The West Virginia Comprehensive Cancer Control Plan

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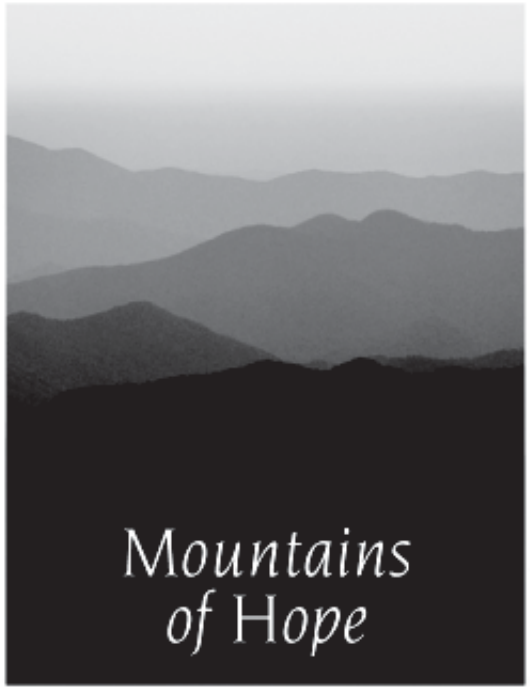
Foreword

Cancer is the second leading cause of death in West Virginia, second only to heart disease. Each year from 1993 to 1998, over 9,000 West Virginians were diagnosed with cancer. The *West Virginia Comprehensive Cancer Plan* is a strategic plan of action, developed by over 120 organizations concerned with the burden of cancer on West Virginia citizens. The *Cancer Plan* describes the current extent of the cancer burden in the state and sets forth measurable goals and objectives with suggested strategies. The West Virginia Healthy People 2010 Cancer Objectives were utilized as a guide throughout the establishment of this *Cancer Plan.* Successful implementation will require the continued support and assistance of many different partners including the state legislature, state and local health agencies, and grassroots organizations. Comprehensive cancer control is the key to developing an integrated and coordinated approach for reducing the incidence, morbidity, and mortality of cancer. Through effective prevention, early detection, treatment, rehabilitation, and palliation efforts, the burden of cancer on West Virginians can be reduced.

The *Cancer Plan* was accomplished through the hard work and dedication of the West Virginia Comprehensive Cancer Control Coalition, "Mountains of Hope," and its participating partners from around the state. We are thankful for those participants and those individuals who facilitated the production of this action agenda.

Chris Curtis, M.P.H.
Acting Commissioner
West Virginia Bureau for Public Health



West Virginia Comprehensive Cancer Control Coalition

EXECUTIVE SUMMARY

The West Virginia Comprehensive Cancer Control Plan is the results of years of patient and hard work by state, county and local health organizations and agencies, health care providers and educators, cancer patients and survivors, and others dedicated to reducing the burden of cancer in the Mountain State.

Mountains of Hope was founded by the Office of Epidemiology and Community Health Promotion of the West Virginia Bureau for Public Health, the Mary Babb Randolph Cancer Center of West Virginia University, the West Virginia Breast and Cervical Cancer Screening Program, and the American Cancer Society, Mid-Atlantic Division, Regions 10 and 11.

West Virginia and the CDC

West Virginia is one of only 13 states, tribes or territories to receive a four-year cooperative agreement (2002) from the Centers for Disease Control and Prevention (CDC) to implement comprehensive cancer control (CCC) plans. Mountains of Hope, the state's comprehensive cancer control coalition with its 100-plus organizations representing West Virginia's many cancer programs and health care institutions, created this plan and will coordinate its many activities.

The cooperative agreement between the CDC and West Virginia specifies that the state's comprehensive cancer program

- Enhance coordination among partners involved in all aspects of the comprehensive cancer control program, from prevention to pain control
- Develop a coordinated approach to cancer programs
- Establish ongoing support for CCC
- Establish linkages among existing data and surveillance systems
- Develop and implement a comprehensive evaluation plan to measure the success of CCC activities

Cancer in West Virginia

Since 1945 cancer has been the second leading cause of death in West Virginia, surpassed only by heart disease. For the past two decades, however, the number of heart disease deaths has been on the decline, while cancer deaths have been increasing. If present trends continue, epidemiologists project that cancer will become the leading cause of death in the Mountain State by the year 2026. In 1999, 4,737 West Virginians died from cancer, which is nearly one out of every four deaths (23.0 percent). The state's age-adjusted rate of cancer mortality in that year was 10.9 percent higher than the U.S. rate of 202.4. Since 1985, West Virginia's rate of cancer mortality has exceeded the U.S. rate every year but two.

Each year from 1993 through 1998, over 9,000 West Virginians were diagnosed with cancer, with the number of new cancer cases each year distributed virtually equally between men and women. Cancer incidence increases with age, and West Virginia has the distinction of having the "oldest" population of the 50 states, with a median age of 37.7 in 1996. Hobbs and Damon report in *65+ in the United States* that West Virginia ranks fourth in the nation in the proportion of its population that is elderly. Given these facts, it is only logical to conclude that cancer will continue to increase in the state if steps are not taken toward its control.

The four most deadly types of cancer are the same in West Virginia and the United States. For both sexes, lung cancer is the top killer; in 1999, it claimed the lives of 929 of our men and 648 of our women, about one-third of all cancer deaths. Breast cancer is the second leading cause of cancer death among women, killing 274 West Virginia women in 1999. Prostate cancer took 217 lives in 1999, making it the second most deadly cancer among men. Colorectal cancer followed as the third leading cause of cancer mortality for both sexes, with 205 men and 210 women in the state losing their lives to this disease in 1999.

Nearly 1,800 new cases of lung cancer are diagnosed each year (1994-98) in West Virginia. Still a disease more prevalent among men than women, it was diagnosed at an average rate of 104.2 new cases among every 100,000 men and 54.4 new cases among women annually from 1994 through 1998. However, if the smoking rate among West Virginia women continues its present upward trend, the gap between men and women in lung cancer deaths will continue to narrow. Only 24.5 percent of the lung cancer cases diagnosed from 1994-98 with known stage of disease were diagnosed at an early stage, i.e., in situ or local, when the cancer is more treatable.

Breast cancer is the most commonly diagnosed cancer among West Virginia women. Each year from 1993 through 1998, an average of 1,271 new cases were diagnosed. The incidence rate in 1998 was 97.4 cases per every 100,000 women in the state. Of the cases diagnosed from 1994-98 with a known stage of disease, 70 percent were diagnosed at an early stage, due in part to preventive screening through breast examinations and mammograms.

Among West Virginia men, prostate cancer is the most commonly diagnosed cancer, accounting for one in every four cancer diagnoses. An average of 1,213 new cases were diagnosed annually from 1993 through 1998. The 1998 incidence rate for prostate cancer was 113.9 cases for every 100,00 men in the state. Over two-thirds (81 percent) of the cases of prostate cancer diagnosed over the four-year period with known stage were found at the early stage of the disease.

Colorectal cancer is the third most common cancer diagnosed in both men and women in the mountain state. There were an average of 611 new cases diagnosed annually among women from 1993 through 1998, compared to an average of 573 new cases among men. Only 40 percent of 1994-98 colorectal cancer cases with known stage were diagnosed at an early stage where five-year survival rates are excellent.

Comprehensive Cancer Control Four-Year Goals

Coordination
Continue strengthening our integrated and effective network of cancer control partners.

Public Education
Increase relevant and effective public and patient education programs.

Professional Education
Increase relevant and effective professional education.

Tobacco Cessation
Decrease the rate of tobacco use among West Virginians of all ages and support those who want to quit using tobacco.

Diet and Nutrition
Increase to 35 percent the proportion of people age 18 and older who consume at least five servings of vegetables and fruits per day and increase to 75 percent the proportion of people aged 18 and older who consume less than 10 percent of total calories from saturated fat.

Physical Activity
Decrease the sedentary lifestyle of West Virginians and increase public knowledge about the association of physical activity and cancer risks.

Exposure to Ultraviolet Radiation
Decrease ultraviolet radiation exposure and decrease the number of persons who will experience sunburn with redness over 12 hours within the past 12 months.

Early Detection of Breast Cancer
Reduce breast cancer deaths to no more than 21 per 100,000 West Virginia females by 2010.

Early Detection of Cervical Cancer
Determine why the cervical cancer mortality rate for women in West Virginia is 51 percent higher (1995) than the U.S. rate.

Early Detection of Ovarian Cancer
Increase public awareness of ovarian cancer.

Early Detection of Colorectal Cancer
Attain a level where at least 50 percent of people aged 50 and older have received a colorectal cancer screening examination (fecal occult blood testing) within the preceding 1-2 years and increase to at least 40 percent those who have ever received a proctosigmoidoscopy.

Early Detection of Prostate Cancer
Reduce prostate cancer-related deaths to 19.5 per 100,000 West Virginia males.

Patient Access to Information
Increase public and provider awareness about the availability of high-quality information, resources for patients, and support programs in West Virginia.

Financial Access
Reduce financial barriers in the care of cancer patients.

Access to Care
Increase access to care and support services for cancer patients and survivors.

Diagnosis and Treatment
Ensure that the highest quality diagnosis, treatment and care are available to all West Virginians.

Pain Control and End-of-Life Issues
Ensure that each West Virginia cancer patient has access to treatment and resources that allow for optimal pain control and end of life support.

Advocacy
Create a strong network of community volunteers, survivors and providers working together on public awareness, legislative action and funding for priority cancer issues.

Acknowledgments

The West Virginia Comprehensive Cancer Control Plan is a collaborative effort of many individuals and organizations affiliated with the Mountains of Hope Comprehensive Cancer Control Coalition. Mountains of Hope (MOH) especially appreciates the contributions of the following, who led in the development and writing of this blueprint for action.

- Comprehensive Cancer Plan Authors
  - Pamela Brown, Mary Babb Randolph Cancer Center of West Virginia University
  - Linda Jacknowitz, Mary Babb Randolph Cancer Center of West Virginia University (MOH Coalition Coordinator)
  - Jennifer Weiss, Manager, West Virginia Bureau for Public Health Comprehensive Cancer Control Program

- Mountains of Hope Steering Committee
  - James Frame, MD, Charleston Area Medical Center Health Education and Research Institute (MOH Coalition Chair)
  - Gerard Oakley, MD, Joan C. Edwards School of Medicine, Marshall University (MOH Coalition Vice Chair)
  - Amy Reasinger Allen, NCI Cancer Information Service
  - Pamela Brown
  - Sharon Cope, West Virginia Breast and Cervical Cancer Screening Program
  - Anne Harmon, West Virginia University Center on Aging
  - Diana Harrison, American Cancer Society Mid-Atlantic Division, Regions 10 & 11
  - Alan Holmes, West Virginia Bureau for Public Health Office of Epidemiology and Health Promotion
  - Carol Mangone, North Central Appalachia Cancer Network
  - Elizabeth Prendergast, West Virginia University Prevention Research Center
  - Robin Seabury, West Virginia Bureau for Public Health Office of Maternal, Child and Family Health

- Mountains of Hope Subcommittees
  - Early Detection
  - Prevention
  - Patient Care and Survivorship

- Mountains of Hope Founding Organizations
  - West Virginia Bureau for Public Health, Office of Epidemiology and Health Promotion
  - Mary Babb Randolph Cancer Center of West Virginia University
  - West Virginia Breast and Cervical Cancer Screening Program
  - American Cancer Society Regions 10 and 11, Mid-Atlantic Division

- Healthy West Virginia Coalition

The Coalition also recognizes the visionary leadership of Ms. Leslie Given in furthering this effort during her tenure at the Mary Babb Randolph Cancer Center.

We are also grateful to the following individuals for their assistance in the preparation of this document:

- Elsa Nadler, NCI Cancer Information Service
- Elizabeth Austin, Rita Kuis, and Emily Vunjak, Cancer Control and Prevention, Mary Babb Randolph Cancer Center of West Virginia University
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- Tom Light, West Virginia Health Statistics Center
- Carol Grimes, Office of Biomedical Illustration, Robert C. Byrd Health Sciences Center of West Virginia University

Mountains of Hope applauds the pioneering work done by Colorado, Massachusetts, Michigan, North Carolina, the Northwest Portland Area Indian Health Board, and Texas, the initial CDC comprehensive cancer control implementation programs.

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To all West Virginians who have committed resources to achieve the cancer control priorities identified in this plan, a sincere thank you. The achievement of these priorities will benefit all citizens of the Mountain State.

James N. Frame, MD
Chair
Mountains of Hope Coalition
July 2002

Contents

If present trends continue, epidemiologists project that cancer will become the leading cause of death in the Mountain State by the year 2026.

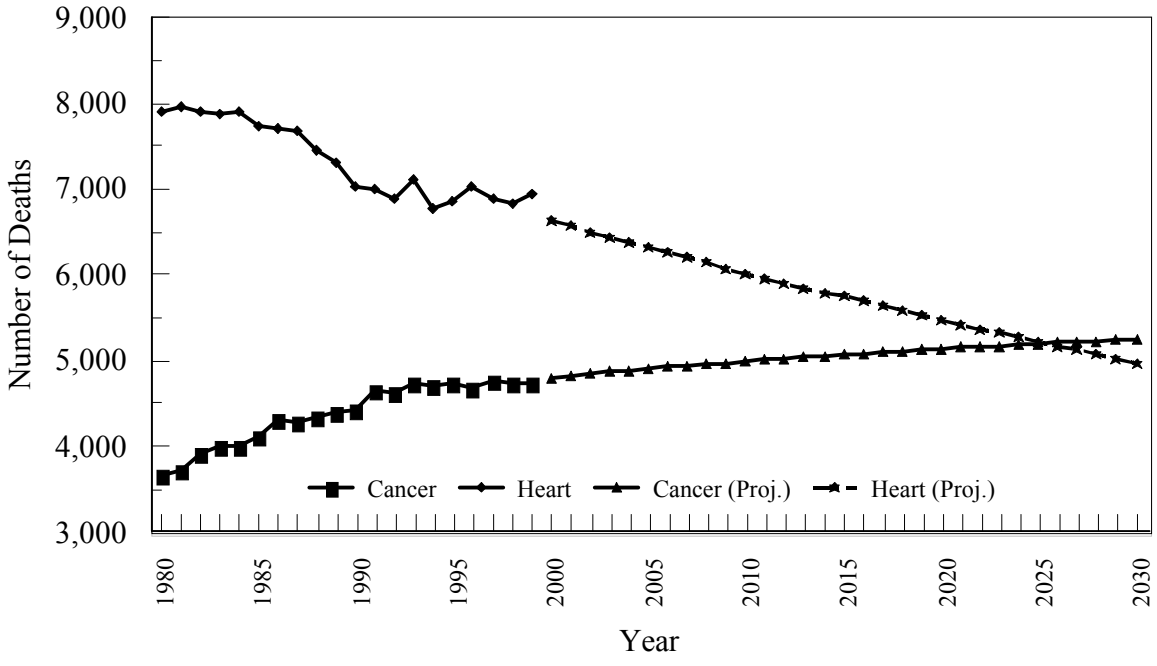
I

The Burden of Cancer in West Virginia

Cancer Mortality

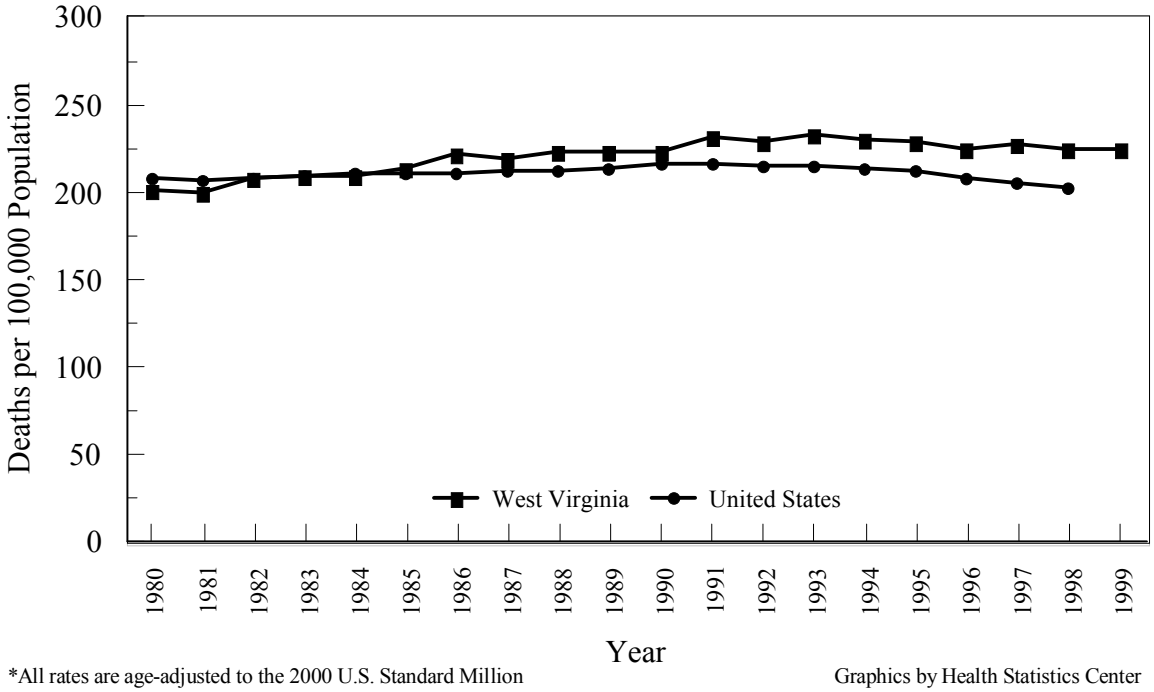
Since 1945 cancer has been the second leading cause of death in West Virginia, surpassed only by heart disease. For the past two decades, however, the number of heart disease deaths has been on the decline, while cancer deaths have been increasing. If present trends continue, epidemiologists project that cancer will become the leading cause of death in the Mountain State by the year 2026. In 1999, 4,737 West Virginians died from cancer, representing nearly one out of every four deaths (23.0 percent). The state's age-adjusted rate of cancer mortality in that year was 224.5 deaths per 100,000 population, 10.9 percent higher than the U.S. rate of 202.4. Since 1985, West Virginia's rate of cancer mortality has exceeded the U.S. rate every year but two.

Deaths Due to Heart Disease and Cancer
West Virginia (1980-1999) and Projected (2000-2030)



Graphics by Health Statistics Center

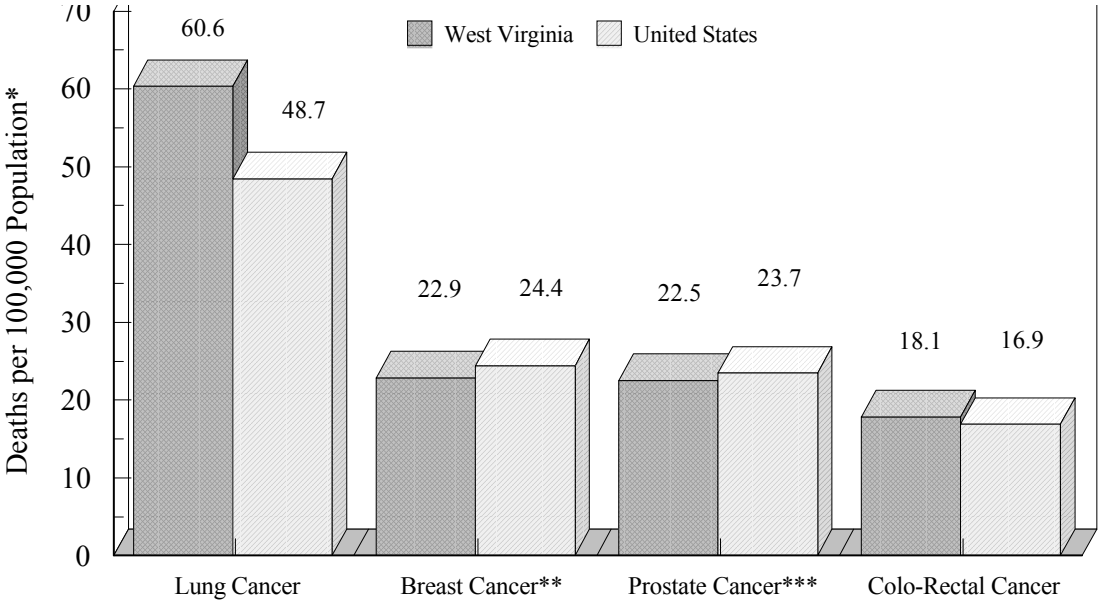
Mortality Rates* Due to All Cancers
West Virginia (1980-1999) and United States (1980-1998)



*All rates are age-adjusted to the 2000 U.S. Standard Million

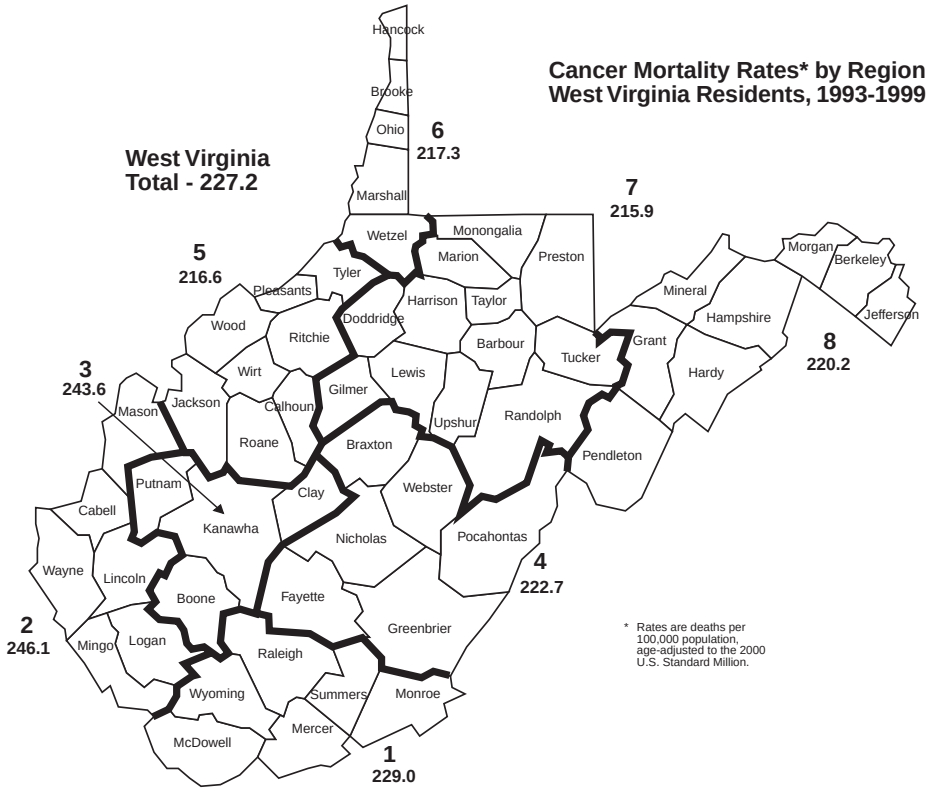
Graphics by Health Statistics Center

Four Leading Causes of Cancer Mortality
West Virginia (1993-1999) and United States (1996)



*All rates are age-adjusted to the 1970 U.S. population distribution.
**Per 100,000 Females ***Per 100,000 Males

Graphics by Health Statistics Center



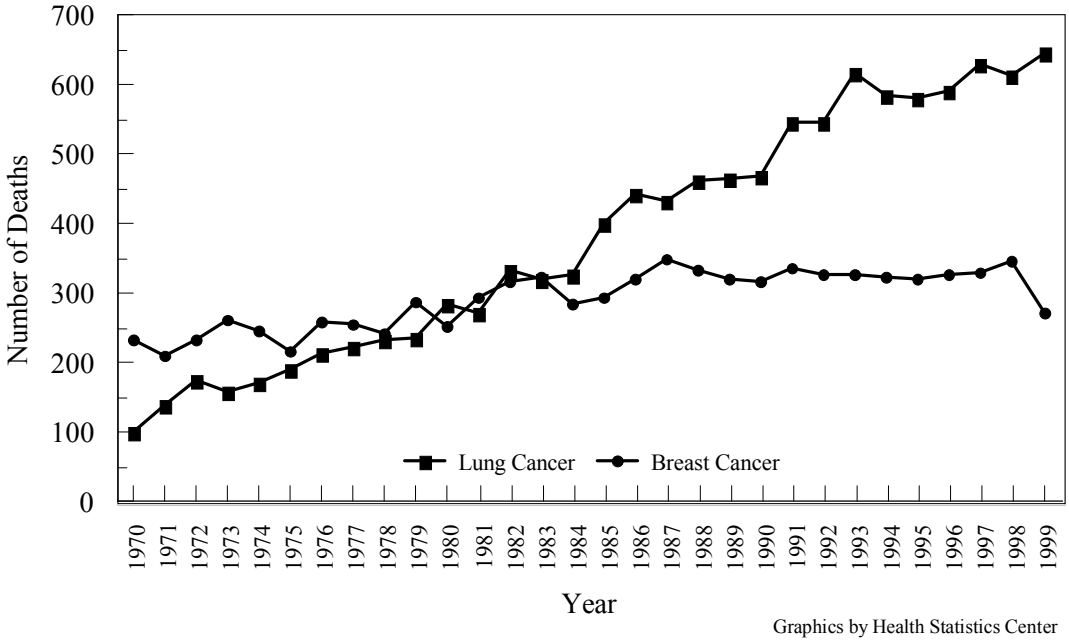
The four most deadly types of cancer (lung, prostate, breast and colorectal) are the same in West Virginia and the United States. For both sexes, lung cancer is the top killer; in 1999, it claimed the lives of 929 of our men and 648 of our women, about one-third of all cancer deaths. Breast cancer is the second leading cause of cancer death among women, killing 274 West Virginia women in 1999. Until 1980, breast cancer deaths outnumbered lung cancer deaths among women; since then, mortality due to lung cancer has increased at a faster rate than breast cancer mortality.

If the smoking rate among our women continues its present upward trend, the gap between men and women in lung cancer deaths will continue to narrow. Prostate cancer took 217 lives in 1999, making it the second most deadly cancer among men. Colorectal cancer followed as the third leading cause of cancer mortality for both sexes, with 206 men and 240 women in the state losing their lives to this disease in 1999.

Just as demographics such as race, income, unemployment, and population density vary within the various regions in the state, so do the rates of cancer mortality. Using average annual rates calculated from 1993-1999 aggregated data (and age adjusted to the 2000 U.S. Standard Population), Region 2 had the highest rate of overall cancer mortality among the eight regions for the four-year period, reporting 246.1 deaths per 100,000 resident West Virginians, while Region 7 reported the lowest rate at 215.9.

Lung cancer mortality rates were found to be highest in Regions 2 and 3, which comprise the southwestern and south-central counties of the state, and lowest in the north

Deaths of Women Due to Lung Cancer and Breast Cancer
West Virginia Residents, 1970-1999



Graphics by Health Statistics Center

Leading Causes of Cancer Mortality by Region
Average Annual Age-Adjusted Rates*
West Virginia Residents, 1993-1999

Region	Cancer, All Sites	Lung and Bronchus	Female Breast	Prostate	Colorectal
Region I	229.0	73.2	29.5	35.5	17.5
Region II	246.1	86.3	29.0	33.5	20.8
Region III	243.6	81.1	28.4	38.4	21.2
Region IV	222.7	72.7	28.6	33.1	18.2
Region V	216.6	74.3	24.3	26.1	18.6
Region VI	217.3	64.8	28.1	32.9	21.5
Region VII	215.9	67.6	26.8	31.0	19.3
Region VIII	220.2	63.4	27.2	35.3	24.2
Total	**227.2**	**73.4**	**27.8**	**33.2**	**20.1**

Health Statistics Center

*Seven-year average annual rates per 100,000 West Virginia residents, age-adjusted to the 2000 U.S. Standard Population. Breast cancer rates per 100,000 females; prostate cancer rates per 100,000 males.

central counties of Region 7. Less fluctuation was seen in breast cancer mortality rates, with slightly higher rates recorded in Regions 3 and 4. Region 3 also had the highest rates of death from prostate cancer, while colorectal cancer mortality rates were highest in Region 8, located in the easternmost part of the state.

Cancer Incidence

Each year from 1995 through 1999, the most recent five-year period for which data is available, an average of 9,923 West Virginians were diagnosed with cancer. The number of new cancer cases each year were distributed virtually equally between men and women. Of the total of 49,615 cases diagnosed during that period, 25,199 (50.8 percent) were in men and 24,416 (49.2 percent) were in women. Cancer incidence increases with age, and West Virginia has the distinction of having the "oldest" population of the 50 states with a median age of 37.7 in 1996, higher even than Florida (37.6). Hobbs and Damon report in 65+ *in the United States* that West Virginia ranks fourth in the nation in the proportion of its population that is elderly. Given these facts, it is only logical to conclude that cancer will continue to increase in the state if steps are not taken toward its control.

Lung, breast, prostate, and colorectal cancers are the most deadly and most frequently diagnosed forms of the disease. Nearly 1,800 new cases of lung cancer are diagnosed each year (1994-98) in West Virginia. Still a disease more prevalent among men than women, it was diagnosed at an average rate of 104.2 new cases among every 100,000 men and 54.4 new cases among women annually from 1994 through 1998. The gap between men and women was larger in the past; however, it will continue to close as the smoking prevalence rises among young women in our state. Only 24.5 percent of the lung cancer cases diagnosed from 1994-98 with known stage of disease were diagnosed at an early stage, i.e., in situ or local, when the cancer is more treatable. Breast cancer is the most commonly diagnosed cancer among West Virginia women. Each year from 1993 through 1998, an average of 1,271 new cases were diagnosed. The incidence rate in 1998 was 97.4 cases per every 100,000 women in the state. Of the cases diagnosed from 1994-98 with a known stage of disease, 70 percent were diagnosed at an early stage due in part to preventive screening through breast examinations and mammograms.

Among West Virginia men, prostate cancer is the most commonly diagnosed cancer, accounting for one in every four cancer diagnoses. An average of 1,213 new cases were diagnosed annually from 1993 through 1998. The 1998 incidence rate for prostate cancer was 113.9 cases for every 100,00 men in the state. Over two-thirds (81 percent) of the cases of prostate cancer diagnosed over the four-year period with known stage were found at the early stage of the disease.

Colorectal cancer is the third most commonly diagnosed cancer in both men and women in West Virginia. There were an average of 611 new cases diagnosed annually among women from 1993 through 1998, compared to an average of 573 new cases among men. Only 40 percent of 1994-98 colorectal cancer cases with known stage were diagnosed at an early stage where five-year survival rates are excellent.

Burden of Cancer References and Resources

Cancer in West Virginia: Incidence and Mortality 1993-1998. 2001. West Virginia Cancer Registry. West Virginia Department of Health and Human Resources, Division of Surveillance and Disease Control.

Ries LAG, Eisner MP, Kosary CL, Hankey BF, Miller BA, Clegg L, Edwards BK (eds). 2001. *SEER Cancer Statistics Review, 1973-1998*. National Cancer Institute. Bethesda, MD. <http://seer.cancer.gov/Publications/CSR1973_1998/>.

