

Alaska Comprehensive Cancer Control Plan

2005 - 2010



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Department of Health and Social Services
Division of Public Health

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November 2006

Letter to Alaskans

Dear Alaskans:

The Alaska Division of Public Health is pleased to present the Alaska Comprehensive Cancer Control Plan, 2005–2010. This plan was produced by the Alaska Comprehensive Cancer Control Program in collaboration with over 80 partners around the state, and our National Partners. This plan addresses the burden of cancer and strategies to reduce cancer incidence and mortality in Alaska.

Cancer is the leading cause of death in Alaska. Each year approximately 2,300 Alaskans are diagnosed with cancer, and 760 Alaskans die from this disease. Reduction in the rates of cancer in Alaska will be accomplished through lifestyle changes that eliminate tobacco use, improve dietary habits, increase physical activity, maintain a healthy weight, avoid harmful ultraviolet light, increase early detection through cancer screening, and increase the receipt of appropriate and timely cancer treatment.

The Alaska Comprehensive Cancer Coalition is comprised of a diverse group of state-wide organizations, advocates, individuals, and health agencies who are committed to reducing the burden of cancer in Alaska. The Alaska Comprehensive Cancer Control Plan was developed over the past three years through participation and input from our partners. It is our hope this plan will be used widely throughout the state to implement strategies appropriate to individual communities and organizations that will positively impact the cancer burden.

The Alaska Division of Public Health would like to extend its appreciation to all the individuals and organizations who committed time and resources to the development of this plan. The information presented serves as a foundation on which to further build activities and establish initiatives to address the cancer issues throughout the state.

I encourage you to become involved in reducing the cancer burden on Alaskans. Let us work together to fulfill the mission to make Alaska Cancer Free.



Richard Mandsager, M.D.
Director, Division of Public Health
Alaska Department of Health and Social Services

Message from the Chair

Dear Cancer Prevention and Control Partners:

The Alaska Comprehensive Cancer Partnership is pleased to present you with the 2005–2010 Cancer Plan for the State of Alaska. This plan has been developed over the past three years with contributions from many Alaskans from all corners of the state and our National Partners.

Cancer has been the leading cause of death in Alaska since 1993. We need to change that, and can only do so by combining our knowledge and resources to prevent, detect and treat this disease with the best research, practice and technology available. To do that, we need your help.

This plan is intended to be used by the full spectrum of Alaskans, individuals within organizations and acting individually, ranging from health agencies, advocacy organizations, businesses wanting to improve employee health, health care providers, cancer survivors and anyone involved in health planning. Our hope is that you can find strategies you may want to implement, or share those you may already be implementing, to improve the health of Alaskans and reduce the risk of cancer in the Alaskan population.

The Alaska Comprehensive Cancer Partnership is here to assist you with becoming involved in cancer prevention and improving the cancer care available in the state. We invite you to join us to make Alaska Cancer Free. Please contact us if you need more information at (907) 269-2020.

Thank you for your contributions toward making Alaska Cancer Free.

Sincerely,

A handwritten signature in black ink that reads "Pamela Warren". The signature is written in a cursive, flowing style.

Pamela Warren, Ph.D.
Chair, Alaska Comprehensive Cancer Partnership

Executive Summary

Since 1993, cancer has been the leading cause of death for Alaskans, surpassing even cardiovascular disease. As more Alaskans are surviving cancer, it is increasingly being treated as a chronic condition. To address the issues around cancer prevention, control, and treatment in Alaska, the Division of Public Health applied for and received a planning grant in 2003 from the Centers for Disease Control and Prevention's (CDC) National Comprehensive Cancer Control Program (NCCCP) to develop a current comprehensive cancer control plan for the state.

As a result of the NCCCP planning grant, the Alaska Comprehensive Cancer Partnership (ACCP) was created to provide a formal structure with the task of assessing the cancer burden in the state and determining priorities and strategies that will positively impact the cancer burden. This plan is a result of those efforts and is intended to serve as a road map for action.

Defining cancer control: This plan provides an overview of the cancer burden in the state. Using the top five cancers for Alaska Natives and non-Natives, information is provided which describes each cancer and the challenges each presents. Gaps in care are discussed as well as disparities where they exist. Cancer risks are discussed and corresponding strategies were developed to work toward risk reduction if implemented.

Setting goals: The plan provides a background of past cancer control planning efforts and the subsequent successes achieved, leading up to current efforts. Included are the vision, mission, goals, and guiding principles of the ACCP. Many goals with measurable outcomes were established and/or adopted from Healthy Alaskans 2010. Three strategies were selected to be acted on during the first year of implementation. These include:

- ❖ Raise public awareness of the increased cancer risk due to poor nutrition and lack of physical activity.
- ❖ Increase colorectal cancer screening, with strategic effort to reach the medically underserved in both urban and rural communities.
- ❖ Collaborate with the Palliative Care Symposium Planning Committee on statewide efforts to provide education on palliative care and end-of-life issues, and increase certification of health care personnel in palliative and hospice care.

Setting a course for action: This plan identifies strategies that can be adapted to the many community settings across Alaska. While three strategies were selected for the Partnership to focus their efforts, there are many other strategies that will be addressed and carried out by individuals and organizations. Implementation will include local activities in communities across the state, collaborative efforts among small groups around specific areas of interest, and statewide efforts involving many partners. Progress toward meeting the goals in this plan will be evaluated annually and reports provided. This plan will be updated on a regular basis to incorporate changing needs of the state as well as emerging research in cancer and other related sciences.

This plan is dedicated to the many Alaskans who have been touched by cancer.

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Comprehensive Cancer Control in Alaska

What is comprehensive cancer control?

Comprehensive cancer control (CCC) integrates and coordinates a range of activities to maximize resources and achieve desired cancer prevention and control outcomes. It is a collaborative process through which a community and its partners pool resources to promote cancer prevention, improve cancer detection, increase access to health and social services, and reduce the burden of cancer. The Centers for Disease Control and Prevention (CDC) supports comprehensive cancer control by providing grants and technical expertise to states, tribes, and territories.

The first comprehensive cancer control plan for the state of Alaska was published in January 1994. The goals and objectives of that plan centered on three main areas:

- ▶ Risk reduction
- ▶ Early detection and treatment
- ▶ Surveillance

In the 1994 Alaska Cancer Control Plan, the goal of risk reduction focused on tobacco prevention and cessation, and dietary modifications. Since the 1994 plan was published, the state has established a comprehensive Tobacco Prevention and Control Program using CDC funding and funds authorized by the state legislature from the Tobacco Master Settlement Agreement (MSA). Efforts in tobacco prevention and control now include local coalitions, tribal health organizations, and voluntary organizations. Efforts in tobacco control are based on CDC *Best Practices for Comprehensive Tobacco Control Programs* and include community programs to reduce tobacco use; statewide programs to increase the capacity of local organizations around community development,

media advocacy, clean indoor air policies and reducing minor's access to tobacco products; counter marketing; and cessation programs including a statewide, toll-free quitline.

Besides tobacco, other cancer risk reduction efforts included dietary modification. One program developed to help prevent and reduce diet-related diseases through healthy eating patterns was the Eat Smart Alaska program. Eat Smart Alaska consists of voluntary members representing consumers, the food service industry, educators, health professionals, governmental agencies, and private businesses. Eat Smart Alaska advocates for increased availability of healthy foods; increased education efforts on the economic benefits of healthful eating; and increased use of media to promote healthful eating messages which emphasize an enhanced quality of life and disease prevention. They support activities state-wide such as health fairs, 5-A-Day for Better Health campaigns, in-store food demonstrations, grocery store tours, and collaboration with teachers, schools and other health care educators.

Efforts aimed at early detection and treatment included securing funding for the early detection of breast and cervical cancer. The State of Alaska's Breast and Cervical Cancer Early Detection Program (BCCEDP) receives CDC funding for the Breast and Cervical Health Check (BCHC) Program. Since 1995, BCHC has provided more than 78,000 breast and cervical cancer screenings to over 26,000 medically underserved Alaska women. More than 173 cases of breast cancer and 30 cases of invasive cervical cancer have been diagnosed. Funding for treatment has been available since 2001. Since that time, 76 women with diagnosed breast cancer and 10

women diagnosed with invasive cervical cancer have been referred to Medicaid for treatment (BCHC, 2006).

The Alaska Cancer Registry (ACR) was established in 1995, and began collecting statewide data in 1996. The ACR achieved the North American Association of Central Cancer Registries (NAACCR) silver status in 1997 and has maintained gold status annually since 1998. This demonstrates the quality, completeness and timeliness of the cancer data collected in Alaska.

In January of 2003, efforts began to further improve cancer control activities. The Alaska Cancer Prevention and Control Program (CPCP) placed a statewide request for partners to develop a coalition to address the burden of cancer in the state. A core planning team was established and began meeting regularly. In June 2003 the first meeting of the Alaska Comprehensive Cancer Partnership (ACCP) was held to provide background on CCC, Alaska cancer issues, and begin the planning process for developing a CCC Plan. Workgroups began meeting in 2004 to review latest research and evidenced-based practice in cancer prevention, early detection and treatment. The four workgroups included Prevention, Early Detection, Treatment (which encompassed palliative care, hospice care, clinical trials, survivorship, and end-of-life care), and Surveillance. Strategies were identified from each workgroup to address the cancer burden and gaps in care, with measurable objectives established.

Priorities for implementation were determined in a two-phase process. The workgroups were convened to prioritize the strategies under Prevention, Early Detection, and Treatment to select the top nine strategies. These nine strategies were then presented to the full Partnership in December 2005 for further

prioritization to the top three strategies. Partners were asked to sign up for those strategies they could best implement. The Steering Committee made the final decision on the top three strategies to implement beginning in 2006. The following principles were employed with each prioritization process.

- What is the strategy's potential impact on the burden of cancer?
- What is the size of the cancer problem that would be addressed by the strategy?
- Can we make significant progress within a year if implementing the strategy?
- Is this strategy already being adequately implemented?
- Is this strategy feasible to be implemented in Alaska?
- Are you or your agency willing to sign on to implementing this strategy?

Goals for Alaska's first year of CCC implementation in 2006/2007 include:

- Maintain and enhance the infrastructure of the Alaska Comprehensive Cancer Partnership.
- Publish and disseminate the Alaska Comprehensive Cancer Control Plan.
- Mobilize support for the implementation of the Alaska Comprehensive Cancer Control Plan.
- Review Alaska data and emerging research to maintain currency of ACCP strategies.
- Implement ACCP priority strategies to reduce the burden of cancer in Alaska.
- Evaluate the implementation of the Alaska Comprehensive Cancer Control Plan.

Through the efforts of over eighty Alaska Comprehensive Cancer Partnership members and other contributors, this plan was developed to provide guidance on measures to take to prevent cancer, detect cancer at the earliest opportunity, and provide quality cancer treatment throughout the state. While the workgroups were centered on prevention, early detection, treatment, and surveillance, the plan categorically addresses the top five cancers among Alaska Natives and non-Natives.



The Alaska Native Tribal Health Consortium (ANTHC) has been involved in planning efforts parallel to the state planning process since 2003. Attention has been given to coordinate and integrate program priorities where appropriate. The *Comprehensive Cancer Plan for the Alaska Tribal Health System (ATHS) 2005–2010* was published in 2006. A commitment has been made between both programs to coordinate and integrate efforts as much as possible. The ATHS CCC Plan will be used as a reference when working with the Alaska Native population.

Vision, Mission, Goals, and Guiding Principles

Vision: A Cancer Free Alaska.

Mission: Working Together for a Cancer Free Alaska.

Goals:

- When possible, prevent cancer before it occurs.
- When cancer occurs, find it as early as possible.
- When cancer is diagnosed, every person will have access to the most appropriate and cost effective care.
- Maximize the quality of life for cancer survivors.
- Reduce suffering and death from cancer.
- Increase equity in access to appropriate preventive, diagnostic, medical and palliative care, and clinical trials.
- Incorporate the latest research and best practices into prevention and treatment of individuals with cancer.
- Educate public, providers, payers, and policy makers on cancer issues.

Guiding Principles

Comprehensive cancer control in Alaska is guided by the following principles:

- All Alaskans are impacted by cancer, either directly or in their families and communities. Therefore, reducing the burden of cancer is the responsibility of all Alaskans.
- Decision-making will be driven by the best available data and evidenced-based practice.
- The full spectrum of cancer will be

addressed, beginning with prevention and early detection through treatment, survivorship, palliation, and end-of-life care.

- Cancer care should be available to all Alaskans and occur as close to one's home and community as possible.
- Disparities in the cancer burden will be identified and addressed throughout the planning and implementation of goals and strategies of the Alaska Comprehensive Cancer Control Plan.
- Planning for the Alaska Comprehensive Cancer Control Program will include collaboration with the Alaska Native Tribal Health Consortium in order to coordinate and integrate resources whenever possible.



- Coordination and collaboration among partners is essential to achieving the goals of the plan and to avoid duplication of efforts.
- It is essential the Partnership monitor federal, state and local legislation and policy development to provide advocacy for changes that enhance our goals and intervene when changes may hinder our goals.

Priorities for 2006/2007

The **three priority strategies** selected for implementation in the first year include:

Raise public awareness of the increased cancer risk due to poor nutrition and lack of physical activity.

Increase colorectal cancer screening, with strategic effort to reach the medically underserved in both urban and rural communities.

Collaborate with the Palliative Care Symposium Planning Committee on statewide efforts to provide education on palliative care and end-of-life issues, and increase certification of health care personnel in palliative and hospice care.

Action plans for these strategies will be developed early in the implementation phase. See Appendix F for a complete list of strategies.

Cancer Surveillance

The Alaska Cancer Registry (ACR) is a population-based, statewide cancer registry. The primary purpose of the registry is to collect information on all reportable cancer cases in Alaska. The registry maintains data on newly diagnosed cancer cases and pertinent information about that cancer. The ACR is funded by the CDC National Program of Cancer Registries (NPCR) grant.

The registry began collecting information January 1, 1996. Alaska hospitals, physicians and other health care practitioners are required by state law to report information to the ACR within six months of diagnosis. Reported cancer cases are analyzed to identify cancer

trends, patterns, and geographic variations. The ACR then creates and disseminates reports on the burden of cancer in Alaska. Cancer incidence and mortality data is critical for targeting public health programs. Data from incidence trends for the different types of cancer will be used to plan intervention strategies to prevent or reduce the occurrence of disease and its impact.

Evaluation Plan

Evaluation of the Alaska Comprehensive Cancer Control Plan is vital to measuring the impact of actions taken to reduce the burden of cancer in Alaska. While many of the measures in this plan will occur over several years, incremental measurements will help guide the ACCP in determining how best to utilize resources to prevent, detect, and treat cancer, and assist cancer survivors in their life journey. Evaluation efforts will measure both process and outcome data for three separate areas: the Alaska Comprehensive Cancer Control Program, the Alaska Comprehensive Cancer Partnership, and the Alaska Comprehensive Cancer Control Plan.

Information learned in evaluation of the plan and program will be integrated annually into planning for the following year. The Partnership will provide annual reports on activities and how they have used the plan within their respective work settings to impact cancer issues. These reports as well as the annual evaluation will be compiled into an annual report to be distributed to partners in the state. Model programs or practices will be highlighted and shared.

Emerging Science and Technology in Cancer Research

Advances in research may reveal prevention, early detection, treatment, and palliation breakthroughs which could decrease the morbidity and mortality of cancer in Alaska. Ongoing monitoring of scientific progress is essential, followed by integration or modification of new information and data into Alaska's Comprehensive Cancer Control Plan and ACCP's implementation activities.



The ACCP Data and Evaluation Committee will make recommendations for changes to the plan or implementation activities based on new research findings. These recommendations may be referred back to the Workgroups for incorporation into any related implementation activities. One example of responding to new developments in cancer prevention is the recent approval of the Human Papillomavirus (HPV) vaccine by the Federal Drug Administration (FDA). The availability of this vaccine in Alaska necessitates its incorporation into cancer prevention activities within the cancer plan and prevention strategies.

Another example of emerging science is in the area of genomics. As more research findings uncover the disruption within

cellular pathways that result in uncontrolled cell growth, there are more opportunities to develop tools that will prevent, detect, and treat cancer at a specific cellular level. The National Cancer Institute (NCI) along with the National Human Genome Research Initiative developed The Cancer Genome Atlas to provide a comprehensive catalog of the many genetic changes that occur in cancers. This information will be placed in free public databases for use by the cancer research community, and will lead to new, innovative approaches to cancer prevention, detection, and treatment.

Collaborating with Partners

The Alaska Native Tribal Health Consortium received a planning grant from the CDC National Comprehensive Cancer Control Program (NCCCP) in 2003 to develop the first comprehensive cancer control plan for Alaska Natives. Joint planning between the Alaska State and the AHTS Comprehensive Cancer Control Programs (CCCP) have been in place since the inception of each program with the goal to coordinate and integrate both programs where possible. Currently there are parallels in both plans' priorities in the areas of increasing screening for CRC and increasing access to palliative care services. Managers for both programs are members of each CCCP Steering Committee, and are committed to working together for a Cancer Free Alaska.

To make this plan and the ACCP truly comprehensive, outreach to communities and groups with diverse ethnicity and culture is essential. There must be ongoing efforts made to increase the diversity of partners across all geographic regions as well to have the greatest impact.

Advocating for Policy Change

Advocacy for the partnership means taking purposeful action to encourage the development of infrastructure and policies that will assist in implementing the plan strategies and priorities. Advocacy for policy change will be carried out at the federal, state, borough and city or community level. Advocacy efforts must be pervasive throughout all prevention, early detection and treatment strategies.

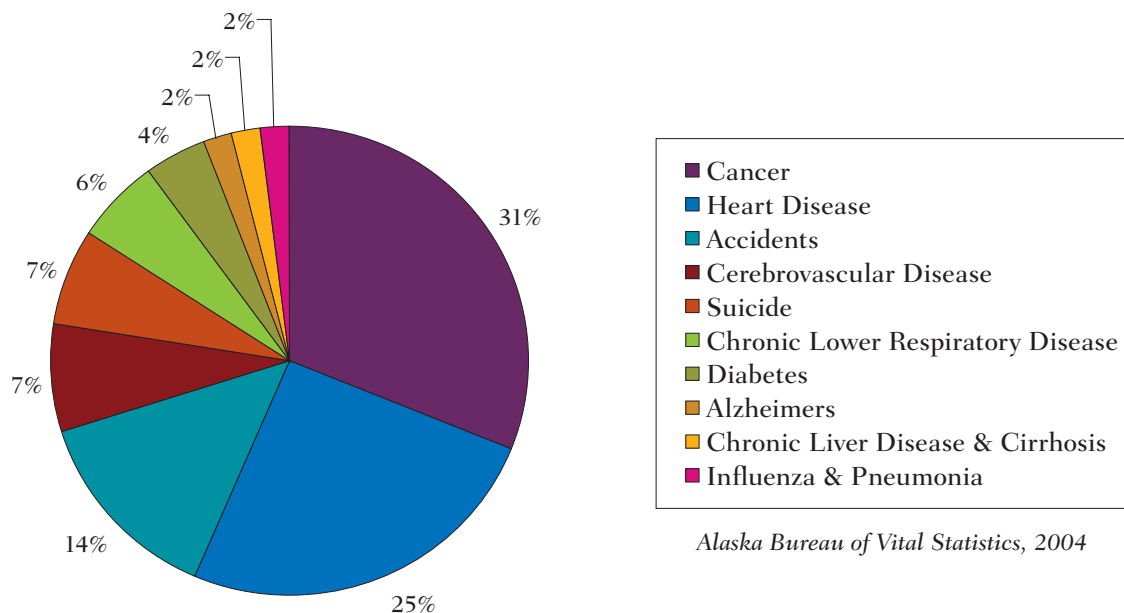
The ACCP is committed to supporting advocacy efforts that will reduce the burden of cancer on Alaskans, and will remain vigilant in opposing those policy changes which may have a negative impact on the reduction of the cancer burden. Advocacy may be proactive, for example initiating legislation, or responsive, such as opposing legislation and policies introduced which will have a negative impact on the goals of the plan or partnership.

Priorities for advocacy will be solicited from the partners and prioritized by the Policy Committee annually. Policy advocacy will be implemented by partnership organizations and individual members through the Policy Committee.

The Burden of Cancer in Alaska

Cancer is the leading cause of death for all Alaskans since 1993 – one of the few states in the United States for which this occurs.

Causes of Death in Alaska

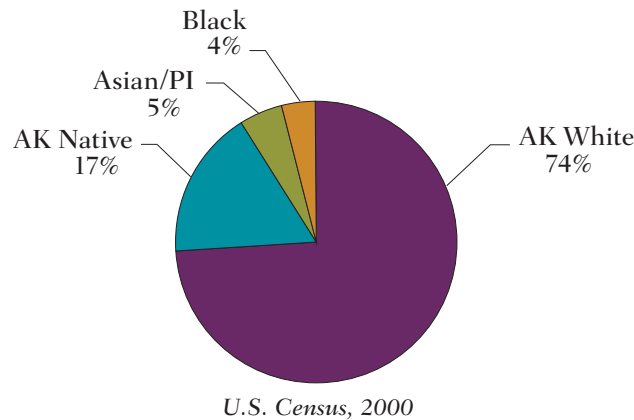


Based on projections by the American Cancer Society (ACS), 2,010 Alaskans will be diagnosed with cancer, and 810 Alaskans will die from cancer in 2006.¹ Alaska Natives experience higher incidence rates of lung, colorectal, stomach, and kidney and renal pelvis cancer than U.S. whites or Alaska whites. Alaska Natives have a higher mortality rate from lung, colorectal, stomach and prostate cancer than U.S. whites or Alaska whites. The top five cancers for Alaska Natives, Alaska whites, and U.S. whites are found in the tables below. More graphs and GIS maps are located in Appendix C.

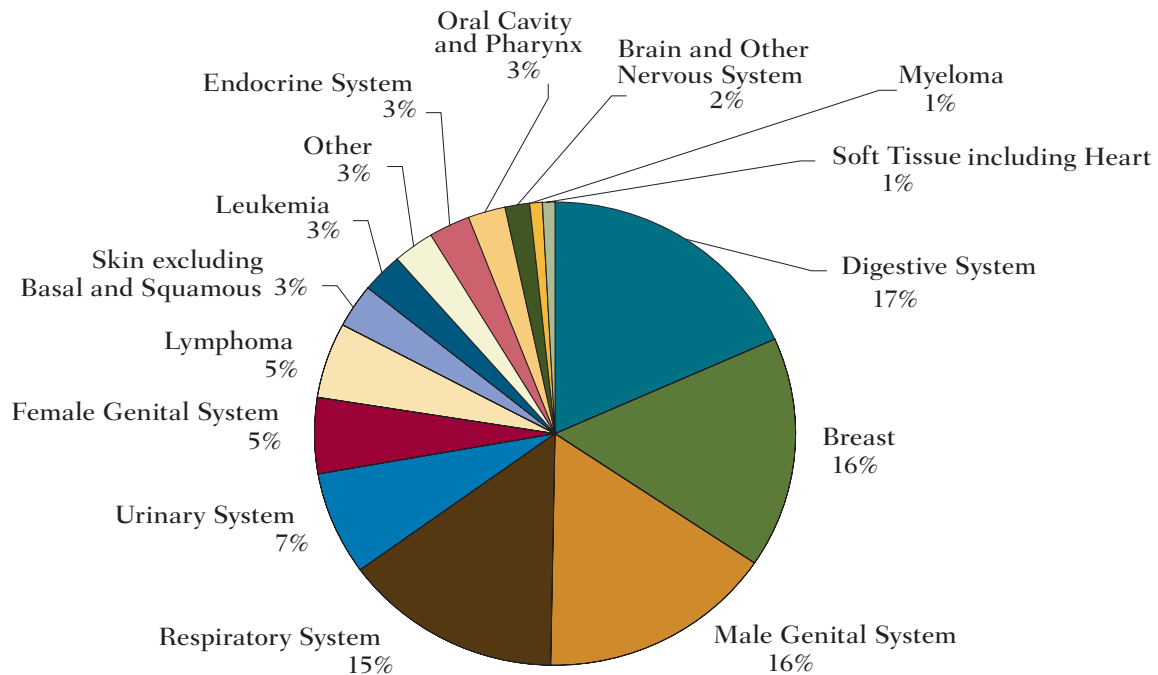
Incidence of Cancer in Alaska, 1996–2002

To understand how cancer rates are calculated and used in Alaska, it is important to know something of the demographics in Alaska according to race. Rates for whites and Alaska Natives are used in this report. These two racial groups composed about 91 percent of the population of the state of Alaska during the period 1996–2002 (74 and 17 percent respectively). The remaining 9 percent are Asian/Pacific Islander and blacks (5 and 4 percent respectively). Due to the large populations of whites and Alaska Natives, cancer rates in these groups are the most stable for the purposes of comparisons between races. Cancer rates for the other races tend to have larger fluctuations from year to year.

