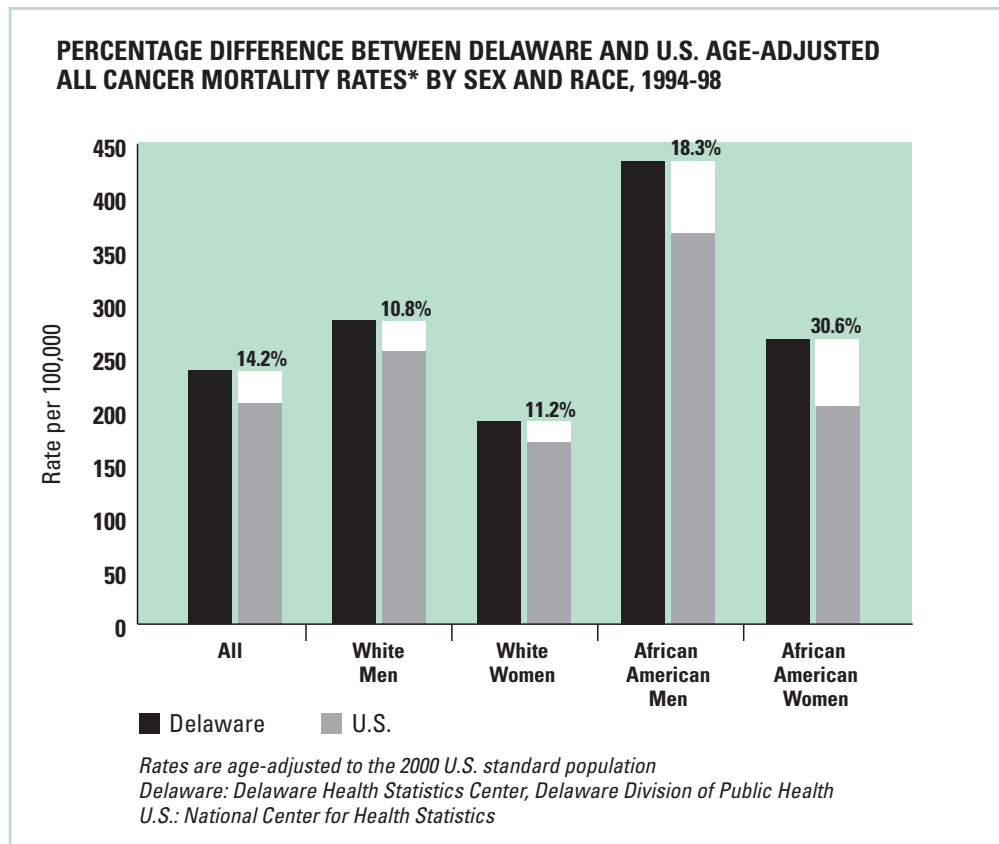
Age 55-64: 86.2%

(Behavioral Risk Factor Surveillance Survey, Delaware Division of Public Health, 2000)

- On average, the cost of care in the first six months of treatment is 33% less when cancers are found in the early stage (in situ) instead of the late stage (distant).

(Eddy 1990; Taplin, Barlow et al. 1995; Penberthy, Retchin et al. 1999)

ARE SOME OF US MORE LIKELY TO BE AFFECTED BY THIS THAN OTHERS?



The rate at which people die from cancer in Delaware is consistently higher than the nation. This gap in cancer deaths can be attributed to the type of cancers, lack of screening and the need for improved access to state-of-the-art care.

WHAT CAN BE DONE?

The Council recognizes that quality of care issues in all levels of cancer care must be addressed on an ongoing basis and the recommendations that follow are first steps. It is the recommendation of the Advisory Council that the Permanent Council (see Implementation of Recommendations, Page 66) have a Medical Committee, led by oncologists, to oversee implementation of these and future recommendations to make Delaware a model for cancer care. The committee will require administrative support and should include professionals in a range of disciplines addressing cancer care such as pediatrics, surgery, dietetics, palliative care and social work.

Provide a care coordinator who is part of a statewide-integrated system to every person diagnosed with cancer in Delaware. Care coordinators will be culturally competent to overcome the language, ethnicity and gender barriers.

The following specific tasks and activities should be included:

<i>TASK/ACTIVITY</i>	<i>RESPONSIBLE PARTY</i>	<i>TIMEFRAME</i>	<i>COSTS</i>	<i>POTENTIAL SOURCES</i>
1. Establish a \$2 million annual allocation for the development of a core group of cancer care coordinators to link patients with medical and support services. 25 coordinators statewide recommended.	General Assembly, Executive Branch	Year 1	None	Proposed tobacco excise tax
2. Define and oversee the development of the care coordinator program that includes a statewide system to link and maintain systems for multi-disciplinary care of all cancer patients	Permanent Council – Medical Committee	Year 1 and ongoing	see implementation recommendations	Delaware Health Fund, proposed tobacco excise tax
3. Conduct care coordination program for all Delawareans diagnosed with cancer	Permanent Council-Medical Committee	Year 2 and ongoing	\$2 million annually	Delaware Health Fund, proposed tobacco excise tax

Assure insurance coverage for state-of-the-art cancer clinical trials

The following specific tasks and activities should be included:

TASK/ACTIVITY	RESPONSIBLE PARTY	TIMEFRAME	COSTS	POTENTIAL SOURCES
1. Amend Section 3559 G (a)(3)(c) of the Delaware Code and Regulation 69.505 A 3 to include cancer prevention trials	General Assembly, Executive Branch	Year 1	None	
2. Encourage the involvement of all seven major Delaware health systems (Nanticoke, Beebe, Bayhealth, Christiana Care, Veterans Hospital, A.I. duPont Hospital for Children and St. Francis) in the establishment of a statewide Cooperative Oncology Group in keeping with the American Cancer Society and the Coalition of National Cooperative Groups: A partnership for Cancer Clinical Trials	Delaware Healthcare Association, DHSS, Medical Society of Delaware	Year 1	None	

Point to note:

Recently passed legislation assures insurance coverage for treatment clinical trials. This recommendation adds prevention clinical trials to those covered services.

Institute centralized credentialing reviews of medical practices by third-party payors that include cancer screening, prevention, early detection and treatment practices as well as ongoing provider education.

The following specific tasks and activities should be included:

TASK/ACTIVITY	RESPONSIBLE PARTY	TIMEFRAME	COSTS	POTENTIAL SOURCES
1. Obtain approval for centralized credentialing from National Center for Quality Assurance	Permanent Council	Year 1	None	
2. Define and oversee the development and continuing quality of the credentialing program	Permanent Council — Medical Committee	Year 1 and ongoing	<i>see note below</i>	
3. Develop and implement a comprehensive program, managed by a vendor selected through Request for Proposal process, that includes: <ul style="list-style-type: none"> • all data elements required by third party payors • all appropriate cancer screening, diagnosis and treatment data elements • education of medical providers and office staff • practice reviews/ data collection • development of practice-specific recommendations • individualized coaching for improvement • evaluation and reporting of progress to Permanent Council 	Permanent Council — Medical Committee, contracted vendor, third-party payors	Year 1 and ongoing	\$210,000 annually	Third-party payors

Point to note:

Practices are currently evaluated by individual third party payors on the content of their records, but effective feedback on how to improve screening methods is lacking. Centralizing the review process would eliminate duplication of efforts and decrease costs. The educational feedback to the individual practices would be comprehensive in nature, tailored to their needs and focused on improving cancer-screening rates.