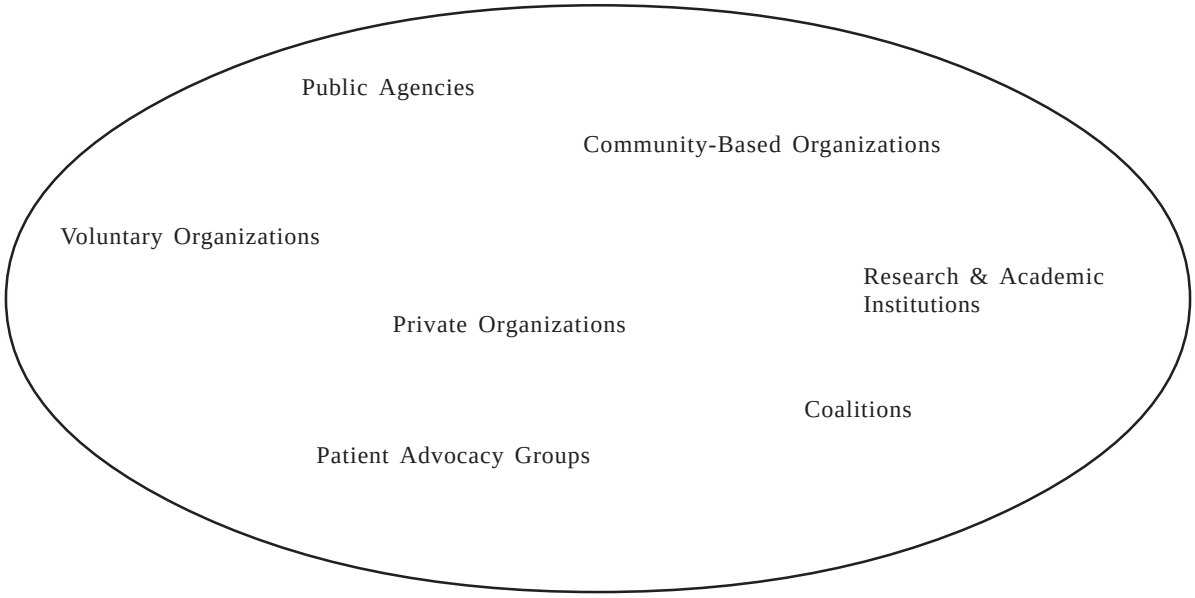
Under the Mountains of Hope umbrella, the Coalition will enhance communication throughout the state's cancer community, maximize scarce resources, identify gaps in services and resources, and identify common challenges in the war on cancer.

II

Coordination of a Comprehensive Cancer Control Program

"Mountains of Hope: The West Virginia Comprehensive Cancer Control Coalition" developed in the late nineties as an expansion of the West Virginia Breast and Cervical Cancer Coalition. At present, more than 120 individuals and organizations make up its membership. The Coalition counts community-based organizations, research and academic institutions, public and private agencies, coalitions, voluntary associations, patient advocacy groups and other cancer-related associations and organizations among its institutional members (Appendix A). In joining together under the Mountains of Hope umbrella, these individuals and organizations seek to enhance communication throughout the state's cancer community; to maximize scarce resources; to identify gaps in services and resources; and to identify common challenges in the war on cancer. In seeking to coordinate cancer control activities statewide, the Coalition will focus its ongoing efforts on the development and maintenance of an inventory of cancer control activities, while encouraging effective interactions among cancer control advocates and their allies.

Mountains of Hope



Partnership development is a well-established approach for leveraging resources and maximizing limited assets within a variety of health promotion programs, including cancer prevention and control (Graffunder 1999; Levine 1992). Collaboration among public health organizations, academic institutions, and the community can reduce disparities in access to information, resources, and skills (Berkowitz, 2000). Such partnerships can help public health personnel gain important insights into community needs and assets, as well as gather from community members valuable qualitative data regarding determinants of health (Thomsen). One model for change proposed by Ahmed and Maurana (1999) utilizes partnerships to provide health care to underserved populations in an approach similar to the one Mountains of Hope has adopted. Members of the medical community and the local community begin the process of improving health by doing needs assessments, identifying resources, developing a dissemination and delivery system, and planning for long-term sustainability. As was demonstrated through the Appalachia Leadership Initiative on Cancer and other National Cancer Institute "leadership initiatives" in the mid-nineties, once the capacity of the local community has been strengthened, key elements of the effort must be taken on and owned by the community; they can then continue to be nurtured and sustained at a distance (Friedell, 2001).

A framework for partnership development established by Scott and Thurston (1997) shows the steps of the process, beginning with awareness of need and followed by exploration with potential partners, formulation of a vision, commitment from partners, agreement, and implementation. The vision is based on identification of 1) potential operations, 2) environmental factors that may affect the partnership, 3) characteristics of the partnership, 4) roles of each partner, 5) future partners, and 6) communications strategies. All potential partners should agree on the characteristics of the partnership, its operations and communications strategies. Evaluation is integral to the entire process.

Himmelman (1996) clearly defined the four common strategies organizations use in working together to serve a common purpose. They run along a developmental continuum of increasing complexity and commitment: networking, coordinating, cooperating, and collaborating. Networking is the exchange of information for mutual benefit. Coordinating adds altering activities for a common purpose. Cooperation goes further—to sharing resources. Finally, collaboration, as defined by Himmelman, is "exchanging information, altering activities, sharing resources, and enhancing the capacity of the other for mutual benefit and to achieve a common purpose." Collaborating is characterized by substantial time commitment, high levels of trust, and broad access to each other's turf. Through partnerships, organizations can better serve their audiences. The partnerships that were forged to create Mountains of Hope were modeled after Himmelman's definition of collaboration.

Using the Centers for Disease Control and Prevention (CDC) definition of comprehensive cancer control—"an integrated and coordinated approach to reducing cancer incidence, morbidity, and mortality through prevention, early detection, treatment, rehabilitation, and palliation"—as the backdrop for coalition development, representatives of the four founding organizations [the West Virginia Breast and Cervical Cancer Screening Program (WVBCCSP), the Office of Epidemiology and Health Promotion (OEHP) in the West Virginia Bureau for Public Health (WVBPH), the American Cancer Society Mid-Atlantic

Division (ACS), and the Mary Babb Randolph Cancer Center (MBRCC) of West Virginia University] initiated efforts to promote the concept of comprehensive cancer control and to generate interest from a diverse spectrum of potential Coalition stakeholders. The membership of the West Virginia Breast and Cervical Cancer Coalition was carefully assessed to determine its existing capacity and potential for expansion. Gaps were identified, and interested agencies and individuals were invited to a planning retreat. The results of the retreat, attended by more than 180 people in September 1999, included a proposed Coalition structure, a set of preliminary decision-making principles, and a draft mission statement.

In January 2000, at the Coalition's first general membership meeting, the membership accepted the organization's mission statement (Appendix B) and purpose and adopted the proposed Coalition Values Statement (Appendix C). By March 2000, interim bylaws were drafted, and from May to August 2000, the Transition Steering Committee coordinated the Coalition's continued development.

Just one year after the planning retreat, at a general membership meeting in September 2000, officers were elected (Appendix D), bylaws were approved (Appendix E), and the committee structure was activated. Throughout this period of organization and development, the founding organizations supported and maintained the Coalition with significant staffing and financial commitments; they continue to do so.

In April 2001, steering committee members and Coalition representatives attended "Working Together for Comprehensive Cancer Control: An Institute for State Leaders—Mid-Atlantic and Florida," sponsored by the CDC, the ACS, the National Cancer Institute (NCI), the Intercultural Cancer Council (ICC) and others. A valuable and energizing education experience, the institute validated the Coalition's approach to building a vital, sustainable, cancer control infrastructure.

At the April 2001 Coalition meeting, the membership voted to do away with the unwieldy and generic name: "West Virginia Comprehensive Cancer Control Coalition." After extensive discussion, the membership chose to name the Coalition and its work "Mountains of Hope," honoring cancer survivors and future generations living in this beautiful state.

The Coalition's mission is "to provide leadership by facilitating and coordinating statewide and community-level collaboration to reduce the human and economic impact of cancer in West Virginia." Using CDC's Building Blocks for Comprehensive Cancer Control Planning as a guide, the Coalition's purpose is "to develop and implement a comprehensive cancer control plan for the state. The Coalition will strive to ensure that all of West Virginia's Healthy People 2010 cancer objectives are addressed in the comprehensive cancer control plan" (Appendix F).

Mountains of Hope holds quarterly general membership meetings. Its steering committee meets monthly, either face to face or via conference call. Subcommittees meet as

needed. As one of its first orders of business, the steering committee developed a one-year action plan to help further the Coalition's mission and purpose:

1. Write the West Virginia Comprehensive Cancer Control Plan
2. Increase awareness about Mountains of Hope among existing and potential Coalition stakeholders and key policy makers and
3. Strengthen Coalition subcommittees

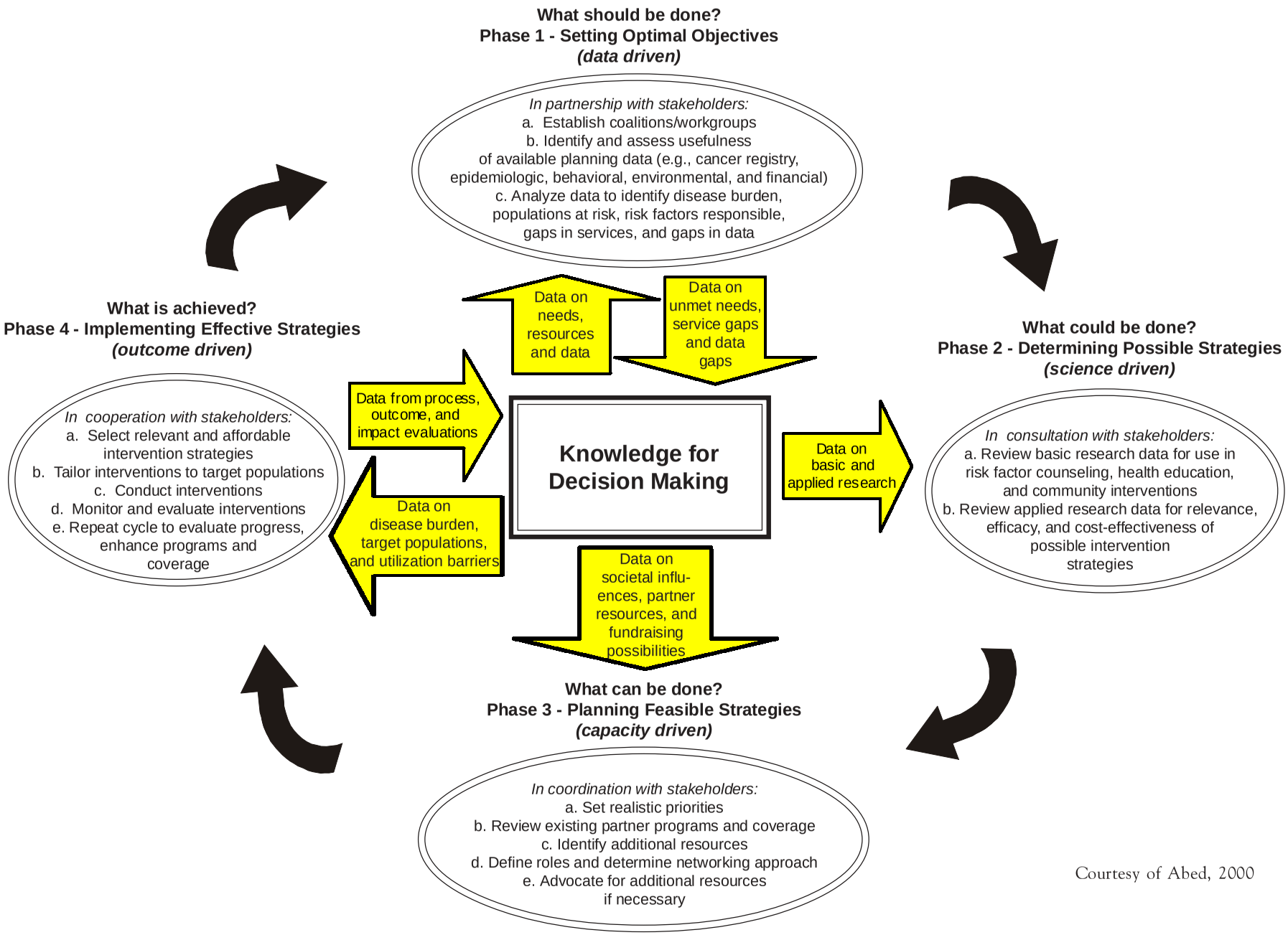
To carry out its 2001 Action Plan, the following activities were undertaken:

- The West Virginia Comprehensive Cancer Control Plan will be completed by Fall 2001.
- A Coalition logo and color scheme were adopted. (April 2001)
- A recruitment brochure was developed and will be printed. (Summer 2001)
- A Coalition Web presence is under discussion. (ongoing)
- Several Coalition-related listservs (general membership, steering committee, prevention, early detection, patient care and survivorship) were formed. (May 2001)
- The Coalition Information Exchange (CIE) is a regular part of all general membership meetings; the CIE is an opportunity for members to share information (i.e. brochures, pamphlets, fact sheets, etc.) about their organization with other Coalition members. (ongoing)
- Quarterly general membership meetings regularly highlight the activities of one or more Coalition members as part of the program agenda. (ongoing)
- Quarterly general membership meetings include capacity-building workshops and presentations, e.g. "Available Data Resources for Planning." (ongoing)
- Coalition membership recruitment continues. (ongoing)
- Ad hoc committees are created when necessary, e.g. Data/Research Work Group. (ongoing)
- Coalition leadership seeks committee input and approval for the Comprehensive Cancer Control Plan and other key policy issues. (ongoing)
- Reference notebooks have been distributed to steering committee members. (ongoing)

The Mountains of Hope Coalition remains committed to promoting comprehensive cancer prevention and control modeled on the framework set forth in "Developing a Framework for Comprehensive Cancer Prevention and Control in the United States" (Abed 2000).

- Setting Priorities
  - ❋ Driven by data
- Determining Program Components
  - ❋ Driven by science
- Defining Roles
  - ❋ Driven by capacity
- Implementing Program Activities
  - ❋ Driven by outcomes

Framework for Comprehensive Cancer Prevention and Control



Courtesy of Abed, 2000

Coordination Goals and Objectives

Four-Year Goal:	**Continue strengthening our integrated and effective network of cancer control partners.**

Goal I: Ensure broad participation from the cancer control community.

Objective I:

Assess the membership quarterly to ensure that we continue to be an integrated coalition of committed people with diverse interests and skills.

Strategies:

1. As new cancer control priorities are identified, ensure that experts in activities related to the priority areas are members of or advisors to the Coalition.

Primary Facilitator: Mountains of Hope Steering Committee

2. Ensure adequate representation of minorities, the elderly, people with limited education and income, gays and lesbians, and people with disabilities.

Primary Facilitators: West Virginia Bureau for Public Health Comprehensive Cancer Control Program, West Virginia Breast and Cervical Cancer Screening Program Cancer Information Specialists, Appalachia Cancer Network Community Coalitions, Benedum Community Cancer Education Programs, Mautner Project, American Association of Retired People, West Virginia University Extension Service, West Virginia Minority Health Program

3. Invite cancer survivors to participate in planning all Coalition endeavors.

Primary Facilitators: Appalachia Cancer Network Community Coalitions, West Virginia Breast and Cervical Cancer Screening Program, North Central West Virginia Chapter of the Oncology Nursing Society

4. Use established and current technologies (e.g., MDTV, Internet, listservs) to communicate new opportunities (advocacy, education, research) available through Coalition membership.

Primary Facilitators: West Virginia Bureau for Public Health Comprehensive Cancer Control Program, Mountains of Hope, Appalachia Cancer Network, West Virginia CONSULT, NCI Cancer Information Service

5. Promote the mission and purpose of Mountains of Hope at conferences and in partner newsletters.

Primary Facilitators: West Virginia Bureau for Public Health Comprehensive Cancer Control Program, Mary Babb Randolph Cancer Center, West Virginia School of Osteopathic Medicine, Marshall University School of Medicine, Charleston Area Medical Center, American Cancer Society, Alderson-Broaddus College Physician Assistant Program, West Virginia Nurses Association, West Virginia Medical Association, West Virginia Chapter of the American College of Surgeons

6. Use data to convince potential partners of the need for involvement in cancer control.

Primary Facilitators: West Virginia Bureau for Public Health Comprehensive Cancer Control Program, West Virginia Cancer Registry, Mountains of Hope Research and Data Work Group

7. Reduce duplication of effort and maximize resources by collaborating and cosponsoring national cancer events (Breast Cancer Awareness Month, Great American Smoke-Out, National Minority Cancer Awareness Week) and state cancer events (Walks for Women, West Virginia Annual Oncology Conference).

Primary Facilitators: Appropriate Mountains of Hope subcommittees

8. Assess the cancer community's awareness of Mountains of Hope.

Primary Facilitators: West Virginia Bureau for Public Health Comprehensive Cancer Control Program, West Virginia Medical Association, West Virginia Hospital Association, West Virginia Chapter of the American College of Surgeons, North Central West Virginia Chapter of the Oncology Nursing Society, West Virginia Nurses Association

Objective II:

Build public support and interest in the Coalition and its work.

Strategies:

1. Use partners and the media to communicate to civic organizations and schools how Mountains of Hope goals and objectives will reduce the impact of cancer in West Virginia.

Primary Facilitator: Mountains of Hope, Public Affairs Network, American Cancer Society, Mary Babb Randolph Cancer Center, West Virginia Breast and Cervical Cancer Screening Program

2. Use the Mountains of Hope logo consistently in any Coalition-related communications.

Primary Facilitator: Mountains of Hope

3. Develop press releases to highlight members.

Primary Facilitator: West Virginia Bureau for Public Health Comprehensive Cancer Control Program, Mary Babb Randolph Cancer Center

4. Annually recognize and promote significant contributions by partners.

Primary Facilitator: Mountains of Hope Steering Committee

5. Assess the extent of the public's awareness of Mountains of Hope.

Primary Facilitators: West Virginia Bureau for Public Health Comprehensive Cancer Control Program, West Virginia University Prevention Research Center, West Virginia University Office of Health Services Research, Mary Babb Randolph Cancer Center

Goal II: Create an effective network of cancer control partners.

Objective I:

Assess the resources of the Coalition by creating a member directory, available also online. Identify the resources that members bring to the Coalition: expertise, skills, areas of interest, and linkages to other networks. Use members and nonmembers and local and national experts to build Coalition capacity.

Objective II:

Enhance the Coalition's capacity to identify cancer control priorities, develop appropriate strategies, identify benchmarks, process and outcome measures.

Strategies:

1. Invite national partners (Centers for Disease Control, National Cancer Institute, American Cancer Society, Intercultural Cancer Council, National Pain Initiative, Department of Defense, etc.) to participate in reviewing and evaluating plans and to provide technical assistance.

Primary Facilitators: Mountains of Hope, West Virginia Bureau for Public Health Comprehensive Cancer Control Program, Mary Babb Randolph Cancer Center, NCI Cancer Information Service, American Cancer Society, West Virginia Breast and Cervical Cancer Screening Program.

2. Build the capacity of Coalition members to participate in cancer control efforts, as needed.

Primary Facilitators: West Virginia Bureau for Public Health Comprehensive Cancer Control Program, West Virginia Breast and Cervical Cancer Screening Program, American Cancer Society, Mary Babb Randolph Cancer Center, NCI Cancer Information Service

3. Enlist partners outside the cancer community (librarians, anthropologists, coaches) who can contribute to cancer control efforts.

Primary Facilitator: Mountains of Hope

4. Invite cancer control investigators to focus on research that provides better data; that assesses the impact of culture, poverty and illiteracy on health; and that answers questions leading to decreased morbidity and mortality in West Virginia.

Primary Facilitators: West Virginia Bureau for Public Health Comprehensive Cancer Control Program, Mountains of Hope Research and Data Work Group, West Virginia Cancer Registry, West Virginia Breast and Cervical Cancer Screening Program, West Virginia University Prevention Research Center, West Virginia University Department of Community Medicine, Mary Babb Randolph Cancer Center.

5. Use data to determine program priorities; base education and communications on science; evaluate all efforts, processes and outcomes.

Primary Facilitators: West Virginia Bureau for Public Health Comprehensive Cancer Control Program, Mountains of Hope Research and Data Work Group, West Virginia University Prevention Research Center

Objective III:

Use the reach of the Coalition to recruit and train (Lay Helper Model) 200 grassroots volunteers, the "Mountains of Hope Volunteer Navigator Network," to provide the vital link between the work of the Coalition (education, dissemination, and advocacy) and our rural communities.

Primary Facilitators: West Virginia Bureau for Public Health Comprehensive Cancer Control Program, Mary Babb Randolph Cancer Center, Appalachia Cancer Network, West Virginia University Prevention Research Center, West Virginia Breast and Cervical Cancer Screening Program, American Cancer Society, NCI Cancer Information Service, West Virginia Rural Health Education Partnerships

Coordination of a Comprehensive Cancer Control Program References and Resources

Abed J, Reilly B, Butler MO, Kean T, Wong F, Hohman K. 2000. Developing a framework for comprehensive cancer prevention and control in the United States: An initiative of the Centers for Disease Control and Prevention. *Journal of Public Health Management and Practice* 6(2): 67-78.

Berkowitz B. 2000. Collaboration for health improvement: models for state, community, and academic partnerships. *Journal of Public Health Management and Practice* 6(1):67-72.

Friedell G, Rubio A, Maretzki A, Garland B, Brown P, Crane M, Hickman P. 2001. Community cancer control in a rural, underserved population: The Appalachia Leadership Initiative on Cancer project. *Journal of Health Care for the Poor and Underserved* 12(1):5-19.

Graffunder CM, Wyatt SW, Bewerse B, Hall I, Reilly B, Lee-Pethel R. 1999. Skin cancer prevention: the problem, responses, and lessons learned. *Health Education Behavior* 26(3): 308-316.

Himmelman AT. 1996. Collaboration and the three T's: time, trust and turf constraints. *Health Systems Leader* 3(10): 13-16.

Levine DM, Becker DM, Bone LR. 1992. Narrowing the gap in health status of minority populations. *American Journal of Preventive Medicine* 8(5):319-23.

Scott CM, Thurston WE. 1997. A framework for the development of community health agency partnerships. *Canadian Journal of Public Health* 88 (6): 416-420.

Thomsen C, Brady K, Brown P, Rolon L, Rubenstein L, Vanchieri C. An innovative model for partnership development at the national, state, and local levels: the CIS/CDC Breast and Cervical Cancer Outreach Demonstration Project. Report to CDC Cancer Prevention and Control.

Mountains of Hope recognizes that public and professional education is crucial to having a positive impact on health behavior.

III

Public and Professional Education

The long-term goals of the West Virginia Comprehensive Cancer Control Coalition are

- to reduce cancer incidence and mortality and prevent future increases
- to reduce barriers to accessing cancer control services and programs (national, state and local) and increase utilization of such services
- to increase cancer survival and
- to stimulate greater coordination and participation among cancer control programs and agencies.

Mountains of Hope recognizes that public and professional education, provided through strategic and effective training and outreach, is crucial to having a positive impact on health behavior. Through statewide education, the Coalition will expand cancer control awareness. Through outreach and cancer control activities, the Coalition will address the key barriers to utilization of cancer control services and access to optimal cancer care within the state.

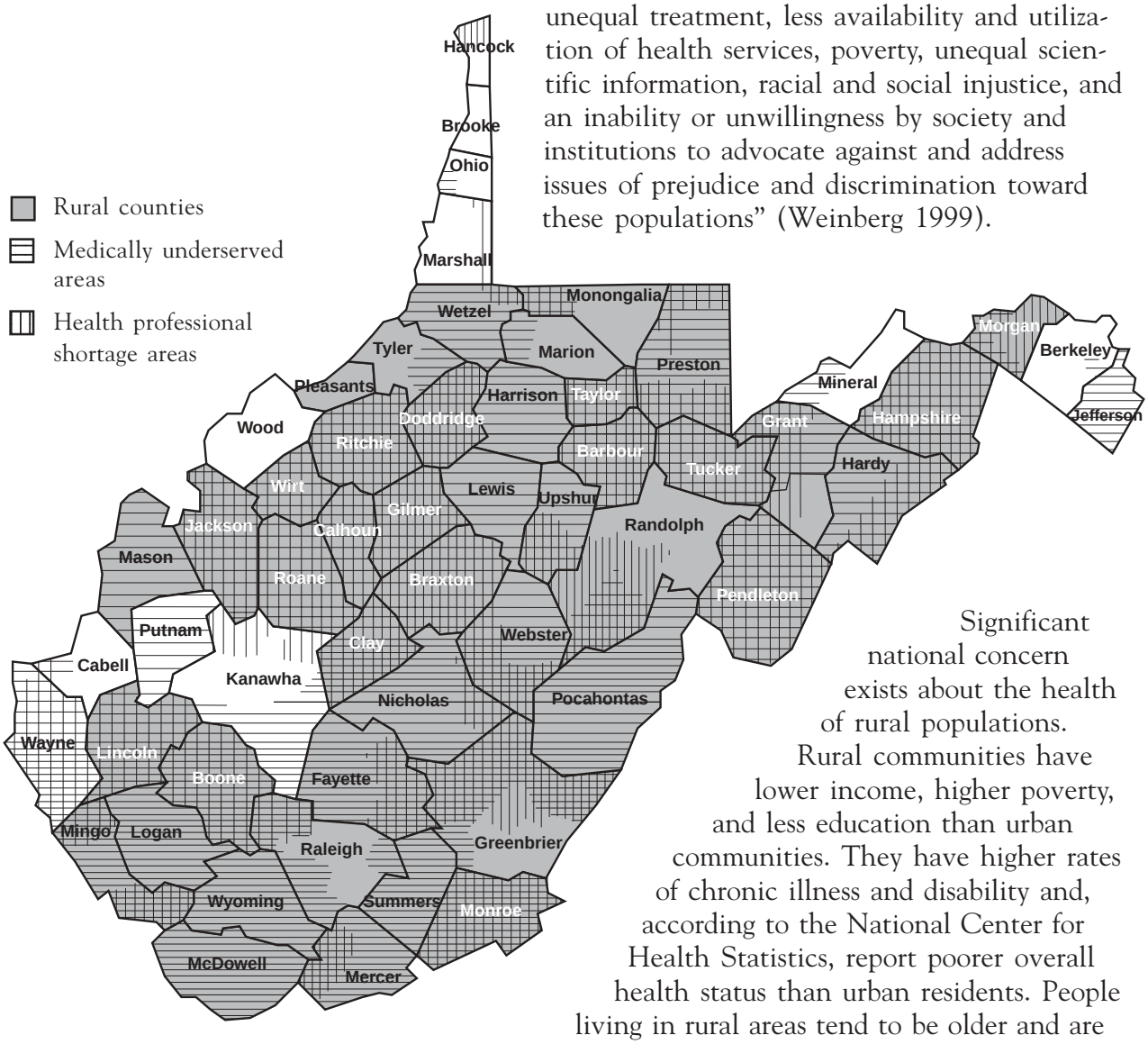
Specific education-related goals and objectives are identified within the "Prevention," "Early Detection," and "Patient Care and Survivorship" chapters. For the Public and Professional Education Plan, the Coalition has created overarching education "themes"—goals and objectives intended to guide the development of cancer control efforts that are directed toward people most in need of intervention. These goals and objectives take into consideration important characteristics of West Virginia: it is a predominantly rural state, and many of its residents are older and have limited income and education.

West Virginia: A "Special Population"

According to the Centers for Disease Control and Prevention, the National Cancer Institute, the American Cancer Society and the Intercultural Cancer Council (ICC), many

people in West Virginia are part of a "special population." When national cancer data show that certain populations within the United States have disproportionately high incidence rates or are at higher-than-average risk of death or prolonged illness, they are termed "special populations." For example, because of the persistent high cervical cancer mortality in Appalachia, the NCI Center for Health Disparities is developing a plan to conduct epidemiological and applied research on cervical cancer in this "special population."

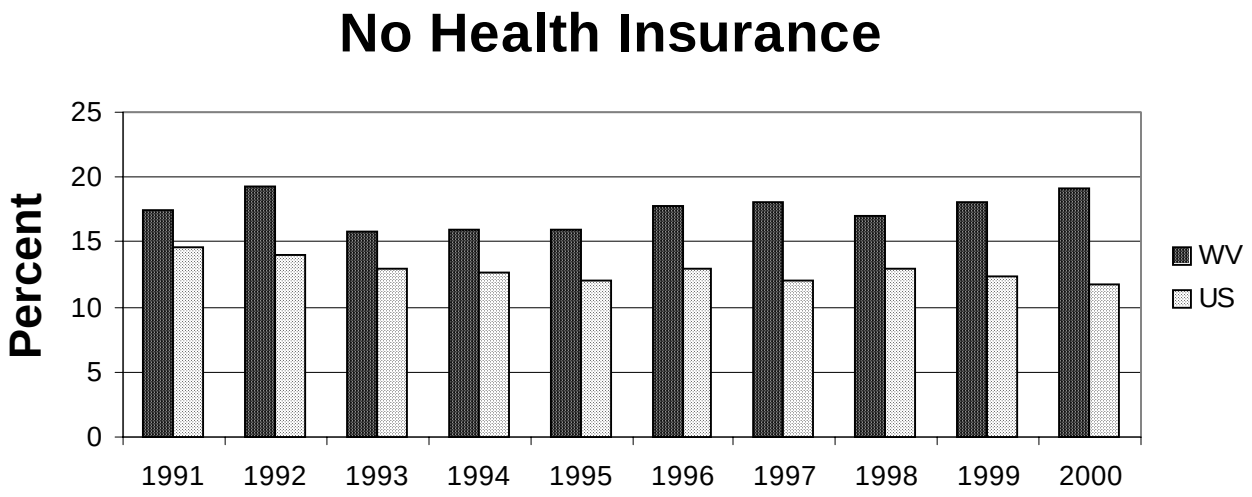
The "special population" designation changes as new data are examined but currently includes African Americans; Hispanics; American Indians; Asian Americans and Pacific Islanders; Alaskan Natives; the elderly; and rural, low-income, illiterate and underserved populations. Although genetics may be a contributing factor, most disparities are believed to relate to risk behaviors such as tobacco use and diet; underutilization of prevention, screening, treatment and rehabilitation services; lack of access to high-quality cancer-related services; and environmental exposures (Abrams 1997). The ICC goes further in stating that "the reasons for these inequalities include unequal treatment, less availability and utilization of health services, poverty, unequal scientific information, racial and social injustice, and an inability or unwillingness by society and institutions to advocate against and address issues of prejudice and discrimination toward these populations" (Weinberg 1999).



Significant national concern exists about the health of rural populations. Rural communities have lower income, higher poverty, and less education than urban communities. They have higher rates of chronic illness and disability and, according to the National Center for Health Statistics, report poorer overall health status than urban residents. People living in rural areas tend to be older and are

more likely to be uninsured. West Virginia ranks fifth in the nation in the percent of the population over the age 65. Recently released U.S. Census figures, show there are 268,897 West Virginians (15 percent of the state's population) at 65 years of age or older, a small increase over the past decade. It is no surprise that in 1993, West Virginia ranked second among the 50 states in percent of its population enrolled in Medicare, 17.3 percent compared to 13.8 percent nationally.

Because of the large proportion of low-income families, underinsured workers, and medically underserved people living in rural areas, rural populations are considered a special population (Portnoy 1994). According to U.S. Census Bureau estimates, West Virginia is the second most rural state in the nation, with 64 percent of its population living in communities of less than 2,500 population. Categorized by population density, 43 (or 78 percent)



BRFSS data (accessed April 2002):
http://apps.nccd.cdc.gov/brfss/index.asp

of its 55 counties have a rural designation. More than 18 percent of the population lives below the Federal Poverty Level. It ranked 48th out of 50 states in personal income per capita (1995) and 5th among the states in percent of population below the poverty level (1994). The total unemployment rate in 1997 was 6.3 percent.