Population of Alaska by Race



Cancer Incidence in Alaska, 1996-2002

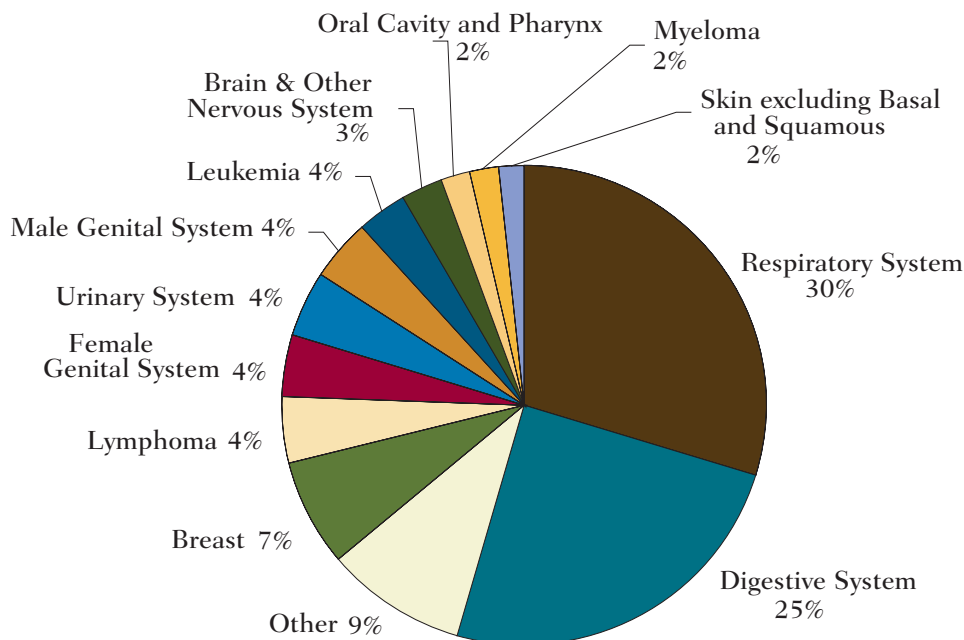


This pie chart illustrates the percentage of cases during 1996-2002 for all types of cancers greater than 1 percent of the total. (SEER, 1996-2002)

Presented in the tables below are the top five cancers by incidence in Alaska according to race. They represent 63.4% of all cancers diagnosed in Alaska between 1996 to 2002. Rates are age-adjusted to the 2000 US standard population. (SEER, 1996–2002)

Cancer Incidence: Top 5 Sites (Incidence per 100,000)		
AK Native	AK White	US White
1. Female Breast (132.9)	1. Prostate (184.9)	1. Prostate (173.2)
2. Colorectal (108.6)	2. Female Breast (143.4)	2. Female Breast (134.4)
3. Lung and Bronchus (93.4)	3. Lung and Bronchus (73.9)	3. Lung and Bronchus (62.1)
4. Prostate (84.3)	4. Colorectal (51.1)	4. Colorectal (53.5)
5. Stomach (25.8)	5. Bladder (27.1)	5. Bladder (20.4)

Cancer Mortality in Alaska, 1996-2002



This pie chart illustrates the percentage of deaths during 1996-2002 for all types of cancers greater than 1 percent of the total. (SEER, 1996-2002)

Below are the top five cancers by mortality in Alaska according to race. They represent 59.4% of all cancer deaths in Alaska between 1996 to 2002. Rates are age-adjusted to the 2000 US standard population. (SEER, 1996–2002)

Cancer Mortality: Top 5 Sites (Mortality per 100,000)		
AK Native	AK White	US White
1. Lung and Bronchus (67.9)	1. Lung and Bronchus (57.3)	1. Lung and Bronchus (56.2)
2. Colorectal (37.0)	2. Prostate (29.3)	2. Prostate (31.6)
3. Female Breast (22.2)	3. Female Breast (24.8)	3. Female Breast (27.1)
4. Prostate (21.8)	4. Colorectal (17.8)	4. Colorectal (20.8)
5. Stomach (17.5)	5. Pancreas (10.8)	5. Pancreas (10.5)

The Burden of Cancer in Alaska

Data Sources

Statistics were generated using the statistical software program SEER*Stat version 6.2.3 (<http://seer.cancer.gov/seerstat/>) from the Surveillance, Epidemiology, and End Results (SEER) Program of the National Cancer Institute.

Cancer incidence data for the U.S. were provided by the SEER program and has the following citation: Surveillance, Epidemiology, and End Results (SEER) Program (www.seer.cancer.gov) SEER*Stat Database: Incidence – SEER 13 Regs Public–Use, Nov 2005 Sub (1992–2003) – Linked To County Attributes – Total U.S., 1969–2003 Counties, National Cancer Institute, DCCPS, Surveillance Research Program, Cancer Statistics Branch, released April 2006, based on the November 2005 submission.

Cancer mortality data for the U.S. were provided by the SEER program and has the following citation: Surveillance, Epidemiology, and End Results (SEER) Program (www.seer.cancer.gov) SEER*Stat Database: Mortality – All COD, Public–Use With County, Total U.S. (1990–2003) – Linked To County Attributes – Total U.S., 1969–2003 Counties, National Cancer Institute, DCCPS, Surveillance Research Program, Cancer Statistics Branch, released April 2006. Underlying mortality data provided by NCHS (www.cdc.gov/nchs).

Cancer incidence data for Alaska were provided by the Alaska Cancer Registry and was formatted for use in SEER*Stat in May 2006.

Profile of Leading Cancers in Alaska

► Lung Cancer

Lung cancer is the leading cause of cancer death in the U.S., and cigarette smoking causes the majority of lung cancers. The 2004 *Surgeon General's Report on the Health*

Consequences of Smoking added evidence to a previous conclusion that smoking causes cancers of the oral cavity, pharynx, larynx, esophagus, lung, and bladder. The same report further identified additional cancers caused by smoking, including cancers of the stomach, cervix, kidney, and pancreas as well as acute myeloid leukemia.

Smoking causes about 90 percent of lung cancer deaths in men and almost 80 percent in women. Compared to non-smokers, men who smoke are 23 times more likely, and women who smoke are 13 times more likely, to develop lung cancer. For smoking attributable cancers, the risk generally increases with the number of cigarettes smoked and the number of years of smoking. The risk decreases after quitting completely, though it may take years.²

Lung and bronchus cancer in Alaska is the second leading cancer in incidence among men and women combined in Alaska, but it is the leading cause of cancer mortality. Alaska Natives have a higher incidence (93.4 per 100,000) and mortality rate (67.9 per 100,000) of lung and bronchus cancer than whites (73.9 and 57.3 per 100,000 respectively) (SEER, 1996–2002). Since the state began collecting cancer data in 1996, the incidence of lung and bronchus cancer has dropped from 67% to 61.6% in 2002 (SEER, 1996–2002). The mortality from lung and bronchus cancer has declined from 53.4% in 1996 to 51.0% in 2002 (SEER 1996–2002). Between 1996 and 2003, an average of 270 Alaskans were diagnosed annually with lung cancer, and an average of 195 Alaskans died each year from this disease (SEER 1996–2002). The American Cancer Society (ACS) estimates there will be 240 new cases of lung and bronchus cancer in Alaska, and 220 Alaskans will die from this type cancer in 2006.³

Currently there are no tests for the early detection of lung cancer. The National Cancer Institute (NCI) is conducting a clinical trial with spiral computerized tomography (CT) to determine its efficacy and cost effectiveness. The United States Preventive Services Task Force (USPSTF) offers no recommendation on using chest X-ray, CT scan, or sputum cytologic examination to look for lung cancer in people who have no symptoms to suggest the disease. Patients should be aware there are no studies showing that screening helps people live longer. False-positive test results are common and can lead to unnecessary worry, testing, and surgery. If early detection is being considered, doctors and patients should discuss the pros and cons of screening before proceeding with X-ray, CT scan, or sputum cytologic examination to screen for lung cancer.

► **Breast Cancer**

Female breast cancer ranks second highest for incidence and mortality among all cancers in Alaska. Alaska's breast cancer mortality rates generally mirrored the US rates for years 1996–2002 (SEER, 1996–2002). However, incidence rates were higher for Alaska whites (143.4 per 100,000) than Alaska Native women (132.9 per 100,000). Between 1996 and 2003, an average of 317 Alaska women were diagnosed annually with breast cancer and an average of 49 Alaska women died each year from this disease (SEER 1996–2003). The American Cancer Society estimates there will be 310 new cases in 2006, and an estimated 60 breast cancer deaths.⁴

Mammography is the most effective means of detection for early breast cancer diagnosis.⁵ A clinical breast exam (CBE), by a health care provider, complements a mammogram by offering the opportunity for the provider and patient to discuss medical and family history, and any changes in the breast. The USPSTF recommends screening mammography, with

or without CBE, every 1-2 years for women aged 40 and older. The USPSTF found fair evidence that mammography screening every 12 to 33 months significantly reduces mortality from breast cancer.⁶ Breast self-exams alone, however, are not effective for detecting early breast cancer.

Additionally, women are encouraged to perform breast self-exams (BSE) monthly beginning at age twenty, to become familiar with how their breasts look and feel. Any changes should be promptly reported to their health care provider.⁷ Breast self exams alone, however, are not effective for detecting early breast cancer.

In 2004, 67% of women, age 40 and over, reported having a mammogram in the last two years. Alaska Native women reported the same rate of screening as white women (both 67%). Overall women age 65 and over had the lowest percentage at 67.8%; and women age 40-49 had the highest screening rates at 79%. The area of the state with the lowest percentage of women over 40 years that reported having a mammogram in the last two years was the Gulf Coast Region at 69.9% while the Anchorage Region has the highest at 78.4% (Alaska BRFSS, 2004).



Angoon, Alaska

©Nicole Grewe

There is a lack of mammography in most rural

communities where 34% of Alaskans live. Two mobile mammography programs make occasional visits to several rural communities. Traveling from a village to a regional center is limited in most cases to air travel and can cost from \$500 to \$1200. The Medicaid program in Alaska will not pay for mobile mammography services, nor will it pay for women to travel into a regional center for annual screening. Currently, eligible Medicaid beneficiaries are referred to one of five CDC funded Breast and Cervical Cancer Early Detection Programs (BCCEDP).

Within the State, five programs are currently funded by the CDC's National Breast and Cervical Cancer Early Detection Program (NBCCEDP). They consist of one state-wide program and four tribal programs, located at SouthEast Alaska Regional Health Consortium in Sitka, Southcentral Foundation in Anchorage, Arctic Slope Native Association in Barrow, and the Yukon-Kuskokwim Health Corporation in Bethel. Together, these NBCCEDP grantees provide an average of 16,000 breast and cervical health screenings each year.

Since 1995, the state BCCEDP, known as the Breast and Cervical Health Check (BCHC) Program has provided more than 78,000 breast and cervical cancer screenings to over 26,000 medically underserved Alaska women. Through this state program, more than 173 cases of breast cancer have been diagnosed, with 76 women referred to Medicaid for treatment since 2001 (BCHC, 2006).

The Alaska Tribal Health System, which provides the majority of health care in Alaska's remote rural village communities, has developed and implemented a breast health education program that trains Community Health Aides/Practitioners (CHA/P) in providing early breast cancer detection

at the village level. The program includes teaching women how to complete a BSE while emphasizing the need to have regular CBEs and mammograms. This breast health program includes a case management and follow-up component. Women age 40 and above receive both reminders on the need for a CBE and mammogram, and coordination of all their medical needs so that a trip into a regional medical center can include an appointment for a mammogram.

► **Colorectal Cancer**

Colorectal cancer (CRC) was the fourth most commonly diagnosed cancer and cause for cancer deaths for Alaska males and females in the years 1996–2002. Between 1996 and 2003, an average of 202 Alaskans were diagnosed annually with colorectal cancer, and an average of 62 Alaskans died each year from this disease (SEER, 1996–2003). The American Cancer Society estimated that in 2006 Alaska would have 220 new cases of colorectal cancer, and 80 deaths from colorectal cancer.⁸

Alaska Natives, both male and female, have statistically significant higher incidence and death rates from colorectal cancer compared to race-specific U.S. rates, all-race Alaska rates, or all-race U.S. rates. Alaska Natives are diagnosed with colorectal cancer at over twice the rate of Alaska whites. For the years 1996–2002, the incidence rate of CRC for Alaska Natives was 108.6 per 100,000 compared to rates of 51.1 per 100,000 for whites. Additionally in the same time period, CRC was fourth in mortality for all races; Alaska Native colorectal cancer mortality rates were 37 per 100,000 compared to whites at 17.8 per 100,000 (SEER, 1996–2002).

For black Alaskans, the incidence rate of CRC is difficult to provide due to the low numbers of this group in the total population of Alaska (4%). The count of CRC incidence in blacks for

years 1996 to 2002 was 38 compared to 400 cases in Alaska Natives and 941 cases in whites in the same time period. While most of the literature highlights the high rates in blacks, this is not the case in Alaska.

Colorectal cancer is an almost entirely preventable disease. In its early stages, colorectal cancer causes no or few symptoms, which is why screening is so important. CRC is one of the few cancers which can be prevented through screening because adenomatous polyps, from which colon cancers develop, can be identified and removed.⁹ Survival rates are as high as 90% when colorectal cancer is detected in its early stages. However nationally, only 39% of cases are diagnosed early, mostly due to low screening rates.¹⁰

The US Preventive Services Task Force (USPSTF) strongly recommends men and women 50 years of age or older be screened for colorectal cancer. They found that several screening methods are effective in reducing mortality from colorectal cancer. These include fecal occult blood testing (FOBT), double-contrast barium enema, flexible sigmoidoscopy and colonoscopy. They concluded that the benefits from screening substantially outweigh potential risks, but the quality of evidence, magnitude of benefit, and potential risks vary with each screening method.

The USPSTF found good evidence that periodic FOBT reduces mortality from colorectal cancer and fair evidence that sigmoidoscopy alone or in combination with FOBT reduces mortality. They did not find direct evidence that screening colonoscopy is effective in reducing colorectal cancer mortality. Double-contrast barium enema offers an alternative means of whole-bowel examination, but it is less sensitive than colonoscopy, and there is no direct evidence

that it is effective in reducing mortality rates. There are insufficient data to determine which strategy is best in terms of the balance of benefits and potential harms or cost-effectiveness. Studies reviewed by the USPSTF indicate that colorectal cancer screening is likely to be cost-effective (less than \$30,000 per additional year of life gained) regardless of the strategy chosen.¹¹

The American College of Gastroenterology (ACG) bases screening recommendations on risk assessments. For those persons at average risk (no risk factors for CRC), the preferred screening strategy is a colonoscopy every 10 years beginning at age 50. An alternative strategy for persons at average risk is a flexible sigmoidoscopy every 5 years plus an annual fecal occult blood testing. At this time neither barium enema nor virtual colonoscopy are recommended for CRC screening for persons at average risk by the ACG.¹²

The ACG further defines high risk colon cancer screening for persons with family history of colon cancer or rare syndromes of familial adenomatous polyposis and hereditary non-polyposis colorectal cancer. Recommendations vary with the specific risk factor, but all persons at high risk of colon cancer should be screened much earlier than those persons at average risk. Persons with previous history of colorectal cancer or adenomas, and persons with ulcerative colitis and Crohn's Disease are considered to be under surveillance, thus specific recommendations for screening are not provided.¹³

In March of 2005, the ACG called for changes in CRC screening of blacks. They stated colonoscopy is the preferred method of screening for blacks due to the higher numbers of right-sided cancers and polyps. They further recommend that blacks begin screening at age

45 instead of age 50 due to higher rates of CRC at an earlier age.¹⁴

In 2004, 51% of all Alaskans over age 50 reported having had colorectal screening by either sigmoidoscopy or colonoscopy. American Indians/Alaska Natives reported a rate of colorectal screening of 50% by either sigmoidoscopy or colonoscopy. The area of the state with the lowest percentage of colorectal screening was the Gulf Coast (36.7%) followed by Rural Alaska (41.4%) (Alaska BRFSS, 2004).

Colorectal cancer screening is not readily available in at least one third of the state. There are three contributing factors to low screening rates. One is the high demand on health care providers for acute care services. The second is that flexible sigmoidoscopy and colonoscopy are generally performed by physicians and specialists (gastroenterologists), who are only available at the tertiary care centers and intermittently at the regional hubs. A third problem is the high cost of transportation in rural Alaska to locations where screening services and follow up care are consistently available. This generally requires expensive air travel which is weather dependent.

While the fecal occult blood test (FOBT) is a commonly recommended screening test, health care providers do not currently recommend this test among Alaska Natives. Extensive testing in the past, especially in rural areas, resulted in exceedingly high numbers of (false) positive results. This was believed to be due to chronic blood loss related to chronic gastritis from *Helicobacter Pylori* (*H. pylori*) infection.

► **Prostate Cancer**

Prostate cancer ranked first in incidence for all cancers in Alaska, and third in mortality during the years 1996 to 2002. Black males have the highest incidence rate of any ethnic group in

the state at 266.8 per 100,000. Whites have the second highest incidence rate at 176.6 per 100,000, Asian/Pacific Islander's rate is 139.7, and the lowest rate is in Alaska Natives at 83.9 per 100,000 (SEER, 1996–2003). Between 1996 and 2003, an average of 283 Alaska males were diagnosed annually with prostate cancer with prostate cancer, and an average of 26 Alaska males died each year from this disease (SEER, 1996–2003). The American Cancer Society estimates there will be 260 new cases in 2006, and an estimated 50 or less prostate cancer deaths.¹⁵

The USPSTF concludes that the evidence is insufficient to recommend for or against routine screening for prostate cancer using prostate specific antigen (PSA) testing or digital rectal examination (DRE). They found good evidence that PSA screening can detect early-stage prostate cancer but mixed and inconclusive evidence that early detection improves health outcomes. Screening is associated with several concerns, including frequent false-positive results and unnecessary anxiety, biopsies, and potential complications of treatment of some cancers that may never have affected a patient's health. The USPSTF concludes that evidence is insufficient to determine whether the benefits outweigh the harms for a screened population.¹⁶

Fifty-seven percent of the Alaska male population 40 years of age and older have had a PSA test. Seventy-eight percent have had a DRE (Alaska BRFSS, 2004).

► **Bladder Cancer**

Bladder cancer ranks fifth in incidence of cancers for whites. Whites have an incidence rate of 27.1 per 100,000 compared to the Alaska Native rate of 11.2 per 100,000. Bladder cancer does not rank in the top five cancers for mortality for any race group in Alaska. Between 1996 and 2003, an average of 79 Alaskans were

diagnosed annually with bladder cancer, and an average of 14 Alaskans died each year from this disease (SEER 1996–2003). The American Cancer Society estimates 90 new cases of urinary bladder cancer in 2006, but does not provide estimates of mortality from bladder cancer.¹⁷

The greatest risk factor for bladder cancer is smoking, with smokers experiencing twice the risk of this cancer than non-smokers. Other risk factors include exposure to chemicals in the dye, rubber, and leather industries, as well as communities with high levels of arsenic in their drinking water. Avoiding these exposures can reduce a person's risk of bladder cancer, along with eating more fruits and drinking more water.¹⁸

There are no recommended screening tests for bladder cancer for persons at average risk. Screening for persons who are at an increased risk due to occupational exposure, or for persons requiring follow-up treatment after experiencing bladder cancer, requires an examination of cells in the urine or an examination of the bladder wall with a cystoscope to diagnose this type cancer.¹⁹

► **Stomach Cancer**

Stomach cancer is the fifth leading cancer in incidence and mortality in Alaska Natives. It occurs at a higher rate in Alaska Natives (25.8 per 100,000) than in Alaska whites (6.1 per 100,000). Between 1996 and 2003, an average of 34 Alaskans annually were diagnosed with stomach cancer, and an average of 23 Alaskans died annually from this disease (SEER, 1996–2003). The American Cancer Society provides no estimates of new cancer cases for stomach cancer. *H. pylori* is suspected of being a contributing factor. The CDC Arctic Investigations Program and Alaska Native Tribal Health Consortium (ANTHC) plan to further study *H. pylori* in the Alaska Native

population to determine if this infection is associated with their higher rates of stomach cancer.

H. pylori is a bacterium that colonizes the stomach. It is not known exactly how *H. pylori* is transmitted, but the most likely route of spread is from person-to-person through the fecal-oral or oral-oral route. Infection with *H. pylori* is the main cause of gastric ulcers and chronic gastritis, and infected persons have a two- to six-fold increased risk of developing mucosa-associated lymphoid tissue lymphoma and gastric cancer compared with uninfected counterparts.²⁰

Since the 1950s, high rates of iron deficiency anemia have been documented in Alaska Natives. One cause appears to be blood loss in the stool associated with *H. pylori*. This has led to the finding that 99 percent of those with increased fecal blood loss had chronic gastritis caused by *H. pylori*.²¹

► **Oral Cancer**

Oral cancer screening was addressed in the Prevention Workgroup by the Alaska Oral Health Program in recognition of an oral cancer screening protocol being available as a component of a health care exam.

The incidence rate for oral cancer in Alaska was 11.5 per 100,000 (SEER, 1996–2003). This is slightly higher than the U.S. rate for oral cancer of 10.7 per 100,000 (SEER, 1996 to 2003). The highest incidence rate in Alaska occurred in Alaska Natives who had a rate of 17.7 per 100,000; significantly higher than the next highest race rate in whites of 10.6 per 100,000 (SEER, 1996–2003).

The death rate from oral cancer for Alaskans is 3.7 per 100,000; higher than the U.S. death rate from oral cancer at 2.8 per 100,000 (SEER, 1996–2003). Alaska Natives had the

highest rate of death from oral cancer in this same time at 8.7 per 100,000; double the rate of any other race in Alaska (SEER 1996–2003). The higher rates of death from oral cancer in Alaska Natives may be attributed to their higher use of spit and smokeless tobacco.

Between 1996 and 2003, an average of 49 Alaskans were diagnosed annually with oral cancer, and an average of 14 Alaskans died each year from this disease (SEER, 1996–2003).

Not all Alaskans have access to dental services. Studies have noted that many adults at-risk for development of oral cancer do not routinely have access to dental care. Therefore, training non-dental health professionals to do oral exams is an important strategy for early detection of oral cancer. Individuals aged 65 and older, especially those with dentures, may not routinely seek dental care. Medicare does not provide coverage for routine dental care. Public knowledge about oral cancer and self-exams is limited and individuals delay professional advice even when they become aware of a lesion.²²

A national survey indicates almost all dentists agreed that patients 40 and older should have an oral cancer examination annually, yet 30% of dentists do not provide the exams during the initial patient visit, and 41% do not examine these patients at recall visits.²³ Studies have found that dentists either do not assess or are unaware of their patients' risk behavior for development of oral cancer, including alcohol and tobacco use.²⁴ Physicians are less likely than dentists to provide an oral cancer exam.^{25 26}

While the most damaging carcinogens are found in the tars of tobacco smoke, many forms of smokeless (spit) tobacco have been implicated in development of oral cancer.²⁷ Trends in sales of smokeless (spit) tobacco

in Alaska are not currently being monitored. There appears to be a strong association with spit tobacco use and sporting events (e.g., baseball, football, hockey and wrestling).



One homemade form of spit tobacco used in Alaska is called Iqmik. Iqmik is made from mixing leaf tobacco with one or more ashes derived from burning tree fungus and various types of wood found in the area. Further discussion on Iqmik can be found in Section III b. under Tobacco.

Disparities exist in smokeless tobacco use among Alaska adolescents. The 2003 Alaska Youth Risk Behavior Survey (YRBS) reported the percentage of Alaska boys who reported having used chewing tobacco or snuff in the 30 days prior to the survey was 15.6%. This reflects an 8% decline from the 1995 Alaska YRBS results, and is slightly above the US rate of 14.8 in 2003. Alaska girls (6.2%) are far more likely to report use of smokeless tobacco than are U.S. girls (1.9%).²⁸

► **Cervical Cancer**

The incidence rates for cervical cancer in Alaska remain low. Black women had the highest incidence rate for the years 1996–2002 at 14.2 per 100,000. White women had a rate of 9.2 per 100,000, Alaska Native women had a rate of 7.5 per 100,000, and Asian/Pacific Islanders had a rate of 9.2 per 100,000. For the years 1996–2002, 45.5% of Alaska Native

women diagnosed with cervical cancer were at a late stage of the disease compared to only 32.3% of white women who were diagnosed at a late state of this disease. Between 1996 and 2003, an average of 24 Alaska women were diagnosed annually with cervical cancer, and an average of 5 Alaska women died each year from this disease. The American Cancer Society does not provide estimates for new cervical cancer cases in Alaska when fewer than 50 cases annually are expected. The success of low cervical cancer rates is related to the higher rates of screening that occur through the five BCCEDPs providing services in Alaska, as well as intensive screening initiated early in 1990 throughout the Alaska Native Health System.



The primary cause of cervical cancer is infection with certain types of the Human Papillomavirus (HPV). An HPV vaccine was developed and recently approved in June 2006 by the US Food and Drug Administration (FDA) for use in females age 9 to 26 years. This vaccine has been proven effective in preventing cervical cancer caused by HPV types 16 and 18. On June 29, 2006, the Advisory Committee on Immunization Practices (ACIP) recommended HPV vaccine be routinely administered to girls 11 to 12 years of age.²⁹ The Prevention Workgroup of the ACCP will explore ways to promote the vaccine within the state based on recommendations by the Federal Drug Administration (FDA) and ACIP.

CDC's Division of Cancer Prevention and Control issued the following statements in support of the FDA and ACIP:

Regular cervical screening (the Pap test) is recommended for all women (within 3 years of beginning sexual activity or at age 21, whichever comes first);

All women receiving the HPV vaccine should continue to receive the Pap test according to established screening recommendations;

HPV vaccination is not a substitute for routine cervical cancer screening (Pap tests) and is not intended to treat cervical cancers.³⁰

The USPSTF strongly recommends screening for cervical cancer in women who have been sexually active and have a cervix. The USPSTF found good evidence that screening with cervical cytology (Pap smears) reduces incidence of and mortality from cervical cancer. They found most of the benefit can be obtained by beginning screening within three years of onset of sexual activity or age 21 (whichever comes first) and screening at least every three years. The USPSTF recommends against routinely screening women older than age 65 for cervical cancer if they have had adequate recent screening with normal Pap smears and are not otherwise at high risk for cervical cancer.³¹

Since 1995, through the state BCHC, nearly 30 cases of invasive cervical cancer have been diagnosed. Funding for treatment has been available since 2001. Since that time, 10 women diagnosed with invasive cervical cancer have been referred (BCHC, 2006).

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Addressing Cancer in Alaska through Comprehensive Cancer Control

Causes of Cancer

The causes of most cancers are not well understood. However, certain lifestyle choices are known to contribute toward cancer, especially tobacco use, poor diet, and lack of physical activity. The following established causes of cancer are responsible for these estimated total cancer deaths.¹

Risk Factor	% of Total Cancer Deaths
Tobacco	30
Adult diet/obesity	25
Sedentary lifestyle	10
Occupational factors	5
Family history of cancer	5
Viruses/other biological events	5
Perinatal factors/growth	5
Reproductive factors	5
Alcohol	3
Socioeconomic status	*
Environmental pollution	2
Ionizing/ultraviolet radiation	2
Prescription drugs/medical procedures	2
Salt/other food additives/contaminants	1

* An important underlying factor operating through other specific causes.