Support training for physicians and other health care providers in symptom management and end-of-life care approaches

The following specific tasks and activities should be included:

TASK/ACTIVITY	RESPONSIBLE PARTY	TIMEFRAME	COSTS	POTENTIAL SOURCES
1. Promote and fund "Education for Physicians on End-of-Life Care" (EPEC) and "End-of-Life Nursing Education Consortium" (ELNEC) (existing programs). Two programs per county each year.	DHSS, Medical Society of Delaware	Year 2 and ongoing	\$1,800 annually	proposed tobacco excise tax, Robert Wood Johnson Foundation
2. Establish physician and related health care professional accrediting based on EPEC program content.	DHSS, Medical Society of Delaware	Year 2	see note below	
3. Require that all patient advocates receive credentialing in pain management, palliative care and end-of-life care issues.	DHSS, health systems (see recommendation on care coordinators)	Year 2	see note below	Robert Wood Johnson Foundation
4. Fund broad based community education programs related to end-of-life choices (to include long-term care, palliative care and hospice care).	DHSS	Year 2	To be determined	

Points to note:

EPEC and ELNEC are nationally recognized education programs that educate physicians and nurses in essential clinical competencies around end-of-life care. Existing efforts include Delaware End-of-Life Consortium, Christiana Care Health Systems and Delaware Hospice. This recommendation seeks to enhance existing programs. Coordination with existing Continuing Medical Education (CME) sources throughout Delaware could enhance education to the medical community.

WHAT IF

Every person diagnosed with cancer in Delaware had a qualified case manager to make sure they had access to all the services they needed...

THEN differences in the death rates between whites and minorities would decline

THEN many barriers to care could be eliminated

THEN the quality of life for people with cancer would be better

THEN treatment outcomes would improve

WHAT IF

Physicians improved their cancer screening practices...

THEN Cancer screening rates would increase

THEN follow-up on abnormal results would improve

THEN cancers would be diagnosed and treated earlier

THEN cancer death rates would decrease

REIMBURSEMENT OF CANCER TREATMENT COSTS

"I was in the Screening for Life program. They paid for my mammogram and biopsy but nothing else. My radiation bill alone was \$10,000. It's like once you have cancer, they'll tell you you have it and then you're on your own. My husband also has cancer. I'm on disability and he's on Social Security. There's just no extra money for medical bills. This has been a financial tragedy for us. I don't know what we're going to do." | SHIRLEY MOORE, WILMINGTON.



PAY FOR CANCER TREATMENT FOR THE UNINSURED

WHY? 275 Delawareans without health insurance will be diagnosed with cancer this year. *(Delaware Cancer Registry, Delaware Division of Public Health; University of Delaware's Center for Applied Demography and Survey Research, 1994-1998)*

THE AVERAGE COST OF THE FIRST YEAR OF CANCER TREATMENT

(Eddy 1990; Taplin, Barlow et al. 1995; Penberthy, Retchin et al. 1999)

TYPE OF CANCER	STAGE OF DIAGNOSIS	AVG COST OF FIRST YEAR TREATMENT
Colorectal	Local	\$34,362
Colorectal	Distant	\$40,670
Breast	Local	\$20,348
Breast	Distant	\$34,396
Cervical	Local	\$30,304
Cervical	Distant	\$48,560

WHAT CAN BE DONE?

Reimburse the cost of cancer treatment for every uninsured Delawarean diagnosed with cancer up until one year after diagnosis

The following specific tasks and activities should be included:

TASK/ACTIVITY	RESPONSIBLE PARTY	TIMEFRAME	COSTS	POTENTIAL SOURCES
1. Establish a \$5.0 million annual allocation for cancer treatment of the uninsured	General Assembly, Executive Branch	Year 1	None	Proposed tobacco excise tax
2. Establish a system for billing and payment for cancer treatment whereby funds would be paid directly to health providers for reimbursable services based on Medicare rates. Develop a comprehensive monitoring and evaluation program	DHSS	Year 1	To be determined	Proposed tobacco excise tax
3. Begin reimbursements for treatment for uninsured Delawareans diagnosed with cancer based on established system	DHSS	Year 2	\$5.0 million annually	Proposed tobacco excise tax
4. Revise allocation based on actual costs and projections	General Assembly	Year 2 and annually	None	

Points to note:

Billing and payment system to be determined and should take into consideration existing programs that could be built on or used as a model (e.g., Medical Society of Delaware's MEDNET).

Estimates based on:

- Medicare reimbursements for cancer care
- 10% uninsured population
- Current Delaware cancer incidence rates and stage at diagnosis
- Costs for one year of treatment assumed to be twice the cost of six months of care



PROVIDE RELIABLE AND
USEABLE CANCER INFORMATION

“I put off having my annual mammogram because we didn’t have insurance at the time. I was persuaded to get one through Screening for Life. I was just two months late for it, but it showed a mass in my breast that turned out to be cancer. If I had not had the mammogram, it would’ve probably been too late for me. It was an aggressive tumor.” | NELLIE FOSTER, DOVER.





PROVIDE RELIABLE AND USEABLE CANCER INFORMATION

WHY?

Cancer is a complex disease. New information about causes, early detection and treatment is available to us every day. We need to have reliable and useable information in order to make healthy choices. The decisions we make today will affect Delaware's cancer rates in the future.

ARE SOME OF US MORE LIKELY TO BE AFFECTED BY THIS THAN OTHERS?

Minority populations are less likely to get routine cancer screening tests. As education and income levels decrease, cancer screening rates also decrease. Cancer-related public education is inadequate to ensure individuals are able to make informed lifestyle and cancer care decisions. Education efforts must be carefully targeted to communities where cancer prevention can make the most difference.

PROPORTION OF DIFFERENT GROUPS EVER SCREENED FOR CANCER*(Center on an Aging Society, 2000)*

	Prostate Cancer	Breast Cancer		Cervical Cancer	Colorectal Cancer			Skin Cancer
	Men 50+	Women 40+		Women 40+	Adults 50+			All Adults
<i>Screening Service</i>	<i>Exam (%)</i>	<i>Exam (%)</i>	<i>Mammogram (%)</i>	<i>Pap Test (%)</i>	<i>Blood Stool Test (%)</i>	<i>Digital Rectal Exam (%)</i>	<i>Proctoscopic Exam (%)</i>	<i>Exam (%)</i>
ALL GENDER	—	—	—	—	48	57	36	21
Male	84	—	—	—	48	63	41	20
Female	—	87	80	91	48	52	32	22
RACE								
White	86	88	81	92	49	59	37	23
Black	80	83	75	90	40	48	28	11
INCOME								
<\$20,000	80	79	71	86	42	49	30	16
\$55,000+	88	94	88	96	56	65	42	27
RESIDENCE								
Urban	86	87	81	91	50	58	37	22
Rural	78	86	78	92	42	54	33	19
MARITAL STATUS								
Married	86	89	82	94	50	61	38	23
Not Married	80	83	76	88	44	51	32	18

WHAT CAN BE DONE?

Initiate and support statewide and district-level school health coordinating councils. The statewide council will serve as a model, resource and funding vehicle for the district councils.

The following specific tasks and activities should be included:

TASK/ACTIVITY	RESPONSIBLE PARTY	TIMEFRAME	COSTS	POTENTIAL SOURCES
1. Draft and pass enabling legislation	General Assembly	Year 1		
2. Use current coordinator position at DOE as base for planning and connect to DPH liaison (Phase 1)	DOE, DHSS	Year 1	\$100,000 all Phase 1 activities	Proposed tobacco excise tax
3. Identify council structure, charge, potential participants, priorities and job descriptions (Phase 1)		Year 1		
4. Apply for CDC infrastructure grant (Phase 1)	DOE with support of DHSS	Year 1		
5. Conduct needs assessments (Phase 1)	DOE, DHSS	Year 1	Existing resources	
6. Select, fund, implement and evaluate two pilot councils at the district level (Phase 2)	Statewide council	Year 2	\$100,000 all Phase 2 activities	Proposed tobacco excise tax, CDC grant
7. Work with districts to gain participation in Phase 3 (Phase 2)	Statewide council	Year 2		
8. Apply model statewide (include .5 Full Time Equivalent (FTE) in each district) (Phase 3)	Statewide council, all districts	Years 3-4	\$195,000 all Phase 3 activities	Proposed tobacco excise tax, CDC grant
9. Oversight and evaluation (Phase 3)	Statewide council	Year 3 and ongoing		

Form a statewide, permanent alliance to coordinate and promote public education on cancer.