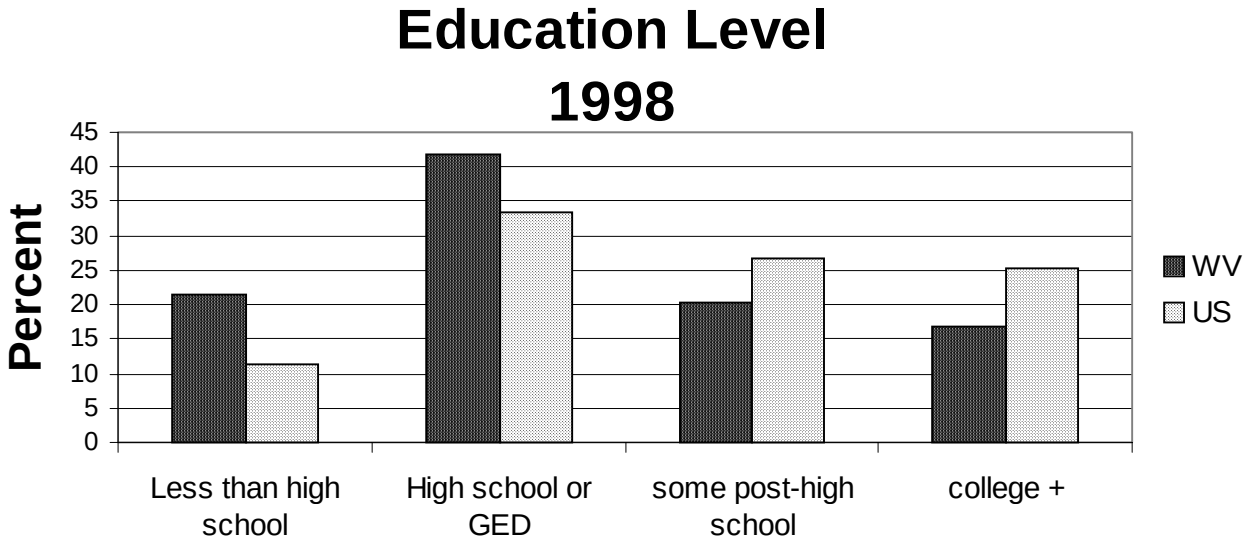
Physician shortages in rural areas have troubled West Virginia for more than two decades. Almost 30 percent of the state's population does not have access to a primary care provider; in 1998 there were 122 unfilled requests for primary care physicians for rural underserved areas (West Virginia Rural Health Plan 1998). Over one-half of the state is officially designated by the U.S. Department of Health and Human Services (DHHS) as medically underserved and Health Profession Shortage Areas. Residents of rural areas often have fewer visits with healthcare providers and lower levels of preventive care (Harris 1993). Nineteen counties in the state (35 percent) do not have any community hospital facilities. Public transportation and other community services are not always available in rural areas, which makes access to cancer control programs and services more difficult (Friedell 2001).

People are considered functionally competent when their literacy skills permit them to fully function in society. The 27 million people in this country who cannot read above a 5th grade level cannot fully function in society. They cannot read most health information—information about dosage, drug interactions and dietary restrictions—not to mention informed consent. People with low literacy skills may have limited comprehension skills; they may miss the context and be unable to make inferences from written or spoken communications (Doak 1996).

In the last decade, national health organizations have become increasingly aware of the impact of literacy on health care and health costs. According to a recent national study, approximately 27 million American adults, almost one out of five, read at a 5th grade level or below. Among Americans aged 65 and older, almost two out of five read below the 5th grade level. The average reading level among adults in the United States is between 8th and 9th grade (Kirsh 1993).

Health professionals are often unaware that a substantial number of their patients may be poor readers. People with limited literacy skills may lack the confidence and self-esteem necessary to navigate through the increasingly complex healthcare system. Low literacy may contribute to noncompliance, errors in treatment, and poor outcomes. Studies show that average healthcare costs are significantly higher for individuals who cannot read well (Weiss 1998).

According to 1999 census data, approximately 36 percent of West Virginians 25 years of age or older did not graduate from high school. Almost 22 percent of the population did not attend school beyond 8th grade. In the most rural West Virginia counties, as much as 60 percent of the population 25 and older did not graduate from high school, and as much as



BRFSS data (accessed April 2002):
http://apps.nccd.cdc.gov/brfss/index.asp

32 percent of the population did not attend high school. But years of schooling is not a proxy for literacy; it does not define an acquired reading level. Surveys have shown that, currently, adults read three to five grades lower than the years of schooling completed. And, as adults with limited reading skills age, they lose some of the skills they once had (Doak 1980). These statistics imply that as many as 40-50 percent of West Virginians may have difficulty reading at an 8th grade level, and 20-30 percent of our residents may be functionally illiterate.

Mountains of Hope has the infrastructure and organizational capacity to disseminate knowledge about scientific advances to reach and benefit the population. Coalition members will work with community leaders to incorporate cultural beliefs and attitudes in a focus on prevention and risk behaviors. Working with organizations, agencies and individuals that are trusted by the community is critical to effective promotion and implementation of education programs and services.

Throughout the Comprehensive Cancer Control Plan, the Coalition has identified goals, objectives and strategies that reflect the challenges that make cancer control in West Virginia unique. This plan is intended to reach many aging, poor, isolated and uneducated people who engage in risky health behaviors. The West Virginia Comprehensive Cancer Control Coalition will coordinate the efforts of the Prevention, Early Detection and Patient Care and Survivorship subommittees to design, implement and evaluate scientifically based cancer education activities that reflect the culture of West Virginia and that will advance our state's cancer control objectives.

Public Education Goals and Objectives

Four-Year Goal: Increase relevant and effective public and patient education programs.

Goal I: Create a Web-based West Virginia Resource Guide for the public and patients; include information on how to access services and programs related to early detection, diagnosis and treatment, public education, support for survivors, end-of-life care, and other reliable cancer information.

Objective:

Create a geographically diverse Mountains of Hope Resource Work Group.

Strategies:

1. Assess existing resources and program guides to identify what information should be included in the West Virginia Resource Guide to improve community and patient access to cancer information resources and services.

Primary Facilitators: West Virginia Bureau for Public Health, Appalachia Cancer Network, American Cancer Society, West Virginia Cancer Registry, NCI Cancer Information Service, Mountains of Hope Steering Committee

2. Develop a dissemination plan to make the resource guide accessible to all communities.

Primary Facilitator: Mountains of Hope Steering Committee

Community Linkages: Mountains of Hope Volunteer Navigator Network, Appalachia Cancer Network Community Coalitions, West Virginia Breast and Cervical Cancer Screening Program Cancer Information Specialists

Goal II: Educate the public about cancer prevention, early detection, and patient care and survivorship.

Objective:

Provide relevant and effective public and patient education programs.

Strategies:

1. Involve community representatives, patients, and survivors in all phases of the education process.

Primary Facilitators: West Virginia Bureau for Public Health, Mountains of Hope, Appalachia Cancer Network, American Cancer Society, West Virginia University Extension Service, West Virginia Breast and Cervical Cancer Screening Program, West Virginia Rural Health Education Partnerships, North Central West Virginia Chapter of the Oncology Nursing Society

Community Linkages: West Virginia Health Promotion Specialists, Benedum Community Cancer Education Programs, public health nurses, Mountains of Hope Volunteer Navigator Network, Appalachia Cancer Network Community Coalitions, West Virginia Breast and Cervical Cancer Screening Program Cancer Information Specialists, Health Rights, Health Sciences and Technology Academy

2. Increase understanding of how West Virginia's history, culture and beliefs affect health behavior.

Primary Facilitators: West Virginia University Prevention Research Center, Appalachia Cancer Network, West Virginia Bureau for Public Health, West Virginia Library Commission and West Virginia University, Mary Babb Randolph Cancer Center, Charleston Area Medical Center, West Virginia School of Osteopathic Medicine, Alderson-Broaddus College, Marshall University

Community Linkages: See Strategy 1

3. Choose topics for public and patient education programs by using West Virginia Cancer Registry data to identify needs for education and information.

Primary Facilitators: West Virginia Cancer Registry, Mountains of Hope, West Virginia Bureau for Public Health, Mary Babb Randolph Cancer Center, American Cancer Society, West Virginia Breast and Cervical Cancer Screening Program, Medicare, West Virginia Medical Institute

Community Linkages: See Strategy 1

4. Assess public and patient cancer education programs currently underway and identify programmatic gaps that correspond to Mountains of Hope priorities.

Primary Facilitators: Mountains of Hope, American Cancer Society, West Virginia Bureau for Public Health, Mary Babb Randolph Cancer Center, NCI Cancer Information Service, Charleston Area Medical Center, Appalachia Cancer Network, Oncology Nursing Society, AARP West Virginia, West Virginia University Center on Aging, Mountains of Hope Cancer Prevention Subcommittee, Mountains of Hope Early Detection Subcommittee, Mountains of Hope Patient Care and Survivorship Subcommittee, West Virginia Breast and Cervical Cancer Screening Program, YWCA EncorePlus, Susan G. Komen Breast Cancer Foundation

Community Linkages: See Strategy 1

5. Assess and maximize available resources for public and patient education.

Primary Facilitators: West Virginia Bureau for Public Health, Mountains of Hope, Mary Babb Randolph Cancer Center, American Cancer Society, West Virginia Breast and Cervical Cancer Screening Program, Susan G. Komen Breast Cancer Foundation, EncorePlus, Mountains of Hope Cancer Prevention Subcommittee, Mountains of Hope Early Detection Subcommittee, Mountains of Hope Patient Care and Survivorship Subcommittee, and private companies with a presence in West Virginia such as Nextel, Union Carbide/Dow Chemical Company, Wendy's

*Community Linkages:*See Strategy 1

6. Develop or adapt education programs that are theory-based.

Primary Facilitators: West Virginia Bureau for Public Health, Mary Babb Randolph Cancer Center, West Virginia University Prevention Research Center, West Virginia University Department of Community Medicine

Community Linkages: See Strategy 1

7. Invite researchers to participate in developing assessments and conducting cancer communications research.

Primary Facilitators: West Virginia Bureau for Public Health, Mountains of Hope, Mary Babb Randolph Cancer Center, West Virginia University Prevention Research Center, NCI Cancer Information Service, Charleston Area Medical Center, West Virginia University Department of Community Medicine, Marshall University Joan C. Edwards School of Medicine, West Virginia School of Osteopathic Medicine

Community Linkages: See Strategy 1

8. Ensure that education programs are culturally appropriate.

Primary Facilitators: Community Representatives, Appalachia Cancer Network, West Virginia Coalition for Minority Health, Office of Minority Health, West Virginia University Center on Aging, West Virginia Breast and Cervical Cancer Screening Program, NCI Cancer Information Service, American Cancer Society

*Community Linkages:*See Strategy 1

9. Develop or adapt public and patient education programs that will reach minorities, people with limited income and education, older people, and those who reside in very rural areas.

Primary Facilitators: Mountains of Hope, Mary Babb Randolph Cancer Center, Appalachia Cancer Network, NCI Cancer Information Service, American Cancer Society, West Virginia Minority Cancer Coalition, Office of Minority Health, Literacy Volunteers of America—West Virginia, West Virginia University Center on Aging, AARP West Virginia, West Virginia State College, Marshall University, West Virginia Rural Health Education Partnerships, YWCA EncorePlus, Mountains of Hope Cancer Prevention Subcommittee, Mountains of Hope Early Detection Subcommittee, Mountains of Hope Patient Care and Survivorship Subcommittee, private companies with a presence in West Virginia such as Walmart, Family Dollar Stores, Toyota

Community Linkages: See Strategy 1

10. Identify new partnership opportunities through the education process.

Primary Facilitators: Mountains of Hope, West Virginia Bureau for Public Health, Mary Babb Randolph Cancer Center, Appalachia Cancer Network, West Virginia Breast and Cervical Cancer Screening Program

Community Linkages: See Strategy 1

11. Improve community access to reliable cancer information resources and services.

Primary Facilitators: American Cancer Society, NCI Cancer Information Service, Appalachia Cancer Network, West Virginia Breast and Cervical Cancer Screening Program, West Virginia University Extension Service, West Virginia University School of Pharmacy

*Community Linkages:*See Strategy 1

12. Incorporate "new technology" into cancer education programs.

Primary Facilitators: West Virginia Bureau for Public Health, West Virginia CONSULT, West Virginia MDTV, West Virginia Rural Health Education Partnerships, West Virginia Library Commission

Community Linkages: See Strategy 1

13. Evaluate public and patient education programs to determine changes in audience knowledge, attitude and behavior.

Primary Facilitators: West Virginia Bureau for Public Health, Mountains of Hope, West Virginia University Prevention Research Center, Mary Babb Randolph Cancer Center, West Virginia University Office of Health Services Research, West Virginia Cancer Registry

Community Linkages: See Strategy 1

14. Present and publish on successes and "lessons learned."

Primary Facilitator: Mountains of Hope Research and Data Work Group

Community Linkages: See Strategy 1

15. Create a repository for public education models, materials, modules, training tools, and other information and resources.

Primary Facilitator: Mountains of Hope

Community Linkages: See Strategy 1

Professional Education Goals, Objectives and Strategies

Four-Year Goal: Increase relevant and effective professional education.

Goal I: Ensure that the Web-based resource guide includes appropriate information for health professionals.

Goal II: Encourage healthcare providers to offer patients and the public accurate, up-to-date information and services related to cancer prevention, early detection, and patient care and survivorship.

Objective:

Provide relevant and effective professional education opportunities.

Strategies:

1. Increase the participation of health professionals in Mountains of Hope.

Primary Facilitators: Mountains of Hope Medical Advisory Committee, West Virginia Medical Association, North Central West Virginia Chapter of the Oncology Nursing Society, West Virginia Chapter of the American College of Surgeons, American College of Obstetrics and Gynecologists, West Virginia Board of Pharmacy, West Virginia Health Care Association, Mary Babb Randolph Cancer Center, Charleston Area Medical Center, Marshall University School of Medicine, West Virginia School of Osteopathic Medicine, Alderson-Broaddus College Physician Assistant Program, College of West Virginia

2. Increase understanding of how West Virginia's history, culture and beliefs affect health behavior.

Primary Facilitators: West Virginia University Prevention Research Center, Appalachia Cancer Network, West Virginia Bureau for Public Health, West Virginia Library Commission, West Virginia University, Charleston Area Medical Center, West Virginia School of Osteopathic Medicine, Marshall University and Alderson-Broaddus College Physicians Assistant Program, College of West Virginia

3. Choose topics for professional education programs based on needs for education and information identified by West Virginia Cancer Registry data.

Primary Facilitators: West Virginia Cancer Registry, Medicare, West Virginia Public Employees Insurance Agency, West Virginia Breast and Cervical Cancer Screening Program, Coalition for a Tobacco Free West Virginia, Mountains of Hope Cancer Prevention Subcommittee, Mountains of Hope Early Detection Subcommittee, Mountains of Hope Patient Care and Survivorship Subcommittee, American Cancer Society, West Virginia Medical Institute

4. Assess patterns of care in West Virginia.

Primary Facilitators: West Virginia Cancer Registry, West Virginia Medical Association, West Virginia Chapter of the American College of Surgeons, West Virginia Cooperative Community Oncology Groups, West Virginia University School of Medicine, Marshall University Joan C. Edwards School of Medicine, Charleston Area Medical Center, West Virginia School of Osteopathic Medicine, West Virginia Bureau for Public Health

5. Identify gaps in cancer prevention, early detection services, diagnosis, and treatment, especially in minority and very rural communities.

Primary Facilitators: West Virginia Cancer Registry, West Virginia Bureau for Public Health, West Virginia Breast and Cervical Cancer Screening Program, American Cancer Society, Mountains of Hope Medical Advisory Subcommittee, Mountains of Hope Cancer Prevention Subcommittee, Mountains of Hope Early Detection Subcommittee, Mountains of Hope Patient Care and Survivorship Subcommittee, West Virginia Office of Minority Health, West Virginia Rural Health Education Partnerships

6. Assess and maximize available resources for professional education.

Primary Facilitators: Mountains of Hope Medical Advisory Subcommittee, Mountains of Hope Cancer Prevention Subcommittee, Mountains of Hope Early Detection Subcommittee, Mountains of Hope Patient Care and Survivorship Subcommittee, West Virginia University School of Medicine, Marshall University Joan C. Edwards School of Medicine, Charleston Area Medical Center, Alderson-Broaddus College, West Virginia School of Osteopathic Medicine, College of West Virginia, private companies with a presence in West Virginia such as Mylan Pharmaceutical and Purdue Pharma L.P.

7. Involve patients and their families in developing and reviewing professional education programs and materials.

Primary Facilitators: Community Representatives, Appalachia Cancer Network, American Cancer Society, North Central West Virginia Chapter of the Oncology Nursing Society

8. Incorporate topics related to culture and communications into medical school and other health professions curricula.

Primary Facilitators: West Virginia University School of Medicine, West Virginia University School of Nursing, West Virginia University School of Pharmacy, West Virginia School of Dentistry, Marshall University Joan C. Edwards School of Medicine, Charleston Area Medical Center, West Virginia School of Osteopathic Medicine, Alderson-Broaddus College Physician Assistant Program, College of West Virginia

9. Encourage minority and rural science students to enter the health professions.

Primary Facilitators: Appalachia Cancer Network, West Virginia University School of Medicine, Marshall University Joan C. Edwards School of Medicine, Charleston Area Medical Center, West Virginia School of Osteopathic Medicine, Health Sciences & Technology Academy, West Virginia Rural Health Education Partnerships

10. Improve provider access to reliable cancer information resources and services.

Primary Facilitators: NCI Cancer Information Service, American Cancer Society, West Virginia Rural Health Education Partnerships, Appalachia Cancer Network, Mountains of Hope

11. Incorporate current technologies into professional education and provider communications.

Primary Facilitators: West Virginia Bureau for Public Health, West Virginia CONSULT, West Virginia MDTV, West Virginia Library Commission

12. Evaluate professional education programs to determine changes in audience knowledge, attitude and behavior.

*Primary Facilitators:*West Virginia Bureau for Public Health, West Virginia Breast and Cervical Cancer Screening Program, Mountains of Hope, West Virginia University Prevention Research Center, Mary Babb Randolph Cancer Center, West Virginia University Office of Health Services Research

13. Present and publish on successes and "lessons learned."

Primary Facilitator: Mountains of Hope Research and Data Work Group

14. Create a repository for professional education models, materials, modules, training tools, and other items and information.

Primary Facilitator: Mountains of Hope

Public and Professional Education References

Abrams DB. 1997. Cancer Control Review Group Report to NCI Director Richard Klausner.

Doak CC, Doak LG, Root JH. 1996. *Teaching patients with low literacy skills*. 2nd edition, JB Lippincott 2-9.

Doak LG, Doak CC. 1980. Patient comprehension profiles. Recent findings and strategies. *Patient Counseling and Health Education* 2(3):101-106.

Friedell GH, Maretzki A, Garland B, Brown P, Crane M, Hickman P. Feb 2001. Community cancer control in a rural, underserved population: the Appalachia Leadership Initiative on Cancer Project. *Journal of Health Care for the Poor and Underserved*. Meharry Medical College 12(1):5-17.

Harris R, Leininger L. Aug 1, 1993. Preventive care in rural primary practice. *Cancer*. 72:113-18.

Portnoy B. 1994. Healthy people in rural areas by the year 2000. In: Couto RA, Simpson NK, Harris G, eds. *Sowing seeds in the mountains: community-based Coalitions for cancer prevention and control*. NIH, National Cancer Institute, Pub No. 94-3779:102-119.

Weinberg A D, Iammarino, NK. Nov 1999. Unequal burden, unequal data: registries help close the gap. *Journal of Registry Management* 26(4):122-123.

Weiss B, Coyne C, Michielutte R, Davis T, Meade C, Doak L, Doak C, Brown P et al. 1998. Communicating with patients who have limited literacy skills: report of the National Work Group on Literacy and Health. *Journal of Family Practice* 46:168-176.

West Virginia Rural Health Plan. 1998. WV Rural Hospital Flexibility Program. West Virginia Office of Rural Health Policy.

Possibly 80 percent of all cancers could be avoided if exposure to risk factors were eliminated or reduced.

IV

Prevention

The primary challenge for public health in West Virginia is to develop cancer prevention programs and strategies that will

- eliminate the excess cancer morbidity and mortality present in our state and
- reduce risk throughout all segments of our population.

According to National Institutes of Health (NIH) estimates, cancer continues to place an enormous financial burden on society. The NIH estimates total annual costs for cancer at $180.2 billion, with $60 billion for direct medical costs (total of all health expenditures), $15 billion for morbidity costs (cost of lost productivity due to illness), and $105.2 billion for indirect mortality costs (cost of lost productivity due to premature death) (American Cancer Society 2001).

Cancer continues to impose a costly burden on West Virginians. Each year from 1993 through 1998, over 9,000 residents of the Mountain State were diagnosed with the disease (Cancer in West Virginia 1993-1998). This heavy burden is made even more devastating because so many cancers may be preventable (Weinstein 1985). The literature suggests that if these cancers were prevented, average Americans could significantly extend their lifespan (Cole 1994).

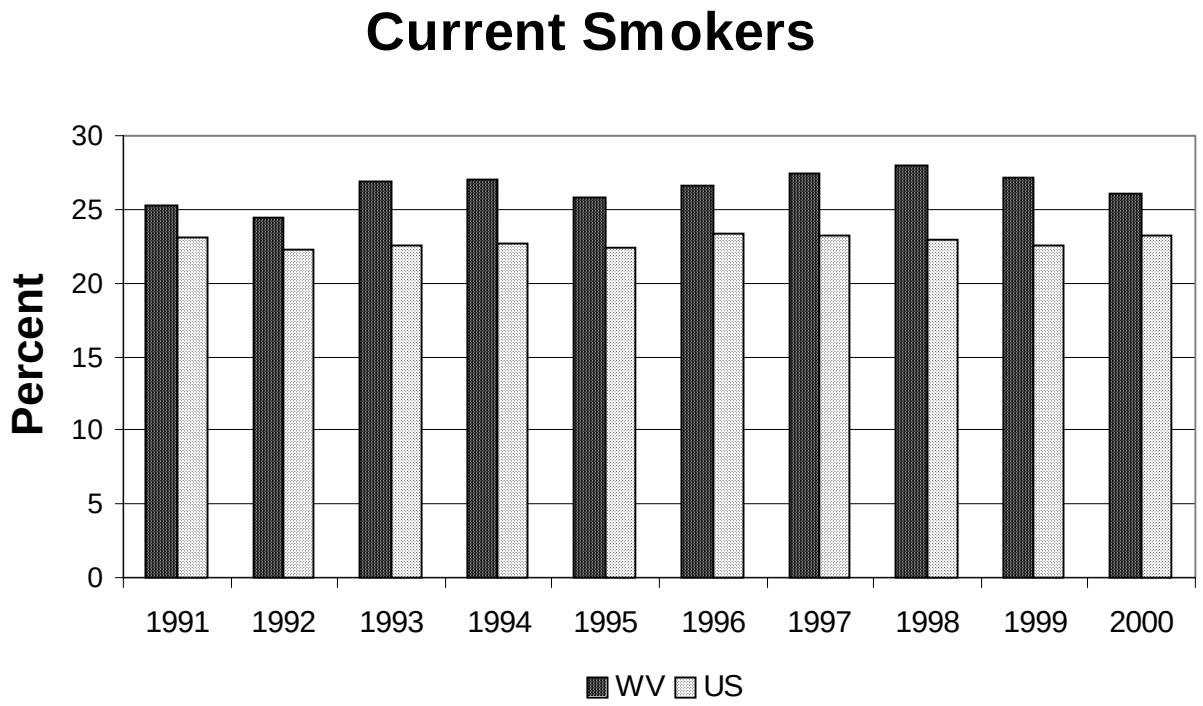
Possibly 80 percent of all cancers could be avoided if exposure to risk factors were eliminated or reduced (Weinstein 1985). Risk factors for cancer include tobacco, alcohol, diet and nutrition, food additives, reproductive and sexual behavior, occupation, pollution, industrial products, medicines and medical procedures, radiation and ultraviolet light, and infection. Prevention of approximately 65 percent of all cancers may be achieved by eliminating use of all tobacco products and by understanding how diet can either increase or decrease cancer risk (Swanson 1996). According to I-Min Lee, ScD at Brigham & Women's Hospital and Harvard Medical School, "Two of the important avoidable causes of cancer are cigarette smoking and alcohol consumption. If we totally eliminated these two factors, perhaps one-third of all cancers might be avoided. In the search for other modifiable aspects of human behavior that potentially may reduce risk of developing cancer, physical activity emerges as a promising candidate."

Mountains of Hope seeks to reduce the incidence of cancer in West Virginia. In order to accomplish this, the Coalition encourages West Virginians to make healthy lifestyle choices and actively seeks to limit the harm that rampant poverty, illiteracy, and other negative socioeconomic and cultural forces may cause. The Coalition has made cancer prevention a priority by focusing attention upon several critical risk factors: exposure to ultraviolet radiation, tobacco use, poor or inadequate diet, and sedentary lifestyle. The selection of these risk factors was based on data from the West Virginia Cancer Registry describing the disease burden and current lifestyle choices prevalent in our population. An examination of each of these factors will help the Coalition and its partners identify gaps in related services, activities and resources and enable them to develop strategies for improving cancer prevention and control.

Tobacco Use

Each year from 1993-1998 on average 1,841 West Virginians were diagnosed with cancers of the lung and bronchus. This number accounts for almost one in every five invasive cancers diagnosed in West Virginia residents, making them the state's most commonly diagnosed cancers (Cancer in West Virginia 2001). Accounting for approximately one of every three cancer deaths, in 1997, cancers of the lung and bronchus remained the leading cause of cancer-related deaths.

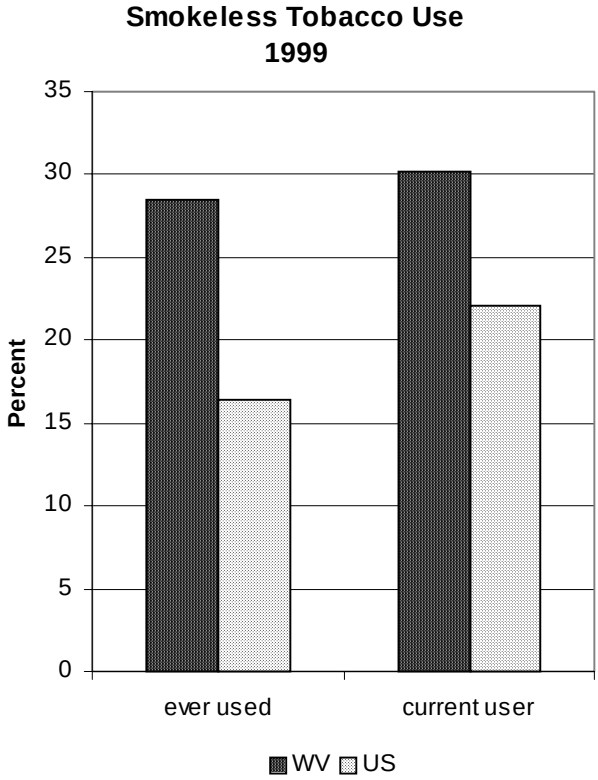
By state-specific data (1993-1997), West Virginia ranks sixth highest for men and fourth highest for women in age-adjusted mortality for cancers of the lung and bronchus



BRFSS data (accessed April 2002):
http://apps.nccd.cdc.gov/brfss/index.asp

among the 50 states and the District of Columbia. Mortality rates for both men and women were over 20 percent higher than national rates. Lung and bronchial cancers are the primary contributors to West Virginia's having an all-site cancer mortality rate higher than the U.S. average.

During the past decade (1990-99) the number of estimated adult smokers in West Virginia has ranged from a low of 329,587 in 1992 to a high of 386,716 in 1998. The most recent estimate is 375,747 smokers in 1999.



BRFSS data (accessed April 2002):
http://apps.nccd.cdc.gov/brfss/index.asp

According to the CDC, approximately 80 percent of adult smokers started smoking before the age of 18. Underage smoking rates remain at historically high levels; over the past ten years the number of U.S. youth under the age of 18 who have started smoking each year has increased by more than 70 percent (The Toll of Tobacco in West Virginia 2000). West Virginia continues to have one of the highest rates of youth tobacco use and cigarette smoking (Big Tobacco vs. Our Kids 1999). According to West Virginia's 1999 Youth Risk Behavior Survey (YRBS) results, 74.7 percent of students in grades 9-12 had tried cigarette smoking; 42.2% admitted to having smoked cigarettes in the past 30 days; and 33.7 percent admitted to having smoked their first cigarette before the age of 13. In relation to smokeless tobacco use, 15.7 percent of youth reported using chewing tobacco or snuff on one or more of the past 30 days.

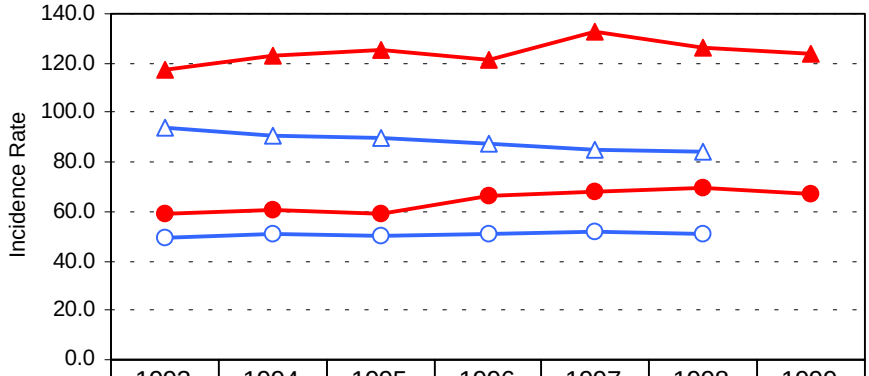
The National Cancer Institute has conducted over 15 years of research on strategies to reduce the number of cancer deaths attributable to tobacco in this country (Strategies to Control Tobacco Use in the United States 1991). Recognizing the importance of environmental factors in smoking behavior has lead to broadening tobacco control strategies to include community-based interventions within the healthcare system, schools and worksites. These interventions are designed to affect public opinion on tobacco use and health.

School-based prevention and intervention programs can reduce cigarette and smokeless tobacco use and initiation in school-age children. Unfortunately, such programs are usually of short duration, sporadic in nature, and utilize a traditional teaching model. Combining innovative programs with alternative methods of reaching the underage population can increase the potential impact on health issues.

Cancer of the Lung & Bronchus

Incidence Rates*, Age-Adjusted

West Virginia Residents 1993 - 1999, U.S. Residents 1993 - 1998



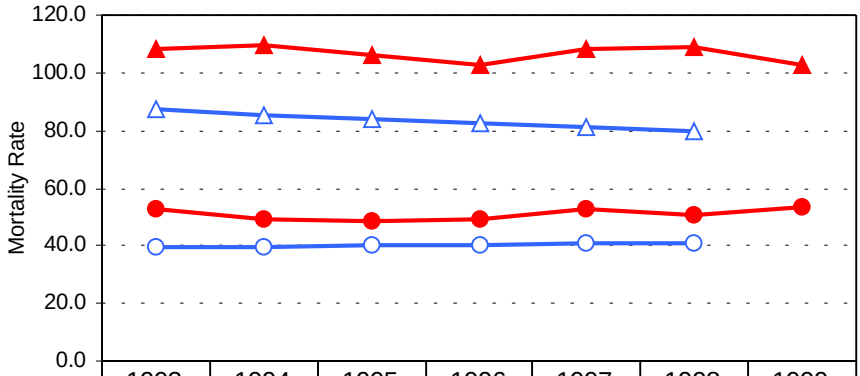
	1993	1994	1995	1996	1997	1998	1999
WV Males	117.1	122.7	125.5	121.4	132.9	126.5	123.7
US Males	94.0	90.9	89.8	87.3	85.0	84.2	
WV Females	59.4	60.6	58.7	66.0	67.9	69.2	67.1
US Females	49.2	50.6	50.5	51.0	52.0	50.9	

*Rates are per 100,000 and are age-adjusted to the 2000 U.S. standard population.
U.S. rates were calculated using SEER*Stat Version 4.0.9.