Fifty percent of all cancer deaths may be prevented through eliminating and reducing specific unhealthy behavior.² Scientific study has revealed specific risk factors that have direct causal or associative relationship

with cancer. Primary prevention focuses on eliminating and reducing these known key cancer risk factors, such as tobacco. In the US, smoking is estimated to cause over one-third of all cancer deaths.³ Some risk factors are not modifiable such as age, heredity and sex. However there are many modifiable risk factors that, when eliminated or reduced, can prevent cancer from occurring. This includes certain cancers that are related to infectious exposures, such as Hepatitis B (HBV) and Hepatitis C (HCV), Human Papillomavirus (HPV), Helicobacter pylori and others, which can be prevented through behavioral changes, vaccines, or antibiotics.⁴ Many skin cancers can also be prevented by protection from the sun's rays.⁵

Risk Factors

► Tobacco

Tobacco is responsible for approximately 500 deaths in Alaska annually. It is the single most preventable cause of disease in the state. In addition to the harmful effects of tobacco use by individuals, an estimated 120 Alaskans die every year from disease caused by secondhand smoke.⁶

Use of Tobacco Products

Alaska's adult smoking prevalence of 24.3% is higher than the national rate of 20.9%.⁷ At 44%, Alaska Natives have the highest smoking prevalence of any racial/ethnic group within Alaska.⁸ Cancer mortality increased among Alaska Natives in the years 1994 to 1998, while it declined in most other ethnic groups.⁹ Smoking is also high among women in the last three months of their pregnancy. In 2003,

almost 17% of pregnant Alaska women smoked (Alaska PRAMS, 2000).

Analysis of data from the 2003 Alaska YRBS shows that fewer Alaska high school students are trying cigarettes at all (56% versus 72% in 1995), and overall the percentage of students who smoke is roughly half of what it was eight years ago (19% versus 37% in 1995). Over three times as many Alaska Native students smoke (40% among boys, 49% among girls) as do non-Native students (13% among boys, 11% among girls).

The use of smokeless tobacco among Alaska adults has remained relatively constant over the last twelve years. Alaska Native adults were twice as likely to report current use of smokeless tobacco at 10% compared to non-Native adults at 5% (Alaska BRFSS 2002). The use of smokeless tobacco by youth in Alaska is higher than in other states, ranking 6th in the nation. The use of smokeless tobacco has decreased among youth since 1995, but Alaska Native and non-Native males account for the majority of that drop. In 2003, 6% of high school girls in Alaska were smokeless tobacco users as compared to 7% in 1995. Twenty-four percent of male high school students used smokeless tobacco in 1995, but use decreased to 16% in 2003.¹⁰

Use of Iqmik

Iqmik is a form of spit tobacco that is made from mixing leaf tobacco with ash obtained from burning punk fungus (*Phellinus igniarius*) found on birch trees, alder or willow bushes, or driftwood. This process of adding ash to the leaf tobacco increases the pH level, thereby raising the amount of free nicotine available for absorption by the user.¹¹ Considering the effect iqmik may have on the user, ongoing research by the Alaska Native Tribal Health Consortium is being conducted to determine if treatment for nicotine addiction should be tailored for

users of Iqmik. Since 2004, the Alaska PRAMS asked questions meant to differentiate Iqmik use from commercial smokeless tobacco product use during the prenatal period. This data is not yet available. Additionally, the Alaska BRFSS has asked specific questions about the prevalence of Iqmik use since 2004.

Exposure to Secondhand Smoke

Secondhand smoke (SHS), also known as environmental tobacco smoke (ETS), contains a mixture of more than 4,000 chemicals of which 50 are known or probable cancer causing agents. SHS is associated with an increased risk for lung cancer and coronary health disease in nonsmoking adults. Young children are particularly susceptible when exposed to SHS due to their developing lungs, and are at an increased risk of sudden infant death syndrome, asthma, bronchitis, and pneumonia.¹²

In June 2006, the U.S. Surgeon General released a comprehensive scientific report which concludes there is no risk-free level of exposure to secondhand smoke. “Nonsmokers exposed to secondhand smoke at home or work increase their risk of developing heart disease by 25 to 30 percent and lung cancer by 20 to 30 percent. Nearly half of all nonsmoking Americans are still regularly exposed to secondhand smoke.”¹³

Tobacco Control in Alaska

In 1997, a \$0.71 per pack cigarette tax increase was implemented in Alaska. Per capita taxable cigarette consumption has decreased by 30% since the introduction of this statewide excise.¹⁴ In 2004, the state increased the cigarette tax by \$1.00 per pack to be phased in over three years with full implementation by July 1, 2008, effectively bringing the tax to a full \$2.00 per pack. Alaska is one of the few states to attain the taxation rate considered high enough to be preventative toward the induction of new smokers, especially teenagers.

A percentage of the new revenue is intended for tobacco prevention and control programs with the goal of increasing funding to the CDC recommended level. However, these funds must still be appropriated by state government annually.

Although smoking rates in Alaska have remained relatively stable since 1991, the 2004 smoking prevalence estimate (24.3%) was the lowest since 1991. Alaska Natives smoke at twice the rate of non-Natives, and this disparity has remained constant over the last decade – for both adults and youth. Smoking among high school students dropped from 36.5% in 1995 to 19.2% in 2003.¹⁵

The Tobacco Prevention and Control Program (TPC) is based on CDC’s Best Practices for Comprehensive Tobacco Control Programs. The four goal areas of the state Tobacco Prevention and Control Program for 2006 include:

- 1) Prevent initiation of tobacco use among Alaska’s youth
- 2) Promote tobacco cessation among adults and young people
- 3) Eliminate exposure to secondhand smoke
- 4) Identify and eliminate tobacco-related disparities in specific populations

► **Obesity, Nutrition and Physical Activity**

Currently 63% of Alaskans are either overweight or obese, increasing their risk of cancer. While consumption of five to nine fruits and vegetables per day has been shown to provide some protection against cancer, only 25% of Alaskans are eating five fruits and vegetables per day. Physical inactivity is another area of public health concern. Approximately 21% of Alaskans lead a sedentary lifestyle.

Alaska Natives have a higher rate of no activity (16%) than non-Natives (7%)(Alaska BRFSS, 2005). These lifestyle measures indicate a need for personal change in nutrition and physical activity, to promote health.

The State of Alaska worked with many private and public partners to develop a comprehensive plan to address both physical activity and nutrition. The plan was published in 2005, titled *Alaska in Action: Statewide Physical Activity and Nutrition Plan*. The plan identifies the lack of indoor recreational spaces in the winter months, dependence on fast and unhealthy food, and electronic entertainment replacing physical activity for fun as major barriers to maintaining healthy eating and physical activity levels.

Among Alaska Natives there is concern that subsistence foods may contain environmental contaminants such as PCBs. Often the perceived risk of contaminants outweighs the actual risk of other lifestyle choices such as tobacco use and poor diet. The need for education about relative risk is being addressed through the Office of Alaska Native Health Research (OANHR). Another large-scale effort to address nutrition, physical activity, and cancer among Alaska Natives is the Education And Research Toward Health (EARTH) Study, funded by the National Cancer Institute. EARTH is a prospective research study designed to determine how diet, physical activity, and other lifestyle and cultural factors relate to the development of chronic diseases, such as cancer, cardiovascular disease, and diabetes. This study will provide a better understanding of links between specific factors and these diseases.

► **Alcohol**

Use of alcohol can increase the risk of several types of cancer, including breast, mouth, pharynx, larynx, esophagus, and colon. In the

case of breast cancer, two alcoholic drinks per day probably increase the risk by about 25 percent.¹⁶ Alcohol is a primary cause of liver cancer. Oral cancers are six times more common in alcohol users than in nonalcohol users. About 75% to 80% of all patients with oral cancer consume alcohol frequently. Limiting the amount of alcohol a person drinks may help prevent a number of cancers.¹⁷

Alcohol is the drug of choice for Alaskans. The occurrence of heavy drinking, defined as more than one drink per day for women and more than two drinks per day for men, is currently at 5-6%. The rate of occurrence of binge drinking, defined as having five or more drinks on at least one occasion, one or more times in the past 30 days, is at 18% (Alaska BRFSS 2005).

Family History of Cancer

Increasingly, family history and genetics are playing a larger role in cancer screening. An accurate family history is a well-established method to recognize genetic disorders and susceptibilities that may pose risks for future health problems, including cancer. Many people are unaware of their family health history and its importance. What is known is anecdotal and may not be written down or communicated to the primary care provider.

When someone refers to a “family history of cancer”, they are describing either an inherited or familial cancer. Inherited cancers are caused by mutations from parents to their children. Five to 30 percent of cancers are inherited, and may vary significantly by the type of cancer.

It is estimated that up to 30% of all cancers are Familial. Cancer is referred to as Familial when a combination of factors come together to cause a cluster of cancers. The affected family members not only share multiple genes, but

also their environment and lifestyle. This type of a family history is more difficult to assess, but does provide clues as to which relatives are at risk and what cancer screening might benefit them.



Examples of cancers in which family history of cancer in a first-degree relative (immediate family members such as mothers, fathers, or siblings) increases cancer risk can be found in the table below. The level of risk varies with the age at which the affective relative was diagnosed. The younger the affected relative, the greater the risk for cancer posed to relatives.¹⁸

Cancer Site	Risk
Breast	Double the risk of breast cancer if a mother or sister was diagnosed.
Prostate	Two- to five-fold increased risk.
Ovarian	Three-fold increased risk.
Colorectal	Two- to three-fold risk.
Melanoma	Eight-fold increased risk. ¹⁹

Due to the increasing knowledge of the links between genetics and cancer risk, more people are seeking genetic counseling. Early identification of families with increased risk for chronic disease such as heart disease,

diabetes, and certain cancers, (e.g., breast, prostate, or colorectal) can often improve, delay, or even prevent adverse health outcomes to individual members. Examples of prevention and treatment options include increased surveillance, lifestyle changes, prophylactic medical measures, surgical intervention, or genetic testing.

Genetic counselors are a valuable resource to help explain the complexities of genetic testing, how a genetic test result may be used in the prevention and treatment of cancer, and interpreting genetic test results accurately as it relates to the person tested. On-line resources are listed in Appendix G under Family History.

► **Infectious Agents**

Certain viruses and bacteria, such as Human Papillomaviruses (HPV), Hepatitis B (HBV), Hepatitis C (HCV), and Epstein-Barr virus (EBV) are proven carcinogens. Helicobacter pylori (*H. pylori*) was previously discussed in the section on gastric cancer. There is limited public knowledge about the connection between infectious agents and cancer. Sexually Transmitted Disease (STD) education and literature currently does not link infectious agents specifically with cancer.

HPVs are a group of more than 100 different types of viruses. Of those, over 30 types can be passed from one person to another through sexual contact. Of the many HPVs, a select few are known to be carcinogenic. HPVs are the major cause of cervical cancer and may also play a role in cancers of the anus, vulva, vagina and some cancers of the soft palate, tongue, and tonsils. An HPV vaccine was approved for use in June 2006, and is discussed more in-depth under Section II, Cervical Cancer.

Infections with HBV and HCV viruses can result in liver cancer. HBV infection risk factors

include exposure to blood products or other body fluids, injection drug use, and high-risk sexual behavior (unprotected sex with multiple partners). Currently there are vaccines for HBV, but not HCV.

Epstein-Barr virus is a ubiquitous virus that causes infectious mononucleosis, a benign disease generally of young adults. Almost all persons are infected at sometime in their lives with EBV. EBV has been associated with some types of lymphoma and nasopharyngeal carcinoma.

There is need for increased awareness of the relationship between sexually transmitted infectious agents and cancer. Resources are needed to ensure that health care providers have access to the education materials needed to effectively communicate with patients regarding sexual health issues, including the promotion of HPV vaccine.

► **Environmental Factors**

Ultraviolet Rays

Due to the cold climate, Alaskans often underestimate the risk of getting sunburn. Depletion of the ozone layer is reducing the protective properties of the atmosphere, resulting in an increase in solar radiation. At the same time, global climate change is resulting in warmer weather and an opportunity for Alaskans to wear less clothing and expose more skin to the effects of the sun. Skin cancer is largely preventable when sun protection measures (e.g., sunscreen, protective clothing) are used consistently, and sunburn is avoided. This is especially important for babies and children, and those working outdoors. Most skin cancers are curable if detected in the earliest stages.

Arsenic

There is little public awareness concerning the association between cancer and arsenic.

Although many of the state public water systems were able to meet the new standard of 10 parts per billion (ppb) required by January 2006, the Alaska Drinking Water Program reports that 45 to 60 public water systems are still unable to meet that requirement.²⁰ Well water currently does not have regulatory testing requirements for arsenic levels statewide; however that may vary according to municipality. For example, the Municipality of Anchorage requires testing only when a transfer of property title occurs. The cost of treatment for those wells found not in compliance will vary according to level of arsenic and technology used to improve the level to EPA standards.²¹

PCB

The use of many man-made contaminants in Alaska is relatively new, introduced as recently as the 1940s. Many PCB contaminated sites occurred during military actions in WWII. Alaska Natives have expressed concern about environmental contamination of subsistence foods. The Alaska Native Tribal Health Consortium Division of Environmental Health and Engineering and the Office of Community Health Services are studying and monitoring this concern, but continue to recommend that subsistence food remain the first choice of food for Alaska Natives, because of high nutrient content, but also because of its cultural value and the added benefit of physical activity required to hunt and gather, and preserve food.

Benzene

Higher levels of benzene are added to Alaska's gasoline due to the cold temperatures. There are also many urban homes with attached garages, which increases the level of exposure to benzene by 500% (1.6 ppb to 6.6 ppb). The Municipality of Anchorage (MOA) has been conducting studies to determine specifically which types of homes and construction methods impact the level of benzene exposure. The MOA will

also test and design an intervention for current homes with attached garages to reduce the exposure to benzene to an acceptable level.

Elevated levels of benzene in homes have been detected in urban areas but information about levels in rural homes is currently unavailable. The tight design of Arctic homes, combined with the use of interior space for fuel storage and engine maintenance, raises questions about the health risk associated with poor indoor air quality. Public education and construction standards must be established to decrease exposure to benzene.

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Access to Care

Health Care Coverage and Access

Access to health care remains a challenge in Alaska. Twenty–nine percent of Alaskans report they do not have a primary care provider and seventeen percent of Alaskans have no health care coverage (Alaska BRFSS, 2005). The Alaska Medicaid program does not cover prevention and early detection health care services. Regular health checks are not covered

by all private insurance plans. Fifteen percent of Alaskans reported not being able to see a doctor due to the cost (Alaska BRFSS, 2005). Many of these individuals are utilizing the emergency rooms for their primary health care. Having a usual medical provider is an important link to prevention and early detection. There is currently a shortage of physicians accepting new Medicare patients in Anchorage and in other areas of the state.

Early Detection

Scientific study has revealed that early detection and treatment of some cancers can greatly improve the likelihood of survival. Screening is a means of detecting disease early in asymptomatic people. Early detection involves routine screening, such as tests, for the general population and at-risk groups before cancer symptoms appear. Screening is viewed as a vital approach to decreasing cancer mortality.¹ Empirical evidence reveals that specific cancers can be detected early. These include breast, cervical, and colorectal cancer.² Although prostate screening has the potential to identify cancer in an early stage, the advantages and disadvantages provoke considerable discussion among the experts. Currently the National Cancer Institute has taken a neutral position leading many states to include prostate cancer on their early screening goal list.³

It is important to note that capacity for the full range of evidenced-based cancer screening tests are not available in some areas of Alaska, most notably breast mammography and endoscopy. This is due to both a lack of providers and infrastructure, as well as high transportation costs and lack thereof to travel into areas that have adequate capacity for screening and early detection services.

► **Access to Cancer Information, Treatment, and Clinical Trials**

Geography presents one barrier to providing cancer prevention, early detection, and treatment in cancer care in Alaska. With a total estimated population of 664,000 in 2005, Alaska ranks 48th of 50 states in population size, yet has a land mass over twice the size of the next largest state, Texas. Alaska covers 586,412 square miles of predominantly roadless terrain. Alaska has 229 federally recognized tribes, and 119,241 Alaska Native residents, according to the 2000 U.S. Census.



Despite Alaska's low population density (1.1 people per square mile), more than 7 out of 10 persons live in places of 2,500 people or more (defined as urban places by the Census Bureau).

Forty-one percent of Alaska's population resides in Anchorage, and 79% of the population resides in the six largest census areas: Anchorage, Fairbanks, the Kenai Peninsula, Ketchikan, the Matanuska-Susitna Borough, and Juneau, the capitol of Alaska. About 30 percent of the population lives in rural places, (less than 2,500 residents), or outside any community. Approximately 72 percent of the state's population lives in areas that for the most part are connected by the highway system. The remainder of the population lives in roadless areas where access to urban centers

or to the lower 48 states, is only by air, boat, or snow machine, making travel difficult, expensive, and hazardous. Many Alaskans travel 200 to 500 miles for health care services, including hospital care.

Fairbanks and Anchorage are the only two cities which have facilities where medical and radiation oncologists practice. Cancer treatment clinical trials are only available in these locations at this time. This requires Alaskans to travel in from outlying communities to Anchorage, Fairbanks, or to treatment facilities outside the state, which is done by a significant number of cancer patients. There has been a history of inconsistency in maintaining a Pediatric Oncologist in the state, which necessitates children traveling outside the state for cancer assessment and treatment.

Travel outside the state for the cancer patient and their family is an added expense and significant burden when treatment can take weeks to months. The ACCP is committed to supporting treatment of patients as close to their community as possible, and increasing the treatment options available in Alaska.

► **Palliative Care**

Palliative care improves the quality of life for cancer patients and their families who face life-threatening illness, by providing pain and symptom relief, spiritual and psychosocial support from diagnosis to the end-of-life and bereavement. The World Health Organization defines palliative care as "the active total care of patients whose disease is not responsive to curative treatment. Control of pain, of other symptoms, and of psychological, social and spiritual problems is paramount. The goal of palliative care is the achievement of the best possible quality of life for patients and their families."⁴

Palliative care:

- provides relief from pain and other distressing symptoms;
- affirms life and regards dying as a normal process;
- intends neither to hasten or postpone death;
- integrates the psychological and spiritual aspects of patient care;
- offers a support system to help patients live as actively as possible until death;
- offers a support system to help, the family cope during the patients illness and in their own bereavement;
- uses a team approach to address the needs of patients and their families, including bereavement counseling, if indicated;
- will enhance quality of life, and may also positively influence the course of illness; and
- is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.

Providing palliative care in Alaska is challenging in rural and remote areas with limited or no health support infrastructure. The Alaska Native Tribal Health Consortium (ANTHC) is addressing this challenge by providing annual symposia over five years and convening teams from these areas to address specific barriers to care, while promoting

innovations in palliative care in rural and remote communities to support patients returning home as soon as possible.

► **End-of-Life Care**

The concept of hospice is one of comprehensive care for the dying. The physical facilities may be very extensive or quite minimal and should be thought of in terms of what it does rather than the institution in which it is performed. A hospice provides support and care for persons with incurable disease during their last phase of life so they are comfortable and experience minimal to no suffering. Hospice care encompasses all aspects of the person's life during their final days to include physical, mental, psychosocial, and spiritual care. Unfortunately Alaska has too few hospice services, especially outside the major population centers. Often there is no alternative for dying in the home as communities lack experienced health care providers and family members are not prepared.

In 2004, Alaska joined other states which enacted Advanced Directive legislation modeled after the "Five Wishes" which allows Alaskans to provide guidance on their health care if they become incapacitated. Advanced directives are helpful to both family and health care providers in following the desires of the patient during their final days, or when they are incapacitated.

► **Care for Children**

Childhood cancers are rare. Although uncommon, cancer is the second leading cause of death in children, exceeded only by accidents. The American Cancer Society estimates 9,500 new cases will occur in children 0-14 years in 2006.⁵ An average of 30 new cases have been diagnosed annually in Alaska. Leukemia comprises the majority of cancer cases (43%) in Alaska children. Second to leukemia for cancer in children is brain and other central nervous

system cancers which occurred at 11% (SEER, 1996–2003).

Due to the low numbers of cancer in children, it has been difficult to maintain a Pediatric Oncologist in Alaska. Children and their families often are required to travel outside of Alaska for cancer care. Alaska's children can now receive initial and follow-up hematology and oncology services in Anchorage as part of the Providence Alaska Medical Center Children's Hospital Sub-Specialty Clinic. This provides Alaska families the option to stay closer to home, their schools and the support of their community.

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Cancer Health Disparities

Health Disparities

What are health disparities? A National Institutes of Health (NIH) working group defined health disparities as differences in the incidence, prevalence, mortality, and burden of cancer and related adverse health conditions that exist among specific population groups in the United States. These population groups may be characterized by gender, age, ethnicity, education, income, social class, disability, geographic location or sexual orientation.¹

Research shows that individuals from underserved populations are more likely than the overall U.S. population to:

- be diagnosed with and die from preventable cancers;
- be diagnosed with late-stage disease for cancers that are detectable at an early stage through screening;
- receive either no treatment or treatment that does not meet currently accepted standards of care;
- die of cancers that are generally curable; and
- suffer from terminal cancers in the absence of adequate pain control and other palliative care.²

The burden of cancer is higher for some racial groups in Alaska. For instance, higher incidence rates of colorectal cancer occur in Alaska Natives and higher incidence rates of prostate cancer are found in black men (SEER 1996–2002).

Identifying cancer health disparities among the populations in Alaska is a priority. Both the Alaska Cancer Registry and the Alaska Comprehensive Cancer Partnership are committed to incorporating cancer health disparities data when available in all planning, and implementation of any and all strategies. Future reports will look across all measured racial groups to identify differences in rates of cancer, and examine any other identifying data, such as stage of tumor at diagnosis and rural vs. urban locations, to further define the cancer burden.

One of the challenges in identifying disparities in cancer is the small numbers of people with cancer from minority groups, with the exception

of Alaska Natives. Whites and Alaska Natives composed about 91 percent of the population of the state of Alaska during the period 1996–2002 (74 and 17 percent respectively). The remaining 9 percent are Asian/Pacific Islander and blacks (5 and 4 percent respectively). Cancer rates for whites and Alaska Natives are the most stable for the purposes of comparisons between races due to their large populations. Cancer rates for the other races tend to have larger fluctuations from year to year. Determining trends in races with small numbers of cancer cases will require many years of data, and efforts will be made by the partnership to perform this review.



Hoonah, Alaska

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The partnership will convene a Disparities Workgroup to look at cancer incidence and mortality data of all races available since the cancer registry began in 1996. Findings will be included in the annual report and disseminated.

Addressing Survivorship: Supporting Alaskans Facing Cancer

Currently it is estimated there are 10 million people who have had cancer or are living with cancer in the United States.³ The term "cancer survivor" refers to those people who have been diagnosed with cancer and the people in their lives who are affected, including family

members, friends, and caregivers. As survival rates increase, the long-term effects of cancer and cancer treatment are being revealed. Cancer is emerging as a chronic health condition, rather than a terminal disease. Cancer patients need to be aware of their treatments and how to advocate for future care related to their past cancer treatment.

The Institute of Medicine (IOM) in 2005 recommended that cancer survivors receive a "survivorship care plan" to help guide them and their health care providers in their long term care. Since many times survivors are disengaged from their oncology specialist once treatment is completed, more emphasis on cancer aftercare by primary care providers must be emphasized. Since secondary tumors can occur due to treatment of the primary cancer, both the survivor and primary care providers need to have a record of treatment and be informed of any follow-up care necessary to protect the patient's health. New guidelines are also available for pediatric cancer survivors who may experience latent side effects from their treatment.

Many national and local organizations offer resources for cancer survivors. More information on these can be found in Appendix G.

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Appendix

Acknowledgements

We wish to acknowledge and thank those who participated in the development of the 2006–2010 Alaska Cancer Control Plan since 2003.

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Comprehensive Strategic Health Care Plans

► *Healthy People 2010*

Healthy People 2010 (HP 2010) is the plan that serves as a framework for health policy development in the United States. The lead agency for HP 2010 is the CDC. HP 2010 contains a comprehensive set of disease prevention and health promotion objectives to achieve over the first decade of the new century. HP 2010 identifies a wide range of public health priorities and specific, measurable objectives.



HP 2010 objectives are designed to achieve two goals: Increase quality and years of healthy life and eliminate disparities. These two goals are supported by specific objectives in 28 focus areas, one of which is cancer, where the goal is to reduce the number of new cancer cases and to reduce the illness, disability, and death caused by cancer. Each objective was developed with a target to be achieved by the year 2010. Specific objectives within the cancer focus area include reducing lung cancer deaths, reducing the harmful effects of sun exposure, and providing counseling about preventive measures. HP 2010 indicators are useful for setting cancer control baselines and objectives where other data sources are not available.

► *Healthy Alaskans 2010*

Using the framework of the national Healthy People 2010, Healthy Alaskans 2010 (HA 2010) outlines the targets and strategies for improved health in Alaska. HA 2010 reflects Alaska's priorities and objectives for improving health status; modifying exposures to health risks; and strengthening health care services and environmental and occupational conditions. Chapter 22 addresses cancer.

Database Descriptions

► *Alaska Cancer Registry*

The Alaska Cancer Registry (ACR) is a population-based, statewide cancer registry. The primary purpose of the registry is to collect information on all reportable cancer cases in Alaska. The registry maintains data on newly diagnosed cancer cases and pertinent information about that cancer. The ACR is funded by the CDC National Program of Cancer Registries (NPCR) grant.

The registry began collecting information January 1, 1996. Alaska hospitals, physicians and other health care practitioners are required by state law to report information to the ACR within six months of diagnosis. Reported cancer cases are analyzed to identify cancer trends, patterns, and geographic variations. The ACR then creates and disseminates reports on the burden of cancer in Alaska. Cancer incidence and mortality data is critical for targeting public health programs. Data from incidence trends for cancer of different sites will be used to plan intervention strategies to prevent or reduce the occurrence of disease and its impact.

► *Behavioral Risk Factor Surveillance System (BRFSS)*

Alaska BRFSS is part of an ongoing national telephone survey conducted by the State of

Alaska Department of Health and Social Services, Division of Public Health, funded by a grant from the CDC. It utilizes standard protocol and interviewing methods developed by the CDC. Alaska began participating in the BRFSS in 1991. The survey includes questions about health status and perceptions, preventive health practices, and risky behaviors that influence the occurrence of chronic diseases, injury, and preventable infectious diseases.

The BRFSS is a standardized telephone interview conducted with adults using a computer-assisted script. There is a fixed core of questions asked by all states every year and a rotating core asked by all states in alternate years. In addition, there are a number of optional modules that states may choose to use. States may also add questions of their own. Interviews are conducted every month of the year. Currently, over 200 Alaska residents age 18 and older are interviewed over the telephone every month to reach an annual sample size of 2500.