The following specific tasks and activities should be included:

<i>TASK/ACTIVITY</i>	<i>RESPONSIBLE PARTY</i>	<i>TIMEFRAME</i>	<i>COSTS</i>	<i>POTENTIAL SOURCES</i>
1. Solicit participation in the alliance of all stakeholders	Permanent Council — Education Committee	Year 1	None	
2. Select an independent facilitator to assist the alliance in needs assessment, planning, organizational structure and program focus	Permanent Council, Alliance	Year 1	\$190,000 all activities Tasks 2 through 6.	Proposed tobacco excise tax
3. Develop a unified mission to provide consumer information and education on prevention, screening, detection and treatment, best practices for care and available resources	Alliance, facilitator	Year 1		
4. Investigate methods to reach populations at higher risk for cancer with screening, early detection and prevention messages	Alliance	Year 2		
5. Collect and integrate data on public education in cancer	Alliance, facilitator	Year 2		
6. Conduct a statewide summit to review findings and opportunities for integration, collaboration and unique product development	Alliance	Year 3		

Point to note:

\$190,000 estimate includes materials and operational costs to support the needs assessment, planning, data collection and integration, evaluation of media formats and messages, and administrative costs for sustaining this initiative.

(Brownson and Ross 1999)





REDUCE ENVIRONMENTAL
CANCER THREATS

“Justin was diagnosed with a malignant brain tumor in July of 1998, 4 weeks before he was to start his freshman year at Penn State. He died two years later. It seemed as though I was holding my infant son once again as I looked down at his face and half-closed eyes. I made a promise to him that we would find out what caused his cancer. That promise rings in my ears...to find the answers to questions he never wanted another parent to have to ask. Why did my child get cancer and why did he have to die?”

MARY ELLEN NANTAIS OF NEWARK WHOSE SON, JUSTIN,
DIED OF CANCER IN 2000 AT AGE 19.

REDUCE THE THREAT OF CANCER FROM THE ENVIRONMENT

WHY?

Exposure to cancer-causing substances can occur anywhere — including our home, our workplace, during our commutes, the buildings we enter and where we spend time outside. If we know more about our environment, we can make healthy decisions and good policies. To guide us, it is also important that we collect data to have a better understanding of environmental links to cancer.

WHAT CAN BE DONE?

The Council recognizes that carcinogens can be present in the air we breathe, the water we drink, the food we eat, things that touch our skin and many other places. The decision to address the following issues on a limited basis was based on the amount of reliable information that is available and the potential to effect a change in exposure levels. It is the recommendation of the Advisory Council that the Permanent Council have an Environment Committee to oversee implementation of these recommendations and that carcinogens from water, food and other sources be included in future recommendations on a more comprehensive basis.

Reduce exposure to carcinogenic substances in the ambient environment

The following specific tasks and activities should be included:

TASK/ACTIVITY	RESPONSIBLE PARTY	TIMEFRAME	COSTS	POTENTIAL SOURCES
A. Related to Delaware Air				
A1. Conduct specialized ambient air quality monitoring to determine actual concentrations of air toxins in Delaware	DNREC	Year 1	\$300,000 plus \$300,000 existing resources	Proposed tobacco excise tax
A2. Evaluate the types of cancers associated with those substances found at elevated levels and compare to those cancers for which Delaware is elevated in incidence and mortality (link databases)	DNREC, DHSS	Year 2	Existing resources	
A3. Notify the public of past and current levels of carcinogenic substances that are monitored in	Delaware.DNREC, Permanent Council	Year 2	Existing resources	
A4. Acting on the information from monitoring, develop and implement strategies to reduce air contamination from those sources	DNREC, Permanent Council	Year 2 and Ongoing	Existing resources	

Reduce exposure to carcinogenic substances in the ambient environment

(continued)

TASK/ACTIVITY	RESPONSIBLE PARTY	TIMEFRAME	COSTS	POTENTIAL SOURCES
B. Related to Delaware Drinking Water				
B1. Expand monitoring of state's shallow aquifers for pesticides by increasing the number of pesticides/herbicides and their degradants analyzed	DDA, DHSS, DNREC		\$80,000 annually to support DDA monitoring network	U.S. EPA
B2. Initiate screening of all public water systems using shallow wells. Continue monitoring of public water systems and private shallow wells near known hazardous waste sites for cancer-causing substances not currently regulated by the U.S. EPA or the state	DHSS, DNREC	Year 1 and ongoing	\$400,000 annually	Hazardous Substance Control Act (HSCA), proposed tobacco excise tax, increase fees for services to public water systems
B3. Evaluate the types of cancers associated with those substances found at elevated levels and compare to those cancers for which Delaware is elevated in incidence and mortality	DHSS	Year 2 and ongoing	Existing resources	
B4. Notify the public of past and current levels of carcinogenic substances that are monitored in Delaware	DHSS, Permanent Council	Year 2 and ongoing	Existing resources	
B5. Acting on the information from monitoring, develop and implement strategies to reduce water contamination from those sources	DHSS, Permanent Council	Year 2 and ongoing	Existing resources	N/A
C. Related to Delaware Waterways				
C1. Increase location, frequency, and number of fish sampled, from 20 total samples to 40 total samples annually	DNREC, DHSS	Years 1-3	\$50,000 per year	Proposed tobacco excise tax
C2. Determine the level of awareness and actual compliance rates with fish advisory information and develop recommendations for improvement	DNREC, DHSS	Years 1 and 2	\$10,000 per year	Proposed tobacco excise tax
C3. Conduct an education/awareness campaign related to C2 above	DNREC, DHSS	Years 2 and 3	\$35,000 per year	Proposed tobacco excise tax
C4. Enhance on-site advisory information and warnings to include postings with metal and Tyvek® signs, tamper-resistant hardware, bilingual signs, and related literature	DNREC, DHSS	Years 1-3	\$30,000 per year	Proposed tobacco excise tax

Coordinate with federal OSHA to reduce workplace carcinogenic risk and exposure

The following specific tasks and activities should be included:

<i>TASK/ACTIVITY</i>	<i>RESPONSIBLE PARTY</i>	<i>TIMEFRAME</i>	<i>COSTS</i>	<i>POTENTIAL SOURCES</i>
1. Establish full cooperative agreement with federal OSHA leading to the creation of an Office of Occupational Health to monitor, investigate, and enforce workplace OSHA violations and identify populations at risk from occupational exposure to carcinogens initially, but with intent to extend to other toxic hazards	General Assembly, Executive Branch	Year 1	\$400,000, (Year 1) \$250,000 (Year 2 and on)	Proposed tobacco excise tax
2. Obtain exposure data for exposures to Delaware workplace carcinogens from OSHA	Office of Occupational Health	Year 1		
3. Review federal OSHA requirements limiting exposure from carcinogens and determine if there are gaps relevant to DE that need to be addressed regarding employee protection	Office of Occupational Health	Year 1		
4. Identify high-risk workers by reviewing the Toxic Release Inventory (TRI) data and targeting occupations not covered by OSHA at high risk for cancer	Office of Occupational Health	Year 2		
5. Implement educational, regulatory and "right-to-know" programs to reduce exposure	Office of Occupational Health	Years 3-4	\$50,000 annually	Proposed tobacco excise tax

Reduce exposure to carcinogens in the indoor environment

The following specific tasks and activities should be included:

<i>TASK/ACTIVITY</i>	<i>RESPONSIBLE PARTY</i>	<i>TIMEFRAME</i>	<i>COSTS</i>	<i>POTENTIAL SOURCES</i>
1. Create and promote new initiative to increase radon testing and provide financial assistance for remediation to low-income homeowners	DHSS	Year 1 and ongoing	\$75,000 annually	Delaware Health Fund
2. Require radon testing in all residential real estate transfers (model after lead testing requirements)	General Assembly	Year 1		
3. Create industry incentives (e.g., interest-free loans) for dry-cleaners to eliminate the use of cancer-causing solvents	DEDO, DNREC	Years 2-5	To be determined	DEDO Strategic Fund
4. Develop and maintain a broad-based public education campaign based on findings from the national Total Exposure Assessment Methodology (TEAM) studies (Research Triangle Institute 1996)	DNREC, DHSS	Year 1 and ongoing	\$80,000 (Year 1) \$50,000 (Years 2 on)	Proposed tobacco excise tax

INCREASE OUR KNOWLEDGE ABOUT CANCER
INCLUDING ENVIRONMENTAL CAUSES

WHY? If we are to make sound decisions about controlling cancer in Delaware we must have reliable and complete information. Data can tell us about what we are doing well and where improvements are necessary. Even though we are a state with one of the most complete cancer registries in the nation, there are still improvements to be made. Collecting data is only the beginning — it is meaningless if we don't use it to target our efforts and use information to make real and lasting change.