Cancer of the Lung & Bronchus

Mortality Rates*, Age-Adjusted

West Virginia Residents 1993 - 1999, U.S. Residents 1993 - 1998



	1993	1994	1995	1996	1997	1998	1999
WV Males	107.9	109.7	106.1	102.9	108.4	109.2	103.0
US Males	87.3	85.3	84.0	82.5	81.2	79.9	
WV Females	52.6	49.3	48.9	49.0	52.6	50.9	53.6
US Females	39.4	39.7	40.3	40.5	40.9	41.2	

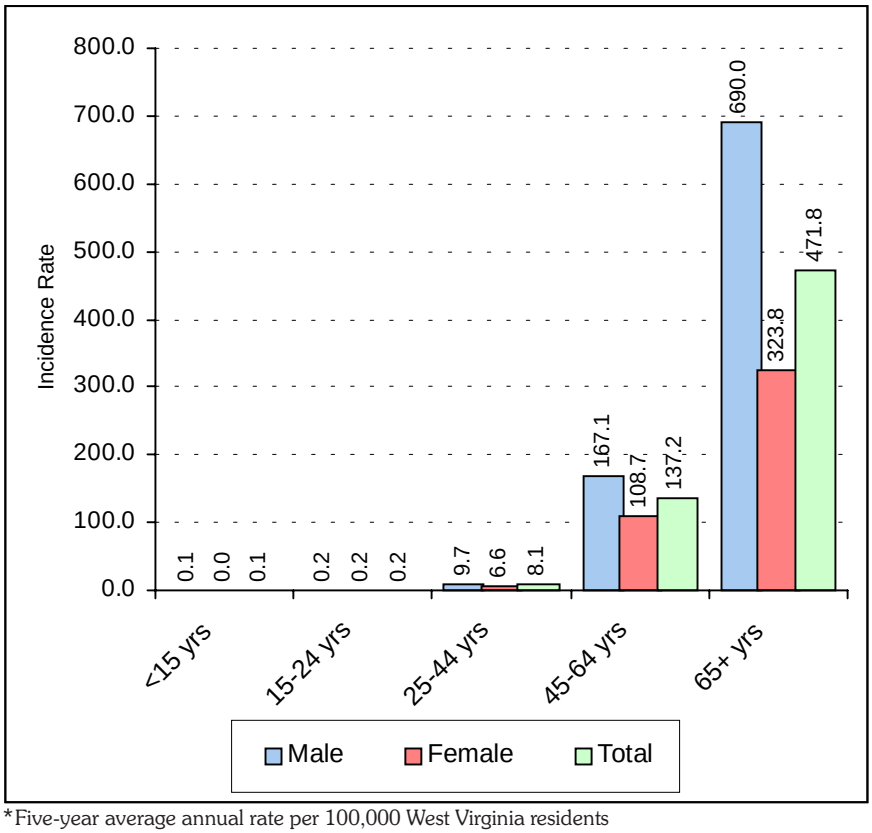
*Rates are per 100,000 and are age-adjusted to the 2000 U.S. standard population.
U.S. rates were calculated by the West Virginia Department of Health and Human Resources, Health Statistics Center, using National Center for Health Statistics mortality data.

Charts courtesy of *Cancer in West Virginia: Incidence and Mortality 1993-1999*. April 2002. West Virginia Department of Health and Human Resources. Charleston, WV

Cancer of the Lung & Bronchus

Incidence Rates*, Age-Specific

West Virginia Residents 1995 - 1999



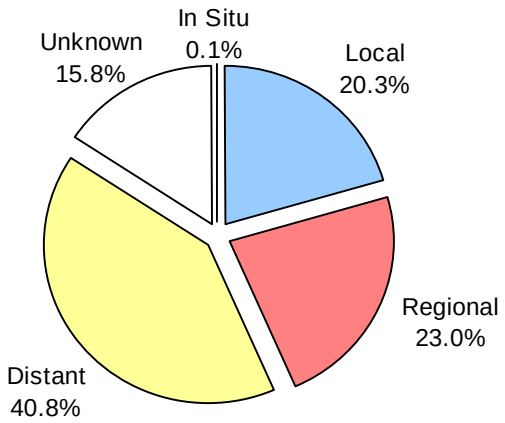
*Five-year average annual rate per 100,000 West Virginia residents

Charts courtesy of *Cancer in West Virginia: Incidence and Mortality 1993-1999*. April 2002. West Virginia Department of Health and Human Resources. Charleston, WV

Cancer of the Lung & Bronchus

Stage of Disease at Diagnosis

West Virginia Residents 1995 - 1999



Self-reported data from the Behavioral Risk Factor Surveillance Survey (BRFSS) indicate that adult smokers account for approximately two-thirds of the cigarette consumption in the state. The number of adult smokers (who smoke daily) who reported smoking a pack or more of cigarettes (20^{+} cigarettes) per day decreased slightly between 1990 and 1999, from an estimated 248,681 in 1990 to an estimated 204,289 in 1999. The estimated number of smokers who smoke two or more packs of cigarettes a day decreased from 58,242 in 1990 to 43,903 in 1999.

Since 1991, the BRFSS has asked the question "During the past 12 months, have you quit smoking for one day or longer?" The percentage of smokers who responded "yes" has ranged from a low of 41 percent in 1995 to a high of 53 percent in 1999, indicating an interest in smoking cessation among approximately half of adult smokers over each year of the decade. Clearly there are numerous opportunities to make a difference.

The West Virginia Bureau for Public Health (WVBPH) is committed to reducing the impact of tobacco and related products on West Virginians. Its Division of Health Promotion coordinates the Coalition for a Tobacco-Free West Virginia. This coalition has developed public education interventions and has successfully advocated for policy changes to reduce tobacco use and exposure to environmental tobacco smoke (ETS). The bureau has also established a youth-centered tobacco prevention program with support from the CDC and the American Legacy Foundation. This program focuses on reducing the number of young West Virginians who currently smoke as well as limiting the number of young people who would join their ranks.

Over the past several years, the WVBPH has provided leadership and technical assistance to groups wishing to promote local clean indoor air regulations. To date, 43 of West Virginia's 55 counties have adopted such regulations through their local boards of health.

The Prevention Research Center (PRC) at West Virginia University has developed interventions with grade school children who are at risk for smokeless tobacco use. In 1998, the PRC developed a program for school coaches and a primary prevention program for high risk youth called CHOICES. In 1996 the West Virginia University Prevention Research Center created a new program called "Not on Tobacco" (NOT) to assist high school students to quit tobacco use; this program will become a nationwide model with endorsement from the American Lung Association.

The Mary Babb Randolph Cancer Center (MBRCC) at West Virginia University has had considerable experience in conducting education programs that promote healthy lifestyles. In 1999, Project ASSIST, a National Cancer Institute-American Cancer Society partnership, funded a collaborative effort with the West Virginia Extension Service to develop a Tobacco Awareness Program to reach West Virginia youth attending summer 4-H camps, as well as extension agents and 4-H volunteers who often are tobacco users themselves.

Tobacco Cessation Goals and Objectives

Four-Year Goal: Decrease the rate of tobacco use among West Virginians of all ages and support those who want to quit using tobacco.

Objective I:

Collaborate with the Coalition for a Tobacco-Free West Virginia, the West Virginia Bureau for Public Health Tobacco Prevention Program, the American Lung Association, and the West Virginia University Prevention Research Center, NOT and the Mary Babb Randolph Cancer Center to support and enhance current programs and efforts.

Strategies:

1. Reduce the prevalence of cigarette smoking among pregnant women.

2. Increase smoking cessation during pregnancy, so that at least 60 percent of women who are cigarette smokers at the time they become pregnant quit smoking early in their pregnancy and maintain abstinence for the remainder of their pregnancy, following delivery, and through postpartum.

3. Increase to at least 80 percent the healthcare providers who routinely advise cessation and provide assistance, follow-up, and document charts for all their tobacco-using patients. Providers to include physicians, dentists, nurses, dental hygienists, mental health professionals, social workers, psychologists, pharmacists, medical assistants, physician assistants, and home healthcare aides.

4. Train people who have given up tobacco to provide peer-to-peer outreach and education in their schools and communities.

Primary Facilitator: West Virginia Bureau for Public Health, Mountains of Hope Coalition, American Cancer Society, American Lung Association, Coalition for a Tobacco-Free WV, local tobacco prevention coalitions

Community Linkages: All Coalition members

Objective II:

Use members of the Mountains of Hope Volunteer Navigator Network (VNN) to provide cessation counseling, support to those attempting to quit, and education outreach in their communities.

Strategies:

1. Work with local businesses to participate in counter-marketing efforts.

2. Provide education on second-hand smoke.

3. Increase worksite sponsorship of smoking cessation programs.

4. Establish community-based cessation and counseling centers in each county.

Primary Facilitators: West Virginia Bureau for Public Health, Mountains of Hope Coalition, American Cancer Society, American Lung Association, Coalition for a Tobacco-Free WV, local tobacco prevention coalitions

Community Linkages: Mountains of Hope Volunteer Navigator Network

Objective III:
Reduce smokeless tobacco use.

Strategies:

1. Reduce smokeless tobacco use among youth in grades 9-12.

2. Reduce the prevalence of smokeless tobacco use among adult men.

Primary Facilitators: West Virginia Bureau for Public Health, American Cancer Society, Mary Babb Randolph Cancer Center Tobacco Research Center, West Virginia University Prevention Research Center, Appalachia Cancer Network, Mountains of Hope, West Virginia Board of Education

Community Linkages: West Virginia University Extension Service, public health nurses, Mountains of Hope Volunteer Navigator Network

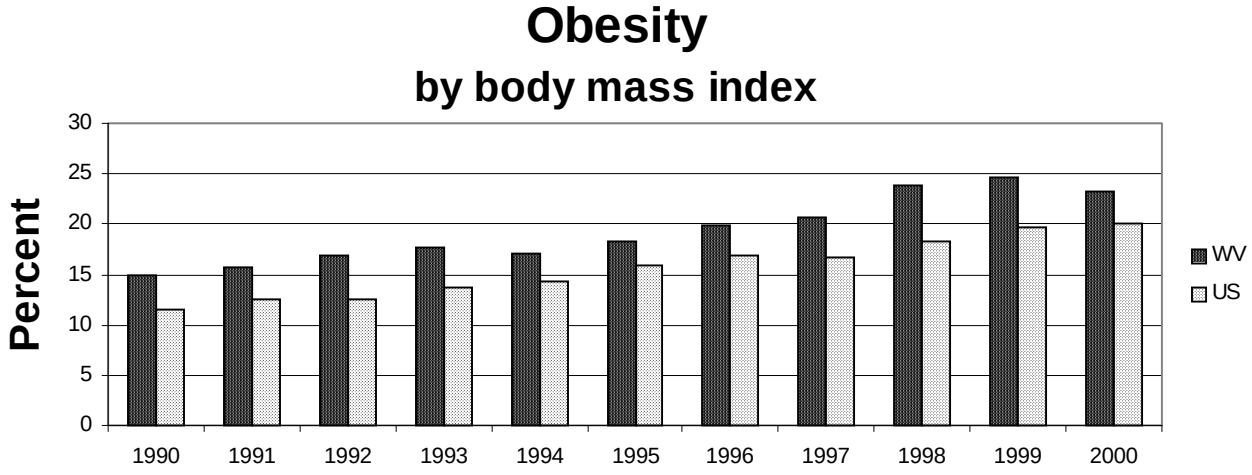
Diet and Nutrition

Crosscultural and epidemiological studies indicate some 35 percent of cancer deaths may be related to nutritional factors (Centers for Disease Control 1999). Evidence suggests that high-fat diets may contribute to cancers of the colon, uterus, and prostate. Obesity may contribute to cancers of the prostate, pancreas, uterus, colon and ovary and may also contribute to breast cancer in older women. Also, several studies conducted by the American Cancer Society have demonstrated an association between excess weight and an increased risk of mortality from certain cancers. For example, the ACS Cancer Prevention Study found that obese women with cancer have 55 percent greater mortality than nonobese women.

Much recent research has found that eating a healthy diet—low in fat and high in fiber—that includes plenty of vegetables and fruits may help to lower some cancer risk

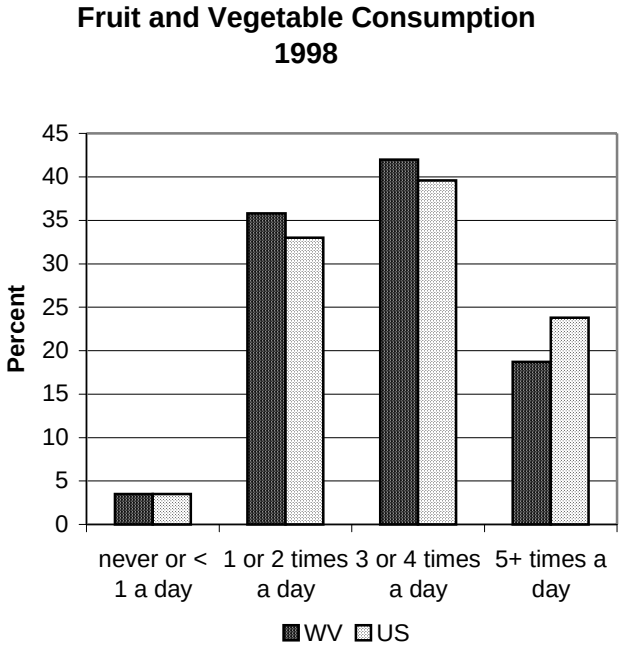
(National Cancer Institute 1997). Some experts believe that, after tobacco use, the most important modifiable determinants of cancer risk are dietary choices and physical activity.

Some people have heard the message and have begun to make changes in their eating behaviors, choosing to eat, cook, and serve healthier foods; however, most people still eat too much fat and not enough vegetables and fruits. In addition, there are individuals who are confused by the sometimes conflicting recommendations for wise food choices.



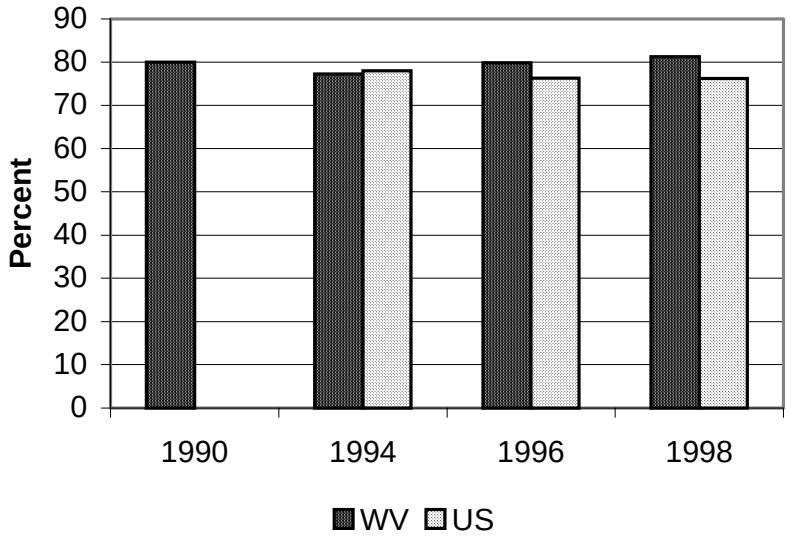
BRFSS data (accessed April 2002):
http://apps.nccd.cdc.gov/brfss/index.asp

The 5-A-Day for Better Health Program is a national, theory-based program that uses a simple approach with a consistent message: eat five or more servings of fruit and vegetables daily as part of a low-fat, high-fiber diet (Heimendinger 1996). Like the Mountains of Hope collaborative approach, the commitment of significant public and private partnerships was essential to the development and integration of the 5-A-Day Program into community life. The 5-A-Day strategy incorporates a variety of approaches including media, education, community organization, and food system changes. The program's message appeals to a broad audience with its positive focus on enhancing consumer skills. Mountains of Hope will build on the 5-A-Day structure already operating in our state to reinforce and expand on the success and visibility of this program.



BRFSS data (accessed April 2002):
http://apps.nccd.cdc.gov/brfss/index.asp

Fewer than Five Servings of Fruit and Vegetables a Day



BRFSS data (accessed April 2002):
http://apps.nccd.cdc.gov/brfss/index.asp

The BRFSS dataset has no nationwide data for 1990.

According to the 1998 BRFSS, West Virginians measured 10th worst in consumption of vegetables and fruits among those responding. Eighty percent of West Virginians reported eating fewer than five servings of vegetables and fruits per day; 77.2 percent of high school students reported eating fewer than five servings of vegetables and fruits. In addition 32.9 percent of West Virginia adults are overweight (based on rates per 100,000 population).

Diet and Nutrition Goals and Objectives

Four-Year Goal: Increase to 35 percent the proportion of people age 18 and older who consume at least five servings of vegetables and fruits per day and increase to 75 percent the proportion of people aged 18 and older who consume less than 10 percent of total calories from saturated fat.

Objective:

Help West Virginians make healthier food choices.

Strategies

1. Based on the 5-A-Day strategy, continue collaboration with food store personnel to design and implement healthy eating programs and promotions in grocery stores.

Primary Facilitators: West Virginia Bureau for Public Health, Mountains of Hope Prevention Subcommittee, Mary Babb Randolph Cancer Center, Appalachia Cancer Network, American Cancer Society, West Virginia University School of Pharmacy, Wellness Council

of West Virginia, West Virginia Media Association, Kroger, Giant Eagle, Shop and Save, United Farm Workers, Healthy West Virginia Coalition, West Virginia University Extension Service, West Virginia Chamber of Commerce

Community Linkages: Benedum Community Cancer Education Programs, West Virginia Health Promotion Specialists, pharmacists, West Virginia Women's Clubs, West Virginia University Extension agents, Community Education Outreach Specialists (CEOS)

2. Collaborate with worksites to encourage programs that promote healthy eating and provide healthy choices in worksite cafeterias.

Primary Facilitators: West Virginia Bureau for Public Health, Mountains of Hope Prevention Subcommittee, Wellness Council of West Virginia, Healthy West Virginia Coalition, West Virginia University Extension Service

Community Linkages: West Virginia University Extension Agents, public health nurses, cafeteria management, employees

3. Provide education on diet and nutrition for children and work with schools to provide healthy foods in cafeterias.

Primary Facilitators: West Virginia Bureau for Public Health, Mountains of Hope Prevention Subcommittee, Wellness Council of West Virginia, Healthy West Virginia Coalition, West Virginia University Extension Service, West Virginia Board of Education

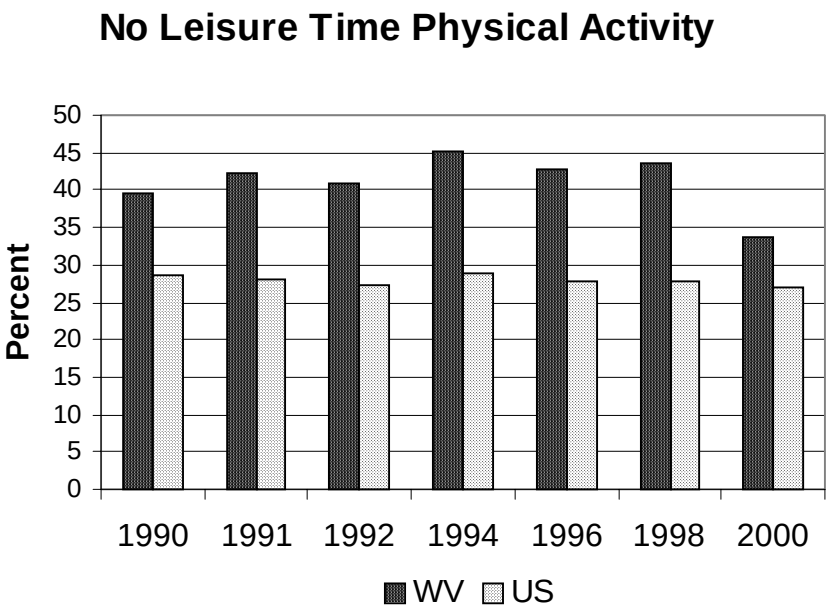
Community Linkages: Public school nurses, health education teachers, physical education teachers, Wetzel County Cancer Coalition Natural Lay Helpers Nutrition and Physical Activity Education Program, 4-H Clubs, West Virginia Boy Scouts, West Virginia Girl Scouts, Future Farmers of America Clubs, West Virginia University Extension Agents

Physical Activity

The incidence of some cancers can be reduced by engaging in regular, moderate to intense physical activity and by maintaining lean body weight. Physical activity can help protect against some cancers, either by balancing caloric intake with energy expenditure or by other mechanisms. An imbalance of caloric intake and output can lead to overweight, obesity, and increased risk for cancers in several sites: colon and rectum (Potter 1996), prostate (Kolonel 1996), endometrium (Hill 1996), breast—among postmenopausal women (Hunter 1996), and kidney (Wolk 1996).

These findings are supported by animal studies and epidemiologic research that have demonstrated an association between physical activity and a reduced risk of developing some cancers (Albanes 1990). For breast and prostate cancer, physical activity may act through

effects on hormone levels (Shephard 1993; Friedenreich 1995). For colon cancer, physical activity stimulates movement through the bowel, thereby reducing the length of time that the bowel lining is exposed to potential 0mutagens.



BRFSS data (accessed April 2002): http://apps.nccd.cdc.gov/brfss/index.asp

Both physical activity and controlled caloric intake are necessary to achieve or to maintain a healthy body weight (Weighing the Options 1995). The CDC, the American College of sports Medicine (Pate 1995), an NIH Consensus Conference (Physical Activity and Cardiovascular Health 1996) and the US Surgeon General (Physical Activity and Health 1996) recommend 30 minutes of moderate physical activity each day as a means to promote health.

Nationally, it appears that there is an epidemic of inactivity, with up to 60 percent of adults getting little or no physical activity. Historically, West Virginia has ranked high for a sedentary lifestyle. The 1996 BRFSS reports that 67.6 percent of the population maintains a sedentary lifestyle. The general trend has been upward, from 60.7 percent in 1984 to 67.6 percent in 1996.

Physical Activity Goals and Objectives

Four-Year Goal:	**Decrease the sedentary lifestyle of West Virginians and increase public knowledge about the association of physical activity and cancer risks.**

Objective:

Help West Virginians increase physical activity.

Strategies:

1. Explore the development of incentives for new residential areas to provide trail systems in and around their properties.

Primary Facilitators: West Virginia Bureau for Public Health, Mountains of Hope Prevention Subcommittee, Mary Babb Randolph Cancer Center, Appalachia Cancer Network, American Cancer Society, Wellness Council of West Virginia, West Virginia Media Association, United Farm Workers, Healthy West Virginia Coalition, West Virginia University Extension Service, West Virginia Chamber of Commerce

Community Linkages: Benedum Community Cancer Education Programs, West Virginia Health Promotion Specialists, West Virginia Women's Clubs, West Virginia University Extension Agents, Community Education Outreach Specialists (CEOS)

2. Collaborate with worksites to provide trail systems on their properties and encourage onsite programs that promote physical activity.

Primary Facilitators: West Virginia Bureau for Public Health, Mountains of Hope Prevention Subcommittee, Wellness Council of West Virginia, Healthy West Virginia Coalition, West Virginia University Extension Service

Community Linkages: West Virginia University Extension Agents, public health nurses

3. Mandate daily physical education K-12 in public and private schools and develop funding to place a qualified physical education specialist in every school.

Primary Facilitators: West Virginia Bureau for Public Health, Mountains of Hope Prevention Subcommittee, Wellness Council of West Virginia, Healthy West Virginia Coalition, West Virginia University Extension Service, West Virginia Board of Education

Community Linkages: Public school nurses, health education teachers, physical education teachers, Wetzel County Cancer Coalition Natural Lay Helpers Nutrition and Physical Activity Education Program, 4-H Clubs, West Virginia Boy Scouts, West Virginia Girl Scouts, Future Farmers of America Clubs, West Virginia University Extension Agents

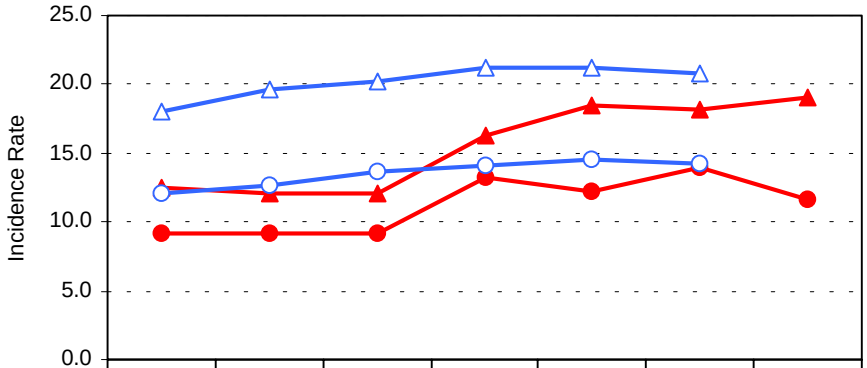
Exposure to Ultraviolet Radiation

Exposure to the sun's ultraviolet rays appears to be the most important environmental risk factor in developing skin cancer. Melanoma is the most serious form of skin cancer, and since 1973 its incidence has been increasing at a faster rate than any other cancer. At the present time, the lifetime risk for melanoma in the United States is one in 75. Most skin cancers appear after age 50, but generally the sun's damaging effects begin at an early age. Raising awareness and educating West Virginians about how to protect themselves against inappropriate exposure to ultraviolet rays, beginning at an early age, would prevent many melanomas and other skin cancers (American Cancer Society 2001).

Melanoma of the Skin

Incidence Rates*, Age-Adjusted

West Virginia Residents 1993 - 1999, U.S. Residents 1993 - 1998



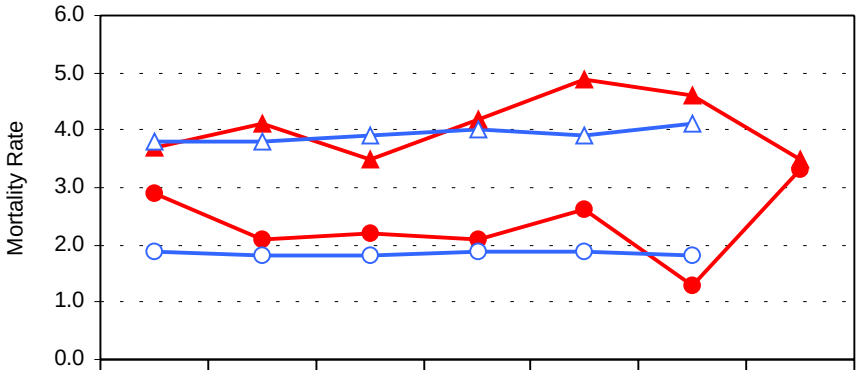
	1993	1994	1995	1996	1997	1998	1999
WV Males	12.5	12.1	12.1	16.3	18.4	18.1	19.1
US Males	18.0	19.6	20.2	21.2	21.2	20.8	
WV Females	9.2	9.1	9.1	13.2	12.2	13.9	11.6
US Females	12.0	12.7	13.6	14.1	14.6	14.2	

*Rates are per 100,000 and are age-adjusted to the 2000 U.S. standard population.
U.S. rates were calculated using SEER*Stat Version 4.0.9.

Melanoma of the Skin

Mortality Rates*, Age-Adjusted

West Virginia Residents 1993 - 1999, U.S. Residents 1993 - 1998



	1993	1994	1995	1996	1997	1998	1999
WV Males	3.7	4.1	3.5	4.2	4.9	4.6	3.5
US Males	3.8	3.8	3.9	4.0	3.9	4.1	
WV Females	2.9	2.1	2.2	2.1	2.6	1.3	3.3
US Females	1.9	1.8	1.8	1.9	1.9	1.8	

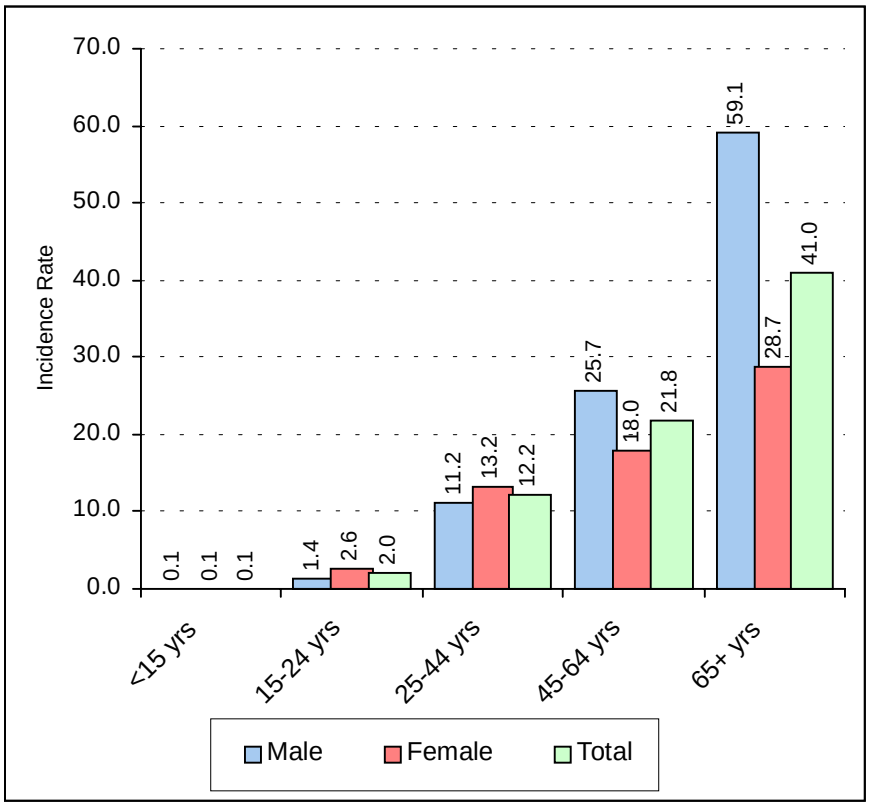
*Rates are per 100,000 and are age-adjusted to the 2000 U.S. standard population.
U.S. rates were calculated by the West Virginia Department of Health and Human Resources, Health Statistics Center, using National Center for Health Statistics mortality data.

Charts courtesy of *Cancer in West Virginia: Incidence and Mortality 1993-1999*. April 2002. West Virginia Department of Health and Human Resources. Charleston, WV

Melanoma of the Skin

Incidence Rates*, Age-Specific

West Virginia Residents 1995 - 1999



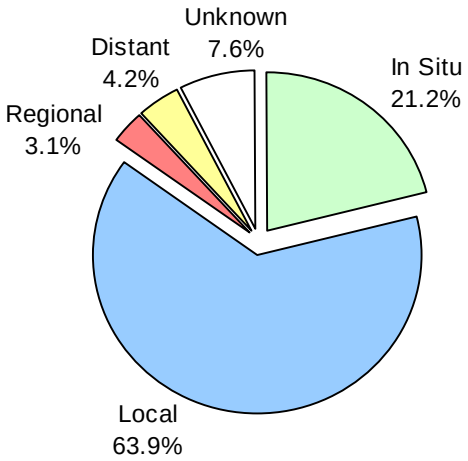
*Five-year average annual rate per 100,000 West Virginia residents

Charts courtesy of *Cancer in West Virginia: Incidence and Mortality 1993-1999*. April 2002. West Virginia Department of Health and Human Resources. Charleston, WV

Melanoma of the Skin

Stage of Disease at Diagnosis

West Virginia Residents 1995 - 1999



Exposure to Ultraviolet Radiation Goals and Objectives:

Four-Year Goal:	**Decrease ultraviolet radiation exposure among West Virginians and decrease the number of persons who will experience sunburn with redness over 12 hours within the past 12 months.**

Objective:

Increase awareness about ultraviolet radiation exposure and skin cancer.

Strategies:

1. Assess public awareness about skin cancer, especially melanoma.

Primary Facilitators: West Virginia Bureau for Public Health, Mountains of Hope Prevention Subcommittee, Mary Babb Randolph Cancer Center, West Virginia University Prevention Research Center, Appalachia Cancer Network, American Cancer Society, West Virginia University Extension Service

Community Linkages: West Virginia Primary Care Association, Appalachia Cancer Network Community Coalitions, Benedum Community Cancer Education Programs, Mineral County Health Department Community Cancer Education Program, Planned Approach to Community Health, Family Resource Networks, home health nurses, Wirt County Cancer Education Program

2. Educate the public, children in elementary schools and their parents about protection from the sun and skin cancer, especially melanoma.