A stratified random sampling design is used on the Alaska BRFSS. The Alaska sample is stratified into five regions. An equal number of interviews are conducted in each region, which purposely over-samples the very large, rural areas of Alaska.

Participation is random, anonymous, and confidential. Respondents are randomly selected from among the adult members of the household. Only those living in households are surveyed. Those living in institutions (e.g. military barracks, dormitories, nursing homes), and other group living situations are excluded. Apart from that exclusion, each state's sample is designed to be representative of the state population. Respondents are contacted by telephone using a selection process based on area codes and prefixes that are highly likely to

be associated with residential listings. Alaska uses an additional sampling procedure to take into account differences in telephone coverage by geographic and economic factors. It is estimated that 97 percent of the households in the state have telephones, but the percentage is substantially lower in some geographic areas and among groups of low socioeconomic status (U.S. Census, 2000).

The analysis of BRFSS data requires complex statistical procedures to take into account the fact that not every adult resident of the state has an equal chance of being contacted for an interview. The analysis assigns a probability to each respondent which reflects his or her likelihood of being contacted. In addition, each person interviewed is treated as a representative for other, similar persons. The probability factor and assumption of representativeness are used to calculate a statistical weighting factor to use in analysis to draw inferences about the overall population.

► *Youth Risk Behavior Survey (YRBS)*

The YRBS is part of an epidemiological surveillance system of youth grades 9–12 who are attending public high schools. The YRBS was established in 1988 by the CDC to help monitor the prevalence of behaviors that not only influence adolescent health, but also put youth at risk for significant health and social problems that can occur during adolescence and adulthood. Prevention coordinators, community mobilization coalitions, community public health and safety networks, and others use this information to guide policy and programs that serve youth.

The YRBS survey, conducted by the Department of Health and Social Services, Department of Public Health, is designed to be administered every two years by distribution in randomly selected schools throughout the state.

YRBS measures cancer specific risk behaviors regarding tobacco use, unhealthy dietary behaviors, and inadequate physical activity. Data from the YRBS is self-reported. Parental consent to participate is required by Alaska Statute.



Alaska first participated in the YRBS survey in 1995 at both the high school and middle school levels and obtained weighted (representative) statewide data. Due to external factors, the YRBS was not administered in 1997. It was administered in 1999; however the 1999 sample did not include the Anchorage School District, the state's largest school district. Without Anchorage, the data were not representative of the state as a whole.

The YRBS survey was administered in 2001 statewide, however not enough student responses statewide were collected, and so no data were analyzed. A major obstacle in 2001 was the active parental consent law that had just gone into effect at the end of the 1999. In 2003, the survey was administered statewide with active parental consent and weighted (representative) data were obtained. YRBS response in 2005, regrettably, was insufficient to obtain statewide generalizable data.

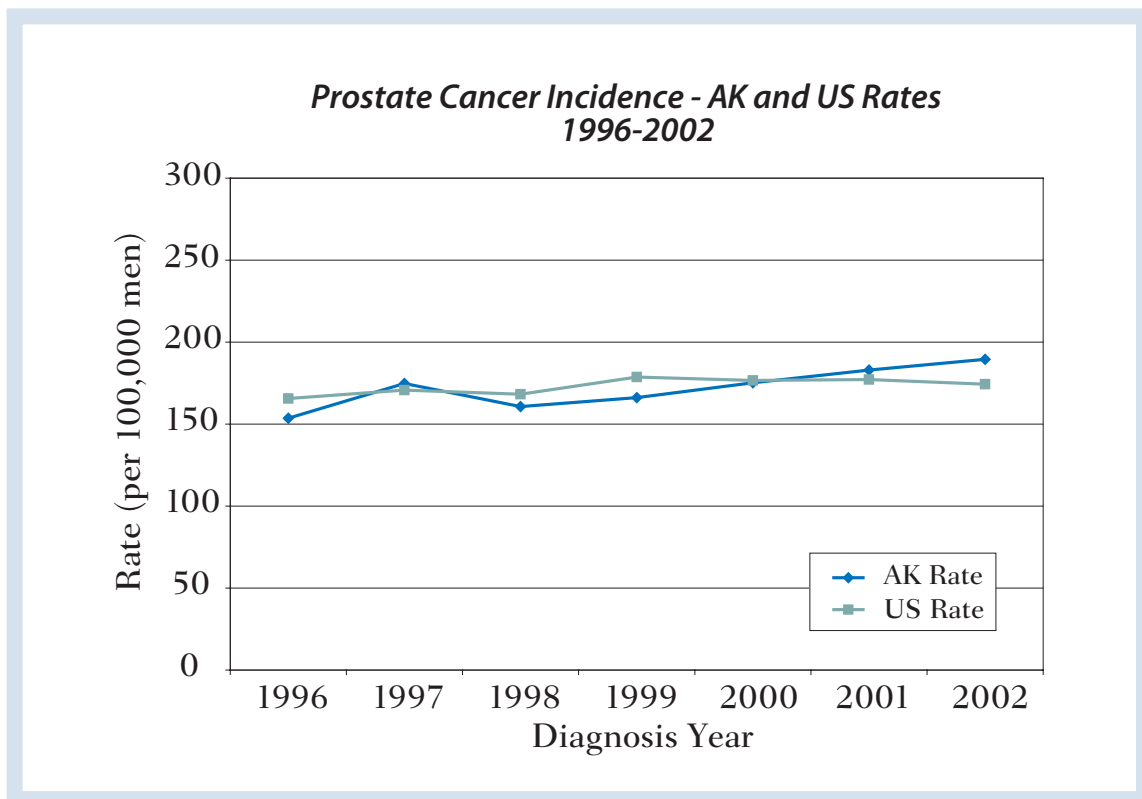
► ***Pregnancy Risk Assessment Monitoring System (PRAMS)***

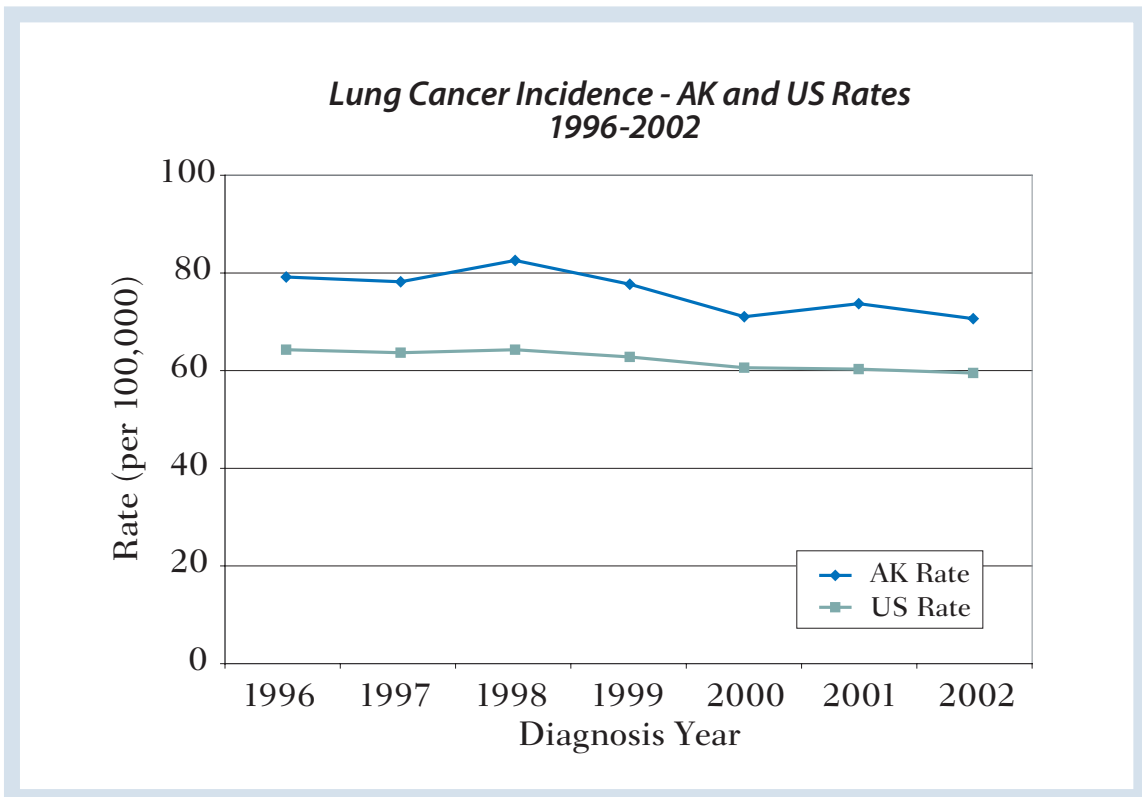
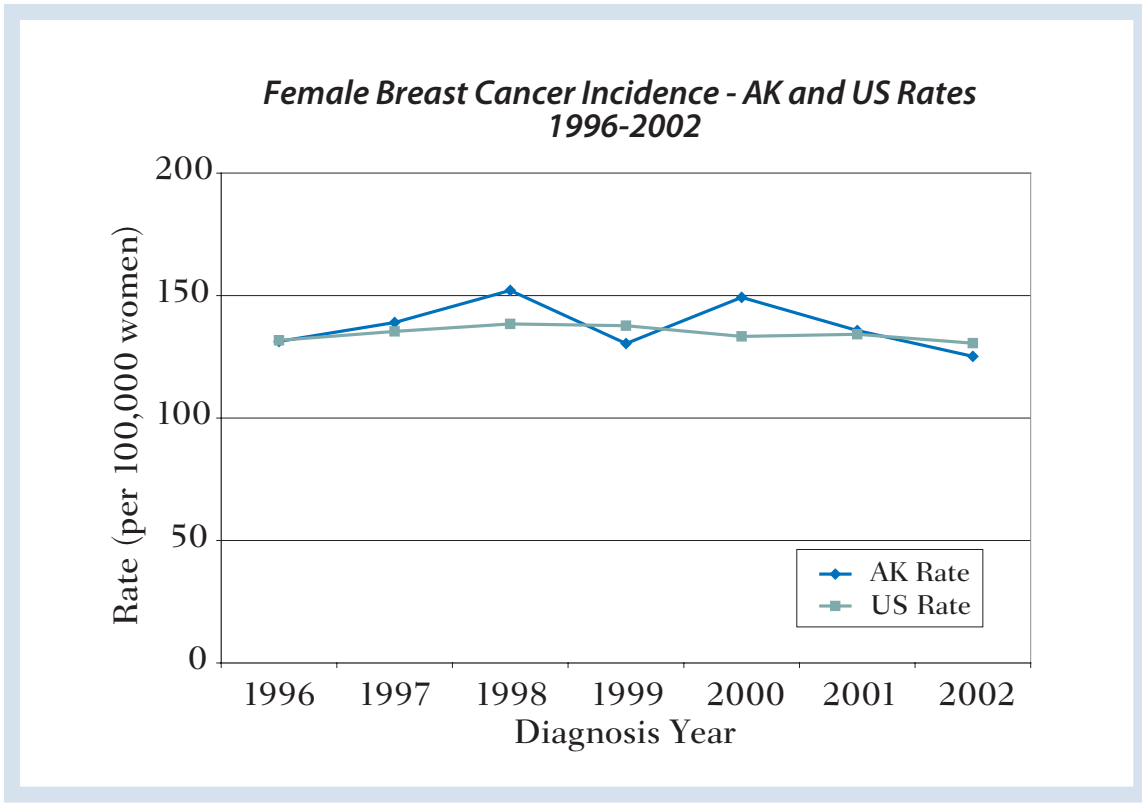
The Pregnancy Risk Assessment Monitoring System (PRAMS) is a surveillance project funded by a grant from the CDC and conducted by the State of Alaska Department of Health and Social Services, Division of Public Health. PRAMS collects Alaska data on maternal attitudes and experiences before, during, and shortly after pregnancy. The project was initiated by the CDC in 1987, because infant mortality rates were no longer declining as rapidly as they had in prior years. In addition, the incidence of low birth weight infants had also not declined in the previous 20 years. Research indicates maternal behaviors during pregnancy may influence infant birth weight and mortality rates.

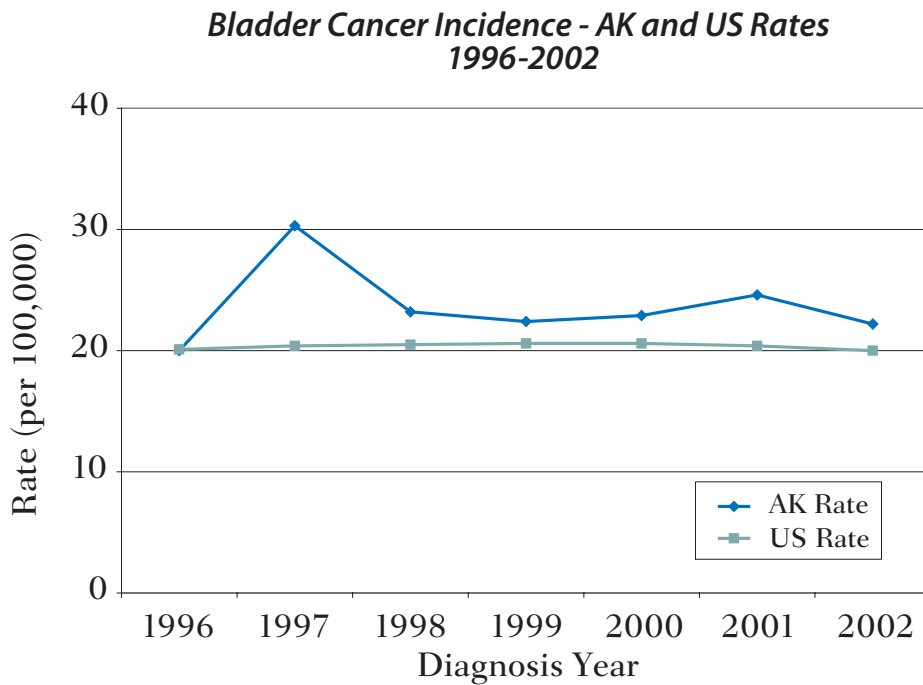
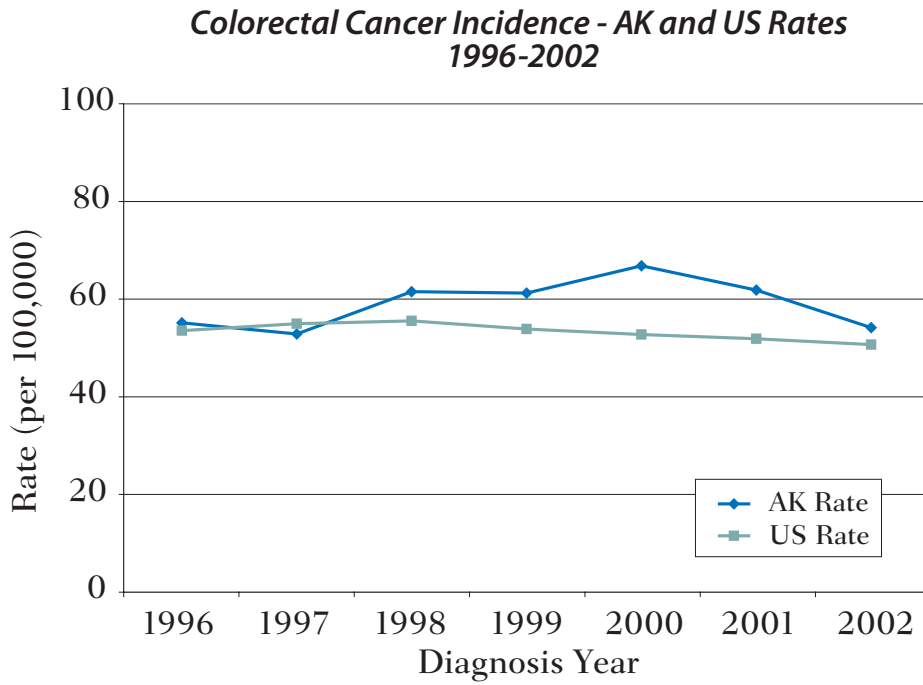
The goal of the PRAMS project is to improve the health of mothers and infants by reducing adverse outcomes such as low birth weight, infant mortality and morbidity, and maternal morbidity. Participants are selected from birth certificate data using a stratified random sample that oversamples for underrepresented populations. Survey information is collected by mail through a self-administered questionnaire with telephone follow-up of non-responders. Alaska uses an additional sampling procedure for Alaska Natives. Because the same data collection methods are used in all states, PRAMS also allows for comparisons between participating states.

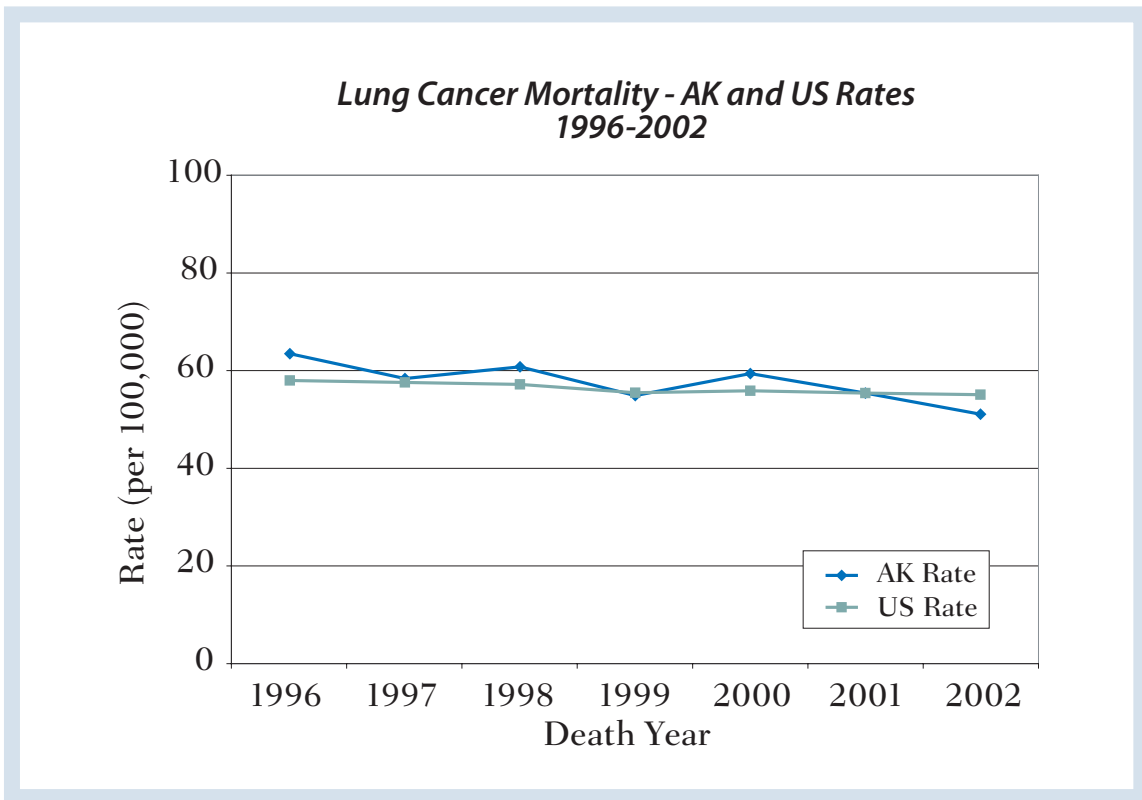
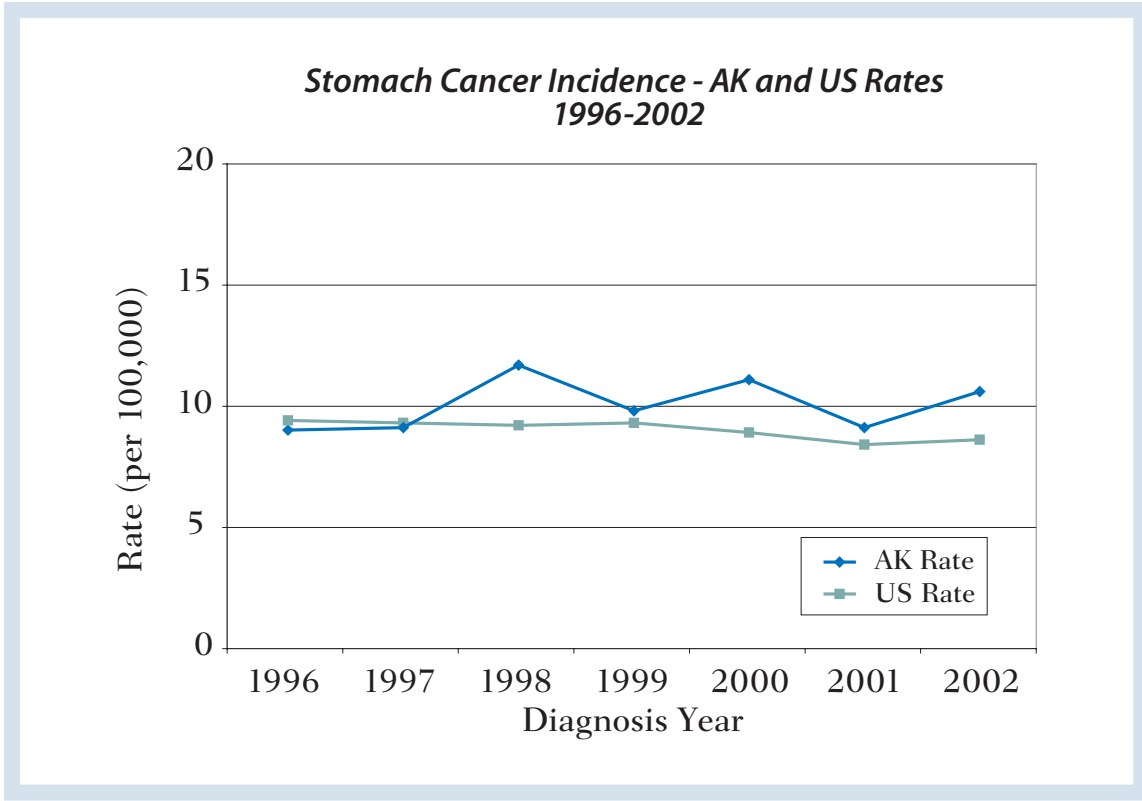
Incidence and Mortality Graphs

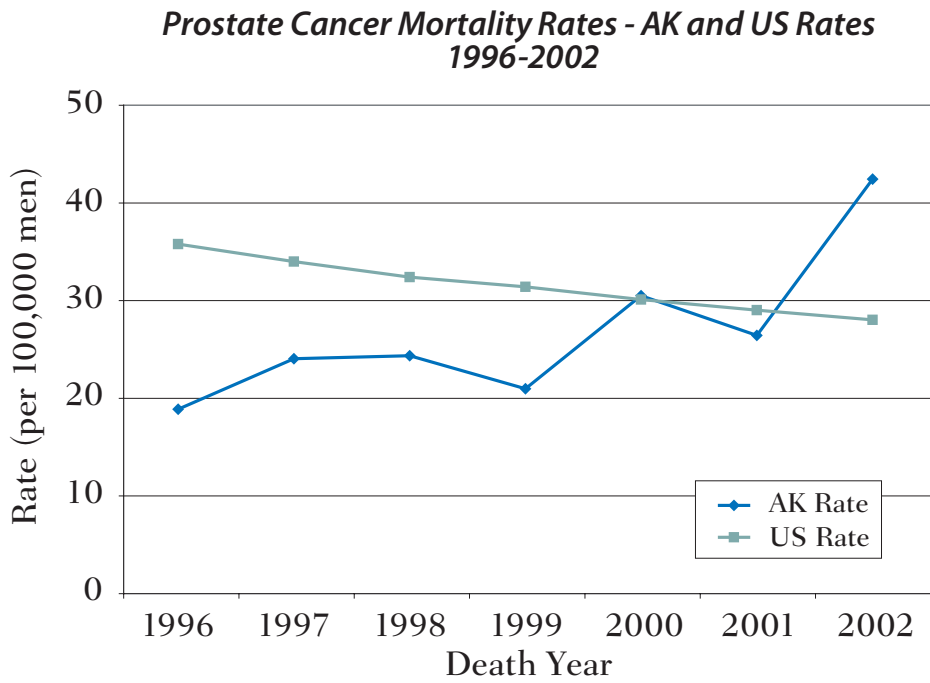
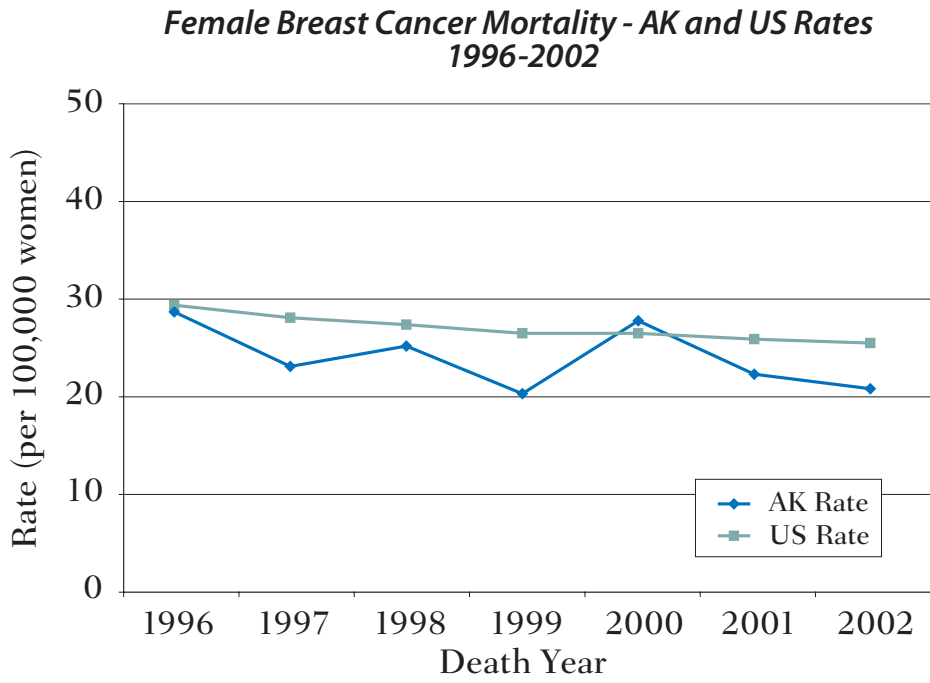
The next several pages consist of graphs illustrating incidence and mortality rate trends for Alaska compared to the United States as a whole. The trend data for Alaska shows a larger variation than the U.S. data because Alaska has such a small population and this information only represents a 7-year period. Rates are per 100,000 people and are age-adjusted to the year 2000 U.S. Standard Population.