ARE SOME OF US MORE LIKELY TO BE AFFECTED BY THIS
THAN OTHERS?

Without data and information, there would be no way of demonstrating that there are some of us more affected by cancer than others. While we often think of these differences in terms of race and ethnicity, we also know that a heavier burden falls on those of us with lower incomes, less education, and no health insurance.

WHAT CAN BE DONE?

Estimate the number of cancers that can be prevented and the number of deaths that can be avoided by primary prevention and early detection. Prioritize our common and preventable cancers

The following specific tasks and activities should be included:

TASK/ACTIVITY	RESPONSIBLE PARTY	TIMEFRAME	COSTS	POTENTIAL SOURCES
1. Collect data on known/suspected risk factors and calculate the number of preventable cancer cases and deaths, by gender, race, and age group, for each risk factor	DHSS, Permanent Council	Year 1	\$50,000	Proposed tobacco excise tax
2. Collect data on cancer diagnosis by stage and calculate the number of preventable cancer deaths, by gender, race, and age group, with earlier detection	DHSS, Permanent Council	Year 1	\$50,000	Proposed tobacco excise tax
3. Summarize and distribute results to improve program planning and healthy lifestyle choices	DHSS, Permanent Council	Year 2	\$25,000	Proposed tobacco excise tax

Improve the collection and reporting of cancer incidence and mortality data*The following specific tasks and activities should be included:*

<i>TASK/ACTIVITY</i>	<i>RESPONSIBLE PARTY</i>	<i>TIMEFRAME</i>	<i>COSTS</i>	<i>POTENTIAL SOURCES</i>
1. Amend the Cancer Control Act to extend the time interval within which a newly diagnosed cancer case must be reported to DPH to 180 days, consistent with standards of the American College of Surgeons	General Assembly	Year 1	None	
2. Enforce reporting requirements. Impose fines for non-reporting	DHSS	Year 1	None	
3. Increase information collected by the cancer registry including demographics, occupational history, and exposures to certain risks	DHSS	Year 2 and ongoing	\$300,000 annually	Proposed tobacco excise tax
4. Improve reporting on death certificates of the cause of death by educating physicians on proper procedure	DHSS	Year 1 and ongoing	\$20,000 annually	Proposed tobacco excise tax
5. Introduce and pass legislation requiring hospitals to staff their registries with a certified tumor registrar	General Assembly	Year 1	None	
6. Provide certification training and annual continuing education for tumor registrars	DHSS	Year 1 and ongoing	Existing resources	
7. Reclassify the director position of Delaware Cancer Registry to a higher pay-grade	DHSS	Year 2	Existing resources	
8. Publish report annually that integrates most recent cancer incidence, mortality, and risk behavior data	DHSS	Year 1 and ongoing	Existing resources	
9. Fully staff the Delaware Cancer Registry and assure appropriate continuing education	DHSS	Year 1 and ongoing	\$40,000 annually	CDC grant, Delaware Health Fund

Improve the collection and reporting of cancer incidence and mortality data*(continued)*

<i>TASK/ACTIVITY</i>	<i>RESPONSIBLE PARTY</i>	<i>TIMEFRAME</i>	<i>COSTS</i>	<i>POTENTIAL SOURCES</i>
10. Expand population-based survey of present and past tobacco use and exposure to environmental tobacco smoke (ETS). Report statistically valid results by age, race, income, educational level, occupation, gender, and zip code.	DHSS	Year 2	\$100,000	Proposed tobacco excise tax
11. Develop a public education campaign on cancer rates and their age-adjustment to the 2000 U.S. standard population	DHSS, Governor's office	Year 1	Existing resources	
12. Evaluate the ability to standardize race and ethnicity data collection across cancer related data sets	DHSS	Year 2	\$25,000	Proposed tobacco excise tax
13. Evaluate the ability to match cancer incidence and mortality records, including special software, and develop matching capabilities	DHSS	Year 2	\$25,000	Proposed tobacco excise tax

Conduct a survey to examine the importance of past exposure to today's cancer rates

The following specific tasks and activities should be included:

<i>TASK/ACTIVITY</i>	<i>RESPONSIBLE PARTY</i>	<i>TIMEFRAME</i>	<i>COSTS</i>	<i>POTENTIAL SOURCES</i>
1. Conduct a retrospective survey of individuals with cancer or family members of cancer patients to collect information on family history, occupation, lifestyle, diet, exercise, migration, etc. (include only those cancers for which the state is elevated in incidence or mortality). Obtain data necessary to determine which environmental factors may contribute to Delaware's heightened cancer rates.	DHSS	Years 1-3	\$250,000	Proposed tobacco excise tax
2. Analyze results and develop appropriate control strategies	DHSS	Year 3	\$50,000	Proposed tobacco excise tax





REDUCE TOBACCO
USE AND EXPOSURE

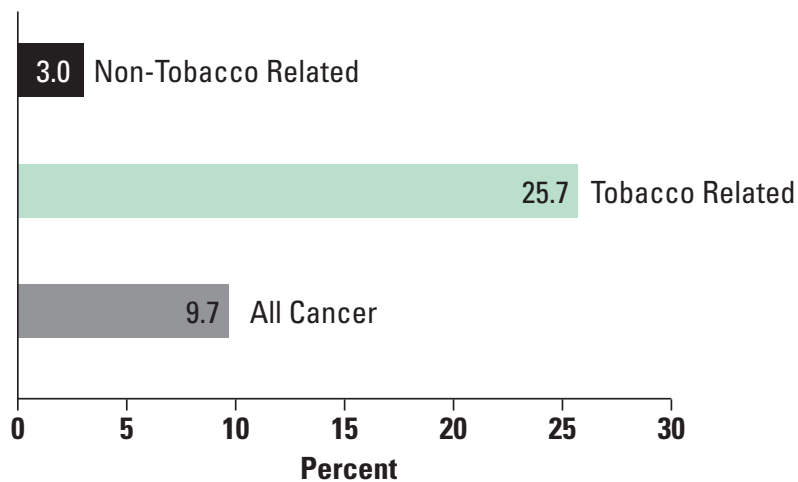
"I smoked for 40 years or more. I never had any problems. Then last May, I had a pain in my shoulder. When my doctor told me to have it X-rayed, they discovered a spot on my lung. It was a total shock. They took a piece of my lung in July." | STERLIN BECKWITH, GEORGETOWN.

REDUCE TOBACCO USE AND EXPOSURE

WHY?

Tobacco related cancers account for more than one third of all the cancers in Delaware. Delawareans smoke at a higher rate than people in 22 other states. Tobacco smoke affects smokers and non-smokers and cancer is only one of many health problems caused by tobacco. Delaware has recently increased its tobacco control spending by more than five times, but there are still actions we can take that will help protect us from the effects of tobacco.

PERCENTAGE INCREASE OF DELAWARE CANCER AGE-ADJUSTED INCIDENCE VS. U.S. ESTIMATE, 1994-1998



Tobacco related cancers: lung, bladder, larynx, esophageal, kidney, pancreas, oral, cervix.

(Delaware: Delaware Cancer Registry, Delaware Division of Public Health; U.S.: Surveillance, Epidemiology and End Results (SEER) Program, National Cancer Institute)

- If not for lung cancer, the overall cancer death rate in the United States would have declined by 14% since 1950. Instead, it has increased 22%. *(Surveillance, Epidemiology and End Results (SEER) Program, National Cancer Institute)*
- The death rate from lung cancer has increased only slightly overall, but is increasing more rapidly among women. In recent years, lung has surpassed breast as the leading cause of cancer death among women. *(National Center for Health Statistics)*
- Delaware has the 32nd lowest cigarette tax in the nation. *(Campaign for Tobacco-Free Kids 2001)*

WHAT CAN BE DONE?