Primary Facilitators: Mountains of Hope Prevention Subcommittee, West Virginia Bureau for Public Health, West Virginia University Prevention Research Center, Mary Babb Randolph Cancer Center, Appalachia Cancer Network, American Cancer Society, West Virginia University Extension Service, West Virginia Department of Education, West Virginia Department of Parks and Recreation, West Virginia Association of Dermatology, West Virginia Fish and Game Licensing Board, West Virginia Rural Health Association, West Virginia Office of Rural Health Policy, West Virginia Health Care Association, Office of Minority Health

Community Linkages: Rural representatives, West Virginia Primary Care Association, Appalachia Cancer Network Community Coalitions, Benedum Community Cancer Education Programs, Family Dollar Stores, Wendy's, West Virginia public school nurses, West Virginia University Department of Family Medicine, public health nurses, certified day care facilities, West Virginia Chapter of the American Academy of Pediatrics, Planned Approach to Community Health, Family Resource Networks, West Virginia University Extension Agents, West Virginia Boy Scouts, West Virginia Girl Scouts, 4-H Clubs, Future Farmers of America Clubs, Tri-County Cancer Outreach for Prevention and Support (Grant, Hardy,

Pendleton) and McDowell County Cancer Coalition, West Virginia Health Right, YWCA EncorePlus, county farm bureaus, PATCH/TEACH coalitions

3. Increase the number of healthcare providers who counsel their patients on the dangers of ultraviolet rays.

Primary Linkages: West Virginia Bureau for Public Health Community Health Promotion, Mountains of Hope Prevention Subcommittee, Mary Babb Randolph Cancer Center, Appalachia Cancer Network, American Cancer Society, West Virginia Association of Dermatology, West Virginia University Department of Family Medicine, Charleston Area Medical Center, Marshall University Medical Center, West Virginia School of Osteopathic Medicine, West Virginia Medical Association, West Virginia University School of Nursing, West Virginia University School of Pharmacy

Community Linkages: West Virginia Primary Care Association, Appalachia Cancer Network Community Coalitions, public health nurses, certified day care facilities, West Virginia Chapter of the American Academy of Pediatrics, West Virginia Rural Health Education Partnerships, county health departments

Cancer Prevention References and Resources

5-A-Day. 1997. National Cancer Institute. NIH Publication No 95-3735.

Albanes D. 1990. Energy balance, body size, and cancer. *Critical Reviews in Oncology/Hematology* 10:283-303.

Big Tobacco vs Our Kids: Where West Virginia Draws the Line, 1999. Coalition for Tobacco Free West Virginia, West Virginia Hospital Association, West Virginia Youth Tobacco Prevention.

Cancer Facts and Figures. 2000. American Cancer Society.

Cancer Facts and Figures. 2001. American Cancer Society.

The Toll of Tobacco in West Virginia. 2000. Campaign for Tobacco Free Kids State Tobacco Settlement Special Report.

Cancer in West Virginia: Incidence and Mortality 1993-1998. 2001. West Virginia Cancer Registry. West Virginia Department of Health and Human Resources, Division of Surveillance and Disease Control.

Chronic Diseases and Their Risk Factors: the nation's leading causes of death. 1999. Centers for Disease Control and Prevention.

Cole P, Amoateng-Adjepong Y. 1994. Cancer prevention: accomplishments and prospectus. *American Journal of Public Health* 84:8-10.

Friedenreich CM, Rohan TE. 1995. A review of physical activity and breast cancer. *Epidemiology* 6:311-317.

Heimendinger J, Duyn MA, Chapelsky SF, Stables G. 1996. The National 5 A Day for Better Health Program: a large-scale nutrition intervention. *Journal of Public Health Management and Practice* 27-35.

Hill HA, Austin H. 1996. Nutrition and endometrial cancer. *Cancer Causes Control*. 7:19-32.

Kolonel LN. 1996. Nutrition and prostate cancer. *Cancer Causes Control* 7:83-94.

Pate RR, Pratt M, Blair SN, et al. 1995. Physical activity and the public health: A recommendation from the Centers for Disease control and Prevention and the American College of Sports Medicine. *Journal of the American Medical Association* 273:402-407.

Physical activity and cardiovascular health. 1996. NIH Consensus Development Panel on Physical Activity and Cardiovascular Health. *Journal of the American Medical Association* 276:241-246.

Physical Activity and Health: A Report of the Surgeon General. 1996. US Department of Health and Human Services. Centers for Disease Control and Prevention, Atlanta, Ga. National Center for Chronic Disease Prevention and Health Promotion. President's Council on Physical Fitness and Sports.

Potter JD. 1996. Nutrition and colorectal cancer. *Cancer Causes Control* 7:127-146.

Hunter DJ, Willett, WC. 1996. Nutrition and breast cancer. *Cancer Causes Control* 7:56-68.

Ries LAG, Eisner MP, Kosary CL, Hankey BF, Miller BA, Clegg L, Edwards BK (eds.). 2000. *SEER Cancer Statistics Review: 1973-1997*. National Cancer Institute. Bethesda, MD.

Shephard RJ. 1993. Exercise in the prevention and treatment of cancer: An update. *Sport Medicine* 15:258-280.

Strategies to Control Tobacco Use in the United States: A Blueprint for Public Health Action in the 1990's. October 1991. Smoking and Tobacco Control Monographs 1 (298 pages). National Cancer Institute.

Swanson GM. 1996. Cancer prevention and control: A Science-Based Public Health Agenda. *Journal of Public Health Management and Practice* 2(2):1-8.

Weighing the Options: Criteria for Evaluating Weight-Management Programs. 1995. Institute of Medicine (Washington, DC: National Academy Press).

Weinstein JB, Santella RM, Perera G. 1985. Molecular biology and epidemiology of cancer in *Cancer Prevention and Control*, Greenwald P, Kramer BS, Weed DL, eds. Marcel Decker, Inc.

Wolk A, Lindblad P, Adami H-O. 1996. Nutrition and renal cell cancer. *Cancer Causes Control* 7:5-18.

The plan seeks to raise awareness about and encourage adherence to authoritative early detection protocols.

V

Early Detection

Numerous studies have found that early detection saves lives and increases patient treatment options, particularly for breast, cervical, and colorectal cancers. Growing evidence also points to a potential impact of early detection on the management of prostate cancer.

The West Virginia Comprehensive Cancer Control Plan promotes public and professional awareness of recommended screening guidelines, a cornerstone of early detection policy. It also encourages consensus building on controversial issues such as developing a unified message regarding prostate cancer screening and the potential role the Coalition may play in assisting patients who face discrimination or loss of health insurance because of their diagnosis.

Mountains of Hope endorses the philosophy that screening guidelines are not meant to replace individual clinician judgments. The screening recommendations referenced in the plan pertain to the general population; those at higher risk should discuss their individual needs and concerns with a healthcare provider.

Although impressive evidence exists to support the benefits of early detection regimens in affecting some cancers, universal adoption of screening methods remains an elusive goal. Individuals give many reasons for not adhering to early detection guidelines, including their lack of knowledge about screening recommendations, financial concerns, fear of cancer and its sequelae, access and time issues, embarrassment in undergoing some screening procedures, and misperceptions about personal risk. Another reason patients often cite for not undergoing a particular screening procedure is the lack of a recommendation by their healthcare provider (Schapira 1993). In order to address these and other barriers, the West Virginia Comprehensive Cancer Control Plan targets both the public and professional sectors with strategies to raise awareness about and encourage adherence to recommended early detection protocols.

Breast Cancer

Cancer of the breast is the most commonly diagnosed cancer among West Virginia women, almost twice as common, according to 1993-1998 West Virginia Cancer Registry data, as any other malignancy. During each of those years, approximately 1,250 Mountain State women were diagnosed with the disease, while approximately 325 died annually of invasive breast cancer.

During this same time period, the West Virginia Cancer Registry reports cancer of the breast was the leading cause of cancer-related deaths among West Virginia women aged 25 to 44. For West Virginia women over 45 years of age, it was second only to lung cancer. The incidence of female breast cancer increases markedly with age. West Virginia women aged 45-64 were more than four times more likely to be diagnosed with the disease than were those aged 25-44; West Virginia women aged 65 and older were almost eight times more likely to contract the disease than their younger counterparts.

According to state-specific, age-adjusted data for 1993-97, West Virginia ranked 39th (7 percent below the national rate) in breast cancer mortality. However, according to the West Virginia Cancer Registry, this difference was not statistically significant. While the state as a whole ranks below national breast cancer incidence and mortality rates, the table below demonstrates that breast cancer mortality rates, relative to incidence, are disproportionately high among many of West Virginia's most rural counties (Cancer in West Virginia 1999).

West Virginia Counties and the Unequal Burden of Breast Cancer on the Rural Poor

	Incidence	Mortality	Mortality/Incidence
U.S.	110.6	25.2	0.23
WV	94.4	23.1	0.24
Barbour	75.6	29.4	0.39
Clay	92.3	31.1	0.34
Calhoun	87.9	45.4	0.52
Gilmer	78.7	40.0	0.51
Lincoln	87.3	34.6	0.39
Mason	79.4	30.8	0.39
Mineral	109.4	32.1	0.30
Monroe	76.8	29.1	0.38
Nicholas	86.0	30.4	0.35
Summers	79.9	27.9	0.35
Wirt	108.7	37.2	0.34

The average population in these counties is approximately 16,000. All but one of these 11 counties are designated as Medically Underserved Areas (Rural Health Plan 2001). In addition, these counties have lower incomes and greater unemployment rates than their urban counterparts and their illiteracy rates run as high as 60 percent, especially among their older residents (U.S. Census 2000). All of these counties evidence the health-related disparities that contribute to the unequal burden of cancer on the rural poor as cited by the CDC, NCI, ICC, ACS and others.

Mammography can identify breast cancers too small to palpate on physical examination; it can also find ductal carcinoma in situ (DCIS) (Breast cancer screening: PDQ). Numerous uncontrolled trials and retrospective series have documented the capacity of mammography to diagnose small, early-stage breast cancers, which have a favorable clinical course (Moody-Ayers 2000).

Clinical Breast Examination is another important component of early detection. As part of a routine physical examination, the healthcare provider should conduct a clinical breast exam to check for lumps or other unusual changes that may not be detected by the patient or by other screening methods (Porter 1999).

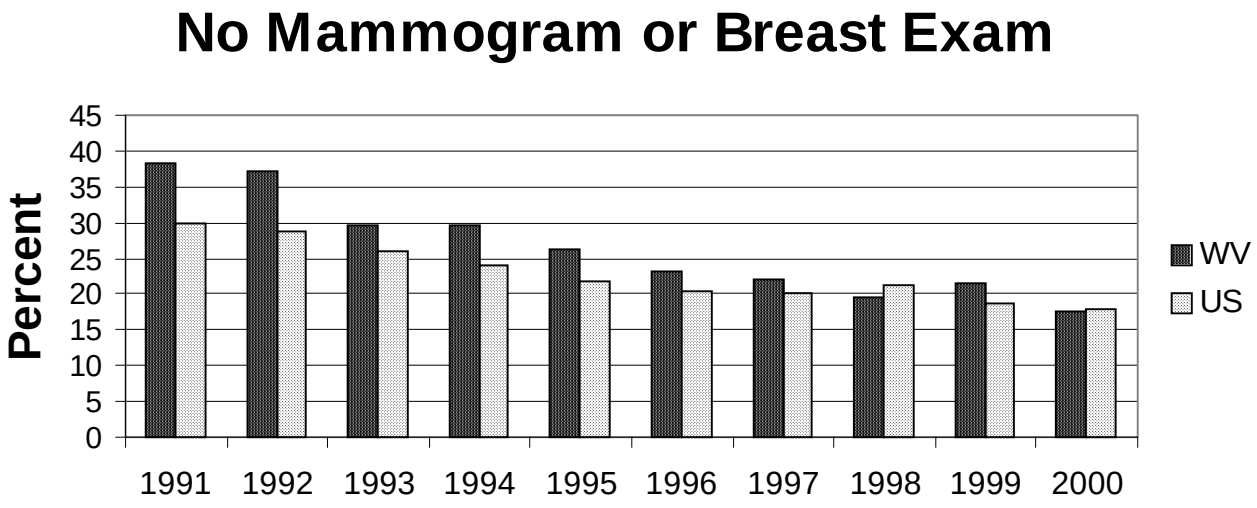
While many clinicians also recommend monthly breast self-exams for women aged 20 and above as a good health habit, the accuracy and effectiveness of this method, as currently practiced, is not fully clear (Cancer in West Virginia 1999). Studies so far have not shown that breast self-exam alone reduces the number of deaths from breast cancer. Therefore, it should not be used in place of clinical breast examination and mammography.

According to a 1992 Morbidity Mortality Weekly Report article on the efficacy, effectiveness, and cost-effectiveness of mammography screening:

> *For breast cancer, certain primary risk factors (i.e. family history, age at menarche and age at menopause) cannot be altered and others (i.e. parity and age at first pregnancy) are not practical targets for intervention. Therefore, as a secondary method for prevention of breast cancer, mammography screening is the most commonly recommended intervention The estimated breast-cancer mortality reduction has ranged from 8-40 percent, reflecting different assumptions among the mathematical models about targeted age groups, screening intervals, sensitivity of the mammography, compliance with regular screening and natural history of the disease. Among women who receive screening regularly, the mortality reduction should be substantially greater than these population estimates. (Mammography 1992)*

Presently, early detection and timely treatment are the best methods to reduce breast cancer mortality. Regular clinical examinations and mammography for women aged 50 and above clearly reduce deaths from breast cancer by about 30 percent (Department of Health and Human Services 1994).

According to the results of the 1997 West Virginia Behavioral Risk Factor Surveillance Survey (WVBRFSS), a randomized telephone survey conducted under the auspices of the CDC, 62 percent of West Virginia women aged 50 and over reported having had a mammogram in the preceding two years. Approximately 14 percent of these women reported having had one sometime in the past, though not within the last two years, while 21 percent of those questioned reported never having had one (Cancer in West Virginia 1999). As with other BRFSS surveys, these findings should be considered in the light of two limitations: individuals, often of lower socioeconomic rank, without home telephones are not questioned, and the data gathered is based on unvalidated self-reports. Since approximately 20 percent of West Virginians living in the state's most rural counties do not have telephone service, their lack of representation in this survey may mean that the state screening and testing rates could be overestimates.



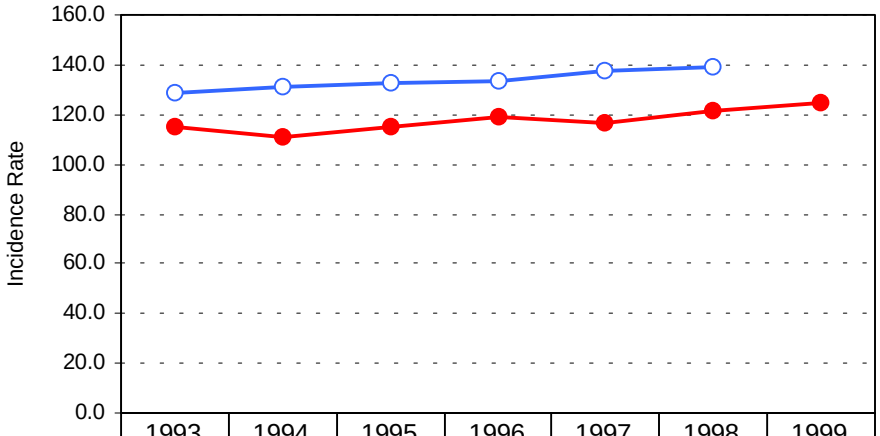
BRFSS data (accessed April 2002):
http://apps.nccd.cdc.gov/brfss/index.asp

For more than a decade, the CDC has supported the work of the West Virginia Breast and Cervical Cancer Screening Program (WVBCCSP), one of the four founding members of the Mountains of Hope Coalition. The WVBCCSP is administered by the West Virginia Department of Health and Human Resources, West Virginia Bureau for Public Health, Office of Maternal, Child and Family Health. They and their partners have worked to raise awareness among the state's women and their healthcare providers about the importance of early detection in the management of breast cancer. The program also helps eligible women gain access to screening and diagnostic services. From the program's inception in 1991 through December 2000, 76,291 mammograms have been provided to 34,513 women. Through these efforts, 451 breast cancers (268 invasive, 183 carcinoma in situ) were diagnosed. It should be noted that more than half of the invasive cancers (52 percent) were diagnosed at an early stage (localized or stage I) (West Virginia Breast and Cervical Cancer Screening Program 2001).

Cancer of the Female Breast

Incidence Rates*, Age-Adjusted

West Virginia Females 1993 - 1999, U.S. Females 1993 - 1998



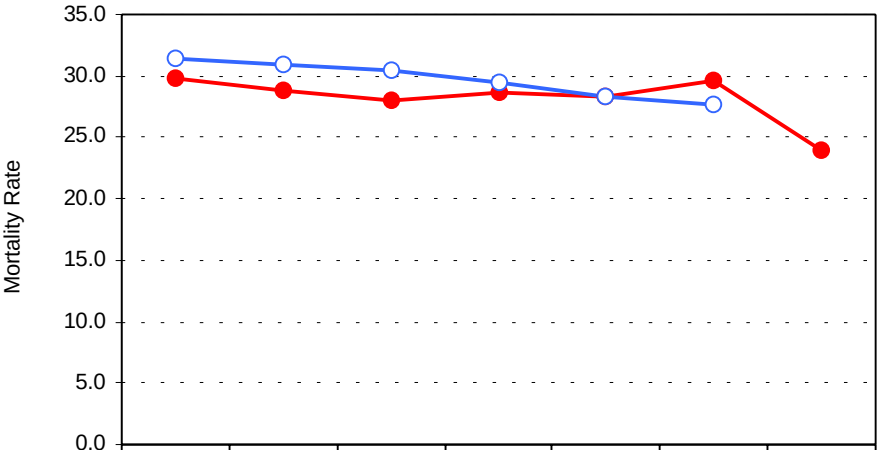
	1993	1994	1995	1996	1997	1998	1999
WV Females	115.2	111.1	115.3	119.1	116.6	121.8	124.3
US Females	129.0	130.8	132.6	133.3	137.3	139.1	

*Rates are per 100,000 females and are age-adjusted to the 2000 U.S. standard population. U.S. rates were calculated using SEER*Stat Version 4.0.9.

Cancer of the Female Breast

Mortality Rates*, Age-Adjusted

West Virginia Females 1993 - 1999, U.S. Females 1993 - 1998



	1993	1994	1995	1996	1997	1998	1999
WV Females	29.8	28.8	28.0	28.7	28.4	29.6	24.0
US Females	31.4	30.9	30.5	29.5	28.3	27.6	

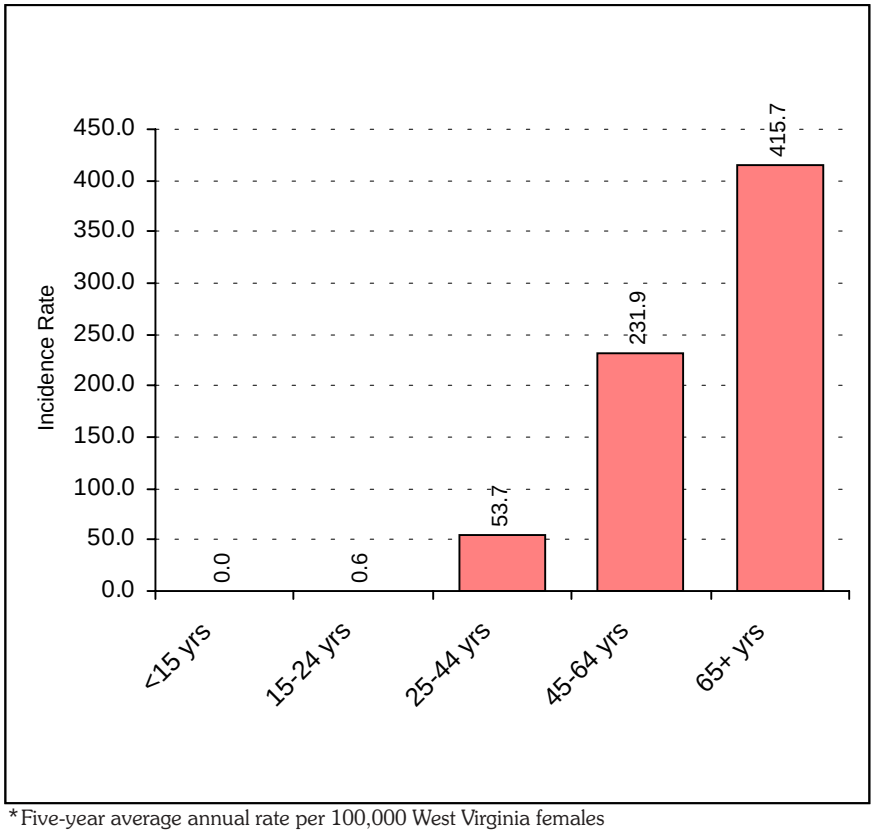
*Rates are per 100,000 females and are age-adjusted to the 2000 U.S. standard population. U.S. rates were calculated by the West Virginia Department of Health and Human Resources, Health Statistics Center, using National Center for Health Statistics mortality data.

Charts courtesy of *Cancer in West Virginia: Incidence and Mortality 1993-1999*. April 2002. West Virginia Department of Health and Human Resources. Charleston, WV

Cancer of the Female Breast

Incidence Rates*, Age-Specific

West Virginia Females 1995 - 1999



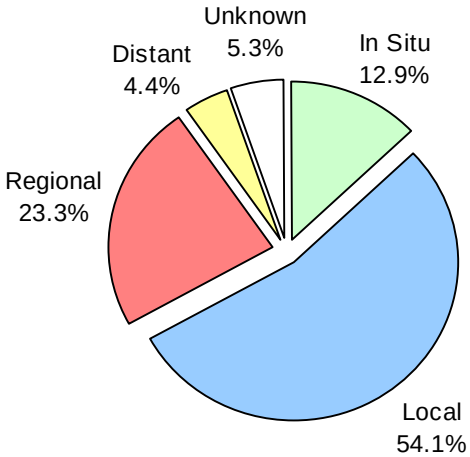
*Five-year average annual rate per 100,000 West Virginia females

Charts courtesy of *Cancer in West Virginia: Incidence and Mortality 1993-1999*. April 2002. West Virginia Department of Health and Human Resources. Charleston, WV

Cancer of the Female Breast

Stage of Disease at Diagnosis

West Virginia Females 1995 - 1999



The WVBCCSP supports breast and cervical early detection services primarily to women aged 50 - 64, at or below 200 percent of the Federal Poverty Level. Last year WVBCCSP staff and volunteers presented information directly to more than 21,000 women, of whom 15,920 (75.8 percent) were 50 or older, through a variety of methods including Breast Cancer Awareness Month activities. These activities are dedicated to raising awareness of the importance of early detection of breast cancer and complement those that take place on the national level each October.

In an effort to provide public education locally and to build local capacity, nine WVBCCSP Cancer Information Specialists coordinate a variety of activities in the state's eight public health districts. An indicator of the positive impact of this decade-long effort was the report that West Virginia is one of two states with the greatest relative increase in mammography screening, approximately 45 percent (Self-reported use of mammography 1997).

The program also provides ongoing professional education opportunities for its more than 200 providers statewide. These activities include local and regional continuing education programs; videotaped lectures for independent study; and quarterly professional educational updates, which include articles from recent literature on relevant topics such as the critical nature of the provider role in screening referrals.

Another important education undertaking is the program's annual provider conference. Approximately 200 program providers attend this ambitious day-and-a-half meeting, which features national, regional and state speakers in plenary and breakout sessions.

An additional professional education opportunity offered by the WVBCCSP is the Public Health Nurses Physical Assessment Training Program (PHNPAT). During this intensive three-day course, nurses from throughout West Virginia are trained to provide clinical breast exams and Pap tests to their patients—women who might not otherwise obtain these potentially life-saving services. The core content of the course includes anatomy and physiology; instruction in the Mammacare method of Clinical Breast Exam and Breast Self-Exam; information on breast and cervical cancer risks; the latest on breast imaging and related breast procedures; the components of a good gynecologic exam; appropriate follow-up to an abnormal breast exam, mammography, or Pap test; information on a variety of cervical lesions and sexually transmitted diseases (STDs); and implications for patient education and treatment. To become fully certified, attendees must pass a written examination and perform 50 Pap tests and clinical breast exams under the supervision of an approved preceptor. At least 25 of these exams must be performed on women aged 50 and older.

Other efforts to promote breast cancer screening efforts throughout the state include programs offered through the American Cancer Society, the Susan G. Komen Breast Cancer Foundation, the YWCA EncorePlus, the Appalachia Cancer Network, Avon Breast Cancer Crusade and the National Alliance of Breast Cancer Organizations (NABCO).

While these efforts to encourage early detection have netted important results, pockets of rarely or never-screened women remain throughout West Virginia. These rarely or never-screened women are often older, members of minority groups, and of lower educational or socioeconomic status. In West Virginia, they often include those who live in rural areas a significant distance from healthcare services. Too often these older women fail to assess their risk of contracting breast cancer as a result of the natural aging process, instead thinking of the disease strictly in hereditary terms.

Many methods have been used to educate West Virginia women about the need for regular breast cancer screening. These include tailored messages, audiovisual aids, telephone counseling, and the use of mass media. In formulating any educational campaign, careful attention must be paid to the needs of the intended audience as well as the results. The Lay Helper model, a methodology that sometimes utilizes more informal, one-on-one interventions, may be an important strategy for health promotion change among rural women, who have been shown to respond positively to one-on-one approaches (Tessaro 2000). The Appalachia Cancer Network and the PRC, members of the Coalition, and their partners provide leadership in the utilization of this strategy in the state. All interventions, regardless of methodology, will include strong evaluation components.

Early Detection of Breast Cancer Goals and Objectives

Four-Year Goal:	**Reduce breast cancer deaths to no more than 21 per 100,000 West Virginia females by 2010.**

Objective I:

Increase utilization of mammography at recommended intervals.

Strategies:

1. Use evidence-based approaches to increase public and worksite education on breast cancer risks, early detection guidelines, clinical breast exams with breast self-exams and to aggressively promote breast cancer screening programs.

Primary Facilitators: West Virginia Breast and Cervical Cancer Screening Program, West Virginia Bureau for Public Health Comprehensive Cancer Control Program, Mary Babb Randolph Cancer Center, Mountains of Hope Early Detection Subcommittee, Charleston Area Medical Center, Marshall University Medical Center, Susan G. Komen Breast Cancer Foundation, American Cancer Society, NCI Cancer Information Service, West Virginia Cancer Registry, West Virginia University Prevention Research Center Center, West Virginia Department of Highways, Appalachia Cancer Network, West Virginia Public Employees Insurance Agency, Wellness Council of West Virginia, West Virginia Primary Care Association, West Virginia School of Osteopathic Medicine, West Virginia University Extension Service, West Virginia Department of Education, Health Promotion Specialists, Family Dollar Stores, Walmart, Toyota, Pier One

Community Linkages: County health departments, Ruby Memorial Hospital, Greenbrier Valley Medical Center, West Virginia Medical Institute, Women's Health Center of West Virginia, Betty Puskar Breast Care Center, Raleigh Boone Medical Center, Wheeling Hospital, Martinsburg City Hospital, United Hospital Medical Center, Planned Approach to Community Health, Family Resource Networks, Union Carbide/Dow Chemical Company, Kellwood Corporation

2. Increase appropriate mammography recommendation by physicians and other healthcare providers.

Primary Facilitators: West Virginia Bureau for Public Health Comprehensive Cancer Control Program, West Virginia Breast and Cervical Cancer Screening Program, Mountains of Hope Medical Advisory Committee, West Virginia Medical Association, West Virginia Hospital Association, West Virginia Health Care Association, West Virginia Rural Health Education Partnerships, Medicare, West Virginia Public Employees Insurance Agency, West Virginia Nurses Association, West Virginia Medical Association

Community Linkages: County health departments, Ruby Memorial Hospital, Greenbrier Valley Medical Center, West Virginia Medical Institute, Women's Health Center of West Virginia, Betty Puskar Breast Care Center, Raleigh Boone Medical Center, Wheeling Hospital, Martinsburg City Hospital, United Hospital Medical Center, Greenbrier Valley Hospital

Objective II:

Increase outreach to women aged 50 and older, especially to minority and rural women with limited income and education.

Strategies:

1. Increase outreach and access (public education, transportation, availability) to counties where breast cancer incidence and mortality rates are highest. Monitor and evaluate.

Primary Facilitators: West Virginia Breast and Cervical Screening Program, Mountains of Hope Early Detection Subcommittee, West Virginia Bureau for Public Health Comprehensive Cancer Control Program, American Cancer Society, Mary Babb Randolph Cancer Center, Charleston Area Medical Center, Marshall University Medical Center, Appalachia Cancer Network, West Virginia Coalition for Minority Health, West Virginia Minority Health Program, Medicare, American Association of Retired People, West Virginia University Center on Aging, Public Housing Authority

Community Linkages: Ebenezer Medical Outreach "Save Our Sisters"; West Virginia Breast and Cervical Cancer Education Program; Monroe County Community-Oriented Primary Care Coalition; Gilmer Primary Care and Concerned Citizens Coalition; Helping Hands Health Right Community Cancer Education Program for Summers, Raleigh and Wyoming counties; Mineral County Health Department Community Cancer Education Program; Lincoln Primary Care Center; Wirt County Family Resources Network Cancer Education Program; Kanawha County Health Right; Monongalia County Health Right; Kanawha

County EncorePlus; Braxton County Memorial Hospital; West Virginia Association for Family and Community Education-Wood County

2. Use knowledge (experience, focus groups, literature review) about culture, perceptions and other barriers to reach these women with education about breast cancer screening.

Primary Facilitators: West Virginia Bureau for Public Health Comprehensive Cancer Control Program, West Virginia Breast and Cervical Cancer Screening Program, West Virginia University Prevention Research Center, West Virginia University Department of Community Medicine, Mary Babb Randolph Cancer Center, Literacy Volunteers of America, Mautner Project, West Virginia Rural Health Education Partnerships, West Virginia University Center for Black Culture and Research, American Association of Retired People, West Virginia University Center on Aging, Health Promotion Specialists

Community Linkages: Charleston Area Medical Center Health Education and Research Institute, Hampshire County Cancer Coalition—SENIOR FOCUS, Wayne County WATCH Coalition—SENIOR FOCUS, Roane County Cancer Education Coalition, PATCH/TEACH coalitions, Wetzel County Cancer Coalition, McDowell County Cancer Coalition, Boone County Education Awareness Task Force on Cancer, Lewis County Cancer Awareness Requires Education and Screening (CARE), Upshur County Cancer Awareness Now (CAN)

3. Increase the pool of community-based volunteers willing to be trained (Lay Helper Model, Sisters Who Care) to deliver outreach on breast cancer to the underserved in their area.