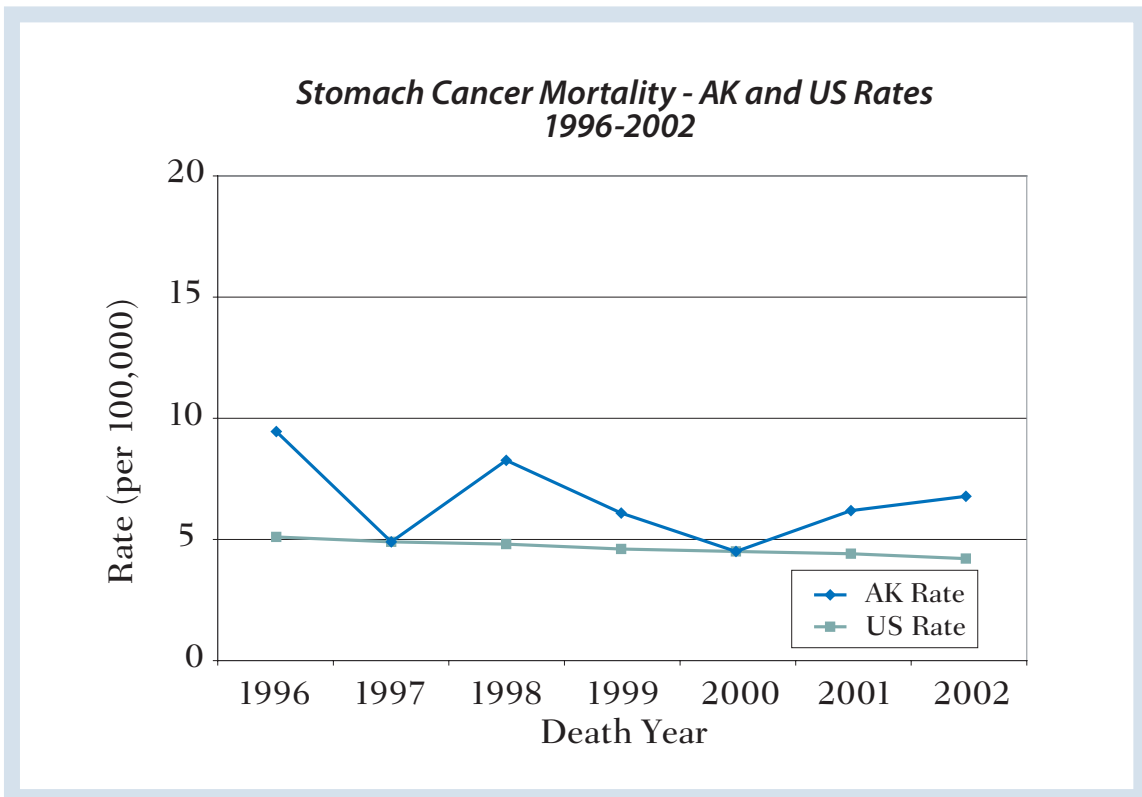
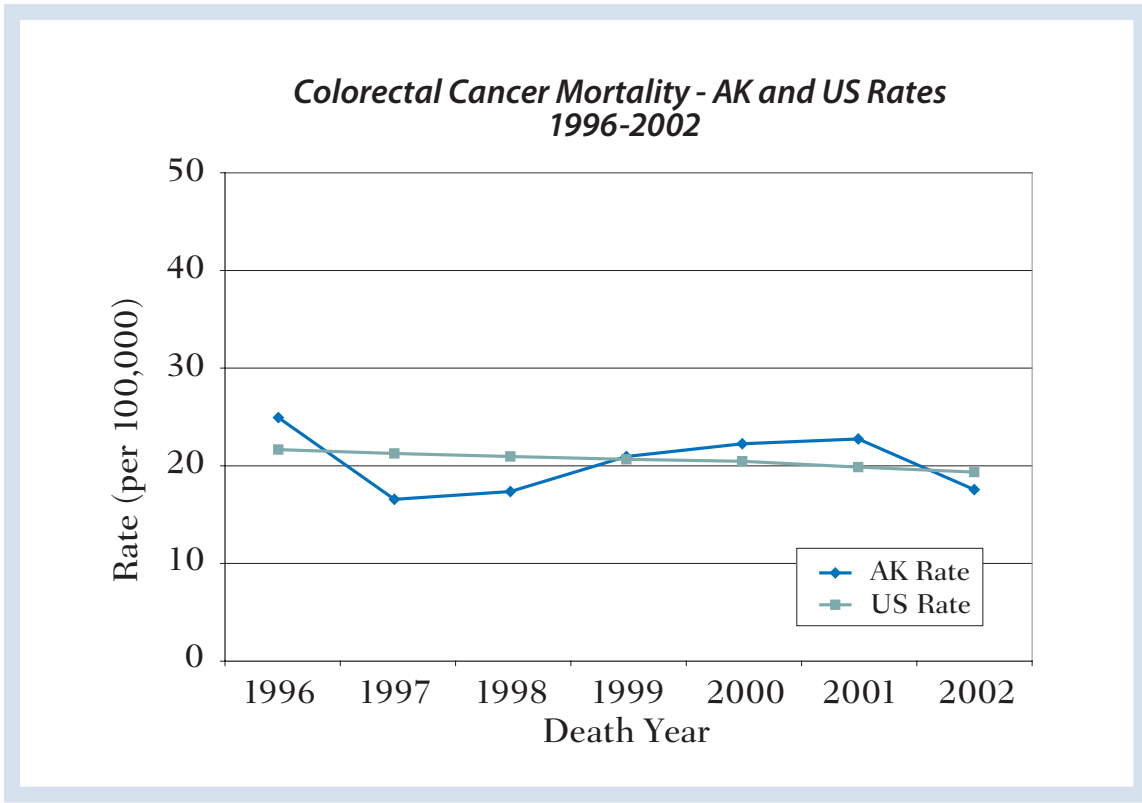


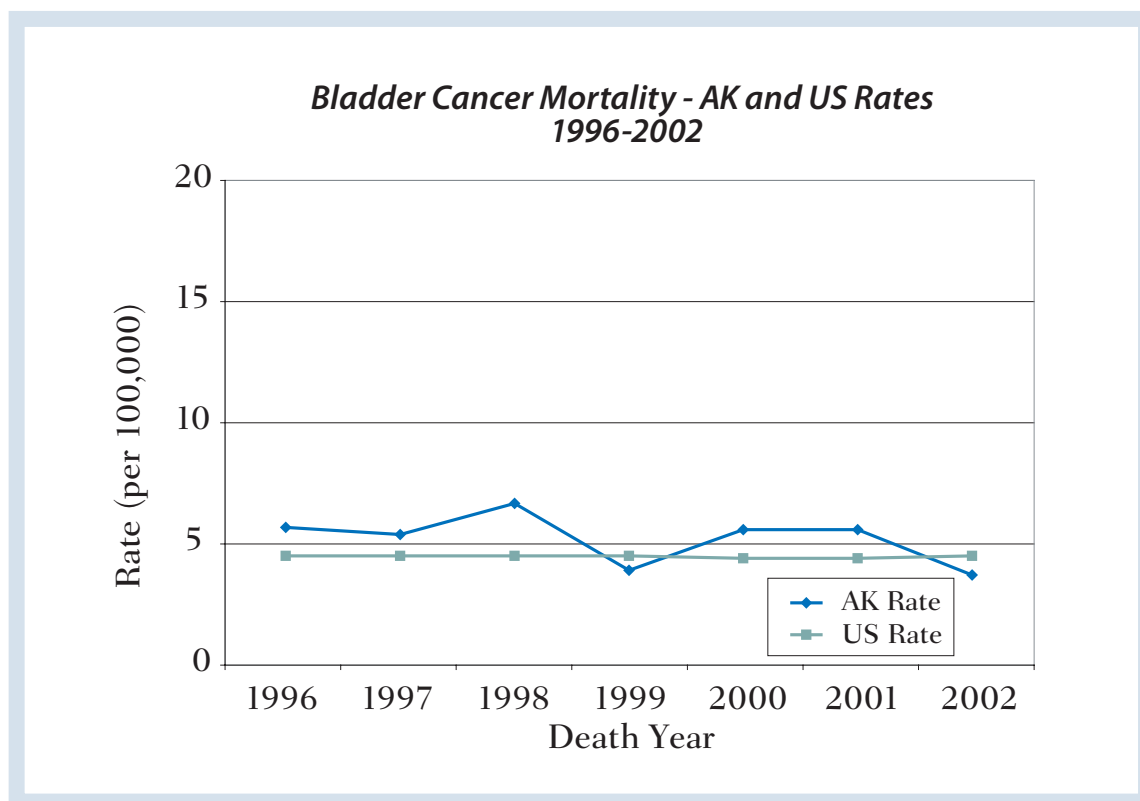








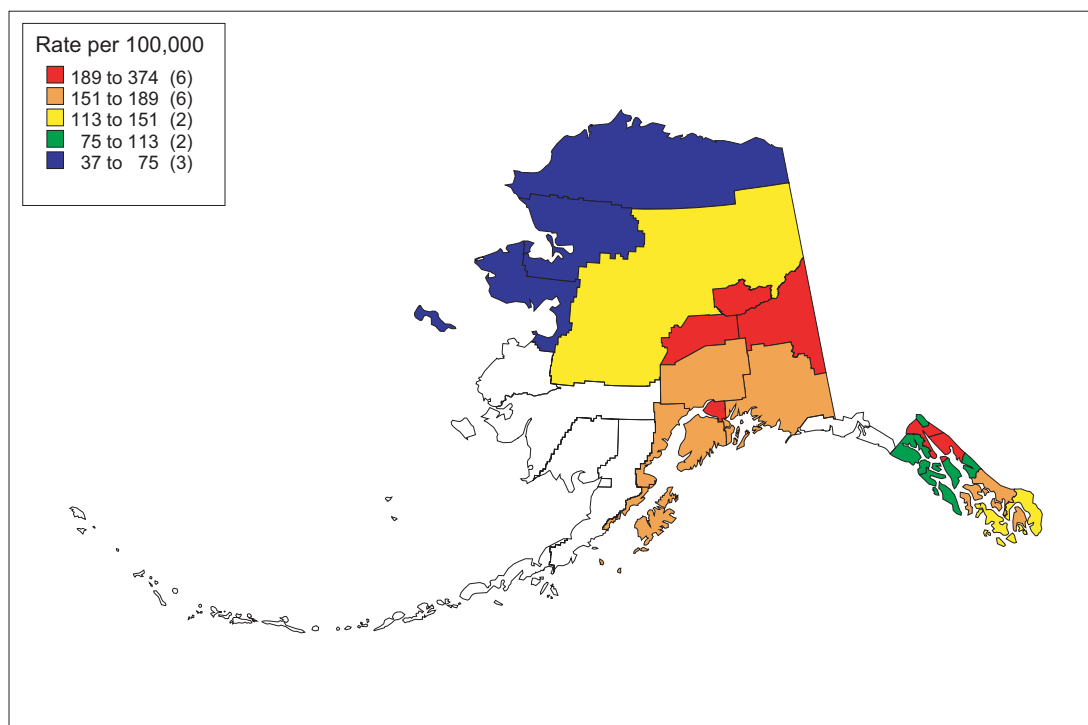




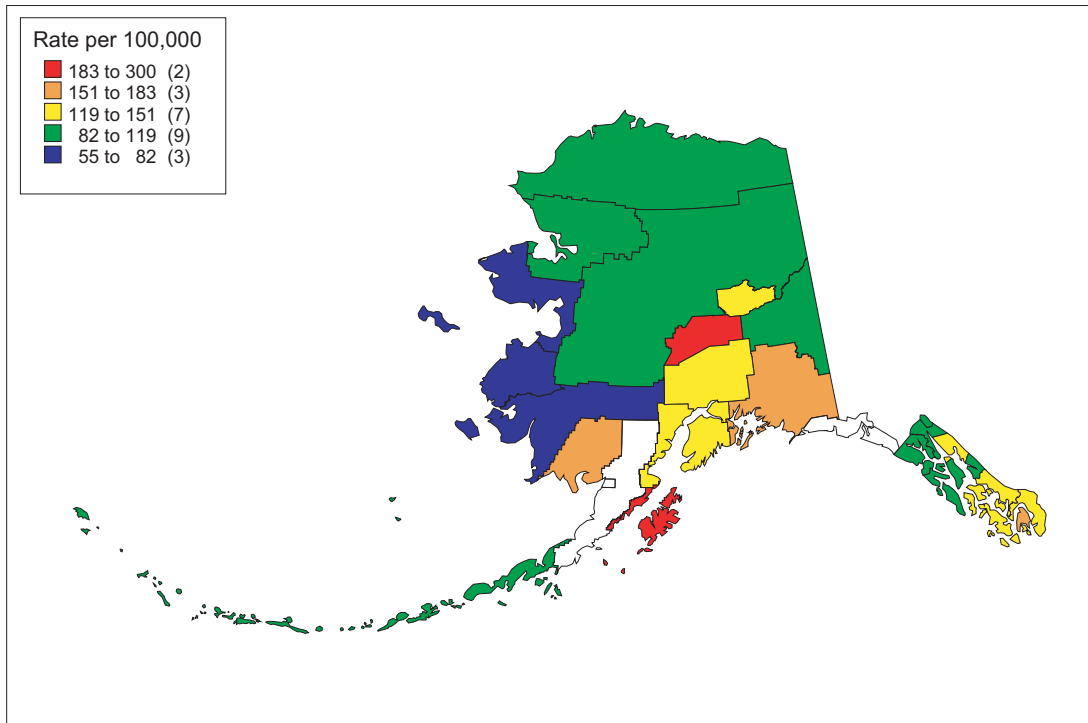
Incidence and Mortality Maps

The next several pages consist of color-coded maps of incidence and mortality rates for the top six cancers in Alaska for each borough/census area. The color scheme is gradational between red (high rates) and blue (low rates). Blank regions on the map represent areas in which cancer rates were not calculated because there were 5 or fewer cancer cases (or none) in that borough/census area. Numbers in the legend indicate the range of rates (up to but not including the upper value) represented by a specific color, and the numbers in parentheses indicate the number of borough/census areas in that range. Rate ranges are in equal intervals (for example, 10-15, 15-20, 20-25, etc.) except when the minimum or maximum value within a data set is much less than or much greater than the majority of the other values. In these situations, the lower or upper range has been extended to accommodate this outlying value. Rates are per 100,000 people and are age-adjusted to the year 2000 U.S. Standard Population.

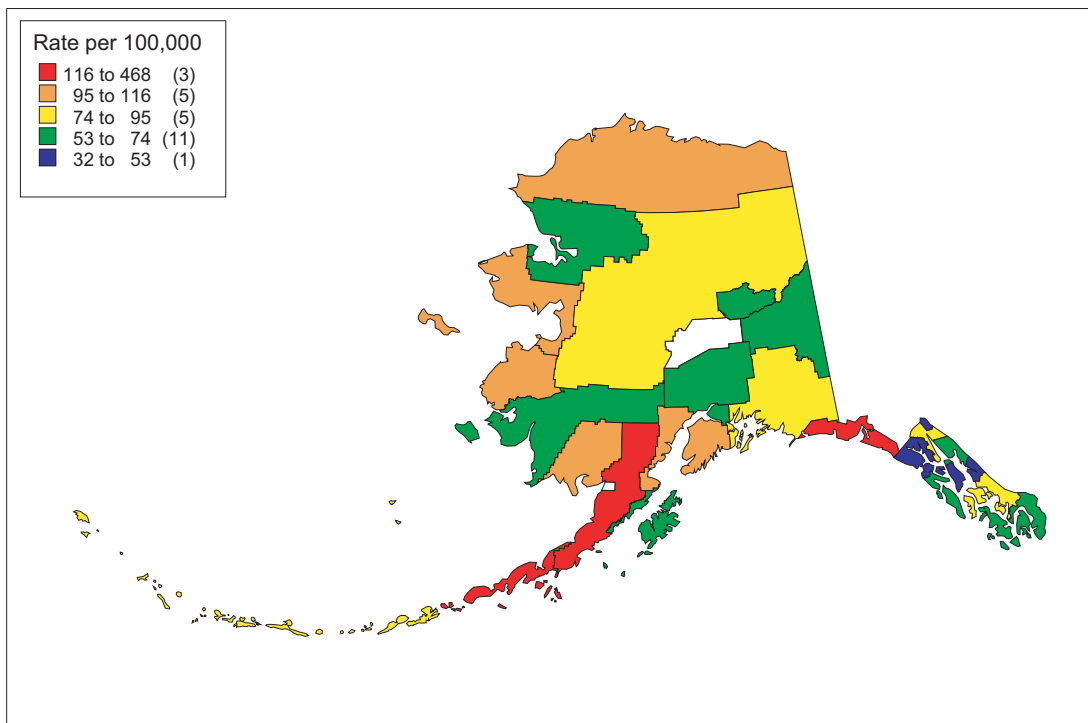
Note that borough/census areas with low populations may have unusually low or high cancer rates. In these situations, the rate may be a result of chance variations within the population rather than a true representation of the burden of cancer. For example, a low-population area may have 5 cases of a certain type of cancer for a given year, and 10 cases the next. If the population is 10,000, then the rate (per 100,000 people) is 50 the first year and 100 the next – a 100% variation. However, a high-population area may have 50 cases of the same type of cancer and 55 cases the next. If the population is 100,000, then the rate (per 100,000 people) is 50 the first year and 55 the next – only a 10% variation. In both situations the number of cases differing year to year is the same.



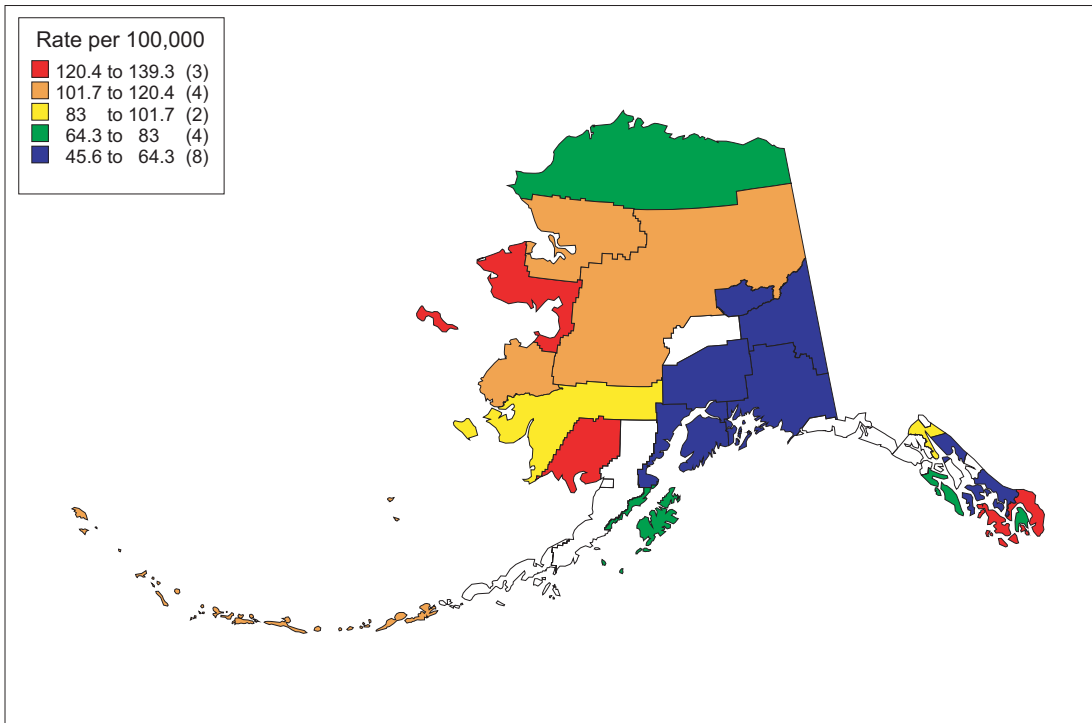
Prostate Cancer Incidence Rates by Borough/Census Area, 1996-2002



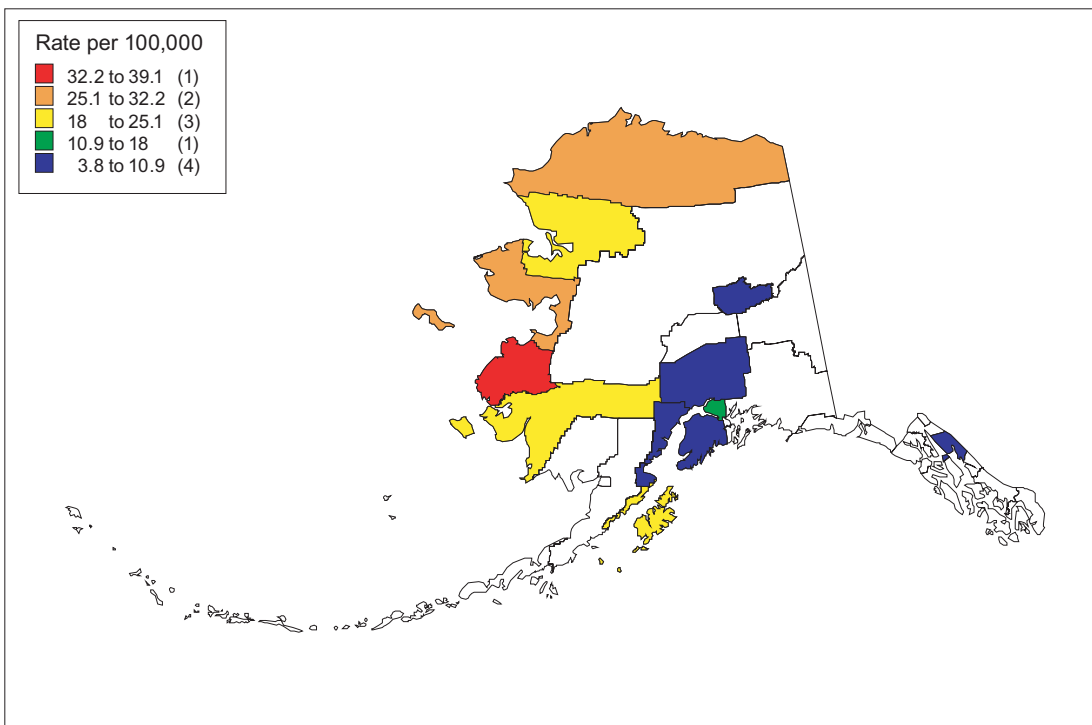
Female Breast Cancer Incidence Rates by Borough/Census Area, 1996-2002



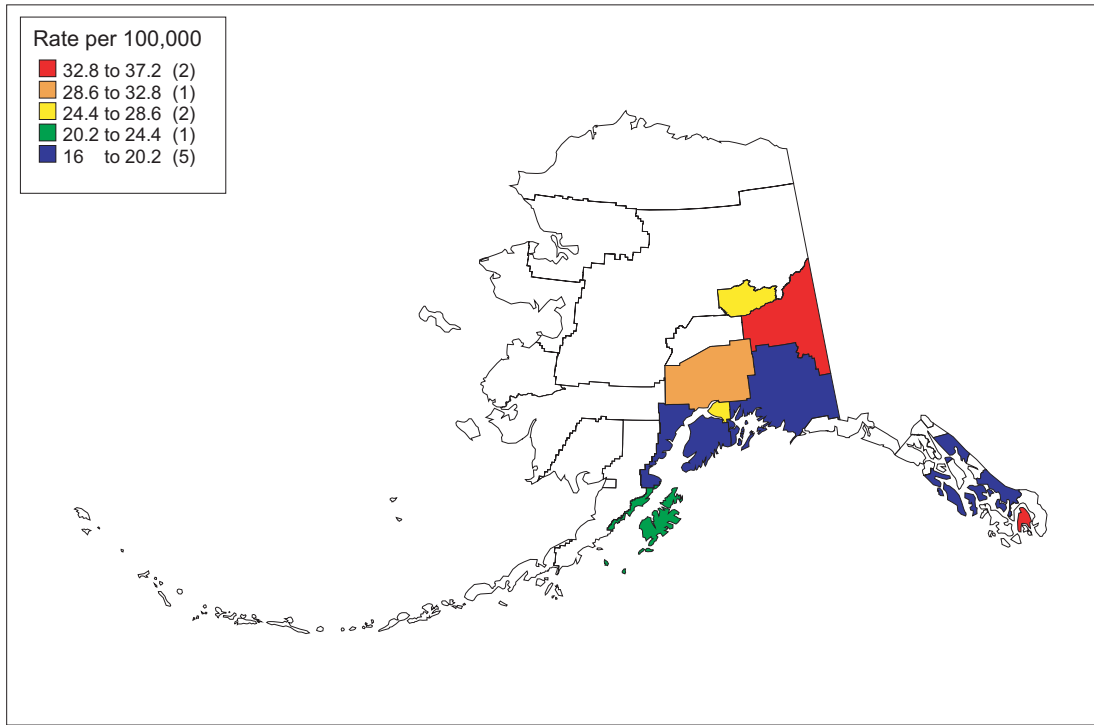
Lung & Bronchus Cancer Incidence Rates by Borough/Census Area, 1996-2002