At a minimum, fund comprehensive statewide tobacco control activities at \$8.6 million (CDC recommended minimum)

The following specific tasks and activities should be included:

TASK/ACTIVITY	RESPONSIBLE PARTY	TIMEFRAME	COSTS	POTENTIAL SOURCES
1. Educate members of the Delaware Health Fund Advisory Committee regarding the need for adequate funding in order to achieve the desired results	IMPACT	Year 1 and ongoing	None	
2. Create increased public demand for a fully funded tobacco control program using polling and public awareness activities	IMPACT	Year 1 and ongoing	\$25,000	Robert Wood Johnson Foundation
3. Advocate for Health Fund allocations at CDC recommended funding levels	IMPACT, DHFAC	Annually	None	
4. Report to the public on the use of tobacco funds	All agencies receiving funds	Annually	Existing funds	
5. Fund tobacco control activities at the CDC minimum recommendations	DHFAC, General Assembly	Year 1 and ongoing	<i>see note below</i>	Delaware Health Fund

Point to note:

An additional \$3.6 million added to existing resources is needed for the CDC recommended minimum funding of \$8.6 million (*"Best Practices for Comprehensive Tobacco Control Programs" 2001*). Recommended uses for this funding are outlined in the remaining tobacco control recommendations.

Strengthen, expand, and enforce Delaware's Clean Indoor Act to include public places and workspace environments

The following specific tasks and activities should be included:

TASK/ACTIVITY	RESPONSIBLE PARTY	TIMEFRAME	COSTS	POTENTIAL SOURCES
1. Advocate passage of a strong anti-exposure to Environmental Tobacco Smoke (ETS) law, Senate Bill 99 as originally written (<i>An Act to Amend Title 16, Delaware Code Relating to the Clean Indoor Air Act, 2001</i>)	General Assembly, Executive Branch	Year 1	None	
2. Mobilize the support of governmental offices and other resources in support of relevant data gathering and dissemination	Executive Branch, DHSS	Year 1	None	
3. Continue ETS media and educational campaigns	DHSS	Year 1 and ongoing	Existing resources	
4. Continue grassroots support efforts begun in 2001	IMPACT, Volunteer Groups	Year 1	None	
5. Begin public polling to assess public support for proposed legislation	IMPACT, Campaign for Tobacco-Free Kids	Year 1	\$50,000-\$75,000	Campaign for Tobacco-Free Kids
6. Communicate with those opposed to new legislation to assure correct information and understanding	IMPACT, Concerned Health Organizations	Year 1	None	
7. Upon passage, enforce law	DHSS	Ongoing after passage	See note below	

Points to Note:

- If the original version of Senate Bill 99 is passed, there will be little or no additional enforcement costs. If a bill requiring physical or mechanical separation barriers is passed, enforcement could cost up to \$500,000 more annually.
- Reducing exposure to secondhand smoke will positively influence all Delawareans. Recent national research suggests that exposure to secondhand smoke is as toxic, if not more toxic, than smoking itself.
- Senate Bill 99 has passed the Senate and is now being considered by the House. While there is clear evidence of public support for the legislation, there is also strong opposition and misinformation suggesting its passage will have a negative impact on select businesses. Extensive experiential data from other states concludes that this would not occur, and can be obtained from the Division of Public Health.
- Resources used to formulate the recommendation: (*Hopkins, Husten et al. 2001*) (*The Center for Social Gerontology 2001*)

Strongly endorse, coordinate and implement the action plan recommendations presented in “A Plan for A Tobacco-Free Delaware”

The following specific tasks and activities should be included:

TASK/ACTIVITY	RESPONSIBLE PARTY	TIMEFRAME	COSTS	POTENTIAL SOURCES
1. Increase visibility of support for current plan actions/activities (IMPACT Delaware Tobacco Prevention Coalition 1999)	General Assembly, Executive Branch	Year 1 and ongoing	None	
2. Conduct activities outlined in the plan	IMPACT, DHSS	Year 1 and ongoing	See note below	Delaware Health Fund
3. Continue process, impact and outcome evaluation of plan goals and objectives	IMPACT, DHSS	Year 1 and ongoing	Existing resources	

Points to Note:

- The Council seeks to verify, acknowledge and support the solid tobacco control activities that have occurred and continue to occur. These efforts are consistent with the Council's agenda.
- Cost: To complete these activities, the CDC minimum recommended funding of an additional \$3.6 million to existing resources would be needed and is outlined in the first tobacco control recommendation (“Best Practices for Comprehensive Tobacco Control Programs” 2001)

Formally adopt, implement and enforce the CDC model policy for tobacco control in all Delaware schools

The following specific tasks and activities should be included:

TASK/ACTIVITY	RESPONSIBLE PARTY	TIMEFRAME	COSTS	POTENTIAL SOURCES
1. Re-educate school leadership regarding the content and merits of the CDC model school policy (“A Coordinated School Health Program: The CDC Eight Component Model of School Health Programs” 2001)	IMPACT, DHSS, DOE	Year 1	Existing staff and resources	
2. Obtain administration's support for model policy adoption	IMPACT	Year 1	None	
3. Draft Legislation requiring model adoption	IMPACT, General Assembly	Year 1	None	
4. Implement the model (including education and enforcement components)	IMPACT, DOE, DHSS, local schools	Year 1	\$100,000	Delaware Health Fund

Point to Note:

An existing federal mandate prohibits the use of tobacco products at any time on properties that serve children and receive federal funds. Yet daily violations by staff, visitors and students continue to be visible.

Expand and sustain a comprehensive public awareness campaign on the health risks of tobacco use and support resources available to help quit smoking

The following specific tasks and activities should be included:

TASK/ACTIVITY	RESPONSIBLE PARTY	TIMEFRAME	COSTS	POTENTIAL SOURCES
1. Conduct a high-profile media campaign	DHSS	Ongoing	\$1.2 million plus \$1.3 million of existing resources	Delaware Health Fund, proposed tobacco excise tax
2. Maintain and enhance integrated cessation services	DHSS	Ongoing	\$1.05 million plus \$450,000 of existing resources	Delaware Health Fund, proposed tobacco excise tax
3. Formulate and coordinate consistent messages to be delivered by all stakeholders (materials development)	Permanent Council — Education Committee	Ongoing	\$250,000	Delaware Health Fund, proposed tobacco excise tax
4. Significantly expand Quitline services	DHSS	Ongoing	See cessation costs above	

Points to Note:

- As proven interventions become available, cessation services specifically targeting youth and young adults should be expanded.
- Resources used to formulate the recommendation: (Hopkins, Husten et al. 2001) (Healthy Delaware 2010)

Increase the Delaware excise tax on tobacco products to \$0.74 and seek to identify other potential funding sources to support tobacco and cancer control efforts

The following specific tasks and activities should be included:

TASK/ACTIVITY	RESPONSIBLE PARTY	TIMEFRAME	COSTS	POTENTIAL SOURCES
1. Draft legislation to increase existing excise tax by \$0.50 per pack	IMPACT, legislative consultants	Year 1	None	
2. Seek legislative and administrative support, identify sponsor for bill	IMPACT, health lobbyists	Year 1	None	
3. Ensure that funds are directed to the Delaware Health Fund with major portion going to tobacco control, cancer control, and other chronic diseases	Executive Branch, IMPACT, legislative sponsors	Year 1	None	
4. Conduct community polling	Campaign for Tobacco-Free Kids (CTFK)	Year 1	\$75,000	Robert Wood Johnson, CTFK, AHA, ALA, ACS
5. Implement grassroots awareness/support campaign	IMPACT	Year 1	\$250,000	same
6. Conduct public awareness campaign	IMPACT, Permanent Council, DHSS	Year 1	\$200,000	same
7. Educate General Assembly	IMPACT, lobbyists	Year 1	\$400,000 PR/lobbying	
8. Pass legislation increasing tax	General Assembly	Year 2		

Point to Note:

Delaware's tobacco excise tax is currently \$0.24, lowest in the region and 32nd lowest nationally. The recommended \$0.50 increase would generate an additional \$49.0 million annually. Delaware has not increased its tobacco excise tax in more than ten years. (Campaign for Tobacco-Free Kids 2001)

WHAT IF THEN

30 years ago, no one in Delaware smoked?

instead of our lung cancer incidence rate today being 10% above national estimate, it would be 12% below the national estimate.