Primary Facilitators: West Virginia Breast and Cervical Cancer Program Cancer Information Specialists, West Virginia University Prevention Research Center, Appalachia Cancer Network, Benedum Community Cancer Education Programs, West Virginia University Extension Service, local ministerial associations, Mission West Virginia

Community Linkages: Planned Approach to Community Health, Family Resource Networks, home health nurses, Meals-on-Wheels, In Touch and Concerned, Avon, West Virginia Women's Club

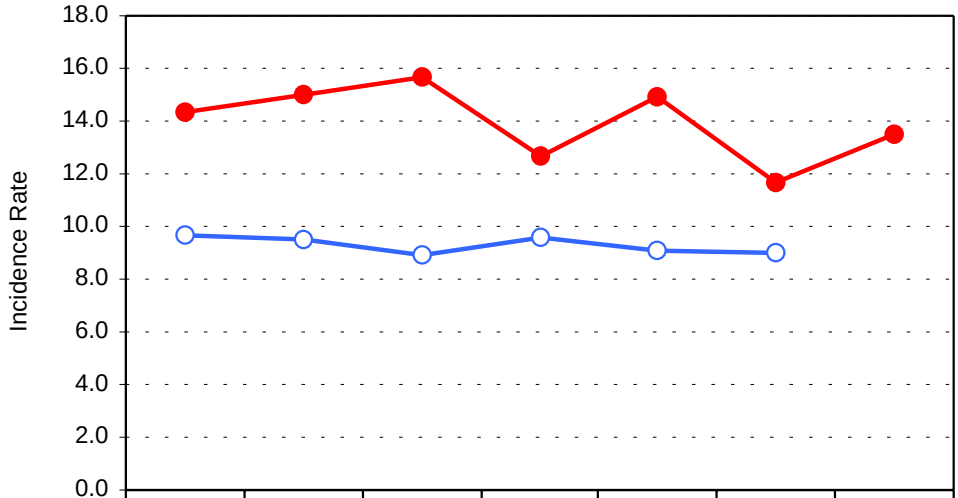
Cervical Cancer

From 1950 to 1970, the national incidence and mortality rates of invasive cervical cancer fell by more than 70 percent. Evidence strongly suggests this decrease in mortality is due to the increase in the use of the Pap tests to screen sexually active women, eighteen years and older (Cervical cancer screening: PDQ health professional summary). While early detection has led to decreasing deaths from cervical cancer, West Virginia continues to rank 4th in the nation in the average age-adjusted mortality rate for this disease. From 1994-1998, invasive cancer of the cervix was the seventh leading cause of cancer among Mountain State women. For West Virginia women aged 25-44, it was the second most commonly diagnosed cancer

Cancer of the Cervix Uteri

Incidence Rates*, Age-Adjusted

West Virginia Females 1993 - 1999, U.S. Females 1993 - 1998



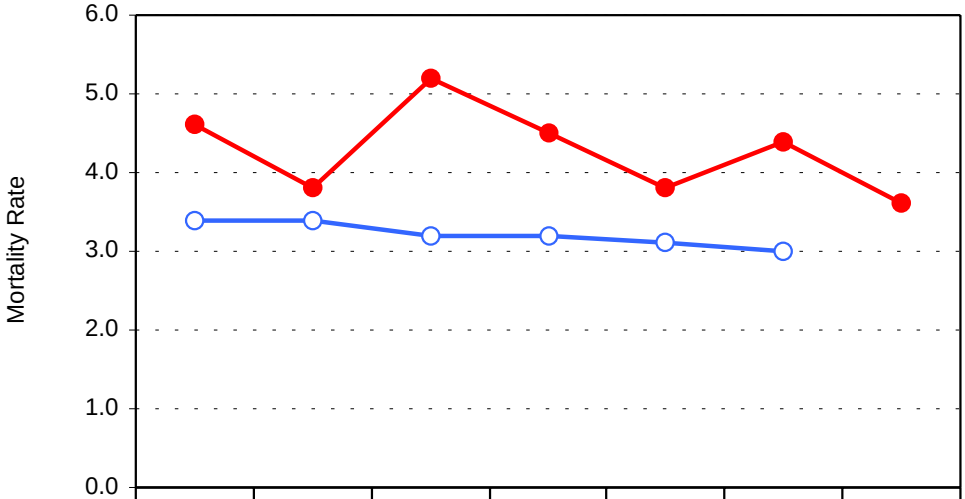
	1993	1994	1995	1996	1997	1998	1999
WV Females	14.3	15.0	15.7	12.7	14.9	11.7	13.5
US Females	9.7	9.5	8.9	9.6	9.1	9.0	

*Rates are per 100,000 females and are age-adjusted to the 2000 U.S. standard population.
U.S. rates were calculated using SEER*Stat Version 4.0.9.

Cancer of the Cervix Uteri

Mortality Rates*, Age-Adjusted

West Virginia Females 1993 - 1999, U.S. Females 1993 - 1998



	1993	1994	1995	1996	1997	1998	1999
WV Females	4.6	3.8	5.2	4.5	3.8	4.4	3.6
US Females	3.4	3.4	3.2	3.2	3.1	3.0	

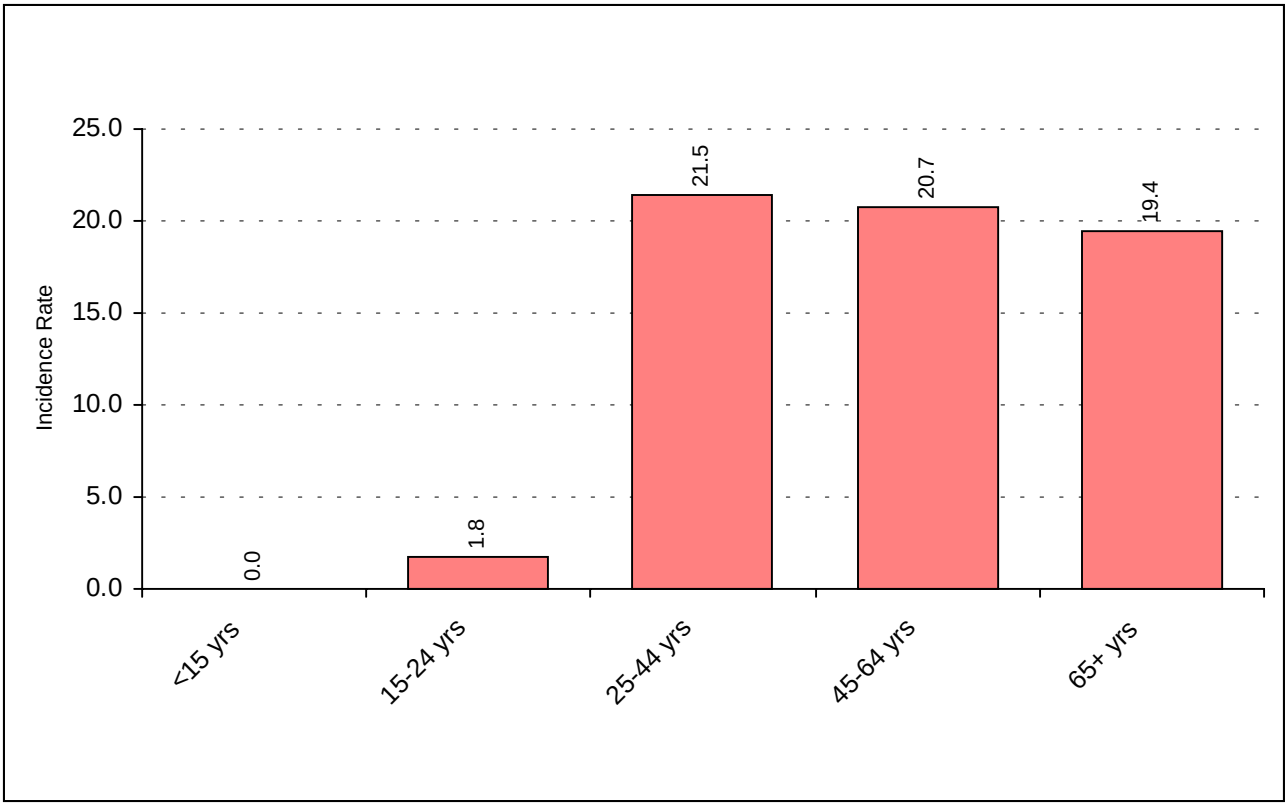
*Rates are per 100,000 females and are age-adjusted to the 2000 U.S. standard population.
U.S. rates were calculated by the West Virginia Department of Health and Human Resources, Health Statistics Center, using National Center for Health Statistics mortality data.

Charts courtesy of *Cancer in West Virginia: Incidence and Mortality 1993-1999*. April 2002. West Virginia Department of Health and Human Resources. Charleston, WV

Cancer of the Cervix Uteri

Incidence Rates*, Age-Specific

West Virginia Females 1995 - 1999

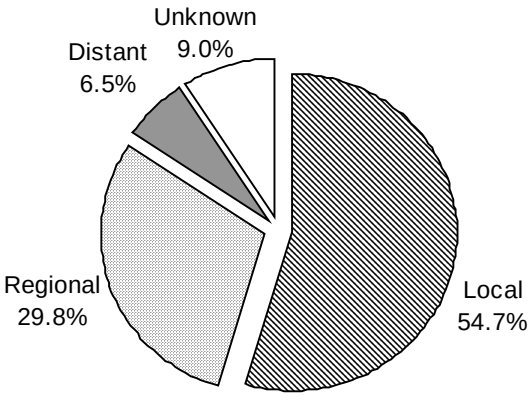


*Five-year average annual rate per 100,000 West Virginia females

Cancer of the Cervix Uteri

Stage of Disease at Diagnosis

West Virginia Females 1995 - 1999



Charts courtesy of *Cancer in West Virginia: Incidence and Mortality 1993-1999*. April 2002. West Virginia Department of Health and Human Resources. Charleston, WV

and the second leading cause of cancer-related mortality (Cancer in West Virginia 2001). Each year from 1994-1998, approximately 50 of the state's women died of the disease.

As with many other cancers, the incidence of invasive cervical cancer increases with age, albeit more slowly in Caucasian women compared to their African-American counterparts (Cervical cancer screening: PDQ health professional summary). Studies show that women who are not screened or who are underscreened are more frequently older, poor, uninsured and living in rural communities (Healthy People 2000 Review 1994).

There are several risk factors associated with cervical cancer. They include exposure to certain strains of human papilloma virus (HPV), a sexually transmitted disease; early age of intercourse; multiple sexual partners; and cigarette smoking (Cancer in West Virginia 2001). Cervical infection with HPV is the primary risk factor for cervical cancer. Approximately 30 of the 80 types of HPV are transmitted sexually and can infect the cervix; about half of these have been linked to cervical cancer. However, HPV exposure is very common and only a very small percentage of women infected with untreated HPV will develop cervical cancer. Women who start to have sexual intercourse prior to age 16, as well as those who have many sexual partners, are also at greater risk for HPV exposure and developing cervical cancer.

Trichomonas and chlamydia infections play a role as free radicals to activate the HPV virus. Therefore herpes, chlamydia and trichomonas are likely to put patients at higher risk for developing cervical cancer. Additionally, because increasing age is a risk factor, the NCI and CDC promote significant efforts to reach older women who have not been screened for the disease. More than a quarter of the total number of invasive cervical cancers are diagnosed in women older than 65, and 40-50 percent of all women who die from the disease are over 65 years of age (National Cancer Institute 1990; Remington 1990).

While there is evidence that cigarette smoking may be associated with an increased risk of cervical cancer, the data are not as yet conclusive (Cervical cancer prevention: PDQ patient summary). According to NCI data, women are also at greater risk for developing cervical cancer if they are HIV positive. Several studies also indicate that low literacy negatively impacts disease prevention. A 1993 U.S. Department of Education Adult Literacy Survey found that one-third of the U.S. population over age16 was functionally illiterate (Lindau 2001); the illiteracy rate in some of West Virginia's most rural counties is almost 60 percent. In West Virginia, low literacy continues to be a major challenge to effective health promotion.

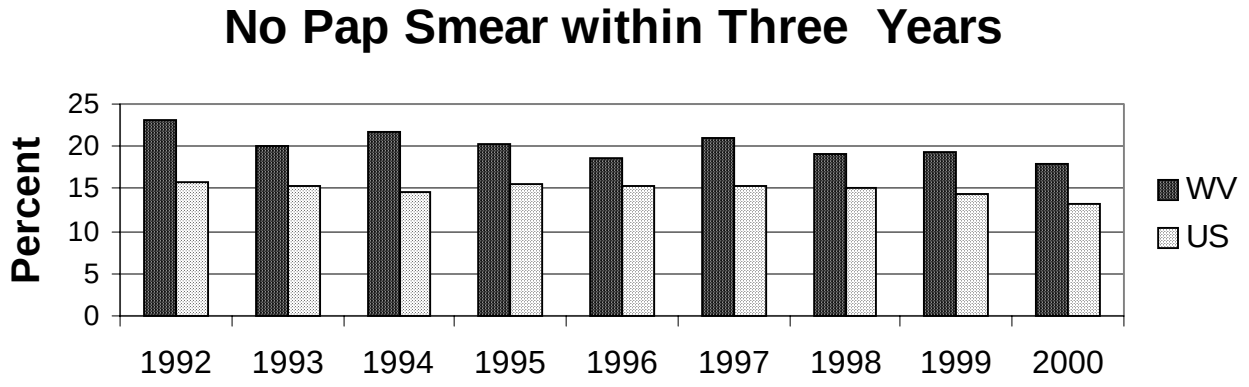
According to the NCI, survival appears to be directly related to the stage of disease at diagnosis. The five-year relative survival rate for cervical cancer is 88 percent for women diagnosed with localized cervical cancer but 13 percent for those diagnosed with distant disease. Early detection, using cervical cytology, is currently the only practical way of detecting cervical cancer in the localized or pre-malignant stages (Cervical cancer screening: PDQ health professional summary). During 1994-1998, 37 percent of West Virginia cases were diagnosed with regional or distant spread. The stage of diagnosis was unknown for 9 percent of cases (Cancer in West Virginia 2001).

Early detection, including regular and widespread use of Pap smears and pelvic examinations followed by appropriate treatment, lowers mortality from cervical cancer. These procedures detect abnormalities that may lead to invasive cancer. Detected early, most invasive cancers can be prevented. All women who are sexually active or have reached the age of 18 should have an annual Pap smear and pelvic exam. The CDC and other reliable sources state that if three or more annual smears have been normal, further screening may be done at one to three year intervals, at the discretion of the healthcare provider, based on patient risk factors. There is no upper age limit at which Pap tests stop being effective. According to the NCI, older women should continue to have regular physical exams, including pelvic exams and Pap tests. Women who have had a hysterectomy should continue to have regular gynecologic examinations; however, they should consult their healthcare provider about whether to continue to have regular Pap tests.

The 1997 WVBRFSS survey found that 78.8 percent of West Virginia women with an intact uterine cervix reported having had a Pap test in the past three years compared to the national median of almost 85 percent (State-specific prevalence of selected health behaviors 2000). Once again the BRFSS methodology, surveying only those with access to a telephone, may underrepresent those people with the least resources, thus overestimating state screening and testing rates. According to Mandelblatt and colleagues (1986), in some areas as many as 75 percent of middle-aged, poor women over 65 have not had a Pap test within the previous five years.

Mountains of Hope supports the efforts the WVBCCSP, the ACS and others have made through the years to raise awareness among the state's women about the importance of early detection. In addition, the Coalition fully endorses the extra efforts necessary to reach the state's older women, especially those women who are among the rarely or never-screened.

In addition to targeting breast cancer, since 1991 the WVBCCSP has offered free or low-cost cervical cancer screenings to eligible women at many county health departments, primary care centers, private physicians, free clinics, and hospital outpatient clinics in all 55 counties. Cervical cancer screening services include Pap tests and pelvic exams for women 25 and older. Related diagnostic services include colposcopy and colposcopy with



BRFSS data (accessed April 2002):
http://apps.nccd.cdc.gov/brfss/index.asp

biopsy. To qualify for these free or low-cost services, women must meet age and income guidelines and not have credible health insurance. The WVBCCSP employs nine Cancer Information Specialists who cover the state's eight public health districts and provide education and guidance to the program's clients. They seek to raise awareness about the importance of adhering to early detection guidelines and to work with eligible women to help remove barriers to adherence.

In March 2001, the WVBCCSP submitted a revised Cervical Cancer Screening Policy Plan to the CDC. The plan is divided into public outreach and professional inreach efforts. The goal is to significantly increase the enrollment of rarely or never-screened West Virginia women, especially those over 50. To reach that population, the plan will determine baseline data to identify eligible women who fall into the rarely or never-screened category and design outreach programs to reach them. Outreach efforts will focus on 10 geographic areas. Using literature reviews, target group focus groups and key informant interviews, program personnel will work with Coalition partners to determine the most appropriate health education method for each area and to implement these efforts. Process and outcome measures will be defined and necessary program materials will be developed. Each intervention will incorporate a strong evaluation component, thus allowing for mid-course corrections.

Complementing the public outreach is a professional inreach effort to assist providers and their associates in identifying and enrolling rarely or never-screened eligible women into the WVBCCSP. Working with provider representatives and other interested parties, several inreach interventions will be designed; each will be piloted at five provider sites. Strong evaluation components will allow for mid-course revisions.

Cervical Cancer Early Detection Goals and Objectives:

Four-Year Goal:	**Determine why the cervical cancer mortality rate for women in West Virginia is 51 percent higher (1995) than the U.S. rate.**

Goal I: **Increase the number of women screened for cervical cancer. Increase to at least 95 percent the proportion of women aged 18 and older who have ever received a Pap test and to at least 85 percent those who received a Pap test within the preceding three years.**

Objective I:

Use WV Cancer Registry incidence data and interviews with cervical cancer survivors to identify the barriers to screening (lack of knowledge, provider did not recommend, no access to screening) that resulted in invasive cervical cancer. Record the diagnosis and treatment process.

Strategies:

1. Using focus groups, develop a proposal and questionnaire.

2. Conduct one-on-one interviews with a representative sample of women in West Virginia.

3. Conduct interviews with providers residing in the same counties as the women interviewed.

4. Use results from focus groups to plan appropriate programs and invite collaboration with research community

Objective II:

Increase utilization of cervical cancer screening at recommended intervals.

Strategies:

1. Use WV Cancer Registry incidence data and interview cervical cancer survivors to identify the barriers to screening (lack of knowledge, provider did not recommend, no access to services) that resulted in invasive cervical cancer.

2. Use evidence-based approaches, increase public and worksite education on cervical cancer risks and early detection guidelines, and aggressively promote cervical cancer screening programs.

Primary Facilitators: West Virginia Breast and Cervical Cancer Screening Program, West Virginia Bureau for Public Health Comprehensive Cancer Control Program, Mary Babb Randolph Cancer Center, Mountains of Hope Early Detection Subcommittee, Charleston Area Medical Center, Marshall University Medical Center, Marshall University Department of Obstetrics and Gynecology, American Cancer Society, NCI Cancer Information Service, West Virginia Cancer Registry, West Virginia University Prevention Research Center, Appalachia Cancer Network, West Virginia Public Employees Insurance Agency, Wellness Council of West Virginia, West Virginia Primary Care Association, West Virginia School of Osteopathic Medicine, West Virginia Department of Highways, West Virginia University Extension Service, West Virginia Department of Education, Health Promotion Specialists, Family Dollar Stores, Walmart, Toyota, Pier One

Community Linkages: County health departments, Ruby Memorial Hospital, Greenbrier Valley Medical Center, West Virginia Medical Institute, Women's Health Center of West Virginia, Betty Puskar Breast Care Center, Raleigh Boone Medical Center, Wheeling Hospital, Martinsburg City Hospital, United Hospital Medical Center, Planned Approach to Community Health, Family Resource Networks, Union Carbide/Dow Chemical Company, Kellwood Corporation

3. Increase appropriate recommendation of cervical cancer screening by physicians and other healthcare providers. Monitor and evaluate.

Primary Facilitators: West Virginia Bureau for Public Health Comprehensive Cancer Control Program, West Virginia Breast and Cervical Cancer Screening Program, Mountains of Hope Medical Advisory Board, West Virginia Medical Association, West Virginia Hospital Association, West Virginia Health Care Association, West Virginia Rural Health Education Partnerships, Medicare, West Virginia Public Employees Insurance Agency, West Virginia Nurses Association, West Virginia Medical Association, West Virginia University Department of Obstetrics and Gynecology, Marshall University Department of Obstetrics and Gynecology

Community Linkages: County health departments, Ruby Memorial Hospital-Morgantown, Greenbrier Valley Medical Center, West Virginia Medical Institute, Women's Health Center of West Virginia, Raleigh Boone Medical Center, Wheeling Hospital, Martinsburg City Hospital, United Hospital Medical Center

Objective III:

Increase outreach to women aged 50 and older, especially to minority and rural women with limited income and education.

Strategies:

1. Increase outreach and access (public education, transportation, availability) in counties where cervical cancer incidence and mortality rates are highest.

Primary Facilitators: Breast and Cervical Screening Program, Mountains of Hope Early Detection Subcommittee, West Virginia Bureau for Public Health Comprehensive Cancer Control Program, West Virginia Cancer Registry, American Cancer Society, Mary Babb Randolph Cancer Center, Charleston Area Medical Center, Marshall University Medical Center, Appalachia Cancer Network, West Virginia Coalition for Minority Health, West Virginia Minority Health Program, Medicare, American Association of Retired People, West Virginia University Center on Aging, Public Housing Authority

Community Linkages: Ebenezer Medical Outreach "Save Our Sisters" Breast and Cervical Cancer Education Program; Monroe County Community-Oriented Primary Care Coalition; Gilmer Primary Care and Concerned Citizens Coalition; Helping Hands Health Right Community Cancer Education Program for Summers, Raleigh and Wyoming counties; Mineral County Health Department Community Cancer Education Program; Lincoln Primary Care Center; Wirt County Family Resources Network Cancer Education Program; Kanawha County Health Right; Monongalia County Health Right; Braxton County Memorial Hospital; West Virginia Association for Family and Community Education-Wood County

2. Use knowledge (experience, focus groups, literature review) about culture, perceptions and other barriers to reach these women with education about cervical cancer screening.

Primary Facilitators: West Virginia Bureau for Public Health Comprehensive Cancer Control Program, West Virginia Breast and Cervical Cancer Screening Program, West Virginia University Prevention Research Center, West Virginia University Department of Community Medicine, Mary Babb Randolph Cancer Center, Literacy Volunteers of America, Mautner Project, West Virginia Rural Health Education Partnerships, West Virginia University Center for Black Culture and Research, American Association of Retired People, West Virginia University Center on Aging, Health Promotion Specialists, West Virginia University Department of Family Medicine

Community Linkages: CAMC Health Education and Research Institute, Hampshire County Cancer Coalition, Wayne County WATCH Coalition—SENIOR FOCUS, Roane County Cancer Education Coalition, PATCH/TEACH coalitions, Wetzel County—SENIOR FOCUS, McDowell County Cancer Coalition, Boone County Education Awareness Task Force on Cancer, Lewis County Cancer Awareness Requires Education and Screening (CARE), Upshur County Cancer Awareness Now (CAN)

3. Increase the pool of community-based volunteers willing to be trained (Lay Helper Model, Sisters Who Care) to deliver outreach on cervical cancer to underserved people in their area. Monitor and evaluate.

Primary Facilitators: West Virginia Breast and Cervical Cancer Program Cancer Information Specialists, West Virginia University Prevention Research Center, Appalachia Cancer Network, Benedum Community Cancer Education Program, West Virginia University Extension Service, local ministerial associations, Mission West Virginia

Community Linkages: Planned Approach to Community Health, Family Resource Networks, home health nurses, Meals-on-Wheels, In Touch and Concerned, Avon, West Virginia Women's Club

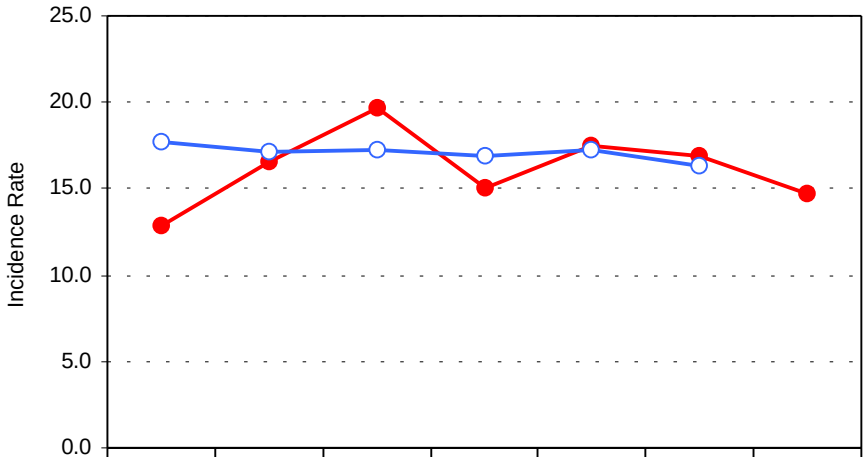
Ovarian Cancer

Ovarian cancer is the most lethal of the gynecologic malignancies. In 2002, nearly 24,000 women will be diagnosed with ovarian cancer in the United States, and 14,000 women will die of the disease. During 1995-99, cancer of the ovary was the fifth leading cause of cancer incidence and the fourth leading cause of cancer-related mortality for women in West Virginia. Although cancer of the ovary was identified in all age groups during 1995-99, incidence increased with age. The increased mortality associated with this cancer is due in large part to the late diagnosis of the disease, when it is already in an advanced stage, having spread to many other abdominal organs. Fully 75% of patients diagnosed with ovarian cancer are diagnosed with stage III (extensive intra-abdominal disease) and stage IV (distant

Cancer of the Ovary

Incidence Rates*, Age-Adjusted

West Virginia Females 1993 - 1999, U.S. Females 1993 - 1998



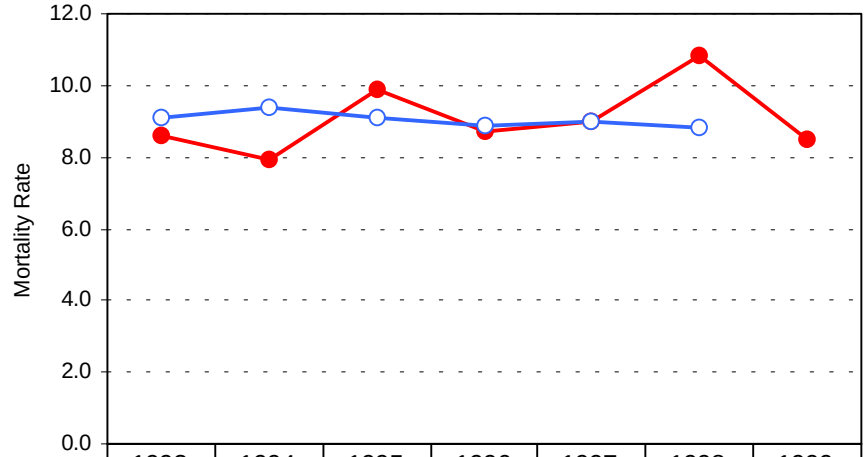
	1993	1994	1995	1996	1997	1998	1999
WV Females	12.9	16.6	19.7	15.0	17.5	16.9	14.7
US Females	17.7	17.1	17.3	16.9	17.2	16.3	

*Rates are per 100,000 females and are age-adjusted to the 2000 U.S. standard population. U.S. rates were calculated using SEER*Stat Version 4.0.9.

Cancer of the Ovary

Mortality Rates*, Age-Adjusted

West Virginia Females 1993 - 1999, U.S. Females 1993 - 1998



	1993	1994	1995	1996	1997	1998	1999
WV Females	8.6	7.9	9.9	8.7	9.0	10.8	8.5
US Females	9.1	9.4	9.1	8.9	9.0	8.8	

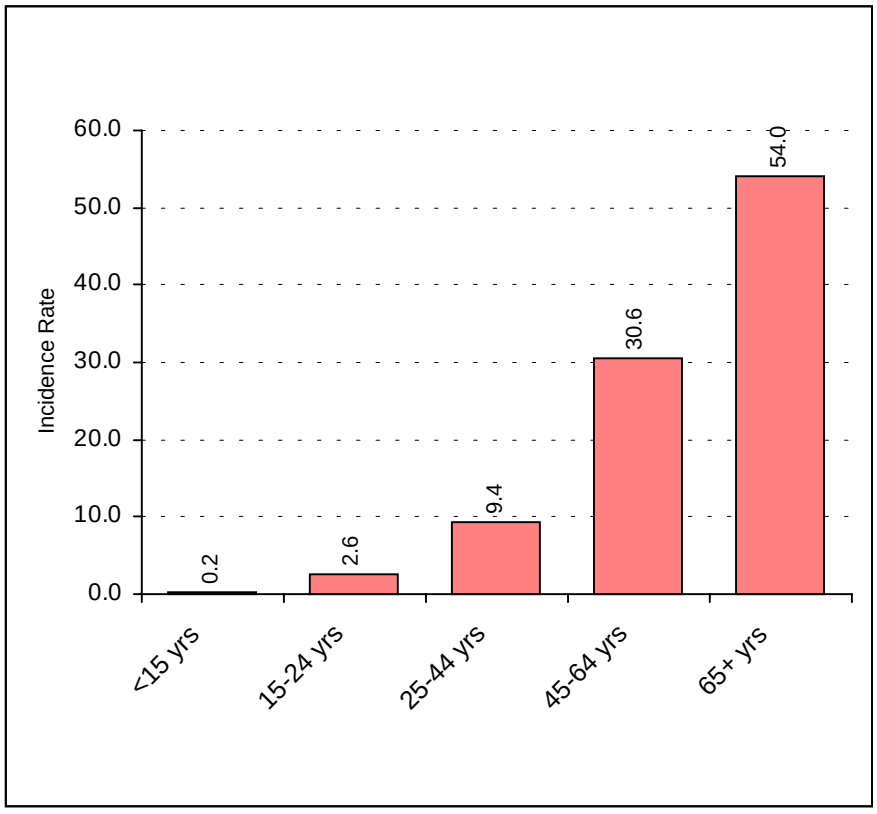
*Rates are per 100,000 females and are age-adjusted to the 2000 U.S. standard population. U.S. rates were calculated by the West Virginia Department of Health and Human Resources, Health Statistics Center, using National Center for Health Statistics mortality data.

Charts courtesy of *Cancer in West Virginia: Incidence and Mortality 1993-1999*. April 2002. West Virginia Department of Health and Human Resources. Charleston, WV

Cancer of the Ovary

Incidence Rates*, Age-Specific

West Virginia Females 1995 - 1999

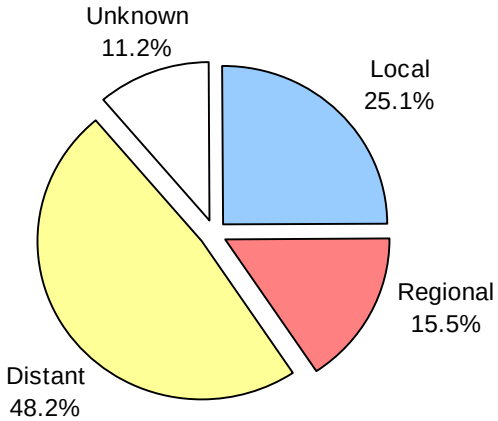


*Five-year average annual rate per 100,000 West Virginia females

Cancer of the Ovary

Stage of Disease at Diagnosis

West Virginia Females 1995 - 1999



Charts courtesy of *Cancer in West Virginia: Incidence and Mortality 1993-1999*. April 2002. West Virginia Department of Health and Human Resources. Charleston, WV

metastatic spread often involving pleural effusions). Survival in early, stage I disease approaches 90% at five years, while survival in advanced disease is as low as 15-20% at the same milestone.

Factors involved in the delayed diagnosis of ovarian cancer include a profound lack of awareness of the myriad of subtle signs and symptoms. Patients often overlook symptoms of the disease until they become so severe that they can no longer be ignored. Symptoms reported by patients are often misinterpreted by health care professionals as associated with other, more benign conditions. Risk increases with age. Pregnancy and use of oral contraceptives reduce the risk of ovarian cancer while a family history of breast or ovarian cancer is associated with an increased risk.

In West Virginia, due to the rural character of the state and relatively limited access to medical care, the ravages of ovarian cancer are particularly acute. The degree of economic disadvantage increases the likelihood that women will ignore or misinterpret the signs and symptoms of ovarian cancer. The advanced rate of disease encountered in West Virginia is at an even higher rate than the country as a whole. It is anticipated that if information regarding this disease could get the widest possible dissemination, then it may be possible to shift the diagnosis to an earlier time when treatment would have a better change of success. Periodic thorough pelvic examinations are important prevention measures for identifying this disease.

Early Detection of Ovarian Cancer Goals and Objectives

Four-Year Goal:	**Increase public awareness of ovarian cancer.**

Objective I:

Use West Virginia Cancer Registry incidence data and interviews with ovarian cancer survivors to identify factors (lack of knowledge, provider did not recommend pelvic exam, no access to services) that may result in invasive ovarian cancer. Explain the diagnosis and treatment process.

Objective II:

Increase outreach to women age 45 and older, especially to minority and rural women with limited income and education.