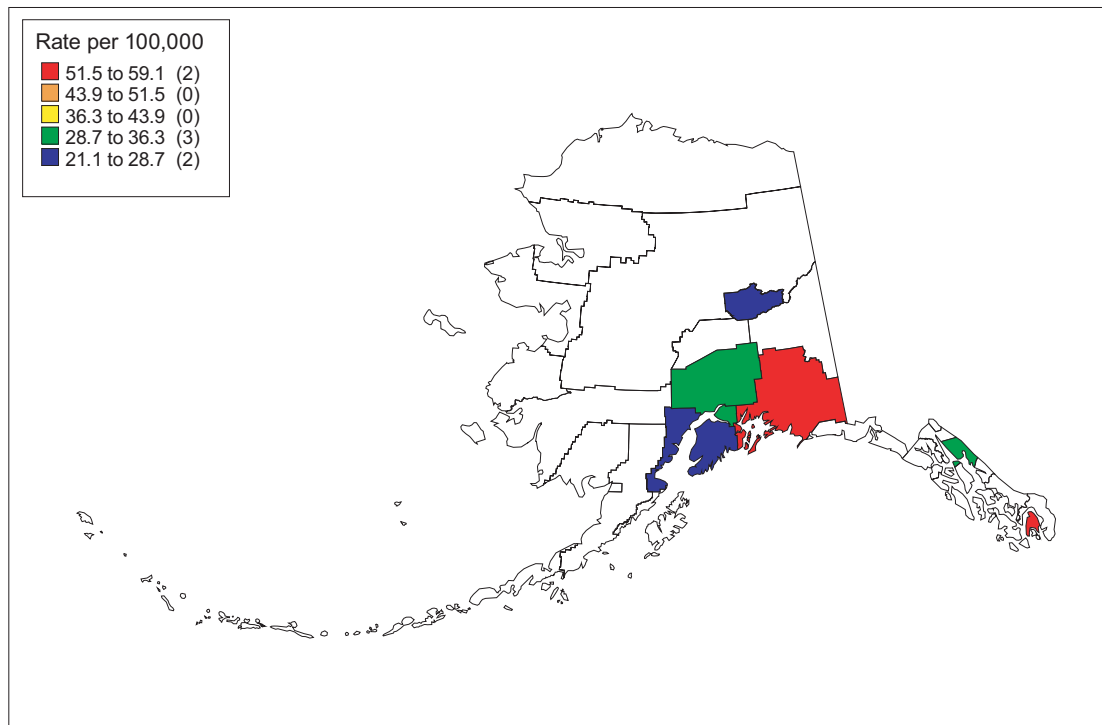
Colorectal Cancer Incidence Rates by Borough/Census Area, 1996-2002



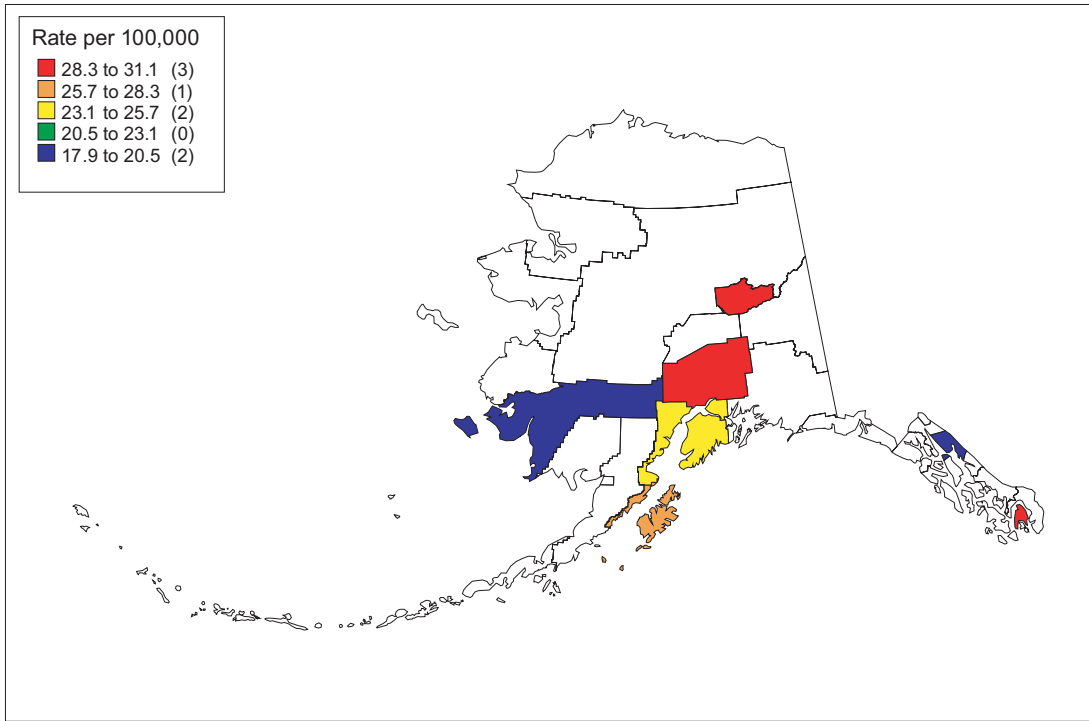
Stomach Cancer Incidence Rates by Borough/Census Area, 1996-2002



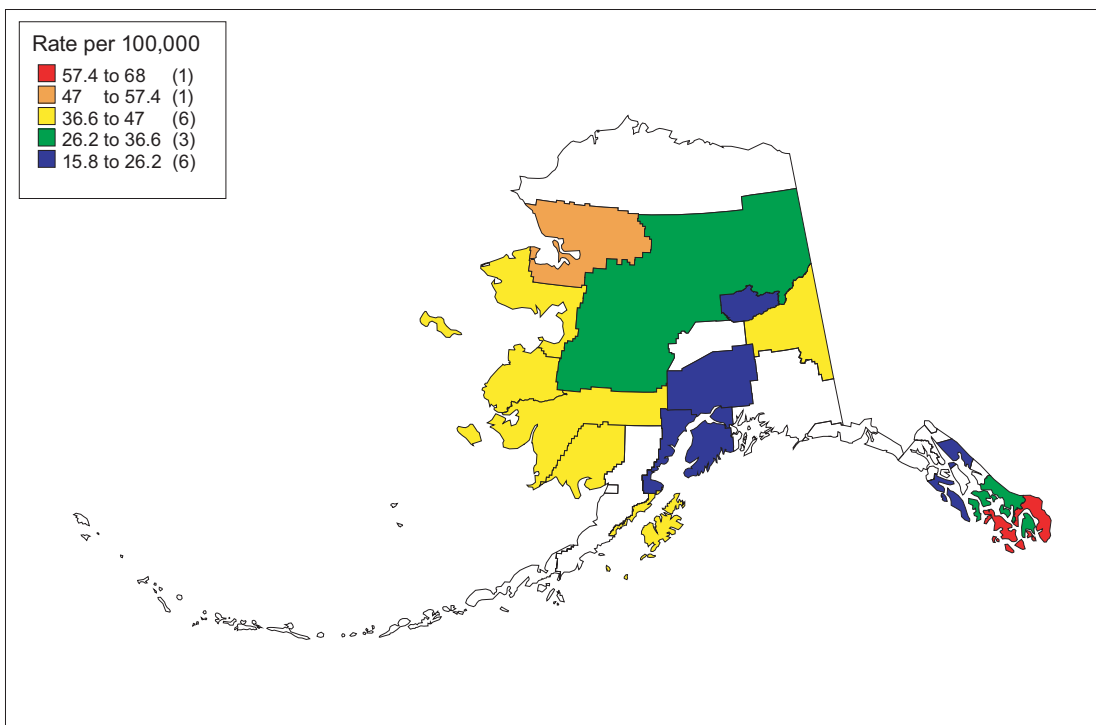
Bladder Cancer Incidence Rates by Borough/Census Area, 1996-2002



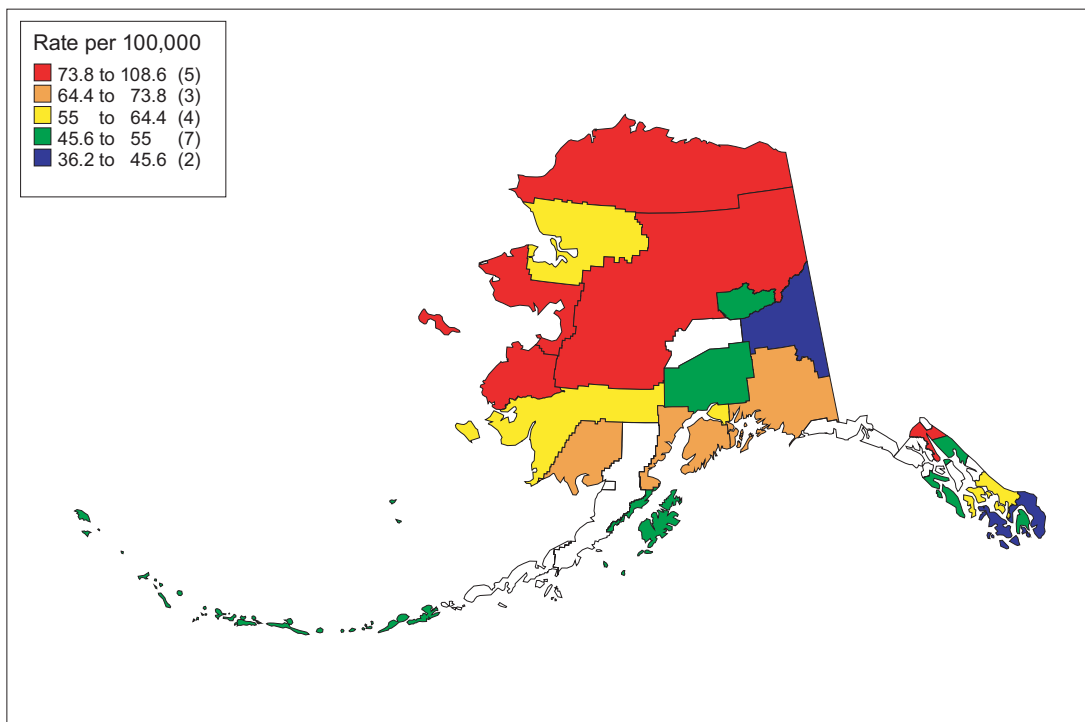
Prostate Cancer Mortality Rates by Borough/Census Area, 1996-2002



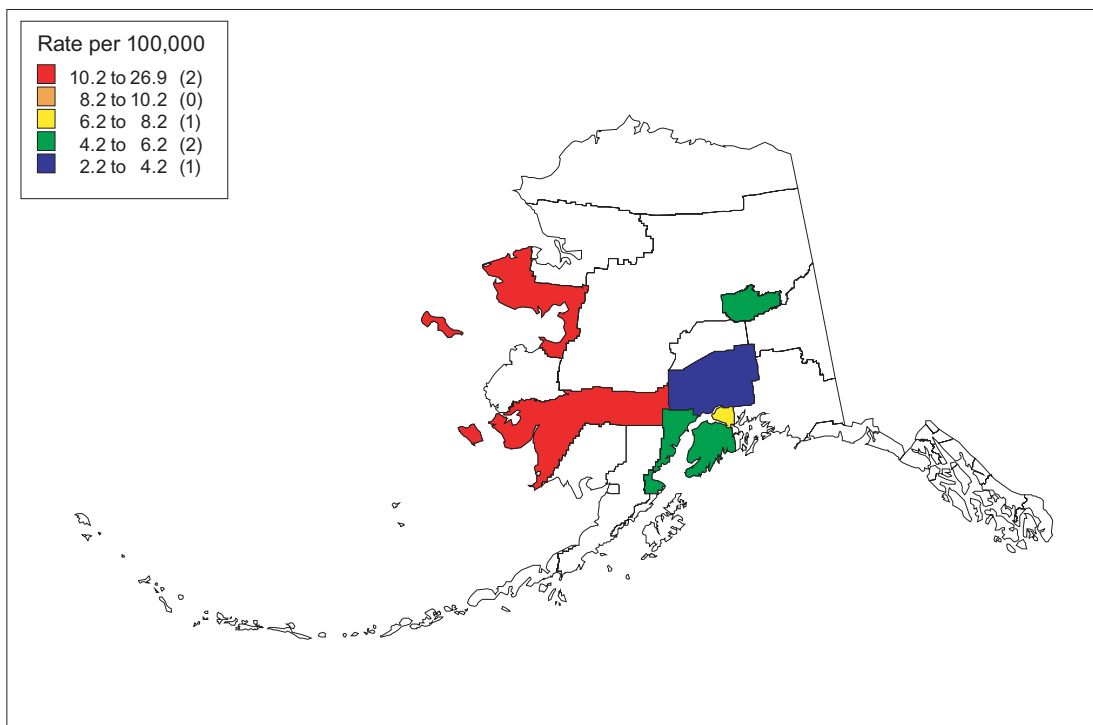
Female Breast Cancer Mortality Rates by Borough/Census Area, 1996-2002



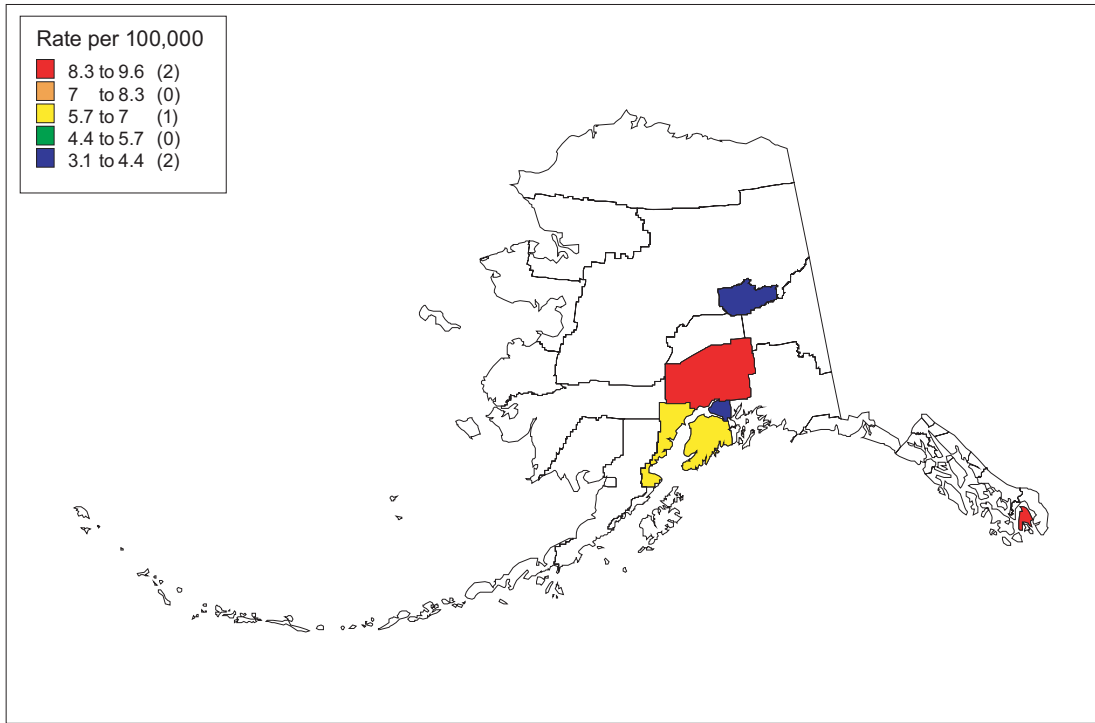
Colorectal Cancer Mortality Rates by Borough/Census Area, 1996-2002



Lung & Bronchus Cancer Mortality Rates by Borough/Census Area, 1996-2002



Stomach Cancer Mortality Rates by Borough/Census Area, 1996-2002



Bladder Cancer Mortality Rates by Borough/Census Area, 1996-2002

Abbreviations and Acronyms

ABVS	Alaska Bureau of Vital Statistics	HCV	Hepatitis C Virus
ACG	American College of Gastroenterology	HPV	Human Papillomavirus
ACIP	Advisory Committee on Immunization Practices	IOM	Institute of Medicine
ACoS	American College of Surgeons	MRI	Magnetic Resonance Imaging
ACCP	Alaska Comprehensive Cancer Partnership	MSA	Master Settlement Agreement
ACR	Alaska Cancer Registry	NAACCR	North American Association of Central Cancer Registries
AHELP	Alaska Health Education Library Project	NBCCEDP	National Breast and Cervical Cancer Early Detection Program
ACS	American Cancer Society	NCCCP	National Comprehensive Cancer Control Program
ANTHC	Alaska Native Tribal Health Consortium	NCI	National Cancer Institute
ANTS	Alaska Native Tribal System	NCI/CIS	National Cancer Institute Cancer Information Services
ATS	Alaska Tobacco Survey	NIH	National Institutes of Health
BCCEDP	Breast and Cervical Cancer Early Detection Program	NPCR	National Program of Cancer Registries
BCHC	Breast and Cervical Health Check Program	OANHR	Office of Alaska Native Health Research
BRFSS	Behavioral Risk Factor Surveillance System	PCBs	Polychlorinated biphenyls
BSE	Breast Self Examination	PRAMS	Pregnancy Risk Assessment Monitoring System
CBE	Clinical Breast Examination	PSA	Prostate Specific Antigen
CCC	Comprehensive Cancer Control	SCF	Southcentral Foundation
CCCP	Comprehensive Cancer Control Program	SEARHC	SouthEast Alaska Regional Health Consortium
CDC	Centers for Disease Control and Prevention	SEER	Statistics, Epidemiology, and End Results
CHA/P	Community Health Aide/Practitioner	SHS	Secondhand Smoke
CPCP	Alaska Cancer Prevention and Control Program	STD	Sexually Transmitted Disease
CRC	Colorectal Cancer	TPC	Alaska Tobacco Prevention and Control Program
CT	Computerized Tomography	USPSTF	United States Preventive Services Task Force
DHSS	Alaska Department of Health and Social Services	UV	Ultraviolet
DRE	Digital Rectal Exam	YRBS	Youth Risk Behavioral Survey
EARTH	Education And Research Toward Health Study		
EBV	Epstein-Barr Virus		
EPA	U.S. Environmental Protection Agency		
ETS	Environmental Tobacco Smoke		
FDA	Federal Drug Administration		
FOBT	Fecal Occult Blood Test		
HBV	Hepatitis B Virus		

ACCP Goals, Outcomes and Strategies

► Tobacco

Goal: Reduce the impact of tobacco use and exposure on Alaska’s cancer incidence and mortality.

Outcomes

- ✓ By 2010, reduce the percentage of adult smokers to 14% (Healthy Alaskans 2010)
Baseline: 26.2%
Data Base: BRFSS 2005
Alaska Native – 40.2%
Non-Native – 21%
- ✓ By 2010, reduce the proportion of pregnant women who smoked during their last three months of pregnancy to 15% (Healthy Alaskans 2010)
Baseline: 16%
Data Base: PRAMS 2003
- ✓ By 2010, reduce the proportion of high school students who smoke to 17% (Healthy Alaskans 2010)
Baseline: 19%
Data Base: YRBS 2003
- ✓ By 2010, reduce the proportion of high school students who use smokeless tobacco in the past 30 days to 8% (Healthy Alaskan 2010)
Baseline: 11% (Alaska Native Youths 32% male and 18% female)
Data Base: YRBS 2003
- ✓ By 2010, reduce the exposure of non-smokers to secondhand smoke more than 1 day a week at work, home and in a car to 22%
Baseline: 27%
Data Base: ATS 2003
- ✓ By 2010, reduce the exposure of children ages 0–5 to secondhand smoke more than 1 day a week in their home to 10%
Baseline: 13%
Data Base: ATS 2003

- ✓ By 2010, reduce the exposure of high school non-smokers to secondhand smoke more than 1 day a week at home and in a car to 30%
Baseline: 47%
Data Base: YRBS 2003

Strategies

- Coordinate efforts toward tobacco control with the Alaska Tobacco Control Alliance and the Alaska Tobacco Prevention and Control Program.
- Study, design and implement a comprehensive approach to address disparities in tobacco use among Alaskans.
- Increase awareness of statewide Quit Line and other resources which support treatment of tobacco dependency.
- Provide the resources and means to assist all willing adults and teens who wish to quit using tobacco.
- Continue and refine mass media and counter marketing campaigns.
- Evaluate the mass media campaign (counter marketing) and how it impacts adults 18–24.
- Increase provider use of reminder systems for counseling patients who use tobacco products to quit, and the provision of information and referral on how to quit the use of tobacco products.
- Research, develop, and implement evidence-based interventions for both pregnant teens and women.
- Promote a health system approach for pregnant women.
- Partner with agencies that interact with pregnant women to enhance efforts to quit using all tobacco products.
- Support targeted provider training using existing programs such as the 5A’s outlined for clinicians in *Treating Tobacco Use and Dependence*.

- Advocate for the creation, implementation, and enforcement of population-based policies that protect residents from secondhand smoke.
- Conduct marketing analysis, and develop a media and/or marketing campaign targeting pregnant women.



- Support continuation of YRBS with full participation of all school districts in the state.
- Expand and evaluate the use of teen cessation programs.
- Support comprehensive school-based prevention initiatives.
- Support community-based teen programs on healthy lifestyles such as ASSETS.
- Integrate anti-tobacco messages with other health messages or programs targeting youth.
- Gather data on middle school students' initiation, use and exposure to tobacco (smoke and smokeless).

► **Breast Cancer**

Goal: Reduce the mortality rate of women from breast cancer in Alaska.

Outcomes

- ✓ By 2010, increase the percentage of women ages 40 + who have had a mammogram in the previous 2 years to 76%. (Healthy Alaskans 2010)
 Baseline: 67%
 Data Base: BRFSS 2004
 Alaska Native Women: 67%
 White Women: 67%

Strategies

- Promote the statewide partnership of Breast and Cervical Cancer Early Detection Programs.
- Establish screening mammography in rural communities with no access.
- Increase access to screening mammography in both rural and urban communities.
- Encourage provider based reminder, follow-up and case management systems.
- Implement mass and small media campaigns to remind and educate women on the importance of early breast cancer detection programs.
- Encourage partnering with other women's health programs so health care needs can be addressed simultaneously – one stop shopping.



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► **Colorectal Cancer**

Goal: Reduce the mortality rate from colorectal cancer in Alaska.

Outcomes

- ✓ By 2010, reduce the mortality rate from colorectal cancer to 12% (Healthy Alaskans 2010).
Baseline: 17.6%
Data Base: ABVS 2002–2004
Alaska Native: 33.5%
White: 15.5%
- ✓ By 2010, increase the percentage of adults ages 50 + who have had a colorectal screening to 70%. (Healthy Alaskans 2010 Target 64% colorectal screening 50+)
Baseline: 51%
Data Base: BRFSS 2004

Strategies

- Develop, test, implement and evaluate a mass and small media campaign for colorectal early detection cancer screening.
- Increase the number of practitioners throughout the state who are trained to administer flexible sigmoidoscopy or colonoscopy.
- Provide education that will enable the general public and providers to understand the current early detection options and where to get the appropriate screening.
- Encourage providers to establish case management and patient reminder systems.
- Utilize private groups and associations to communicate with their constituency about the vital importance of early detection of colorectal cancer.
- Work with Community Health Centers to include a system for ensuring early detection screenings, case management, and patient reminders systems.
- Encourage advocacy efforts to increase health insurance coverage for colorectal cancer screening.

► **Education for Prostate Cancer Screening**

Goal: Increase informed decision-making about prostate cancer screening for all men.

Outcomes

- ✓ By 2010, increase the number of men who have discussed prostate cancer early detection with their provider. (Healthy Alaskans 2010 currently no measure)
Baseline: unknown
Data Base: unknown

Strategies

- Develop, test and evaluate the impact and reach of educational materials specific to Alaskans about prostate health and early detection of prostate cancer.
- Support prostate health education, to include best practice standards, to the full range of health care practitioners.
- Encourage established health fairs to provide education on prostate cancer screening.

► **Oral Cancer**

Goal: Raise awareness on the cause and risk factors for oral cancer

Outcomes

- ✓ By 2010, increase the number of oral health providers that counsel patients on the causal link between alcohol, smoking and cancer. (Healthy Alaskans 2010 – currently no measure)
Baseline: unknown
Data Base: unknown

Strategies

- Support the State of Alaska Oral Health Program on program planning and implementation.
- Include/integrate oral cancer information with all public education campaigns on tobacco and alcohol.

- Promote the role of dentists and other oral health providers in counseling patients on alcohol, tobacco, and oral cancer.
- Coordinate with efforts of the Alaska Tobacco Control Alliance to decrease the use of smokeless (spit) tobacco in Alaska, targeting high-risk communities with higher use.
- Support efforts on tracking the sale of smokeless tobacco.
- Encourage oral health screening for adults 65+.
- Formally encourage all sport organizations, associations and training programs to sign a pledge to end all smokeless (spit) tobacco use during any sporting activity.

► **Cervical Cancer**

Goal: Reduce the mortality rate of women from invasive cervical cancer in Alaska.

Outcomes

- ✓ By 2010, increase the percentage of women, with an intact cervix, ages 18+ years old that report having had a Pap test in the previous 3 years to 95%. (Healthy Alaskans 2010)
Baseline: 89.4%
Data Base: BRFSS 2002

Strategies

- Promote programs that increase access to cervical cancer screening with follow-up reminders and case management systems.
- Promote itinerant practitioner availability, in rural communities, to provide Pap Tests and pelvic exams.
- Provide professional education regarding current screening guidelines for women ages 65 and older.
- Utilize media interventions that match the unique needs of the community or village.

- Promote the use of HPV vaccine throughout the state once it has been released by the FDA for widespread administration.
- Work with the Breast and Cervical Early Detection Programs to increase education of the public and health care providers concerning the HPV vaccine.

► **Lifestyle Factors**

Goal: Reduce the mortality rate of cancer in Alaska due to lifestyle factors.

Obesity, Physical Activity and Nutrition

Outcomes

- ✓ By 2010, increase to 76% the percentage of Alaska adults engaged in efforts to either lose weight or maintain their weight. (AK Physical Activity and Nutrition Plan Target 80% in 2012.)
Baseline: 67%
Data Base: BRFSS 2003
- ✓ By 2010, increase consumption of 5 fruits and vegetables per day to 30%. (Healthy Alaskans 2010)
Baseline: 25%
Data Base: BRFSS 2005
- ✓ By 2010, decrease the percentage of adults who are physically inactive (percent of adults 18+ who report no leisure time physical activity in the last 30 days) to 15%. (Healthy Alaskans 2010)
Baseline: 21%
Data Base: BRFSS 2005

Strategies

- Promote the goals, aims, and strategies outlined in the State of Alaska Physical Activity and Nutrition Plan.
- Raise public knowledge of the increased cancer risk due to being overweight or obese.
- Educate the public on healthy eating instead of “fad” diets.