(Delaware: Delaware Cancer Registry, Delaware Division of Public Health; U.S.: Surveillance, Epidemiology and End Results (SEER) Program, National Cancer Institute)

WHAT IF THEN

Delaware's excise tax on tobacco products were increased by \$0.50 per pack?

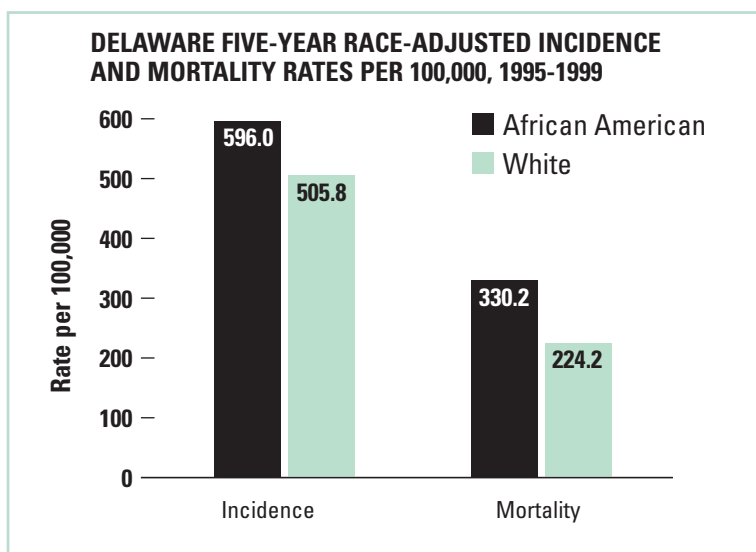
- 4,200 fewer Delaware kids would start smoking
- 1,300 Delaware kids would be saved from a smoking death as an adult
- 4,000 fewer Delaware adults would smoke
- \$83.4 million dollars in long-term health care costs would be saved
- \$49 million dollars each year in revenue would be generated

(Source: Campaign for Tobacco-Free Kids, 2001)

ELIMINATE THE UNEQUAL CANCER BURDEN

WHY?

Our race, ethnicity, gender, where we live, income and whether we have insurance affect our chances of getting cancer, how early it is diagnosed and whether we live or die.



Delaware: Delaware Cancer Registry, Delaware Division of Public Health; U.S.: Surveillance, Epidemiology and End Results (SEER) Program, National Cancer Institute.

Delaware Health Statistics Center, Delaware Division of Public Health; National Center for Health Statistics. Note: 1999 incidence data are provisional.

Rates are age-adjusted to 2000 U.S. standard population.

- White residents are more likely to have cancer diagnosed at an earlier stage than are African American residents (49% diagnosed in early stages for white, 43% for African American).

Note: 1999 data are provisional.

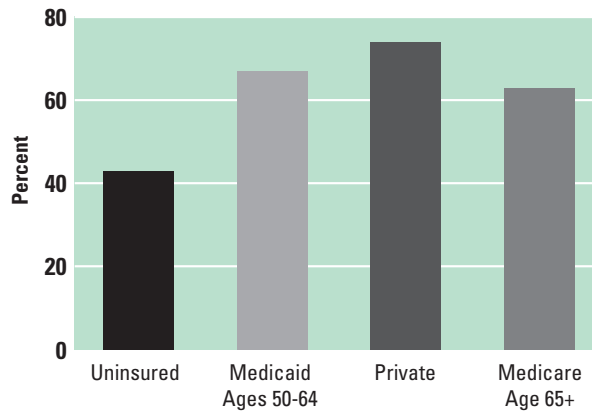
Source: Delaware Cancer Registry, Delaware Division of Public Health

- Residents in Sussex County are less likely to have cancer diagnosed at an earlier stage than are residents in Kent County and New Castle County.

Source: Same as above.

How Insurance Status Affects Screening Rates

PROPORTION OF WOMEN WHO HAVE HAD A MAMMOGRAM IN THE LAST TWO YEARS, BY TYPE OF INSURANCE



Source: Center on an Aging Society analysis of data from the 1996 National Medical Expenditure Panel Survey

WHAT CAN BE DONE?

Some Delawareans are more likely to get and die from cancer, and the differences are often astounding. The Council recognized this as a significant problem and put special emphasis on ways to eliminate these differences. While the following recommendation is the only one that specifically targets this problem, it is also an integral part of nearly every other recommendation in this report. Efforts must be made on all levels to realize change.

Compile and analyze existing data on health disparities and cancer into a report and inform through a public education campaign. The following specific tasks and activities should be included:

The following specific tasks and activities should be included:

TASK/ACTIVITY	RESPONSIBLE PARTY	TIMEFRAME	COSTS	POTENTIAL SOURCES
1. Analyze data on minorities associated with poor health outcomes for cancer overall and for breast, lung, colorectal, and prostate cancers specifically	DPH, university affiliated centers, Permanent Council	Year 1	\$20,000	Proposed tobacco excise tax
2. Analyze trends in disparities related to societal, policy or system level changes that may affect whether certain groups get cancer or die from cancer	DPH, university affiliated centers, Permanent Council	Year 1	\$20,000	Proposed tobacco excise tax
3. Develop a fact sheet with action steps and a public education campaign that correlates with the demographic, health, behavior and social data collected above. Campaign would discuss how to decrease cancer incidence and mortality in DE among minorities and high-risk groups.	DPH, university affiliated centers, Permanent Council	Year 2	\$10,000	Proposed tobacco excise tax



IMPLEMENTATION OF RECOMMENDATIONS

“The recommendations of this Council will be a powerful force for change. We know what needs to be done, who should do it and where we go from here. Delaware has the opportunity to take action and make positive changes in the lives of all its citizens.”

WILLIAM W. BOWSER, ESQUIRE, OF WILMINGTON, DE, COUNCIL CHAIR WHOSE SON, MICHAEL, IS A LEUKEMIA SURVIVOR.



IMPLEMENTATION OF RECOMMENDATIONS

WHY?

The recommendations provided in this report provide a blueprint for action. If implemented, fewer people will die from cancer in Delaware, more people will get quality cancer care, and eventually fewer people will get cancer. However, none of this will happen unless the state institutionalizes a process to continue the work of the Council.

WHAT CAN BE DONE?

Create and maintain a Permanent Council, managed by a neutral party, that reports directly to the Governor to oversee implementation of the recommendations and comprehensive cancer control planning. The Council should have medical, environment, research, policy and education committees that continually evaluate and work to improve cancer care and cancer-related issues in Delaware.

The following specific tasks and activities should be included:

TASK/ACTIVITY	RESPONSIBLE PARTY	TIMEFRAME	COSTS	POTENTIAL SOURCES
1. Re-constitute and make permanent the Delaware Advisory Council on Cancer Incidence and Mortality which shall report directly to the Governor	General Assembly	Year 1	None	
2. Disband DHSS's Advisory Council on Cancer Control as authorized in current legislation and replace with Permanent Council listed in Step 1	General Assembly	Year 1	None	
3. Allocate resources for on-going administrative support to the Council, including one full-time staff person with the sole responsibility of the coordination of this group and its committees	General Assembly	Year 1 and ongoing	\$100,000 annually	Proposed tobacco excise tax
4. Solicit participation of all stakeholders for the general Council. Clear definition of member expectations, roles and responsibilities should be provided	Staff person, neutral party manager	Year 1	\$25,000 — Steps 4-6	Proposed tobacco excise tax

(continued)

<i>TASK/ACTIVITY</i>	<i>RESPONSIBLE PARTY</i>	<i>TIMEFRAME</i>	<i>COSTS</i>	<i>POTENTIAL SOURCES</i>
5. Develop a structure and charge for the Permanent Council and each individual committee	Staff person, Permanent Council	Year 1		
6. Establish the individual committees, medical, environment, research, policy and education. Experts in the respective field should lead each committee and clear definition of member expectations should be provided.	Staff person, Permanent Council	Year 1		
7. Oversee implementation of the current recommendations and any future recommendations in coordination with the planning process	Staff person, Permanent Council and Committees	Year 1 and ongoing		
8. Coordinate an annual conference on the status of cancer in Delaware	Permanent Council	Year 2 and annually	To be determined	
9. Develop an annual report to the Governor and Legislature on the status of current recommendations and the comprehensive cancer control plan and make additional recommendations as necessary	Permanent Council	Year 2 and annually		

Develop and implement a state cancer control and prevention plan. The plan should be based on CDC guidelines and involve multiple stakeholders with assigned responsibilities.