Objective III:

Increase number of women screened for cervical cancer, thereby increasing the number of women who simultaneously receive pelvic exams and are thus checked for ovarian cancer.

Primary Facilitator: Marshall University Joan C. Edwards School of Medicine

Community Linkages: Marshall University Joan C. Edwards School of Medicine Department of OB/GYN, Ebenezer Medical Outreach "Save Our Sisters," county health departments, Lincoln Primary Care, Valley Health Systems, WATCH Coalition, Cameo Ladies, Ovarian Cancer Support Groups, Cabell Huntington Hospital Women's Health Services, St. Mary's Hospital, Mountains of Hope Comprehensive Cancer Control Coalition

Colorectal Cancer

About 135,000 new cases of colorectal cancer are expected in the United States this year, and 56,700 people will die from the disease nationally. The West Virginia Cancer Registry records that from 1993-98, colorectal cancer was the third most commonly diagnosed cancer in West Virginians, regardless of sex, and accounted for slightly over 10 percent of all West Virginia cancer-related deaths (Greenlee 2001; Cancer in West Virginia 2001).

According to the CDC, colorectal cancer risk factors include inflammatory bowel disease, a family or personal history of colorectal cancer or polyps, and selected hereditary syndromes. Those who do not exercise regularly also are at greater risk. As with many cancers, the risk for developing the disease increases as one ages. Early detection and treatment play a critical role in reducing colorectal cancer-related deaths.

The lifestyle of many West Virginians increases their risk for colon cancer. Physical inactivity and obesity are prevalent in this state, and many residents do not limit fat intake or eat high fiber diets. According to the CDC BRFSS, West Virginia has ranked sixth or higher in obesity for more than a decade; over 45 percent of the population reports no leisure-time physical activity.

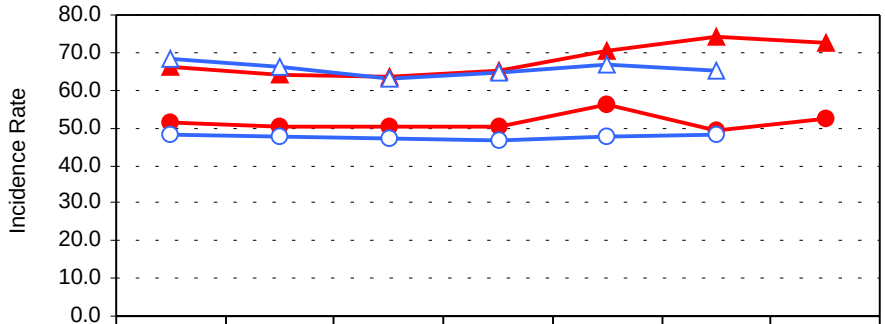
It is generally accepted that colorectal cancer can be prevented if precancerous polyps are removed before they develop into invasive cancers. There are several colorectal cancer screening methods to help identify precancerous polyps and detect colorectal cancer in early, treatable stages. These tests include fecal occult blood test (FOBT), flexible sigmoidoscopy, colonoscopy, and double-contrast barium enema. The digital rectal examination is not recommended as a screening method for colorectal cancer since it only provides the clinician limited access to the area of concern.

Although colorectal cancer screening tests have been available for years, they are generally underutilized. According to the CDC, utilization of screening for colorectal cancer lags far behind utilization of screening for other cancers. The public appears to lack knowledge about the disease and the methods available to detect it. Results from a population survey, presented in March 2000 at the first National Colorectal Cancer Awareness Month Kickoff, found that only 1 percent of those questioned mentioned colorectal cancer when asked to identify a serious life-threatening disease. Almost two-thirds of those questioned

Cancer of the Colon & Rectum

Incidence Rates*, Age-Adjusted

West Virginia Residents 1993 - 1999, U.S. Residents 1993 - 1998



	1993	1994	1995	1996	1997	1998	1999
WV Males	66.0	64.1	63.8	65.0	70.5	74.0	72.7
US Males	68.3	66.2	63.2	64.9	67.0	65.0	
WV Females	51.2	50.5	50.2	50.4	56.3	49.3	52.3
US Females	48.4	47.8	47.1	46.6	47.6	48.3	

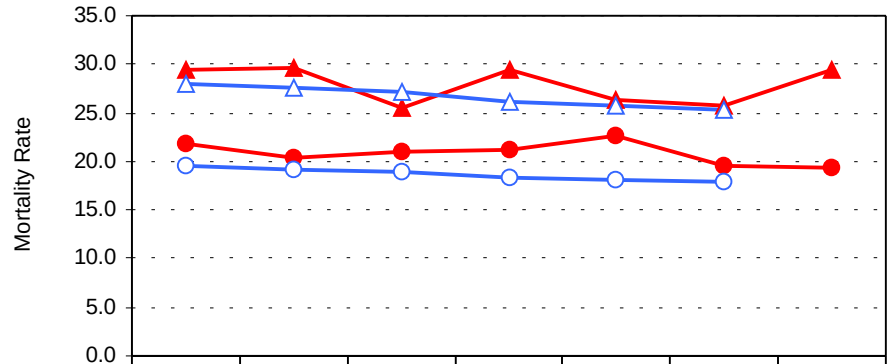
*Rates are per 100,000 and are age-adjusted to the 2000 U.S. standard population.
U.S. rates were calculated using SEER*Stat Version 4.0.9.

Charts courtesy of *Cancer in West Virginia: Incidence and Mortality 1993-1999*. April 2002. West Virginia Department of Health and Human Resources. Charleston, WV

Cancer of the Colon & Rectum

Mortality Rates*, Age-Adjusted

West Virginia Residents 1993 - 1999, U.S. Residents 1993 - 1998



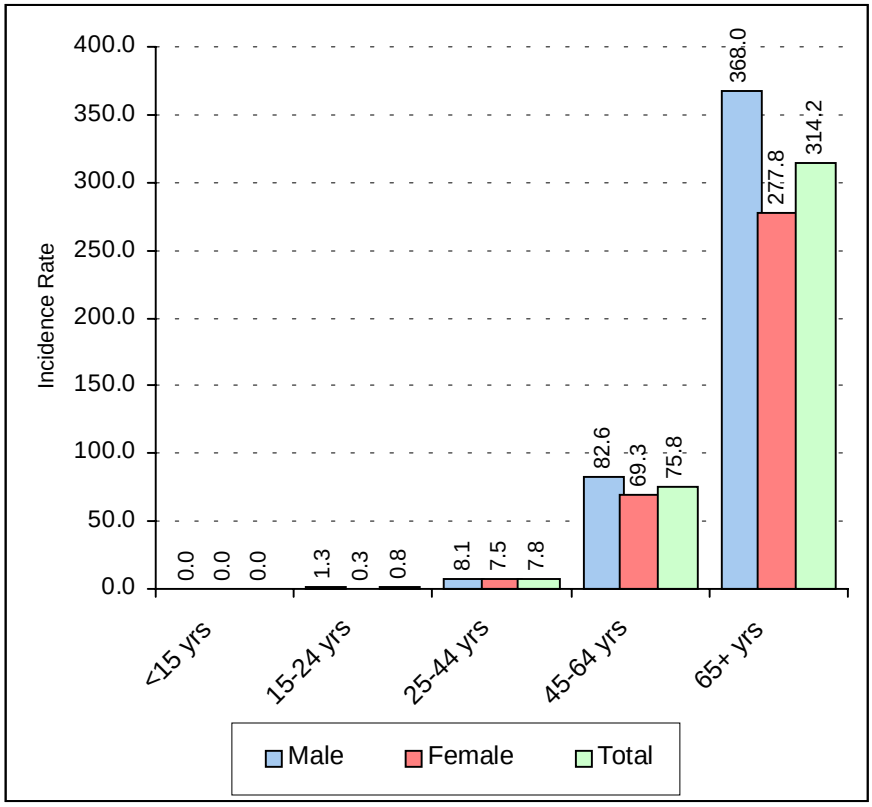
	1993	1994	1995	1996	1997	1998	1999
WV Males	29.4	29.6	25.5	29.5	26.4	25.7	29.4
US Males	28.0	27.6	27.1	26.2	25.8	25.3	
WV Females	21.8	20.3	20.9	21.2	22.7	19.5	19.3
US Females	19.6	19.2	19.0	18.4	18.1	18.0	

*Rates are per 100,000 and are age-adjusted to the 2000 U.S. standard population.
U.S. rates were calculated by the West Virginia Department of Health and Human Resources, Health Statistics Center, using National Center for Health Statistics mortality data.

Cancer of the Colon & Rectum

Incidence Rates*, Age-Specific

West Virginia Residents 1995 - 1999



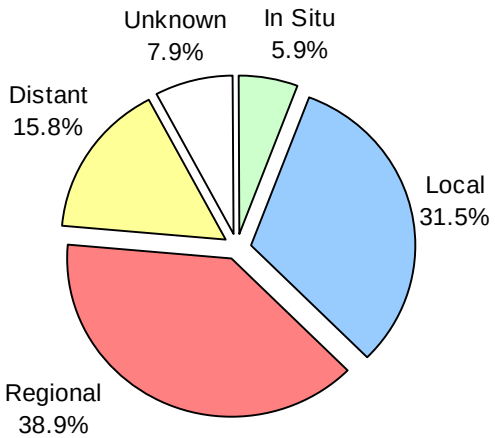
*Five-year average annual rate per 100,000 West Virginia residents

Charts courtesy of *Cancer in West Virginia: Incidence and Mortality 1993-1999*. April 2002. West Virginia Department of Health and Human Resources. Charleston, WV

Cancer of the Colon & Rectum

Stage of Disease at Diagnosis

West Virginia Residents 1995 - 1999



who were older than age 50 had not undergone any colorectal cancer screening, and 25 percent could not name any colorectal cancer screening method. A full 90 percent of those surveyed believed it was their physician's responsibility to recommend colorectal cancer screening to them if the physician felt it was necessary (Fromer 2000).

Corroborative data from the 1997 CDC BRFSS found that in the preceding year, home-administered FOBT was performed by fewer than 20 percent of U.S. adults aged 50 years and older. In this same population, just 30.4 percent had undergone sigmoidoscopy or proctoscopy, during the preceding five years. While these national statistics are disturbing, corresponding 1997 WVBRFSS data is even more alarming. They found only 11.9 percent of respondents aged 50 years or older had completed FOBT in the preceding year (Screening for colorectal cancers-United States 1999). Again, as with all BRFSS results, the fact that approximately one-fifth of West Virginians do not have telephone service may overestimate state screening and testing rates. Colorectal cancer is of significant concern to West Virginia with the growth of its aging population since, as previously mentioned, the incidence of the disease increases markedly with age. Colorectal cancer was more than four times more common among West Virginians aged 65 and older compared to those aged 45-64 (Cancer in West Virginia 2001).

Mountains of Hope endorses the screening guidelines recommended by the CDC and based on the recommendations of several scientific organizations. According to these guidelines, adults 50 and above should

- have an annual Fecal Occult Blood Test
- undergo flexible sigmoidoscopy every 5 years
- total colon examination by colonoscopy every 10 years or by double-contrast barium enema every 5–10 years

Patients sometimes resist following these screening recommendations because of the necessity for advance preparation and because they see the procedures as inconvenient, embarrassing, invasive and uncomfortable. Others are put off by the expense involved, especially if their insurance companies will not pay for these procedures. In addition to promoting public and professional awareness of these colorectal cancer early detection guidelines, the Coalition also seeks to investigate creative ways to communicate information about colorectal cancer and to increase patient acceptance of screening procedures. It also will encourage increased dialogue with health insurers about the importance of covering early detection procedures for colorectal cancer.

Among the colorectal cancer cases diagnosed in West Virginia from 1994-1998, 37 percent were identified at an in situ or local stage where five-year survival rates are excellent. Forty percent were found at a regional stage and 16 percent at a distant stage, for which prognosis is poor and treatment and management costs much higher. Stage was not reported in 8 percent of the cases (Cancer in West Virginia 2001).

Mountains of Hope will provide statewide leadership in both the public and professional sectors to increase knowledge about colorectal cancer and the known primary and

secondary prevention strategies. Utilizing information and materials available through efforts sponsored by the CDC, such as the National Colorectal Cancer Roundtable, the public awareness campaign "Screen for Life," and the professional education effort "A Call to Action," the Coalition will collaborate with state entities to increase colorectal cancer awareness and screening in West Virginia.

Early Detection of Colorectal Cancer Goals and Objectives:

Four-Year Goal:	**Attain a level where at least 50 percent of people aged 50 and older have received a colorectal cancer screening examination (fecal occult blood testing) within the preceding 1-2 years and increase to at least 40 percent those who have ever received a proctosigmoidoscopy.**

Goal I: Increase utilization of colorectal cancer screening at recommended intervals.

Objective I:

Determine public perceptions, attitudes and behaviors toward screening for colorectal cancer and develop an education plan.

Strategies:

1. Using evidence-based approaches, increase public awareness of colorectal cancer risks and recommended screening guidelines.

Primary Facilitators: West Virginia Bureau for Public Health, Mary Babb Randolph Cancer Center, Mountains of Hope Early Detection Subcommittee, Charleston Area Medical Center, Marshall University Medical Center, American Cancer Society, NCI Cancer Information Service, West Virginia Cancer Registry, West Virginia University Prevention Research Center, Appalachia Cancer Network, West Virginia Public Employees Insurance Agency, Wellness Council of West Virginia, West Virginia Primary Care Association, West Virginia School of Osteopathic Medicine, Cooperate Extension Service, West Virginia Department of Education, Health Promotion Specialists

Community Linkages: American Cancer Society - "Active for Life," "Body and Soul," and "Meeting Well," county health departments, Ruby Memorial Hospital, Greenbrier Valley Medical Center, West Virginia Medical Institute, Women's Health Center—Kanawha County, Raleigh Boone Medical Center, Wheeling Hospital, Martinsburg City Hospital, United Hospital Medical Center, Planned Approach to Community Health, Family Resource Networks, Rotary Clubs

2. Increase appropriate recommendation for colorectal cancer screening by physicians and other healthcare providers. Monitor and evaluate.

Primary Facilitators: West Virginia Bureau for Public Health Comprehensive Cancer Control Program, Mountains of Hope Medical Advisory Board, West Virginia Medical Association, West Virginia Hospital Association, Charleston Area Medical Center, West Virginia Health Care Association, West Virginia Rural Health Education Partnerships, Medicare, West Virginia Public Employees Insurance Agency, West Virginia Nurses Association, West Virginia Medical Association, West Virginia University Department of Gastroenterology, West Virginia Cancer Registry

Community Linkages: County health departments, Ruby Memorial Hospital-Morgantown, Greenbrier Valley Medical Center, West Virginia Medical Institute, Women's Health Center-Kanawha County, Raleigh Boone Medical Center, Wheeling Hospital—Ohio County, Martinsburg City Hospital, United Hospital Medical Center, Planned Approach to Community Health, Family Resource Networks

Objective II:

Increase outreach on colorectal cancer to women and men aged 50 and older, especially to minority and rural women and men with limited income and education.

Strategies:

1. Increase outreach and access (public education, transportation, availability) in counties where the colorectal cancer incidence and mortality rates are higher than the national rates.

Primary Facilitators: Mountains of Hope Early Detection Subcommittee, West Virginia Bureau for Public Health Comprehensive Cancer Control Program, American Cancer Society, Mary Babb Randolph Cancer Center, Charleston Area Medical Center, Marshall University Medical Center, Appalachia Cancer Network, West Virginia Coalition for Minority Health, West Virginia Minority Health Program, Medicare, American Association of Retired People, West Virginia University Center on Aging, Public Housing Authority, West Virginia University Prevention Research Center

Community Linkages: County health departments, Primary Care Facilities, Roane Cancer Education Coalition Natural Lay Helpers Colorectal Cancer Education, Helping Hands Health Right Community Cancer Education Program—Raleigh, Fayette, Summers and Wyoming, Mineral County Health Department Community Cancer Education Program, Wetzel County Cancer Coalition Natural Lay Helpers Nutrition and Physical Activity Education Program, PATCH/TEACH coalitions, Beat Cancer Coalition of Boone County "Mug-A-Man" Campaign

2. Use knowledge (experience, focus groups, literature review) about culture, perceptions and other barriers to reach these men and women with education about colorectal cancer screening. Develop "easier to understand" directions for the FOBT.

Primary Facilitators: West Virginia Bureau for Public Health Comprehensive Cancer Control Program, West Virginia Cancer Registry, West Virginia University Prevention Research Center, West Virginia University Department of Community Medicine, Mary Babb Randolph Cancer Center, Literacy Volunteers of America, Mautner Project, West Virginia Rural Health Education Partnerships, West Virginia University Center for Black Culture and Research, American Association of Retired People, West Virginia University Center on Aging, Health Promotion Specialists

Community Linkages: Monongalia County PATCH Nutrition Program, Charleston Area Medical Center Health Education and Research Institute, Monroe County Community-Oriented Primary Care Coalition, Hampshire County Cancer Coalition—SENIOR FOCUS, Wayne County WATCH Coalition—SENIOR FOCUS, Roane County Cancer Education Coalition, PATCH/TEACH coalitions, Wetzel County-SENIOR FOCUS, McDowell County Cancer Coalition, Boone County Education Awareness Task Force on Cancer, Lewis County Cancer Awareness Requires Education and Screening (CARE), Upshur County Cancer Awareness Now (CAN)

Prostate Cancer

Prostate cancer is the most common nonskin cancer in North American males. (What You Need to Know about Prostate Cancer 2000; Cancer in West Virginia 2001). It is also the most commonly diagnosed cancer among West Virginia men. The NCI estimated that in 2000, over 180,400 new cases and 31,900 prostate cancer-related deaths would occur in the United States (Greenlee 2000).

During the years 1994-98 in West Virginia, 68 percent of men with prostate cancer were diagnosed with early (in situ or local) disease. Stage at diagnosis was not reported in 17 percent of cases. During this time, cancer of the prostate was the second leading cause of cancer-related mortality in West Virginia men, accounting for approximately one in nine male cancer deaths (Cancer in West Virginia 2001).

While the causes of prostate cancer are not well understood, researchers are studying the following possible risk factors for the disease: age, diet and lifestyle prevention, family history, and race (What you need to know about prostate cancer 2000). Other potential risks include alcohol consumption, vitamin or mineral interactions, and other dietary habits (Eichholzer 1996; Gann 1994; Morton 1996). Scientists are also studying the potential impact that chemoprevention and hormonal prevention may have on disease suppression or prevention (Prostate cancer prevention: PDQ patient summary).

Prostate cancer screening is controversial because of the lack of definitive evidence of benefit. Prior to the 1990s, clinicians primarily used the digital rectal examination (DRE) for prostate cancer screening (Scardino 1989). At present, prostate-specific antigen (PSA) is a commonly used screening method. Transrectal ultrasound, an imaging procedure, is

also used, although usually as follow-up to an abnormal initial screening (Prostate Cancer Screening: health professional summary 2001).

While the DRE has been used for many years, there is no conclusive study evaluating its effectiveness; in fact, one case control study reported no statistically significant effect of routine screening with DRE on the prevention of metastatic prostate cancer (Friedman 1991). While data about DRE effectiveness as a screening methodology are inconclusive, it is an inexpensive, relatively noninvasive, nonmorbid technique that can be taught to health workers. More study must be done to determine if routine annual screening by rectal examination reduces prostate cancer mortality.

Some clinicians believe the serum PSA methodology is a more promising, if not perfect, screening methodology. Its potential value appears to be its simplicity, objectivity, reproducibility, lack of invasiveness, and lower cost relative to ultrasound. It is often used to supplement or replace DRE (Prostate cancer screening: PDQ health professional summary).

A significant controversy surrounding screening for prostate cancer is whether its promotion among the general public will result in increased false positives that will further result in unnecessary diagnostic procedures and increased public health costs. Further multicenter studies should be encouraged to help clarify this issue.

In the case of early detection for prostate cancer, Mountains of Hope will seek to arrive at a unified public message regarding the status of early detection and prostate cancer and the importance of discussing individual risk factors with a healthcare provider. Coalition partners will incorporate this message into educational tools for use in both the public and professional communities.

Early Detection of Prostate Cancer Goals and Objectives:

Four-Year Goal:	**Reduce prostate cancer-related deaths to 19.5 per 100,000 West Virginia males.**

Objective:

Develop a unified message for the public regarding the status of early detection of prostate cancer and the importance of discussing individual risk factors with a healthcare provider.

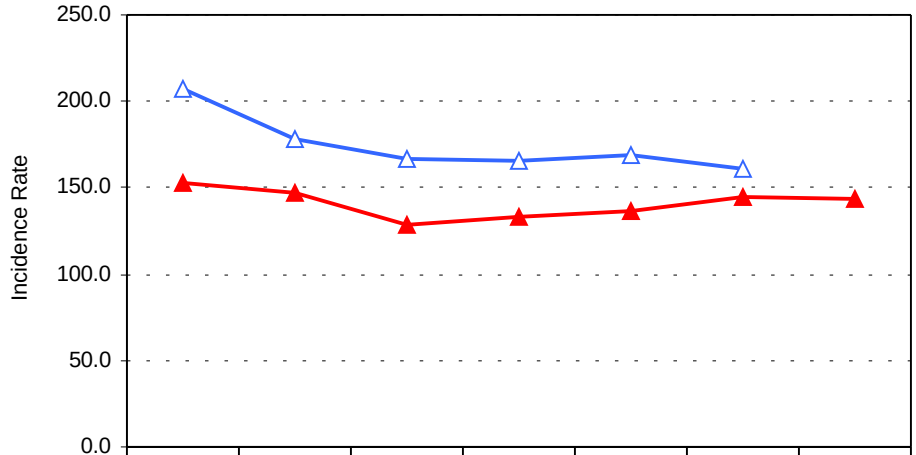
Strategies:

1. Convene a special session to come to a consensus on prostate cancer screening guidelines.

Cancer of the Prostate

Incidence Rates*, Age-Adjusted

West Virginia Males 1993 - 1999, U.S. Males 1993 - 1998



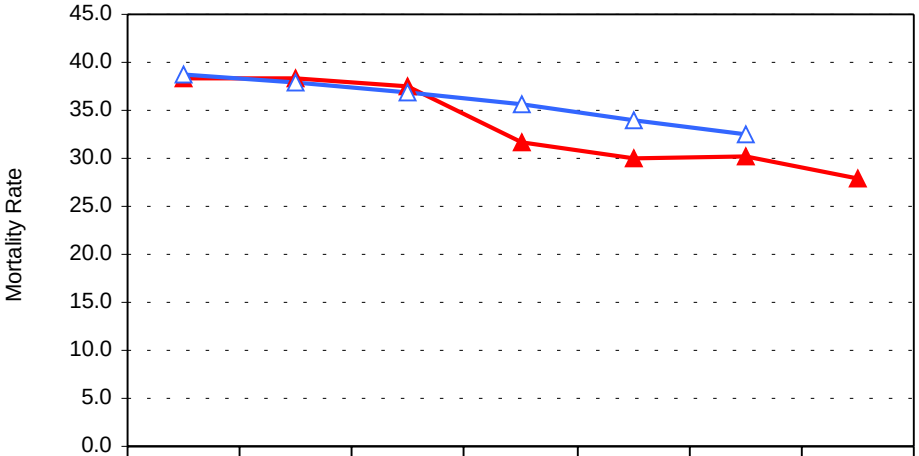
	1993	1994	1995	1996	1997	1998	1999
WV Males	152.5	146.8	128.2	133.2	136.2	144.7	143.1
US Males	207.7	178.4	166.8	165.9	168.9	161.4	

*Rates are per 100,000 males and are age-adjusted to the 2000 U.S. standard population. U.S. rates were calculated using SEER*Stat Version 4.0.9.

Cancer of the Prostate

Mortality Rates*, Age-Adjusted

West Virginia Males 1993 - 1999, U.S. Males 1993 - 1998



	1993	1994	1995	1996	1997	1998	1999
WV Males	38.3	38.4	37.5	31.6	30.1	30.3	27.9
US Males	38.8	38.0	36.9	35.7	33.9	32.5	

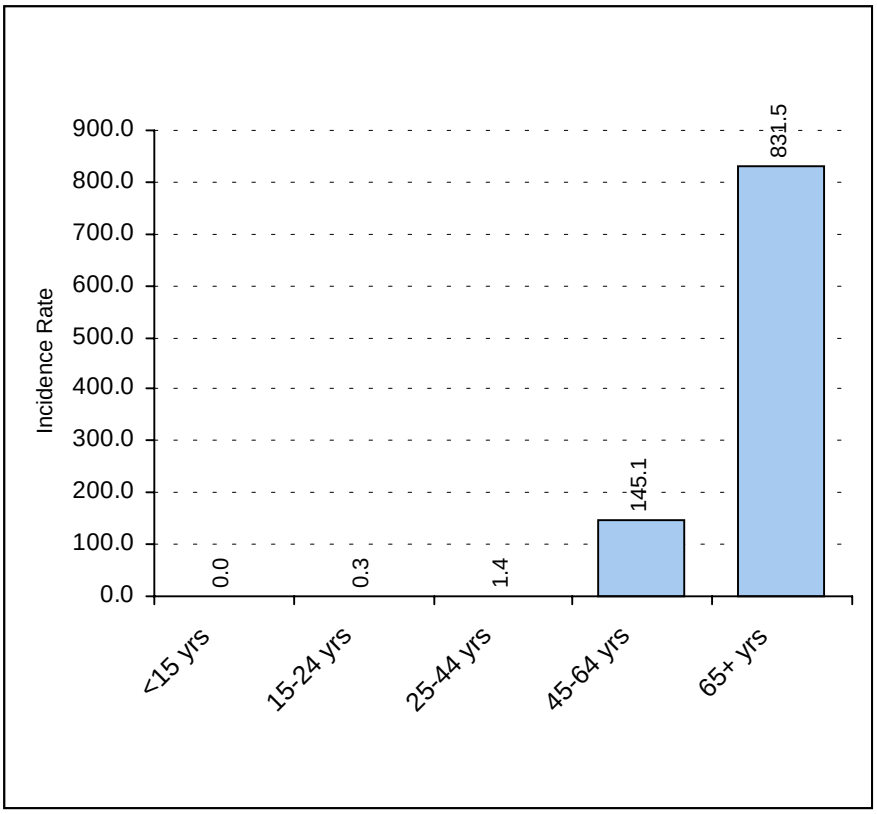
*Rates are per 100,000 males and are age-adjusted to the 2000 U.S. standard population. U.S. rates were calculated by the West Virginia Department of Health and Human Resources, Health Statistics Center, using National Center for Health Statistics mortality data.

Charts courtesy of *Cancer in West Virginia: Incidence and Mortality 1993-1999*. April 2002. West Virginia Department of Health and Human Resources. Charleston, WV

Cancer of the Prostate

Incidence Rates*, Age-Specific

West Virginia Males 1995 - 1999



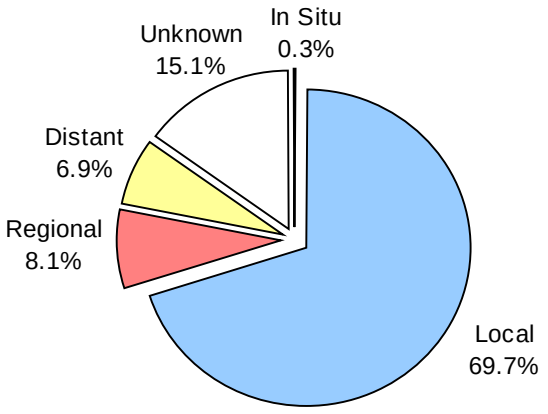
*Five-year average annual rate per 100,000 West Virginia males

Charts courtesy of *Cancer in West Virginia: Incidence and Mortality 1993-1999*. April 2002. West Virginia Department of Health and Human Resources. Charleston, WV

Cancer of the Prostate

Stage of Disease at Diagnosis

West Virginia Males 1995 - 1999



Primary Facilitators: Mountains of Hope Steering Committee, Mountains of Hope Early Detection Subcommittee, Mountains of Hope Medical Advisory Subcommittee

2. Use evidence-based approaches to develop education and information materials and a dissemination plan.

Primary Facilitators: Mountains of Hope Early Detection Subcommittee, West Virginia Bureau for Public Health Comprehensive Cancer Control Program, Mary Babb Randolph Cancer Center, American Cancer Society

Community Linkages: Appalachia Cancer Network Community representatives. Benedum Community Cancer Education Program community representatives.

3. Increase public awareness of prostate cancer risks and recommended screening guidelines.

Primary Facilitators: Mountains of Hope Early Detection Subcommittee, West Virginia Bureau for Public Health Comprehensive Cancer Control Program, Appalachia Cancer Network, American Cancer Society, Mary Babb Randolph Cancer Center, West Virginia Public Employees Insurance Agency, West Virginia Health Plan, West Virginia Minority Health Program, West Virginia Coalition for Minority Health, American Association of Retired People, Medicare, West Virginia Fire and Ambulance Authority, West Virginia State Police, West Virginia University Extension Service

Community Linkages: Helping Hands Health Right Community Cancer Education Program —Raleigh, Fayette, Summers and Wyoming Counties; PATCH/TEACH coalitions; Beat Cancer Coalition of Boone County "Mug-A-Man" Campaign; county health departments of Brooke, Hancock, Wheeling-Ohio, Marshall, Wetzel/Tyler counties; McDowell County Cancer Coalition; American Cancer Society "Man-To-Man"; Veterans of Foreign Wars; Lion's clubs; Rotary clubs; local police and fire persons

Early Detection References and Resources

Breast cancer screening: health professional summary. May 2001. PDQ database. National Cancer Institute.

Cancer in West Virginia: Incidence and Mortality 1993-1997. November 1999. Charleston, WV: West Virginia Department of Health and Human Resources. Division of Surveillance and Disease Control. W.V. Cancer Registry.

Cancer in West Virginia: Incidence and Mortality 1993-1998. March 2001. Division of Surveillance and Disease Control. W.V. Cancer Registry. Charleston, WV: West Virginia Department of Health and Human Resources.

Cervical cancer prevention: patient summary. August 2000. PDQ Database. National Cancer Institute.

Cervical cancer screening: health professional summary. November 2000. PDQ Database. National Cancer Institute.

The National Strategic Plan for the Early Detection of Breast and Cervical Cancers. 1994. Department of Health and Human Services. Atlanta: Centers for Disease Control and Prevention.

Eichholzer M. et al. 1996. Prediction of male cancer mortality by plasma levels of interacting vitamins: 17 year follow-up of the prospective Basel Study. *International Journal of Cancer* 66:145-150.

Frame, JN et al. 2001. Developing a rural colorectal screening program. *Oncology Issues* 16:12-16.

Friedman GD et al. 1991. Case-control study of screening for prostate cancer by digital rectal examinations. *Lancet A*. 337:1526-1529.

Fromer MJ. 2000. New emphasis on colorectal cancer screening with launch of last month's national colorectal cancer awareness month. *Oncology Times* 22:40-41.

Gann PH et al. 1994. Prospective study of plasma fatty acids and risk of prostate cancer. *Journal of the National Cancer Institute* 86:281-286.

Greenlee RT et al. 2001. Cancer statistics 2001. *CA: A Cancer Journal for Clinicians* 51:15-36.

Greenlee RT et al. 2000. Cancer statistics 2000. *CA: A Cancer Journal for Clinicians* 50:7-33.

Hall HI et al. 2000. Breast and cervical carcinoma mortality among women in the Appalachian Region of the U.S., 1976-1996. *Cancer* 89: 1593-1602.

Healthy People 2000 Review, 1993. 1994. Public Health Service, National Center for Health Statistics. Hyattsville (MD): Public Health Service.

Lindau ST et al. 2001. Improving rates of cervical cancer screening and Pap smear follow-up for low-income women with limited health literacy. *Cancer Investigator* 19:316-23.

Mammography. June 26, 1992. *Morbidity and Mortality Weekly Report*. 41(25):454-459.

Mandelblatt J, Gopaul I, Westreich M. 1986. Gynecological care of elderly women: another look at Papanicolaou Smear Testing. *Journal of the American Medical Association* 256:367-371.