- Increase access to healthy foods in school and childcare locations.
- Encourage interventions that imprint the message to parents, guardians and care givers on the importance of eating healthy foods and staying physically active as the way for all children to have a healthy future.



- Communicate the message about subsistence food being a healthy food choice.
- Promote continuing education opportunities in healthy eating for the full range of practitioners and providers.
- Increase efforts to educate the public on the decreased risk of cancer with the consumption of five fruits and vegetables a day.
- Encourage rural community gardens throughout the state.
- Endorse programs that increase public knowledge of the decreased cancer risk for individuals who engage in regular moderate physical activity.
- Support opportunities for families to establish physical activity as a “must do” for life long health.
- Encourage efforts to obtain repaired and recycled physical activity equipment and safety equipment (e.g. bikes and helmets) and make available for all children.

- Establish the continual message that staying physically active is the key to longevity, good health and reducing the risk of cancer.
- Promote efforts to advertise Alaska’s unique natural environment for physical activity.
- Encourage private and public efforts to institute physical activity programs.
- Encourage the State and local governments to seek funding opportunities to promote physical activity and design an environment that promotes physical activity.
- Communicate local physical activity success stories on the AHELP web site and AHELP List Serve.
- Create and make available a list of all physical activities available for adults, children and families in each community.

Alcohol

Outcomes

- ✓ By 2010, decrease the proportion of adults who drink more alcohol than the moderate level (adult women one drink per day and adult men two drinks a day) to 2%.
Baseline: 5%
Data Base: BRFSS 2005
Non-Native: 5%
Alaska Native: 7%
- ✓ By 2010, decrease the proportion of adults who engage in binge drinking (five or more drinks on one occasion) to 12%.
Baseline: 18%
Data Base: BRFSS 2005

Strategies

- Promote programs that increase public knowledge of the increased cancer risk for individuals who engage in excessive and binge alcohol consumption.
- Provide education to providers about counseling their patients on the negative health consequences of excessive and binge drinking.

- Promote the education of individuals in alcohol recovery about healthy eating and physical activity.
- Promote opportunities for continuing education on alcohol and cancer for all medical and behavioral health providers.

D Family History of Cancer

Goal: Increase the early identification of people at risk for developing cancer due to genetic susceptibility or inherited predisposition.

Outcomes

- ✓ By 2010, increase the number of people who are aware of their family history of cancer.
Baseline: none available
Data Base: none available



Strategies

- Promote programs that enhance public knowledge on the importance of knowing and communicating family history of cancer to their health care provider.
- Educate providers regarding the importance of obtaining family history of cancer from their patients and encouraging early interventions.
- Encourage children and adolescents to document their family health history.
- Promote access to and utilization of genetic screening for high-risk populations.

D Infectious Agents

Goal: Reduce the impact of infectious agents on cancer incidence and mortality in Alaska.

Outcomes

- ✓ By 2010, increase the awareness of cancer risk and specific sexual behaviors by including this information in current media campaigns.
Baseline: none
Data Source: 2004 survey of materials used in Alaska
- ✓ By 2010, increase the number of children and adults who receive Hepatitis B vaccinations.
Baseline: unknown
Data Source: AK Division of Public Health

Strategies

- Promote counseling by health care providers to women on the increased risk of cancer caused by the HPV virus, and how to reduce their exposure.
- Promote a public awareness campaign on the risk of cervical cancer related to the HPV virus.
- Promote the use of HPV vaccine throughout the state once it has been released by the FDA for widespread administration.
- Promote public access to sexual health programs.
- Promote the inclusion of an infectious agent cancer link in High School Health Education.
- Promote the increase of pediatric and adult Hepatitis B vaccinations.
- Encourage practitioner and patient education of the signs and symptoms of gastric cancers
- Seek more clinical studies on Alaska Native population and rate of gastric cancer

► *Environmental Carcinogens*

Goal: Reduce the impact of environmental carcinogens on cancer incidence in Alaska.

Ultraviolet Light

Outcomes

- ✓ By 2010, decrease the proportion of adults who report getting sunburn within the last year to 20%.
Baseline: 30%
Data Base: BRFSS 2003
White: 34%
Alaska Native: 21%

Strategies

- Encourage regulations warning consumers about tanning beds and the risk of skin cancer.
- Facilitate a public awareness campaign emphasizing Alaskans' risk for skin cancer.
- Promote the CDC sunburn education program in all sites that provide services to children, e.g. schools, daycare, summer programs, and speaking events.
- Support the addition of sunburn protection for infants when providing parent education.

Arsenic

Outcomes

- ✓ By 2010, reduce the number of people that are drinking arsenic-contaminated water levels above 10 parts per billion (ppb).
Baseline: 70 public water systems unable to meet new standard. Well water systems unable to meet new standards are unknown
Data Source: EPA 2004

Strategies

- Support public education campaigns on arsenic and its relation to cancer.
- Make available to all consumers affordable treatment of any drinking water which does not meet the arsenic levels standard of 10 parts per billion.

- Facilitate efforts that establish laws requiring testing of well water for all properties at time of sale.
- Make the public aware of the issues around arsenic treated wood.

PCBs

Outcomes

- ✓ By 2010, reduce and prevent Alaska's contamination by PCBs.
Baseline: 5 superfund sites requiring clean-up
Data Base: EPA Seattle Office

Strategies

- Provide information and education on the health benefits and safety of native and subsistence foods.
- Advocate for the continuation of clean-up on all remaining superfund sites.
- Monitor reported PCB levels in the environment.
- Promote the reduction of the worldwide use of PCBs.
- Monitor research on PCB levels in Alaska's food supply.

Benzene

Outcomes

- ✓ By 2010, reduce the number of people who are exposed to benzene
Baseline: unknown
Data Source: unknown

Strategies

- Promote public education on benzene exposure and how to lower risk of exposure.
- Support the development of technology necessary to lower exposure to benzene in the home.
- Support and promote building codes which decrease the risk of benzene exposure.

Access to Care

Goal: Reduce the mortality rate of cancer in Alaska due to lack of primary care services.

Outcomes

- ✓ By 2010, increase the percentage of Alaskans who report having a provider of primary care to 100%. (Healthy Alaskans 2010)
Baseline: 71%
Data Base: BRFSS 2005

Strategies

- Expand the network of health care providers who screen for cancer.
- Support community health centers to focus significant efforts on cancer prevention and early detection.
- Increase statewide efforts for primary care providers to incorporate cancer prevention, screening, and early detection into their practice.

Goal: Ensure all Alaskans have equal access to high quality cancer information, treatment, and clinical trials based on nationally recognized best practice standards.

Outcomes

- ✓ By 2010, increase the number of hospitals in Alaska that are approved by the American College of Surgeon’s Commission on Cancer Program from 3 to 5.
Baseline: 3 hospitals
Data Base: ACoS 2006
- ✓ By 2010, increase the number of radiation oncologists and medical oncologists providing care throughout Alaska.
Baseline: 15 medical oncologists and 5 radiation oncologists
Data Base: Alaska State Medical Association 2005
- ✓ By 2010, increase the number of Alaskans who call the toll free lines for Cancer

Information Service (CIS) and the American Cancer Society (ACS).
Baseline: 100 calls to CIS
Data Base: CIS 2005
Baseline: 1607 calls to ACS
Data Base: ACS 2004

- ✓ By 2010, increase the number of patients enrolled in clinical trials in Alaska.
Baseline: unknown
Data Base: unknown



Metlakatla, Alaska

©Nicole Grewe

- ✓ By 2010, increase the number of Alaska Natives enrolled in clinical trials in Alaska.
Baseline: unknown
Data Base: unknown
- ✓ By 2010, increase the number of clinical trials open in Alaska.
Baseline: unknown
Data Base: unknown

Strategies

- Design a mechanism for newly diagnosed cancer patients and cancer survivors to access information which covers the full range of issues faced by cancer, i.e., coaching on being proactive, contact information on accessing “person-to-person” information, local support agencies, employment issues and financial matters.
- Design and implement a small media campaign to get out information on the CIS and ACS toll free lines.

- Design, distribute and devise a system of continual distribution to all cancer providers on how to access live information and connect with local advocacy organizations. Provide information on advocacy organizations that offer financial assistance.
- Support efforts to create pathways to care for and treat Alaskans living in remote communities.
- Improve the continuity of care between the numerous providers and safeguard the continuity of care by specifically giving the patient critical information to hand carry between providers.
- Encourage and recognize all hospitals that achieve approval status from the Commission on Cancer.
- Support efforts to increase the number of oncologists statewide.
- Explore methods to increase the number of patients enrolling in clinical trials.
- Explore ways to increase the breadth and number of clinical trials open in Alaska.
- Develop a process to educate all newly diagnosed cancer patients about the availability of clinical trials before treatment decisions are made.
- Provide a centralized, toll free line for patients to access information concerning clinical trials in Alaska.
- Provide navigators to help guide patients on how to access information on clinical trials in Alaska.
- Develop informational materials relevant to all facilities statewide, which provide resources and guidelines for patients to discuss clinical trials with their cancer treatment provider.
- Develop relationships with key medical providers and their staff throughout the state to educate them on clinical trials and their availability.
- Provide a centralized, on-line resource that lists all clinical trials available in Alaska.
- Continue to improve mechanisms for all persons and facilities offering clinical trials to network and communicate updates in a timely manner.
- Continue to identify and address issues around barriers that prevent participation by Alaska Natives in clinical trials.
- Work with advocacy organizations, tribal entities, Alaska Native Corporations, and non-profit organizations to identify resources to assist persons traveling for cancer care treatment around issues of funding, housing and transportation needs.
- Ensure patients receive education on central line options and care.
- Support annually continuing education on best practices in cancer care for all practitioners and providers of cancer care in the community.
- Promote specific training and continual education for nurses responsible for administering chemotherapy.

Goal: Ensure all Alaskans have access to quality palliative care.

Outcomes

- ✓ By 2010, increase the number of certified palliative care providers.
Baseline: 5 board certified physicians
Data Base: American Board of Hospice and Palliative Medicine 2006
Baseline: 17 Registered Nurses
Data Base: Hospice and Palliative Nurses Association 2006

Strategies

- Provide statewide education of policy makers, health professionals, patients and family (general public) on quality palliative care.
- Encourage reimbursement for palliative care (case management and follow-up).

- Ensure that CEU opportunities include education for providers on symptom management, educating the patient on the disease process and specifically Graft versus Host Disease.
- Increase the number of board certified physicians in palliative care.
- Specifically target nurses as potentially key providers of palliative care and end-of-life care.
- Support efforts to establish certification in palliative care for nurses and the full range of other health professionals.
- Encourage providers to seek consultation or refer patients to palliative care experts.
- Ensure that patients have access to Complementary and Alternative Medicine and these interventions are coordinated with the person’s overall treatment plan.
- Ensure quality symptom management including coordination of side effects between medications, including the pharmacist in treatment planning, and patient education on side effects and how to manage their symptoms.

Goal: Ensure that all Alaskans have access to quality end-of-life care.

Outcomes

- ✓ By 2010, increase the number of people who have written and disseminated advanced directives.
Baseline: unknown
Data Base: unknown
- ✓ By 2010, increase the number of providers promoting the hospice model of care
Baseline: unknown
Data Base: unknown

Strategies

- Establish hospice model as the standard for end-of-life care throughout the state.
- Encourage training for rural providers in the hospice model.

- Collaborate with the Alaska Native Tribal Health Consortium on access in rural areas.
- Work with Life Alaska (organ donations) on getting out information on advance directives.
- Initiate and evaluate the reach and impact of a public education campaign on-end-of life care.
- Support systems that ensure advance directives are discussed, written, and disseminated.
- Provide public education on advance directives and the five wishes legislation.
- Explore option of advance directives cards or other ways of communicating wishes when a person with terminal illness is unable.
- Increase the availability and affordability of long term care insurance/financing.
- Evaluate the potential utility of a “drop in center” staffed with volunteers to provide support, network and information.

► *Disparities*

Goal: Evaluate surveillance and research data to report and monitor cancer health care disparities.

Strategies

- Develop a mechanism to describe and provide ongoing reports on cancer health disparities among Alaskans.
- Research the health disparity population to develop insight into the underlying issues these individuals face.

► *Advocacy*

Strategies

- Advocate for all Alaskans to have access to primary and preventive health care services.
- Advocate for State Medicaid programs to cover primary health care and cancer screening services.

Survivorship

Goal: Ensure all Alaskan cancer survivors have equal access to information, and follow-up medical, rehabilitative and psychosocial services.

Outcomes

- ✓ By 2010, increase the public knowledge of the issues faced by cancer survivors in Alaska.
Baseline: None
Data Base: None

Strategies

- Design and implement a study methodology that gathers insight on the experience of cancer survivors in Alaska.
- Publish and disseminate a report on the number of cancer survivors and the issues they face.
- Design, implement and evaluate a mass and or small media campaign on raising the public's awareness of the issues cancer survivors face.
- Target employers, specifically human resource professionals, on the issues cancer survivors face and what the Americans with Disabilities Act specifies on employer requirements.
- Encourage specific training for primary care providers on the needs of cancer survivors.

Surveillance

Goal: Maintain high quality cancer surveillance data and disseminate timely reports.

Strategies

- Maintain a quality cancer registry.
- Analyze the cost burden of cancer using hospital discharge data and other access data sources.
- Create and disseminate timely reports on the burden of cancer in Alaska.

Evaluation

Goal: Annually evaluate the Alaska Comprehensive Cancer Plan with the Alaska Comprehensive Cancer Partnership and workgroups to determine the success of implementation.



Dutch Harbor, Alaska

©DCA

Strategies

- Convene a Data and Evaluation Committee experienced in monitoring and surveillance, evaluation, and research.
- Develop and implement an evaluation plan to assess objectives and implementation of strategies of the Alaska Comprehensive Cancer Control Plan.
- Assess and evaluate the efficacy of the objectives and strategies of the Alaska Comprehensive Cancer Control Plan by determining impact on changes in cancer-related outcomes.
- Annually survey partners for activities which match strategies in the Alaska Comprehensive Cancer Control Plan
- Report evaluation results annually at the Alaska Comprehensive Cancer Partnership meeting.

D Emerging Science and Technology

Goal: Monitor emerging science and technology to include new breakthroughs and updates in Alaska’s cancer control efforts, as the National Cancer Institute and the US Preventive Services Task Force endorses these.



Nimitchik, Alaska

©Nicole Grewe

Outcomes

- ✓ By 2010, formally review emerging science in cancer annually.
Baseline: Annually
Data Base: ACCP Research 2004

Strategies

- Monitor NCI updates, the US Prevention Task Force updates and changes, and published, scientific peer-reviewed studies.
- Communicate updates to the Partnership and determine if and how the Comprehensive Cancer Control Plan should be modified.

Resources for Cancer Information

People with cancer and their families sometimes need assistance coping with the emotional as well as the practical aspects of their disease. This section offers national and Alaska organizations that provide cancer information and support. It is not intended to be a comprehensive listing of all organizations that offer these services.

American Brain Tumor Association (ABTA)

Address:	2720 River Road Des Plaines, IL 60018
Telephone:	847-827-9910 1-800-886-2282 (1-800-886-ABTA)
E-mail:	info@abta.org
Internet Web site:	http://www.abta.org

The ABTA funds brain tumor research and provides information to help patients make educated decisions about their health care. The ABTA offers printed materials about the research and treatment of brain tumors, and provides listings of physicians, treatment facilities, and support groups throughout the country. A limited selection of Spanish-language publications is available.

American Cancer Society (ACS)

Address:	1599 Clifton Road, NE. Atlanta, GA 30329-4251
Telephone:	404-320-3333 1-800-227-2345 (1-800-ACS-2345)
Internet Web site:	http://www.cancer.org
<i>Alaska Chapter:</i>	
Address:	1057 W. Fireweed Lane, Ste. 204 Anchorage, AK 99503
Telephone:	907-277-8696

The ACS is a voluntary organization that offers a variety of services to patients and their families. The ACS also supports research, provides printed materials, and conducts

educational programs. Staff can accept calls and distribute publications in Spanish. A local ACS unit may be listed in the white pages of the telephone directory under “American Cancer Society.”

American Cancer Society (ACS) Supported Programs:

- **Cancer Survivors Network®** (<http://www.acscsn.org>) — This is a telephone and Web-based service for cancer survivors, their families, caregivers, and friends. The telephone component (1-877-333-HOPE) provides survivors and families access to pre-recorded discussions. The Web-based component offers live online chat sessions, virtual support groups, pre-recorded talk shows, and personal stories.
- **I Can Cope** — I Can Cope is a patient education program designed to help patients, families, and friends cope with the day-to-day issues of living with cancer.
- **Look Good ... Feel Better®** (<http://www.lookgoodfeelbetter.org>) This program was developed by the Cosmetic, Toiletry, and Fragrance Association Foundation in cooperation with ACS and the National Cosmetology Association. It focuses on techniques that can help people undergoing cancer treatment improve their appearance. The entire program is also available in Spanish.
- **Man to Man** — The Man to Man program helps men cope with prostate cancer by providing community-based education and support to patients and their family members. In addition, Man to Man encourages men and health care professionals to actively consider screening for prostate cancer appropriate to each man’s age and risk for the disease. A major part of the program is the self-help and/or support group. Volunteers organize free monthly meetings where

speakers and participants learn about and discuss information about prostate cancer, treatment, side effects, and how to cope with the disease and its treatment.

- **Reach to Recovery** — The Reach to Recovery Program is a rehabilitation program for men and women who have or have had breast cancer. The program helps breast cancer patients meet the physical, emotional, and cosmetic needs related to their disease and its treatment.

American Institute for Cancer Research (AICR)

Address:	1759 R Street, NW. Washington, DC 20009
Telephone:	202–328–7744 1–800–843–8114
E-mail:	aicrweb@aicr.org
Internet Web site:	http://www.aicr.org

The AICR provides information about cancer prevention, particularly through diet and nutrition. They offer a toll-free nutrition hotline and funding of research grants. The AICR also has a wide array of consumer and health professional brochures, plus health aids about diet and nutrition and their link to cancer and cancer prevention. The AICR also offers the AICR Cancer Resource, an information and resource program for cancer patients. A limited selection of Spanish-language publications is available.

American Urological Association Foundation (AUA)

Address:	Suite 410 1000 Corporate Boulevard Linthicum, MD 21090
Telephone:	410–689–3990 1–800–828–7866
E-mail:	Available through the Web site
Internet Web site:	http://www.afud.org

The AUA supports research; provides education to patients, the general public,

and health professionals; and offers patient support services for those who have or may be at risk for a urologic disease or disorder. They provide information on urologic disease and dysfunctions, including prostate cancer treatment options, bladder health, and sexual function. They also offer prostate cancer support groups (Prostate Cancer Network). Some Spanish-language publications are available.

Brain Tumor Society

Address:	Suite 3–H 124 Watertown Street Watertown, MA 02472
Telephone:	617–924–9997 1–800–770–8287 (1–800–770–TBTS)
E-mail:	info@tbts.org
Internet Web site:	http://www.tbts.org

The Brain Tumor Society provides information about brain tumors and related conditions for patients and their families. They offer a patient/family telephone network, educational publications, funding for research projects, and access to support groups for patients.

CancerCare, Inc.

Address:	National Office 275 Seventh Avenue New York, NY 10001
Telephone:	212–712–8080 1–800–813–4673 (1–800–813–HOPE) 212–712–8400 (administration)
E-mail:	info@cancercare.org
Internet Web site:	http://www.cancercare.org

CancerCare is a national nonprofit agency that offers free support, information, financial assistance, and practical help to people with cancer and their loved ones. Services are provided by oncology social workers and are available in person, over the telephone, and through the agency’s Web site. CancerCare’s reach also extends to professionals—providing

education, information, and assistance. A section of the CancerCare Web site and some publications are available in Spanish, and staff can respond to calls and e-mails in Spanish.

Cancer Hope Network

Address:	Two North Road Chester, NJ 07930
Telephone:	1-877-467-3638 (1-877-HOPENET)
E-mail:	info@cancerhopenetwork.org
Internet Web site:	http://www.cancerhopenetwork.org

The Cancer Hope Network provides individual support to cancer patients and their families by matching them with trained volunteers who have undergone and recovered from a similar cancer experience. Such matches are based on the type and stage of cancer, treatments used, side effects experienced, and other factors.

The Cancer Project

Address:	Suite 400 5100 Wisconsin Avenue Washington, DC 20016
Telephone:	202-244-5038
E-mail:	info@CancerProject.org
Internet Web site:	http://www.CancerProject.org

The Cancer Project provides comprehensive educational materials, conducts clinical research studies, and publicizes the value of a healthy diet in cancer prevention and survival. A limited selection of Spanish-language publications is available.

Cancer Research and Prevention Foundation

Address:	Suite 500 1600 Duke Street Alexandria, VA 22314
Telephone:	703-836-4412 1-800-227-2732 (1-800-227-CRFA)
E-mail:	info@preventcancer.org
Internet Web site:	http://www.preventcancer.org

The Cancer Research and Prevention Foundation seeks to prevent cancer by funding research and providing educational materials on early detection and nutrition.

Candlelighters® Childhood Cancer Foundation (CCCF)

Address:	Post Office Box 498 Kensington, MD 20895-0498
Telephone:	301-962-3520 1-800-366-2223 (1-800-366-CCCF)
E-mail:	info@candlelighters.org
Internet Web site:	http://www.candlelighters.org

The CCCF is a nonprofit organization that provides information, peer support, and advocacy through publications, an information clearinghouse, and a network of local support groups. A financial aid list is available that lists organizations to which eligible families may apply for assistance.

Children's Brain Tumor Foundation (CBTF)

Address:	Suite 1301 274 Madison Avenue New York, NY 10016
Telephone:	212-448-9494 1-866-228-4673 (1-866-228-HOPE)
E-mail:	info@cbtf.org
Internet Web site:	http://www.cbtf.org

The CBTF is a nonprofit organization that funds research and provides support, education, and advocacy for children with brain and spinal cord tumors and their families. It also provides educational materials (including a Spanish-language publication) and cosponsors conferences and seminars for families, survivors, and health care professionals that offer the latest information about research, treatments, and strategies for living. Through CBTF's Parent-to-Parent Network, families share their experiences with others in similar situations.

Children’s Hospice International®

Address:	Suite 230 901 North Pitt Street Alexandria, VA 22314
Telephone:	703–684–0330 1–800–242–4453 (1–800–2–4–CHILD)
E-mail:	chiorg@aol.com
Internet Web site:	http://www.chionline.org

Children’s Hospice International provides a network of support for dying children and their families. It serves as a clearinghouse for research programs and support groups, and offers educational materials and training programs on pain management and the care of seriously ill children.

Colon Cancer Alliance (CCA)

Address:	175 Ninth Avenue New York, NY 10011
Telephone:	212–627–7451 (main office) 1–877–422–2030 (helpline)
E-mail:	info@ccalliance.org
Internet Web site:	http://www.ccalliance.org

The CCA is an organization of colon and rectal cancer survivors, their families, caregivers, and the medical community. The Alliance provides patient support and public education, supports research, and advocates for the needs of cancer patients and their families. The CCA offers information including brochures and booklets, a newsletter, a toll-free helpline, and weekly online chats. It also offers the CCA Buddies Network, which matches survivors and caregivers with others in a similar situation for one-on-one emotional support. The CCA has volunteers who speak Spanish.

Colorectal Cancer Network

Address:	Post Office Box 182 Kensington, MD 20895–0182
Telephone:	301–879–1500
E-mail:	ccnetwork@colorectal-cancer.net
Internet Web site:	http://www.colorectal-cancer.net

The Colorectal Cancer Network is a national advocacy group that raises public awareness about colorectal cancer and provides support services to colorectal cancer patients and their families, friends, and caregivers. Services include support groups; an Internet chat room; e-mail listservs for survivors, caregivers, and advocates; hospital visitation programs; and a “One on One” service that connects newly diagnosed individuals with long-term survivors. The Network also provides literature on screening, diagnosis, treatment, and supportive care for colorectal cancer.

CureSearch

Address:	Suite 600 4600 East West Highway Bethesda, MD 20814–3457
Telephone:	1–800–458–6223
E-mail:	info@curesearch.org
Internet Web site:	http://www.curesearch.org

CureSearch is a partnership between the Children’s Oncology Group and the National Childhood Cancer Foundation. CureSearch provides treatment information and support resources for patients, families, and health professionals. A searchable Resource Directory is available on their Web site (<http://www.curesearch.org/resources/>) that lists local, national, and international organizations that offer resources for helping community members, parents, and children dealing with childhood cancer. Users enter in their ZIP code on the Web site to locate local and regional organizations.

ENCORE^{Plus}[®]

Address:	YWCA of the USA Office of Women's Health Advocacy Suite 700 1015 18 th Street, NW Washington, DC 20036
Telephone:	202-467-0801 1-800-953-7587 (1-800-95E-PLUS)
E-mail:	cgould@ywca.org
Internet Web site:	http://www.ywca.org

Anchorage ENCORE^{Plus}[®]

Address:	324 E. 5th Avenue Anchorage, AK 99501
Telephone:	907-644-9621

ENCORE^{Plus} is the YWCA's discussion and exercise program for women who have had breast cancer surgery. It is designed to help restore physical strength and emotional well-being. A local branch of the YWCA, listed in the telephone directory, can provide more information about ENCORE^{Plus}.

Family History: Discover Your Family's Connection to Cancer Risk

Jameslink[®] is an interactive tool that estimates cancer risk by reviewing patterns of cancer in a family. It is a free service designed to help you learn more about your cancer risk and steps you can take to focus your prevention efforts. This tool can be accessed at <http://www.jamesline.com/patientsandvisitors/prevention/cancergenetics/#Start%20Session>.

Family History: U.S. Surgeon General's Family History Initiative

Address:	324 E. 5th Avenue Anchorage, AK 99501
Telephone:	907-644-9621

The U.S. Department of Health and Human Services provides a web-based tool through

the U.S. Surgeon General's Family History Initiative, which helps users organize family history information and then print it out for presentation to the family doctor. In addition, the tool helps users save their family history information to their own computer and even share family history information with other family members. The tool can be accessed at <https://familyhistory.hhs.gov/>.

Fertile Hope

Address:	Post Office Box 624 New York, NY 10014
Telephone:	212-242-6798 1-888-994-4673 (1-888-994-HOPE)
E-mail:	info@fertilehope.org
Internet Web site:	http://www.fertilehope.org

Fertile Hope is a national organization that provides reproductive information, support, and hope to cancer patients whose medical treatments present the risk of infertility. They also offer fertility preservation financial assistance options for patients.