The following specific tasks and activities should be included:

<i>TASK/ACTIVITY</i>	<i>RESPONSIBLE PARTY</i>	<i>TIMEFRAME</i>	<i>COSTS</i>	<i>POTENTIAL SOURCES</i>
1. Develop planning process that incorporates recommendations of the Delaware Advisory Council on Cancer Incidence and Mortality	Staff Person, Permanent Council	Year 1	\$100,000 all activities	Proposed tobacco excise tax
2. Fund implementation of the plan	General Assembly	Year 1		
4. Monitor progress, give advice of needs and resources in DE, and assist with grants or fund development	Permanent Council	Year 2 and ongoing		
5. Assign specific roles and accountabilities of private, non-profit, and government entities involved in implementation	See Above	Year 2	N/A	
6. Publish the plan's development, implementation, and outcomes in the annual cancer report	Permanent Council, DPH	Year 3 and ongoing		

APPENDIX

SPONSOR: Sen. Sharp ; Rep. Spence

On behalf of all Senators, On behalf of all Representatives

DELAWARE STATE SENATE 141st GENERAL ASSEMBLY

SENATE JOINT RESOLUTION NO. 2

ESTABLISHING THE DELAWARE ADVISORY COUNCIL ON CANCER INCIDENCE AND MORTALITY.

WHEREAS, Delaware citizens have expressed understandable concern regarding the comparatively high cancer mortality rate in Delaware, and

WHEREAS, Delaware should strive to achieve the lowest possible rates of cancer incidence and cancer mortality possible given the environment created by its surrounding states, and

WHEREAS, previous efforts to determine the causes of cancer incidence and mortality in Delaware have been inconclusive and fragmented, and

WHEREAS, this critical issue deserves careful but prompt review by an impartial group of experts, citizens, and state officials so that appropriate legislation and fiscal requests can be prepared.

NOW THEREFORE:

BE IT RESOLVED by the Senate and the House of Representatives of the 141st General Assembly of the State of Delaware, with the approval of the Governor, that the Delaware Advisory Council on Cancer Incidence and Mortality is created for the purpose of advising the Governor and Legislature on the causes of cancer incidence and mortality in Delaware and potential methods to reduce incidence and mortality.

The Council shall consist of fourteen members, who shall be selected as follows:

- a. Two representatives of the Delaware House of Representatives and two representatives of the Delaware State Senate (one from each caucus).
- b. One representative of the Governor's Office.
- c. The Secretary of the Department of Health and Social Services or his designee.
- d. One representative of the Department of Natural Resources and Environmental Control.
- e. One representative of the Medical Society of Delaware to be appointed by the Governor.
- f. One professor from Delaware State University or the University of Delaware, to be appointed by the Governor.
- g. Two physicians with relevant medical knowledge, to be appointed by the Governor.
- h. Three public members with relevant professional experience and knowledge, to be appointed by the Governor.

Staff support for the Advisory Council shall be provided by the Department of Health and Social Services.

The Governor shall select one of the Council's members to serve as its chair. The Governor's appointees to the Advisory Council shall serve at the pleasure of the Governor.

Within 120 days after the passage of this resolution, the Advisory Council shall provide initial recommendations to the Governor and Legislature. The Advisory Council shall continue to meet through the calendar year 2001, and shall provide a final report to the Governor and Legislature by December 31, 2001, as well as any interim reports that it deems necessary.

The issues considered by the Advisory Council in both its initial and final reports shall include, but are not limited to, revisions to environmental laws or regulations, revisions to insurance laws or regulations, laws or regulations relating to the sale or distribution of products known to cause cancer, fiscal appropriations, public education campaigns, and potential action against entities in adjacent states that may create the predicate for cancer incidence in this state.

SYNOPSIS

This Joint Resolution creates the Delaware Advisory Council on Cancer Incidence and Mortality and sets forth its responsibilities.

Author: Sen. Sharp

BACKGROUND

Formation of the Advisory Council on Cancer Incidence and Mortality

The Delaware Advisory Council on Cancer Incidence and Mortality was formed in March 2001 in response to Senate Joint Resolution 2 signed by Governor Ruth Ann Minner. The Advisory Council, consisting of 15 members appointed by the Governor, was established to advise the Governor and Legislature on the causes of cancer incidence and mortality and potential methods for reducing both.

Developing a Plan for Action

The Advisory Council on Cancer Incidence and Mortality began meeting in April 2001 with the shared understanding that their work would be focused on developing a clear and useable cancer control plan. Another shared priority was that extensive input would be needed from professionals in cancer control, as well as from Delaware citizens affected by cancer. With these priorities in mind, Advisory Council worked on a system to:

- create a shared awareness and agreement on the range of cancer control issues to be addressed now and in the future;
- create a structure and agenda for addressing these needs;
- enable Delaware to move forward with meaningful action for its citizens

To accomplish these goals, the Advisory Council heard from speakers on Delaware cancer statistics, including Dr. Jon Kerner from the National Cancer Institute, and began monthly presentations from Delaware cancer survivors or family members who had lost a loved one to cancer. The stories, woven throughout this report, provided valuable insight into

some of the concerns and barriers faced by people battling cancer, the stress this disease places on all aspects of their lives, and ideas for ways that Delaware can help ease these burdens on its citizens.

A unique project, called Concept Mapping, was also initiated to get input on cancer issues from Delaware citizens and to help the Advisory Council establish priorities and its scope of work. The Advisory Council invited more than 195 Delaware citizens who are invested in cancer control efforts to participate in the project. Both the Advisory Council and those invited completed the Brainstorming phase, during which they provided their ideas on completing the statement: “A specific issue that needs to be addressed in comprehensive cancer control in Delaware is....” Over 500 statements were submitted and editing of these to avoid duplication resulted in 118 ideas about controlling cancer in Delaware. These ideas were then rated, relative to each other, on importance and feasibility.

Development of Subcommittees and Recommendations

From the results of the Concept Mapping activity and the numerous speakers, the Advisory Council developed a clear set of priorities and established six subcommittees to address these issues. Each subcommittee, chaired by a member of the Advisory Council, was provided with a list of priorities in its focus area, from which specific recommendations were developed. The Advisory Council carefully reviewed the work of the subcommittees, made modifications or additions as needed, and the resulting final recommendations are compiled in this report.

DELAWARE ADVISORY COUNCIL ON CANCER INCIDENCE & MORTALITY MEMBER LISTING

William Bowser, Esquire (Chair)
Young, Conaway Stargatt & Taylor

Matthew Denn, Esquire
Office of the Governor

Nicholas DiPasquale, MA
Secretary, Department of Natural Resources
and Environmental Control

Stephen Grubbs, MD
Christiana Care Health Systems

Bethany Hall-Long, PhD, RNC
University of Delaware

Patricia Hoge, PhD, RN
American Cancer Society

Meg Maley, RN, BSN
Cancer Care Connection

The Honorable David McBride
Delaware Senate

Rita Meek, MD
A.I. duPont Hospital for Children

Julio Navarro, MD
Medical Society of Delaware

The Honorable John Schroeder
Delaware House of Representatives

The Honorable Liane Sorenson
Delaware Senate

Ulder Tillman, MD, MPH
Director, Delaware Division of Public Health

The Honorable Stephanie Ulbrich
Delaware House of Representatives

Access to Care Subcommittee*Chairperson:*

Stephen Grubbs, MD, Christiana Care

Subcommittee Members:

William Bowser, Esquire, Young Conaway Stargatt

& Taylor, LLP

Anthony Brazen, III, DO, MBA, Division of Social Services

Lynn Clayton, American Cancer Society

Susan Lloyd, MSN, RN, Delaware Hospice, Inc.