Gilda's Club[®] Worldwide

Address:	Suite 1402 322 Eighth Avenue New York, NY 10001
Telephone:	1-888-445-3248 (1-888-GILDA-4-U)
E-mail:	info@gildasclub.org
Internet Web site:	http://www.gildasclub.org

Gilda's Club Worldwide works with communities to start and maintain local Gilda's Clubs, which provide social and emotional support to cancer patients, their families, and friends. Lectures, workshops, support and networking groups, special events, and children's programs are offered. Services are available in Spanish.

Harvard Center for Cancer Prevention

Address:	Harvard School of Public Health 401 Park Drive, Landmark 3-East Boston, MA 02215
Telephone:	617-998-1034
E-mail:	hccp@hsph.harvard.edu
Internet Web site:	http://www.hsph.harvard.edu/cancer/

The Harvard Center for Cancer Prevention at the Harvard School of Public Health is dedicated to helping people learn about healthy behavior and decrease their risk of cancer and other chronic diseases. The website offers an interactive tool to help you assess your risk for five different diseases, including twelve cancers. This site also offers educational materials to help reduce your risk of cancer and other diseases through lifestyle changes and preventive health maintenance, such as regular check-ups with your primary care provider.

Intercultural Cancer Council

Address:	6655 Travis, Suite 322 Houston, TX 77030
Telephone:	713-798-4617
E-mail:	info@iccnetwork.org
Internet Web site:	http://iccnetwork.org/

The Intercultural Cancer Council (ICC) promotes policies, programs, partnerships, and research to eliminate the unequal burden of cancer among racial and ethnic minorities and medically underserved populations in the United States and its associated territories. The ICC is housed at Baylor College of Medicine. The ICC provides fact sheets and information on how cancer affects minority and disparate populations. The ICC is a National Partner to the National Comprehensive Cancer Control Program at CDC.

Hospice Education Institute

Address:	Three Unity Square Post Office Box 98 Machiasport, ME 04655-0098
Telephone:	207-255-8800 1-800-331-1620
E-mail:	info@hospiceworld.org
Internet Web site:	http://www.hospiceworld.org

The Hospice Education Institute serves a wide range of individuals and organizations interested in improving and expanding hospice and palliative care throughout the United States and around the world. The Institute works to inform, educate, and support people seeking or providing care for the dying and the bereaved. HOSPICELINK, a service of the Institute, maintains a computerized database and up-to-date directory of all hospice and palliative care programs in the United States. HOSPICELINK helps patients and their families find hospice and palliative care programs, and provides general information about the principles and practices of good hospice and palliative care.

International Association of Laryngectomees (IAL)

Address:	Post Office Box 691060 Stockton, CA 95269-1060
Telephone:	1-866-425-3678 (1-866-IAL-FORU) 209-472-0516
E-mail:	ialhq@larynxlink.com
Internet Web site:	http://www.larynxlink.com

The IAL assists people who have lost their voice as a result of cancer. It provides information on the skills needed by laryngectomees and works toward total rehabilitation of patients.

International Myeloma Foundation (IMF)

Address:	Suite 206 12650 Riverside Drive North Hollywood, CA 91607–3421
Telephone:	818–487–7455 1–800–452–2873 (1–800–452–CURE)
E-mail:	TheIMF@myeloma.org
Internet Web site:	http://www.myeloma.org

The IMF supports education, treatment, and research for multiple myeloma. They provide a toll-free hotline, seminars, and educational materials for patients and their families. Although the IMF does not sponsor support groups, they do keep a list of other organizations' support groups and provide information on how to start a support group. A section of the IMF Web site and some printed materials are available in Spanish.

International Waldenstrom's Macroglobulinemia Foundation (IWMMF)

Address:	3932 D Swift Road Sarasota, FL 34231
Telephone:	941–927–4963
E-mail:	info@iwmmf.com
Internet Web site:	http://www.iwmmf.com

The IWMMF provides encouragement and support to people with Waldenstrom's macroglobulinemia (WM) and their families, and works to increase awareness of issues related to WM. The IWMMF also encourages and supports increased research toward finding more effective treatments and ultimately a cure. The IWMMF offers publications, including a quarterly newsletter, *The IWMMF Torch*, and bulletins. Through its *Internet Talklist*, regional support groups, and telephone Lifeline Project, the Foundation also helps people with WM contact others with this disease. People may also participate in the IWMMF's annual Educational Forum to hear prominent researchers and other speakers, and to share their experiences with other participants.

Kidney Cancer Association

Address:	Suite 203 1234 Sherman Avenue Evanston, IL 60202–1375
Telephone:	847–332–1051 1–800–850–9132
E-mail:	office@curekidneycancer.org
Internet Web site:	http://www.curekidneycancer.org

The Kidney Cancer Association supports research, offers printed materials about the diagnosis and treatment of kidney cancer, sponsors support groups, and provides physician referral information.

Lance Armstrong Foundation (LAF)

Address:	Post Office Box 161150 Austin, TX 78716–1150
Telephone:	512–236–8820
Internet Web site:	http://www.laf.org

The Lance Armstrong Foundation (LAF) inspires and empowers people affected by cancer. From the moment of diagnosis, the LAF provides the practical information and tools people with cancer need to live life on their own terms. The LAF serves its mission through advocacy, public health and research. The LIVESTRONG SurvivorCare program offers counseling services, help with financial, employment or insurance issues and information about treatment options and new treatments in development. The LAF also offers funding for research, community programs and public education and outreach efforts in cancer survivorship. Founded in 1997 by cancer survivor and champion cyclist Lance Armstrong, the LAF is located in Austin, Texas.

The Leukemia and Lymphoma Society

Address:	1311 Mamaroneck Avenue White Plains, NY 10605–5221
Telephone:	914–949–5213 1–800–955–4572
Financial Assistance to Alaskans	1-888-345-4572 ext. 125
E-mail:	infocenter@leukemia-lymphoma.org
Internet Web site:	http://www.lls.org

The goal of The Leukemia and Lymphoma Society is to find cures for leukemia, lymphoma, Hodgkin’s disease, myelodysplastic/myeloproliferative disorders, and multiple myeloma and to improve the quality of life of patients and their families. The Society supports medical research and provides health education materials, as well as the following services: patient financial aid for specified treatment expenses and transportation, family support groups, *First Connection* (a professionally supervised peer support program), referrals, school re-entry materials, and public and professional education. The Society also provides audiotapes in English and some Spanish-language publications.

Living Beyond Breast Cancer (LBBC)

Address:	Suite 204 10 East Athens Avenue Ardmore, PA 19003
Telephone:	610–645–4567 1–888–753–5222 (1–888–753–LBBC) (Survivors’ Helpline)
E-mail:	mail@lbbc.org
Internet Web site:	http://www.lbbc.org

The LBBC is an educational organization that aims to empower women living with breast cancer to live as long as possible with the best quality of life. The LBBC offers an interactive message board and information about upcoming conferences and teleconferences on its Web site. In addition, the organization

has a toll-free Survivors’ Helpline, a Young Survivors’ Network for women diagnosed with breast cancer who are age 45 or younger, and outreach programs for medically underserved communities. The LBBC also offers a quarterly educational newsletter and a book for black women living with breast cancer.

The Lung Cancer Alliance (LCA)

Address:	Suite 800 888 16 th Street, NW Washington, DC 20006
Telephone:	202–463–2080 1–800–298–2436
E-mail:	info@lungcanceralliance.org
Internet Web site:	http://www.lungcanceralliance.org

LCA offers programs designed to help improve the quality of life of people with lung cancer and their families. Programs include education about the disease, psychosocial support, and advocacy about issues that concern lung cancer survivors.

The Lustgarten Foundation for Pancreatic Cancer Research

Address:	1111 Stewart Avenue Bethpage, NY 11714
Telephone:	516–803–1000 1–866–789–1000
E-mail:	Available through the Web site
Internet Web site:	http://www.lustgartenfoundation.org

The Lustgarten Foundation funds research, advocates for research funding, and raises awareness of pancreatic cancer diagnosis, treatment, and prevention. The Foundation assists patients and their families in obtaining the most accurate, up-to-date information about pancreatic cancer. It provides educational materials and publications about pancreatic cancer, including a Spanish-language publication. It also has an on-staff social worker available to make referrals to cancer support services.

Lymphoma Foundation of America

Address:	1100 North Main Street Ann Arbor, MI 48104
Telephone:	734–222–1100 (main office) 1–800–385–1060 (patient hotline)
E-mail:	LFA@lymphomahelp.org
Internet Web site:	http://www.lymphomahelp.org

The Lymphoma Foundation of America offers one-on-one counseling, peer counseling, support, referrals for legal advice and second opinions, and treatment information for lymphoma patients, survivors and their families. They also monitor and disseminate information about research into possible causes of lymphoma.

Lymphoma Research Foundation (LRF)*For patient services:*

Address:	Suite 207 8800 Venice Boulevard Los Angeles, CA 90034
Telephone:	310–204–7040 1–800–500–9976
E-mail:	LRF@lymphoma.org (general information) helpline@lymphoma.org (patient services)
Internet Web site:	http://www.lymphoma.org/

For research and advocacy:

Address:	19 th Floor 111 Broadway New York, NY 10006
Telephone:	212–349–2910 1–800–235–6848
E-mail:	researchgrants@lymphoma.org (research program) advocacy@lymphoma.org (advocacy)

The LRF's mission is to eradicate lymphoma and serve those touched by this disease. The LRF funds research, advocates for lymphoma-related legislation, and provides educational and support programs for patients and their families.

The Multiple Myeloma Research Foundation (MMRF)

Address:	Suite 201 51 Locust Avenue New Canaan, CT 06840
Telephone:	203–972–1250
E-mail:	info@themmrf.org
Internet Web site:	http://www.multiplemyeloma.org

The MMRF supports research grants and professional and patient symposia on multiple myeloma and related blood cancers. The MMRF publishes a quarterly newsletter, and provides referrals and information packets free of charge to patients and family members.

National Asian Women's Health Organization (NAWHO)

Address:	Suite 900 250 Montgomery Street San Francisco, CA 94104
Telephone:	415–989–9747
E-mail:	nawho@nawho.org
Internet Web site:	http://www.nawho.org

The NAWHO is working to improve the health status of Asian women and families through research, education, leadership, and public policy programs. They have resources for Asian women in English, Cantonese, Laotian, Vietnamese, and Korean. Publications on subjects such as reproductive rights, breast and cervical cancer, and tobacco control are available.

National Bone Marrow Transplant Link (nbmtLink)

Address:	Suite 108 20411 West 12 Mile Road Southfield, MI 48076
Telephone:	1–800–546–5268 (1–800–LINK–BMT)
E-mail:	nbmtlink@aol.com
Internet Web site:	http://www.nbmtlink.org/

The nbmtLink motto is “A second chance at life is our first priority.” The nbmtLink operates a 24-hour, toll-free number and provides peer support to bone marrow transplant (BMT) patients and their families. It serves as an information center for prospective BMT patients as well as a resource for health professionals. Educational publications, brochures, and videos are available. Staff can respond to calls in Spanish.

National Brain Tumor Foundation (NBTF)

Address:	Suite 612 22 Battery Street San Francisco, CA 94111– 5520
Telephone:	415–834–9970 1–800–934–2873 (1–800–934–CURE)
E-mail:	nbtf@braintumor.org
Internet Web site:	http://www.braintumor.org

The NBTF provides patients and their families with information on how to cope with their brain tumors. This organization conducts national and regional conferences, publishes printed materials for patients and family members, provides access to a national network of patient support groups, and assists in answering patient inquiries. The NBTF also awards grants to fund research. Staff are available to answer calls in Spanish, and some Spanish-language publications are available.

National Breast Cancer Coalition (NBCC)

Address:	Suite 1300 1101 17 th Street, NW Washington, DC 20036
Telephone:	202–296–7477 1–800–622–2838
E-mail:	info@stopbreastcancer.org
Internet Web site:	http://www.stopbreastcancer.org

The NBCC is a breast cancer advocacy group that educates and trains individuals to become advocates who effectively influence public

policies that affect breast cancer research and treatment. It also promotes breast cancer research, and works to improve access to high-quality breast cancer screening, diagnosis, and treatment for all women.

National Cancer Institute’s Cancer Information Service

Telephone:	1–800–4–CANCER (1–800–422–6237)
TTY for hearing impaired	(1–800–332–8615)
Bilingual Service	(English and Spanish)
Smoking Cessation Assistance	1–877–44U–QUIT (1–877–448–7848) www.smokefree.gov
Internet Web site:	http://www.cancer.gov

NCI’s Cancer Information Service can be reached by calling 1-800-4-CANCER. Highly trained Cancer Information Specialists provide information about cancer, in English and Spanish Monday through Friday, 9 AM –4:30 PM local time. They also provide free written materials from the NCI, assist with referrals into clinical trials and cancer centers, and provide smoking cessation assistance. During other hours, callers can listen to recorded messages. Callers to the 800 # are prompted to connect with a smoking cessation counselor if they are interested in quitting smoking. Access cancer information and free publications are also available by visiting NCI’s website, www.cancer.gov. The website offers LiveHelp, an instant messaging service, and an option to e-mail questions to Cancer Information Specialists.

National Coalition for Cancer Survivorship (NCCS)

Address: Suite 770
1010 Wayne Avenue
Silver Spring, MD 20910–5600

Telephone: 301–650–9127
1–877–622–7937
(1–877–NCCS–YES)

E-mail: info@canceradvocacy.org

Internet Web site: <http://www.canceradvocacy.org>

The NCCS is a network of groups and individuals that offer support to cancer survivors and their loved ones. It provides information and resources on cancer support, advocacy, and quality-of-life issues. A section of the NCCS Web site and a limited selection of publications are available in Spanish.

National Hospice and Palliative Care Organization (NHPCO)

Address: Suite 625
1700 Diagonal Road
Alexandria, VA 22314

Telephone: 703–837–1500
1–800–658–8898 (helpline)

E-mail: info@nhpco.org

Internet Web site: <http://www.nhpco.org>

The NHPCO is an association of programs that provide hospice and palliative care. It is designed to increase awareness about hospice services and to champion the rights and issues of terminally ill patients and their family members. They offer discussion groups, publications, information about how to find a hospice, and information about the financial aspects of hospice. Some Spanish-language publications are available, and staff are able to answer calls in Spanish.

National Lymphedema Network (NLN)

Address: Suite 1111
1611 Telegraph Avenue
Oakland, CA 94612–2138

Telephone: 510–208–3200
1–800–541–3259

E-mail: nlm@lymphnet.org

Internet Web site: <http://www.lymphnet.org>

The NLN provides education and guidance to lymphedema patients, health care professionals, and the general public by disseminating information on the prevention and management of primary and secondary lymphedema. They provide a toll-free support hotline, a referral service to lymphedema treatment centers and health care professionals, a quarterly newsletter with information about medical and scientific developments, support groups, pen pals, and educational courses for health care professionals and patients, and a computer database. Some Spanish-language materials are available.

National Marrow Donor Program® (NMDP)

Address: Suite 500
3001 Broadway Street, NE
Minneapolis, MN 55413–1753

Telephone: 612–627–5800
1–800–627–7692
(1–800–MARROW–2)
1–888–999–6743
(Office of Patient Advocacy)

Internet Web site: <http://www.marrow.org>

The NMDP, which is funded by the Federal Government, was created to improve the effectiveness of the search for bone marrow donors. It keeps a registry of potential bone marrow donors and provides free information on bone marrow transplantation, peripheral blood stem cell transplant, and unrelated donor stem cell transplant, including the use of umbilical cord blood. The NMDP's Office of Patient Advocacy assists transplant patients and

their physicians through the donor search and transplant process by providing information, referrals, support, and advocacy.

National Ovarian Cancer Coalition (NOCC)

Address:	Suite 8 500 Northeast Spanish River Boulevard Boca Raton, FL 33431
Telephone:	561-393-0005 1-888-682-7426 (1-888-OVARIAN)
E-mail:	NOCC@ovarian.org
Internet Web site:	http://www.ovarian.org

The NOCC raises awareness about ovarian cancer and promotes education about this disease. They have a toll-free telephone number for information, referral, support, and education about ovarian cancer. They also offer support groups, a database of gynecologic oncologists searchable by state, and educational materials. A limited selection of Spanish-language publications is available.

National Patient Travel Center (NPTC)

Address:	Suite One 4620 Haygood Road Virginia Beach, VA 23455
Telephone:	1-800-296-1217
E-mail:	mercymedical@erols.com
Internet Web site:	http://www.patienttravel.org
Alaska Specific:	http://www.angelflight.org

The NPTC provides the National Patient Travel Helpline, a telephone service that facilitates patient access to charitable medical air transportation resources in the United States. The NPTC also offers information about discounted airline ticket programs for patients and patient escorts, operates Special-Lift and Child-Lift programs, and brings ambulatory outpatients to the United States from many overseas locations. Angel Flight West specifically covers the western states, including Alaska.

The Oral Cancer Foundation

Address:	Number 205 3419 Via Lido Newport Beach, CA 92663
Telephone:	949-646-8000
E-mail:	info@oralcancerfoundation.org
Internet Web site:	http://www.oralcancerfoundation.org

The Oral Cancer Foundation is a nonprofit organization that is dedicated to saving lives through education, research, prevention, advocacy, and support for persons with oral cancer. The Foundation provides an online Oral Cancer Forum, which includes a message board and chat room that connect newly diagnosed patients, family members, and the public.

Ovarian Cancer National Alliance (OCNA)

Address:	Suite 413 910 17 th Street, NW Washington, DC 20006
Telephone:	202-331-1332
E-mail:	ocna@ovariancancer.org
Internet Web site:	http://www.ovariancancer.org

The Alliance works to increase public and professional understanding of ovarian cancer and to advocate for research to determine more effective ways to diagnose, treat, and cure this disease. The Alliance distributes informational materials; sponsors an annual advocacy conference for survivors and families; advocates on the issues of cancer to the ovarian cancer community; and works with women's groups, seniors, and health professionals to increase awareness of ovarian cancer.

Pancreatic Cancer Action Network (PanCAN)

Address:	Suite 131 2221 Rosecrans Avenue El Segundo, CA 90245
Telephone:	310–725–0025 1–877–272–6226 (1–877–2–PANCAN)
E-mail:	information@pancan.org
Internet Web site:	http://www.pancan.org

PanCAN, a nonprofit advocacy organization, educates health professionals and the general public about pancreatic cancer to increase awareness of the disease. PanCAN also advocates for increased funding of pancreatic cancer research and promotes access to and awareness of the latest medical advances, support networks, clinical trials, and reimbursement for care.

Partnership for Prescription Assistance

Telephone:	1–888–4PPA–NOW (1–888–477–2669)
Internet Web site:	https://www.pparx.org/Intro.php

The Partnership for Prescription Assistance brings together America’s pharmaceutical companies, doctors, other health care providers, patient advocacy organizations and community groups to help qualifying patients who lack prescription coverage get the medicines they need through the public or private program that’s right for them. Many will get them free or nearly free.

Patient Advocate Foundation (PAF)

Address:	Suite B 753 Thimble Shoals Boulevard Newport News, VA 23606
Telephone:	757–873–6668 1–800–532–5274
E-mail:	help@patientadvocate.org
Internet Web site:	http://www.patientadvocate.org

The PAF provides education, legal counseling, and referrals to cancer patients and survivors concerning managed care, insurance, financial issues, job discrimination, and debt crisis matters. The Patient Assistance Program is a subsidiary of the PAF. It provides financial assistance to patients who meet certain qualifications. The toll-free number is 1–866–512–3861.

Prostate Cancer Foundation

Address:	1250 Fourth Street Santa Monica, CA 90401
Telephone:	310–570–4700 1–800–757–2873 (1–800–757–CURE)
E-mail:	info@prostatecancerfoundation.org
Internet Web site:	http://www.prostatecancerfoundation.org/

The Prostate Cancer Foundation is a nonprofit organization that provides funding for research projects to improve methods of diagnosing and treating prostate cancer. It also offers printed resources for prostate cancer survivors and their families. The mission of the Prostate Cancer Foundation is to find a cure for prostate cancer.

Sisters Network[®], Inc.

Address:	Suite 4206 8787 Woodway Drive Houston, TX 77063
Telephone:	713–781–0255 1–866–781–1808
E-mail:	sisnet4@aol.com
Internet Web site:	http://www.sistersnetworkinc.org

Sisters Network seeks to increase local and national attention to the impact that breast cancer has in the black community. All chapters are run by breast cancer survivors and receive volunteer assistance from community leaders and associate members. The services provided by Sisters Network include individual/group support, community education, advocacy, and research. The national headquarters serves

as a resource and referral base for survivors, clinical trials, and private/government agencies. Teleconferences are held to update chapters with the latest information and share new ideas. An educational brochure designed for underserved women is available. In addition, a national black breast cancer survivors' newsletter is distributed to survivors, medical facilities, government agencies, organizations, and churches nationwide.

The Skin Cancer Foundation

Address:	Suite 1403 245 Fifth Avenue New York, NY 10016
Telephone:	212-725-5176 1-800-754-6490 (1-800-SKIN-490)
E-mail:	info@skincancer.org
Internet Web site:	http://www.skincancer.org

Major goals of The Skin Cancer Foundation are to increase public awareness of the importance of taking protective measures against the damaging rays of the sun and to teach people how to recognize the early signs of skin cancer. They conduct public and medical education programs to help reduce skin cancer.

Support for People with Oral and Head and Neck Cancer (SPOHNC)

Address:	Post Office Box 53 Locust Valley, NY 11560-0053
Telephone:	1-800-377-0928
E-mail:	info@spohnc.org
Internet Web site:	http://www.spohnc.org

The SPOHNC is a self-help organization that serves oral and head and neck cancer patients, survivors, and their families. The organization offers support group meetings, information, newsletters, and teleconferences. The SPOHNC also offers a "Survivor to Survivor" network which pairs survivors or their family members with volunteers who have had a similar diagnosis and treatment program.

The Susan G. Komen Breast Cancer Foundation

Address:	Suite 250 5005 LBJ Freeway Dallas, TX 75244
Telephone:	972-855-1600 1-800-462-9273 (1-800-I'M AWARE®)
E-mail:	helpline@komen.org
Internet Web site:	http://www.komen.org

The Susan G. Komen Breast Cancer Foundation's mission is to eradicate breast cancer as a life-threatening disease by advancing research, education, screening, and treatment. This organization operates a national toll-free breast cancer helpline (1-800-I'M AWARE) that is answered by trained volunteers whose lives have been personally touched by breast cancer. Breast health and breast cancer materials, including pamphlets, brochures, booklets, posters, videos, CD-ROMs, fact sheets, and community outreach materials, are available. Staff can respond to calls in Spanish, and some publications are available in Spanish.

Thyroid Cancer Survivors' Association, Inc. (ThyCa)

Address:	Post Office Box 1545 New York, NY 10159-1545
Telephone:	1-877-588-7904
E-mail:	thyca@thyca.org
Internet Web site:	http://www.thyca.org

ThyCa offers a network of services to thyroid cancer survivors, caregivers, family members, and friends. These services include e-mail support groups, person-to-person support, local support groups, and a toll-free survivors' telephone line. ThyCa also offers a low-iodine cookbook, newsletters, conferences, and workshops. The organization has volunteers who are fluent in Spanish.

US[®] TOO! International, Inc.

Address:	5003 Fairview Avenue Downers Grove, IL 60515
Telephone:	630–795–1002 (in the Chicago area) 1–800–808–7866 (1–800–80–US TOO)
E-mail:	ustoo@ustoo.com
Internet Web site:	http://www.ustoo.org

US TOO is a prostate cancer support group organization. Goals of US TOO are to increase awareness of prostate cancer in the community, educate men newly diagnosed with prostate cancer, offer support groups, and provide the latest information about treatment for this disease. A limited selection of Spanish-language publications is available.

Vital Options[®] International TeleSupport[®] Cancer Network

Address:	Suite 645 15821 Ventura Boulevard Encino, CA 91436–2946
Telephone:	818–788–5225 1–800–477–7666 (1–800–GRP–ROOM)
E-mail:	info@vitaloptions.org
Internet Web site:	http://www.vitaloptions.org

The mission of Vital Options is to use communications technology to reach people dealing with cancer. This organization holds a weekly syndicated call-in cancer radio talk show called “The Group Room[®],” which provides a forum for patients, long-term survivors, family members, physicians, and therapists to discuss cancer issues. Listeners can participate in the show during its broadcast every Sunday from 4 p.m. to 6 p.m. Eastern time by calling the toll-free telephone number. A live Web simulcast of “The Group Room” can be heard by logging onto the Vital Options Web site.

The Wellness Community[®]

Address:	Suite 54 919 18 th Street, NW Washington, DC 20006
Telephone:	202–659–9709 1–888–793–9355 (1–888–793–WELL)
E-mail:	help@thewellnesscommunity.org
Internet Web site:	http://www.thewellnesscommunity.org

The Wellness Community provides free psychological and emotional support to cancer patients and their families. They offer support groups facilitated by licensed therapists, stress reduction and cancer education workshops, nutrition guidance, exercise sessions, and social events.

Y-ME National Breast Cancer Organization[™], Inc.

Address:	Suite 500 212 West Van Buren Street Chicago, IL 60607
Telephone:	312–986–8338 1–800–221–2141 (English) 1–800–986–9505 (Spanish)
E-mail:	askyme@y-me.org (English); latino@y-me.org (Spanish)
Internet Web site:	http://www.y-me.org

The Y-ME National Breast Cancer Organization provides information and support to anyone who has been touched by breast cancer. Y-ME serves women with breast cancer and their families through a national hotline (available 24 hours a day), open-door groups, early detection workshops, and support programs. Numerous local chapter offices are located throughout the United States. A section of the Y-ME Web site, a toll-free hotline, and publications are available in Spanish.

Notes

Funding for this publication was provided by the Centers for Disease Control and Prevention (CDC) Cooperative Agreement Number U55/CCU021987-03-1.

This publication was produced by the Alaska Department of Health and Social Services.
It was printed at a cost of \$9.89 per copy in Anchorage, Alaska.
This cost block is required by AS 44.99.210.



Chronic Disease Prevention and Health Promotion
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November 2006