Lolitz Lopez, Westside Health

Francis Mieczkowski, Jr., Private Citizen

LaVaida Owens-White, MSN, RN, Christiana Care, PMRI

Paula Roy, Delaware Health Care Commission

Medical Community Action Subcommittee*Chairperson:*

Julio Navarro, MD, Medical Society of Delaware

Subcommittee Members:

Rita Meek, MD, A.I. duPont Hospital for Children

Nicholas Petrelli, MD, Helen F. Graham Cancer Center

Anthony Policastro, MD, Nanticoke Health Services

Ed Sobel, DO, Quality Insights of Delaware

James Spellman, MD, FACS, FSSO, Private Physician

David Biggs, MD, Delaware Society of Clinical Oncology

Public Awareness and Education Subcommittee*Chairperson:*

Ulder Tillman, MD, MPH, Division of Public Health

Subcommittee Members:

Evelyn Burkle, American Cancer Society

Victoria Cooke, Delaware Breast Cancer Coalition

Constance Green-Johnson, American Cancer Society

Nora Katurakes RN, MSN, OCN, Christiana Care Cancer Outreach Program

Deborah Pfaffenhauser, RN, Bayhealth Medical Center

Rob Simmons, Dr.PH, MPH, Christiana Care Health System

The Honorable Liane Sorenson, Delaware Senate

Janet Teixeira, Cancer Care Connection

Linda Wolfe, RN, Department of Education

Tobacco Control Subcommittee*Chairperson:*

Patricia Hoge, PhD, RN, American Cancer Society

Subcommittee Members:

The Honorable David McBride, Delaware Senate

Deborah Brown, American Lung Association of Delaware

John D'Angelo, M.Ed., RRT, Bayhealth Medical Center

Regina Manley, Delaware Prevention Network

Eileen McGrath, American Cancer Society

Environmental Carcinogen Exposure and Assessment Subcommittee*Chairperson:*

Meg Maley, RN, BSN, Cancer Care Connection

Subcommittee Members:

Matthew Denn, Esquire, Office of the Governor

Nicholas DiPasquale, MA, Secretary, Department of

Natural Resources and Environmental Control

Athena Jolly, MD, MPH, Medical Consultant

Mary Ellen Nantais, Private Citizen

Grace Pierce-Beck, Delaware Audubon Society

J. Thomas Sims, PhD, University of Delaware

H. Grier Stayton, Department of Agriculture

Andrew Walter, MD, MS, A.I. duPont Hospital for Children

Research and Data Analysis Subcommittee*Chairperson:*

Bethany Hall-Long, PhD, RN, University of Delaware

Subcommittee Members:

Paul Akana, MD, American College of Surgeons

Nicholas DiPasquale, MA, Secretary, Department of

Natural Resources and Environmental Control

Jayne Fernsler, PhD, RN, University of Delaware

Robert Frelick, MD, Medical Society of Delaware

HC Moore, RHIT, Nanticoke Hospital

The Honorable Stephanie Ulbrich,

Delaware House of Representatives

Kathleen Wall, American Cancer Society

Judy Walrath, PhD, Christiana Care Health Systems, PMRI

A. Judson Wells, PhD, Private Citizen

REFERENCES AND RESOURCES USED

- An Act to Amend Title 16, Delaware Code Relating to the Clean Indoor Air Act. Senate Bill 99 (2001)
- Brownson and Ross (1999). "Community-Based Prevention: Programs That Work."
- Campaign for Tobacco-Free Kids (2001). Special Report: "Higher Cigarette Taxes Reduce Smoking, Save Lives, Save Money." Campaign for Tobacco-Free Kids Website.
- Center on an Aging Society (2001) "Analysis of data from the 1996 Medical Expenditure Panel Survey and the 1998 National Health Interview Survey Sample Adult Prevention File."
- Centers for Disease Control and Prevention (1999). "Colorectal cancer: The importance of early detection."
- Centers for Disease Control and Prevention, Division of Adolescent and School Health (2001). "A Coordinated School Health Program: The CDC Eight Component Model of School Health Programs."
- Centers for Disease Control and Prevention, National Center for Chronic Disease Prevention and Health Promotion Office on Smoking and Health (2001). "Best Practices for Comprehensive Tobacco Control Programs — August 1999."
- Centers for Disease Control and Prevention, National Center for Chronic Disease Prevention and Health Promotion Office on Smoking and Health (2001). "Investment in Tobacco Control, State Highlights 2001."
- Colditz, G. (2000). "Cost-effectiveness of Screening for Colorectal Cancer in the General Population." *JAMA* 284(15): 1954-1961.
- Delaware Advisory Council for Cancer Control (1996). "Status Report on Recommendations of the Governor's Task Force on Cancer."
- Delaware Advisory Council for Cancer Control (2001). "Cancer: What we know and what we don't know."
- Delaware Health Care Commission, Steering Committee on Cancer (1998). "Reducing Cancer Risks and Deaths in Delaware, A Report on Public Education and Barriers."
- Delaware Health and Social Services, Division of Public Health (1990). "Delaware's Cancer Control Strategy for the 1990s."
- Delaware Health and Social Services, Division of Public Health (1999). Behavioral Risk Factor Surveillance Survey.
- Delaware Health and Social Services, Division of Public Health (2000). Behavioral Risk Factor Surveillance Survey.
- Delaware Health and Social Services, Division of Public Health, Delaware Cancer Registry.
- Delaware Health and Social Services, Division of Public Health, Delaware Health Statistics Center.
- Delaware Department of Public Instruction and Delaware Health and Social Services (1997). "Public and School Education in Relation to Health Risks Associated with Cancer."
- Eddy, D. (1990). "Screening for Cervical Cancer." *Annals of Internal Medicine* 113: 214-226.
- Governor's Task Force on Cancer (1994). "Recommendations of the Governor's Task Force on Cancer."
- Hopkins, D., C. Husten, et al. (2001). "Evidence reviews and recommendations on interventions to reduce tobacco use and exposure to environmental tobacco smoke: A summary of selected guidelines." *American Journal of Preventive Medicine* 20(2s).
- IMPACT Delaware Tobacco Prevention Coalition (1999). "A Plan for a Tobacco-Free Delaware."
- National Cancer Institute, Surveillance, Epidemiology and End Results (SEER) Program.
- National Center for Health Statistics
- Penberthy, L., S. Retchin, et al. (1999). "Predictors of Medicare costs in elderly beneficiaries with breast, colorectal, lung, or prostate cancer." *Health Care Management Science* 2: 149-160.
- Ransohoff, D. and R. Sandler (2002). "Screening for Colorectal Cancer." *The New England Journal of Medicine* (346 (1)): 40-44.
- Research Triangle Institute (1996). "A Proposal for the Development of a Comprehensive Environmental Monitoring Program in Delaware: Three Alternatives in Response to SJR 11."
- State of Delaware (2001). "Healthy Delaware 2010."
- Taplin, S., W. Barlow, et al. (1995). "Stage, comorbidity, and direct costs of colon, prostate, and breast cancer care." *Journal of the National Cancer Institute* 87(6): 417-426.
- The Center for Social Gerontology, I. (2001). "Economics Impacts of Smoke-Free Environments, Smoke-Free Environments Law Project."
- United States Census Bureau (2000).
- University of Delaware's Center for Applied Demography and Survey Research (1994-1998). "Delaware Demographic Database."

ABBREVIATIONS

ACS—American Cancer Society

ALA—American Lung Association

AHA—American Heart Association

BRFSS—Behavioral Risk Factor Surveillance Survey

CFTFK—Campaign for Tobacco-Free Kids

DDA—Delaware Department of Agriculture

DHFAC—Delaware Health Fund Advisory Committee

DHSS—Department of Health and Social Services

DNREC—Department of Natural Resources and Environmental Control

DOE—Department of Education

IMPACT—IMPACT Delaware Tobacco Prevention Coalition

MCO—Managed Care Organizations