Moody-Ayers SY, Wells CK, Feinstein AR. 2000. "Benign" tumors and "early detection" in mammography-screened patients of a natural cohort with breast cancer. *Archives of Internal Medicine* 160:1109-1115.

Morton MS, Griffiths K, Blacklock N. The preventive role of diet in prostate disease. British Journal of Urology 1996; 77:481-493.

National Cancer Institute. Division of Cancer Prevention and Control. Surveillance Program. Unpublished data, 1990.

North Carolina Cancer Control Plan. North Carolina Department of Environment, Health, and Natural Resources: Advisory Committee on Cancer Coordination and Control, May 1996.

Porter PL et al. Breast tumor characteristics as predictors of mammographic detection. Comparison of interval-and screen-detected cancers. *Journal of the National Cancer Institute* 1999; 91:2020-2028.

Prostate cancer and prevention: patient summary. January 2001. PDQ Database. National Cancer Institute.

Prostate cancer screening: health professional summary. March 2001. PDQ Database. National Cancer Institute.

Remington P, Lantz P, Phillips JL. 1990. Cervical cancer deaths among older women: implications for prevention. *Wisconsin Medical Journal* 89:32-34.

Ries LAG, Eisner MP, Kosary CL, Hankey BF, Miller BA, Clegg L, Edwards BK (eds.). 2000. *SEER Cancer Statistics Review: 1973-1997*. National Cancer Institute. Bethesda, MD.

Rural Health Plan. 1991. West Virginia Rural Hospital Flexibility Program. Office of Community and Rural Health Services.

Scardino PT. 1989. Early detection of prostate cancer. *Advances in Urologic Ultrasound* 16:635-655.

Screening for colorectal cancer-United States, 1997. February 19, 1999. *Morbidity and Mortality Weekly Report* 48:116-121.

Self-reported use of mammography among women aged 40 years old or older-United States, 1989 and 1995. October 10, 1997. *Morbidity and Mortality Weekly Report* 46(40): 937-941.

State-specific prevalence of selected health behaviors by race and ethnicity-Behavioral Risk Factor Surveillance System, 1997. March 24, 2000. *Morbidity and Mortality Weekly Report* 49:1-60.

Tessaro IA et al. 2000. Adapting a natural (lay) helper model of change for worksite health promotion for women. *Health Education Research Theory and Practice* 15:603-614.

United States Census 2000. U.S. Census Bureau.

West Virginia Breast and Cervical Cancer Screening Program. May 2001. Noncompeting continuation application, year 11. West Virginia Department of Health and Human Resources. Office of Maternal, Child and Family Health.

What you need to know about prostate cancer. 2000. U.S. Department of Health and Human Services. National Institutes of Health. National Cancer Institute.

The underserved, such as the rural indigent, frequently do not have adequate access to high-quality cancer prevention, screening, early detection, treatment, and rehabilitation services.

VI

Patient Care and Survivorship

During the course of their disease, cancer patients and their families face many challenges: access to information, diagnosis and treatment concerns, access to care, •pain control, financial concerns, and end-of-life issues. Assuring patients that accessible, affordable, state-of-the-art care is available to them is a critical aspect of effective cancer care.

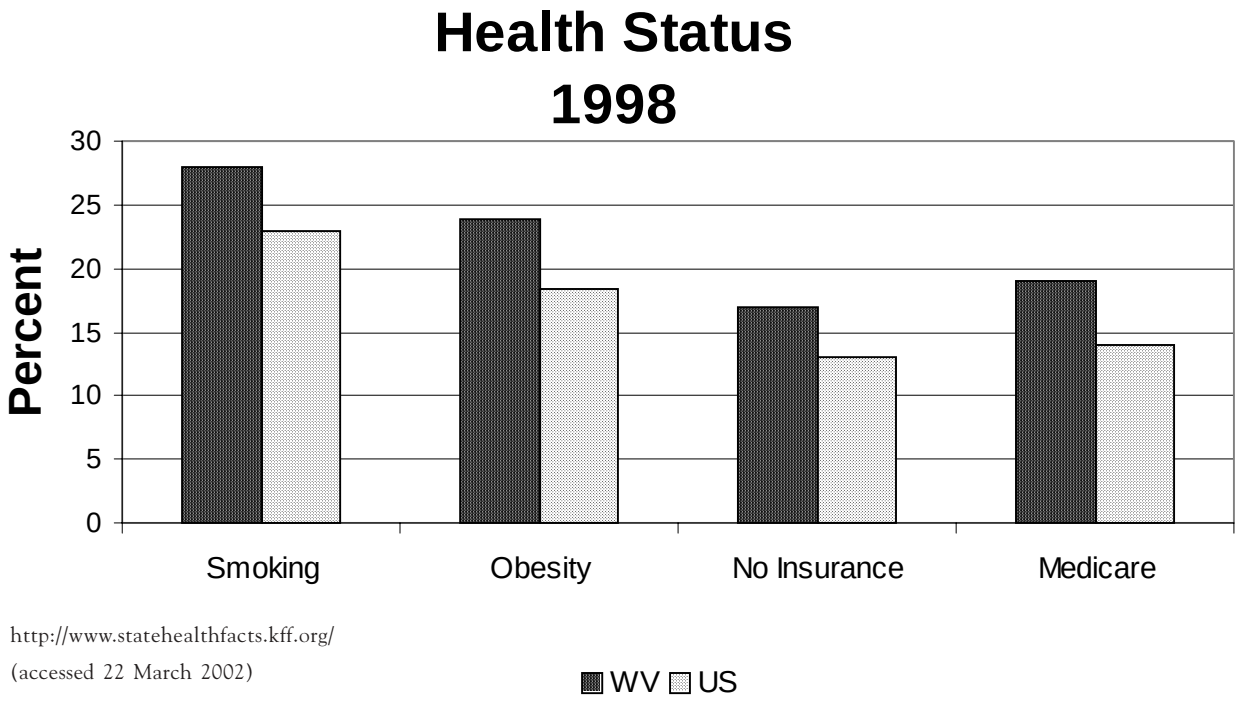
The National Cancer Institute predicted that approximately 1,268,000 new cancer cases would be diagnosed in the United States in 2001; almost 11,000 of these would be in West Virginia. Despite significant strides in cancer management, large numbers of Americans continue to die of the disease. The ACS estimated that 553,400 Americans would die from cancer, of which approximately 4,800 would be West Virginians. Cancer is the second leading cause of death in this country, exceeded only by cardiac disease; it accounts for approximately 25 percent of all deaths in the United States. According to CDC data for the years 1994-1998, West Virginia has the 6th highest age-adjusted cancer mortality rate among the 50 states and the District of Columbia.

West Virginia, known as the Mountain State, has the highest average elevation of any state east of the Mississippi River and is the only state to lie completely within the Appalachian region. According to U.S. Census Bureau estimates, West Virginia is the second most rural state in the nation, with 64 percent of its population living in communities of less than 2,500. Categorized by population density, 43 (or 78 percent) of its 55 counties have a rural designation.

Studies have shown that residents in rural regions areas and those in lower economic strata more often have poorer health profiles than urban residents and middle-income families. Historically, West Virginia statistics have presented a negative view of overall health in the state, which has the second or third worst overall health profile in the nation.

Rural residents often report their health status to be worse than their urban counterparts. According to the 1987 National Medical Expenditure Survey, 28 percent of the nation's adult rural population described its health status as fair/poor compared to only 20.6 percent of those living in core metropolitan areas. That same survey also reported that adult chronic conditions were more prevalent in rural areas, with 46.7 percent of the rural popu-

lation claiming chronic ill health compared to 39.2 percent of the core metropolitan population (Braden 1994). In the 1997 Current Population Survey, the rural elderly also reported their health status as fair/poor more often than their urban counterparts. The number of elderly nonmetro residents who reported fair/poor health status was about 6 percent higher than metro residents 60 years old and older (Rogers 1997).



http://www.statehealthfacts.kff.org/
(accessed 22 March 2002)

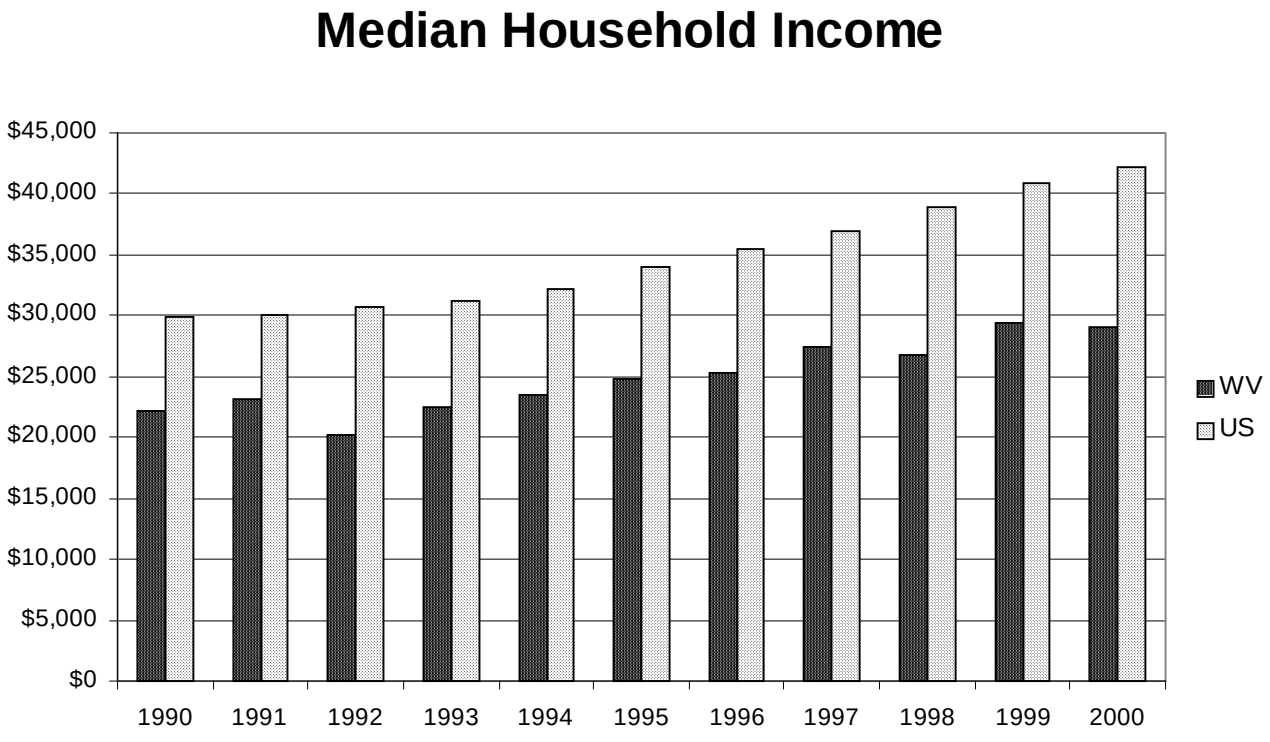
The underserved, such as the rural indigent, frequently do not have adequate access to high-quality cancer prevention, screening, early detection, treatment, and rehabilitation services. There is evidence that, compared to their urban counterparts, rural cancer patients are more likely to be diagnosed at later stages of the disease, more likely to be unstaged at diagnosis, and be at a more advanced stage of illness when referred to home healthcare agencies (Liff et al. 1991; Monroe et al. 1992).

Ironically, reductions in some cancer mortality rates present new challenges. Once seen only as a terminal illness, for many patients cancer is now a chronic disease. Fifty years ago, only 20 percent of cancer patients were alive five years after their diagnosis; today, the five year relative survival rate for all cancers combined is 60 percent. NCI estimated that almost 9 million Americans with a history of cancer were alive in 1997 (Cancer Facts & Figures 2001). This happy change sometimes presents new challenges and significant stresses for both patients and their support systems as affected individuals learn to deal with additional quality of life and related issues.

Access to Information

In order for patients, their family members and healthcare providers to make sound decisions about their disease, they need access to timely, accurate, accessible and understandable information. The highest priority for families of cancer patients, regardless of disease stage, is information about the disease, its treatment and prognosis (Tringali 1986). However, there is compelling evidence that use of health information divides along education and income levels, creating a gap between those termed the "health wealthy" and the "health poor" (Deering 1996). Low-income, rural residents and those with low reading or educational levels are counted among those considered the "health poor." They are often underserved in terms of their access to health information and services.

West Virginia's educational levels have risen in recent decades; however, according to the United States Census 2000, the state still lags behind national averages in several key areas of educational attainment. Eighty-four percent of all adult Americans aged 25 and over completed high school compared to 67.1 percent of West Virginians; 26 percent of all adult Americans aged 25 and over have a bachelor's degrees compared to only 15.3 percent of West Virginians (Newburger 2000). In fact, in many rural counties only 32 percent of the state's population has at least an eighth grade education (West Virginia County Health Profiles 2000).



U.S. Census; Historical Income Tables—Households; Table H-8. Median Household Income by State: 1984 to 2000; <http://www.census.gov/hhes/income/histinc/h08.html>; (accessed: 26 March 2002).

More than 18 percent of the population lives below the Federal Poverty Level. It ranked 48th out of 50 states in personal income per capita (1995) and 5th among the states in percent of population below the poverty level (1994). The total unemployment rate was 6.3 percent (1997).

Deering noted that those in the "health poor" class were three times more likely not to seek health information when they had a health problem, twice as likely to have problems getting information, and three times less likely to read health-related information. In addition, they are also twice as likely to avoid treatment, five times more likely to apply home remedies, two to three times more suspicious of doctors, and have more health risks than the "health wealthy." In partial confirmation of these findings, 44 percent of West Virginia men with a 12th grade education or less smoke, compared to the national average of 28 percent; fewer than 39 percent of West Virginia women with less than a high school education have ever had a mammogram, compared to national rate of over 65 percent (West Virginia County Health Profiles 2000).

The two primary organizations actively involved in disseminating comprehensive cancer information to West Virginians are the NCI Cancer Information Service (CIS) and the ACS. The CIS, housed at the Mary Babb Randolph Cancer Center in Morgantown, serves West Virginia, Virginia, Maryland, and Washington, D.C. The CIS is a resource for the latest and most accurate cancer information for patients and their families, the public, and health professionals via its toll free telephone service (1-800-4-CANCER) and Website [http://www.cancer.gov]. For those with Internet access, the same information is available along with "Live Help," an electronic, instant-messaging service to help users navigate the NCI site. Through either the telephone or Live Help, CIS users may receive

- understandable answers to questions about cancer, including information on prevention, symptoms and risks, diagnosis, current treatments, and research studies;
- screening guidelines, financial assistance, genetic testing and counseling statistics;
- written materials from the NCI;
- referrals to cancer-related services such as treatment centers, mammography facilities, other cancer organizations, and clinical trials; and
- assistance in quitting smoking from information specialists trained in smoking cessation counseling.

CIS Information Specialists undergo rigorous training and must follow strict quality assurance and confidentiality protocols. They are experienced at explaining complex medical information to the public. Because not all people have access to cancer information by telephone, the CIS Partnership Program provides issue-specific training, materials and other technical assistance to organizations and coalitions throughout the state to help ensure access to high-quality information for everyone.

The ACS is a nationwide, community-based, voluntary health organization. There are over 3,500 ACS volunteers in West Virginia and 31 full-time staff. The society has a

long-standing commitment to educating the public about cancer and addressing some of the special needs of cancer survivors. Through the ACS's national toll free service (1-800-ACS-2345) and Website [http://www.cancer.org], West Virginians have access to credible information on research, detection, diagnosis and treatment of various cancers, and rehabilitation and supportive care available in the local community.

Recently, the ACS completed a detailed survey of cancer-related community resources in the state. These county-level community assessments include a description of each community, including population, age, race, income, and an overview of the economics, industry, education, medical services and communication outlets. In addition, the report examined site-specific data for breast, prostate, lung and colon cancers as well as the overall cancer burden for the community and compared that data to state and national incidence and mortality numbers. The assessments also examined patient support, quality-of-life issues and comprehensive school health education issues. There are assessments for all 55 West Virginia counties; they are available from the ACS by calling the toll-free number.

Patient Access to Information Goal

Four-Year Goal:	**Increase public and provider awareness about the availability of high-quality information, resources for patients, and support programs in West Virginia.**

Objective:

Assess the awareness of the public, providers and patients about the cancer information resources and support services available in West Virginia.

Strategies:

1. Assess and map current utilization of national and state cancer information services.

Primary Facilitators: American Cancer Society, NCI Cancer Information Service

Community Linkages: Community Hospital Comprehensive Cancer Programs, American College of Surgeons Hospitals, Cooperative Community Oncology Programs

2. Survey providers about their awareness and use of cancer information and support services and their referral of patients to those resources.

Primary Facilitators: Mountains of Hope Patient Care and Survivorship Subcommittee, Mountains of Hope Medical Advisory Subcommittee, West Virginia Bureau for Public Health Comprehensive Cancer Control Program, West Virginia Registry, NCI Cancer Information Service, American Cancer Society, West Virginia Hospital Association, West Virginia Medical Society, West Virginia University School of Medicine, School of Pharmacy, School of Dentistry and School of Nursing, Marshall University School of Medicine,

Charleston Area Medical Center, West Virginia Osteopathic Medicine, North Central West Virginia Chapter of the Oncology Nursing Society, CAMC Health Education and Research Institute

Community Linkages: Community Hospital Comprehensive Cancer Programs, American College of Surgeons Hospitals, Cooperative Community Oncology Programs

3. Survey cancer patients about their awareness and use of cancer information and support services.

Primary Facilitators: West Virginia Public Employees Insurance Agency, Medicare, West Virginia Medicaid, West Virginia Health Plan, West Virginia Cancer Registry, NCI Cancer Information Service, American Cancer Society, West Virginia University Office of Health Services Research

Community Linkages: cancer patients; Northern Panhandle county health departments of Brooke, Hancock, Wheeling-Ohio, Marshall, and Wetzel/Tyler; Tri-County (Grant, Hardy, Pendleton) Cancer Outreach for Prevention and Support; Hampshire County Cancer Coalition; Wayne County WATCH-Cancer Coalition; Roane County Cancer Education Coalition; Wetzel County Cancer Coalition; McDowell County Cancer Coalition; PATCH/ TEACH coalitions, Brooke-Hancock Family Resources Network; Planned Approach to Community Health Helping Hair-Ums Natural Lay Helpers

4. Use surveys and maps to identify ways to promote access to reliable cancer information and resources, particularly in areas showing low utilization.

Primary Facilitators: Mountains of Hope Patient Care and Survivorship Subcommittee, West Virginia Bureau for Public Health Comprehensive Cancer Control Program, NCI Cancer Information Service, American Cancer Society

Community Linkages: rural representatives, Appalachia Cancer Network Community Coalitions, West Virginia Breast and Cervical Cancer Screening Program Cancer Information Specialists, Pennsboro Medical Center, Valley Health Systems, West Virginia Health Right, West Virginia Medical Institute, Women's Health Center-Charleston, Greenbrier Valley Medical Center, St. Mary's Regional Cancer Center-Huntington, WV State Library Commission

5. Create electronic links to resources for high-quality information about cancer and related services through the Mountains of Hope Website and provide training on how to identify and evaluate trustworthy information on the Internet.

Primary Facilitators: Mountains of Hope Website Work Group, NCI Cancer Information Service, American Cancer Society, West Virginia CONSULT

Community Linkages: Public and patient focus groups

6. Use surveys and maps to identify ways to promote knowledge about the availability of support services for patients and their families and to enhance access to support services in areas of the state where none are available.

Primary Facilitators: West Virginia Bureau for Public Health Comprehensive Cancer Control Program, Mountains of Hope Patient Care and Survivorship Subcommittee, American Cancer Society, West Virginia Association of Social Workers, West Virginia Council of Churches, West Virginia Office of Minority Health, West Virginia University Extension Service

Community Linkages: Cancer patients, Appalachia Cancer Network community coalitions, West Virginia Breast and Cervical Cancer Screening Program Cancer Information Specialists

Financial Concerns

The National Institutes of Health estimates 180 billion dollars was spent on cancer-related costs in the year 2000. About one-third of these dollars went toward direct medical costs, while over 105 billion dollars went toward indirect mortality costs such as those related to lost productivity because of premature death. An additional 15 billion dollars was lost to indirect morbidity costs, or expenses related to lost productivity due to illness (Cancer Facts and Figures 2001). In a 1984 study by Houts et al., adult cancer patients mainly diagnosed with breast, colon, and lung cancer and receiving outpatient chemotherapy spent an average of $73 dollars per treatment week for nonmedical expenses and lost wages and $43 during a non-treatment week. For half of the families studied, the total expenses plus loss of pay totaled more than 25 percent of the weekly family income. In a 1991 study by Stommel et al., researchers calculated the value of unpaid family labor for cancer patients currently undergoing outpatient treatment. They calculated an average annual value of $14,204 in related services. They found average weekly costs due to out-of-pocket expenditures and loss of earnings to be $85, comparable to the results of the Houts et al. study.

Paying for the expenses associated with initial treatment and continuing care can be major concerns for cancer patients and their families. Generally, individuals who have life and health insurance prior to diagnosis are able to keep their policies, although some premiums and benefits may change significantly; however, individuals who change jobs or apply for new policies often find it difficult to get coverage. Cancer patients and their caregivers cited insurance issues and unmet financial needs as their most significant concern (Houts 1986; 1988).

The number and percentage of Americans without health insurance continues to increase. This national problem is even more serious in a predominantly rural state like West Virginia, which in 1993 ranked 10th in the nation in the percentage of its residents who were uninsured. In that year, 18.3 percent of West Virginia's adult population was

uninsured compared to 15.3 percent nationally (WV Rural Health Plan 1998). More recent statistics show the number of West Virginia uninsured closer to 20 percent (Better Health for West Virginia 2001). Some explanations of why greater numbers of rural people are uninsured relative to their urban counterparts include being self-employed, working for small businesses, doing seasonal work, or failing to apply for Medicaid (National Rural Health Association 1999).

From 1991 to 1993, the numbers of uninsured West Virginians increased by more than 50,000. During that same period, the state saw a 192 percent increase in Medicaid expenditures compared to the national increase of 57 percent. In 1993, the state ranked third in the percentage of population receiving Medicaid, which represented 19 percent of the population compared to 13 percent nationally (Better Health for West Virginia 2001).

West Virginia also lags behind many other states in the development of managed care options. In 1998 there were only seven active HMOs in the state (West Virginia Rural Health Plan 1998); however, by 2001 there were only three (Morris, Martha. personal communication. West Virginia Insurance Commission. July 24, 2001).

Compounding this problem is West Virginia's aging population. It is generally accepted that the risk of cancer increases with age. West Virginia ranks fifth in the nation in the percent of the population over age 65. Recently released U.S. Census figures show there are 268,897 West Virginians (15 percent of the state's population) at 65 years of age or older, a small increase over the past decade. These population figures foreshadow a future in which it is likely that the state will need to spend significantly more money to manage cancer and other chronic diseases. Dr. Henry Taylor, the state's Public Health Commissioner has stated, "Aging of the West Virginia population, by however you measure it, is clearly driving the types of healthcare problems in the state. It's also driving the costs, because the highest costs are at the end of life" (Miller 2001). It is no surprise that in 1993 West Virginia ranked second among the 50 states in the percentage of its population enrolled in Medicare—17.3 percent compared to 13.8 percent nationally.

In 1996 the State Legislature established the Breast and Cervical Cancer Diagnostic and Treatment Fund. The state is now able to provide uninsured, low-income women at 200 percent of the Federal Poverty Level with access to diagnostic services and limited treatments for breast and cervical cancers. The fund serves West Virginia residents only. From July 1996 through June 30, 2001, the legislature had appropriated $1,500,000 for this program and has almost doubled its original annual appropriation in the past two years. Since its inception, the fund has received more than 5,500 applications for assistance and provided help to more than 3,700 women.

The Treatment Fund Legislation allows private individuals and organizations to supplement these state-appropriated monies. With leadership provided by the WVBCCSP and Mountains of Hope, thousands of volunteers statewide annually raise money for the fund. In addition, a number of businesses and organizations make significant contributions.

In April 2001, West Virginia became one of three states to implement the new, federally funded Breast and Cervical Cancer Prevention and Treatment Act. Under this legislation, states may extend Medicaid coverage to any woman enrolled in the CDC-sponsored Title XV/Breast and Cervical Cancer Screening Program (BCCSP). To be eligible for full Medicaid benefits, without regard to income or asset tests, a woman must be under 65, be diagnosed with breast or cervical cancer, and be uninsured or otherwise lack credible insurance coverage.

In another effort by the state to ease the financial strain on those suffering from a catastrophic illness, the state's legislature in 1999, established the James "Tiger" Morton Catastrophic Illness Commission. The commission oversees a fund whose purpose is to provide economic assistance to West Virginians facing a catastrophic illness, for whom time is running out, and who have exhausted all financial resources, both public and private. Potential fund recipients must exhibit a critical need for access to medical treatment, care and related services that are unavailable through traditional sources. The applicant must have been a West Virginia resident one year prior to the onset or diagnosis of the disease.

In addition to publicly funded aid, there are a few privately endowed options. One example is the CASSIE Fund (Cancer Alternative Screening and Support Indemnity Endowment), a special fund designed to provide diagnostic and psychosocial services at the Betty Puskar Breast Care Center of the Mary Babb Randolph Cancer Center. Candidates must be uninsured or underinsured women who do not qualify for other state or federally funded programs providing breast diagnostic services.

Financial Access Goal and Objectives

Four-Year Goal: Reduce financial barriers in the care of cancer patients.

Objective I:

Identify and maximize the use of existing financial support options.

Strategies:

1. Identify the existing financial resources for West Virginia patients and details related to insurance coverage provided by major employers.

Primary Facilitators: Mountains of Hope Patient Care and Survivorship Subcommittee, Medicare, West Virginia Medicaid, West Virginia Public Employees Insurance Agency, Healthcare Review Authority

Community Linkages: Cancer patients, low-income and uninsured individuals, public employees

2. Acquire geographic, demographic, and financial information on patients currently without support.

Primary Facilitators: West Virginia Bureau for Public Health Comprehensive Cancer Control Program, West Virginia Breast and Cervical Cancer Screening Program, West Virginia Cancer Registry, American Cancer Society

Community Linkages: American Cancer Society Community Profiles

Objective II:

Seek out opportunities for additional financial support for the diagnosis and treatment of cancer.

Strategies:

1. Replicate the Breast Cancer Diagnostic and Treatment Fund for other cancers.

Primary Facilitators: West Virginia Bureau for Public Health Comprehensive Cancer Control Program, Mountains of Hope Patient Care and Survivorship Subcommittee, West Virginia Legislature, American Cancer Society

Community Linkages: Cancer patients

2. Explore approaches utilized by other states challenged by high rates of uncompensated care and patients without health insurance.

Primary Linkages: West Virginia Bureau for Public Health Comprehensive Cancer Control Program, Mountains of Hope Patient Care and Survivorship Subcommittee, Centers for Disease Control-funded Comprehensive Cancer Control Programs, American Cancer Society

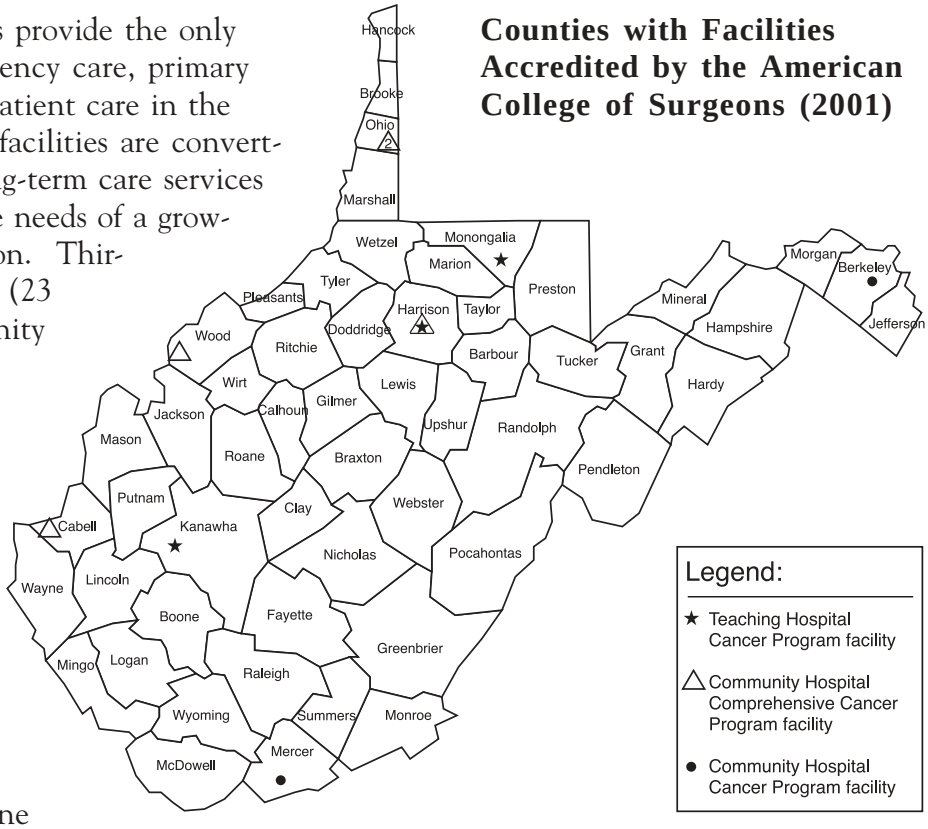
Community Linkages: Cancer patients

Access to Care

There are three medical schools in West Virginia: West Virginia University (Morgantown and Charleston), Marshall University (Huntington), and the School of Osteopathic Medicine (Lewisburg). Each of these schools has radiation therapy facilities, cancer specialists, and options for hospice care, transportation and local housing for cancer patients and their families. Each is affiliated with and supports active, accredited oncology programs. In 1998, half of West Virginia's hospitals were designated as small rural hospitals. The definition of a small rural hospital is a facility with fewer than 100 beds and fewer than 5,000 admissions annually; it must be located in a rural community of fewer than 10,000 persons. Often

these small rural hospitals provide the only obstetrics services, emergency care, primary care, and short-term, in-patient care in the area. Increasingly, these facilities are converting excess capacity to long-term care services in order to respond to the needs of a growing elderly rural population. Thirteen counties in the state (23 percent) have no community hospital facilities.

Counties with Facilities Accredited by the American College of Surgeons (2001)



Presently there are no NCI-designated comprehensive cancer centers in West Virginia. Community hospitals with oncology programs may voluntarily seek American College of Surgeons (ACOS) Commission on Cancer accreditation in one of several categories. Receipt of an ACOS designation indicates that a hospital provides high-quality cancer care to patients. At present, only ten West Virginia hospitals (7.2 percent) have any ACOS designation; nationally the figure is 20-22 percent. These hospitals include West Virginia University Hospitals in Monongalia County, Charleston Area Medical Center in Kanawha County, St. Mary's Hospital in Cabell County, Wheeling Hospital Inc. and Ohio Valley Hospital in Ohio County, City Hospital Inc. in Berkeley County, United Hospital Center and Louis A. Johnson VA Medical Center in Harrison County, Camden Clark Hospital in Wood County, and Princeton Hospital in Mercer County. Of these hospitals, only three—Charleston Area Medical Center, Louis A. Johnson VA Medical Center (military only) and West Virginia University Hospitals—received ACOS approval in the Teaching Hospital Cancer Program category (THCP). This designation is given to hospitals that have a minimum of four residency programs, two of which are in medicine and surgery. The facility must offer the full range of diagnostic and treatment services, on site or by referral. The medical staff must be board certified in the major medical specialties, including those in oncology where applicable. The facility must participate in clinical research and hold cancer conferences at least weekly.

Five other hospitals have Community Hospital Comprehensive Cancer Programs (COMP) designation: United Hospital Center, St. Mary's Hospital, Camden-Clark Memorial Hospital, Ohio Valley Medical Center and Wheeling Hospital Inc. These facilities offer a full range of diagnostic and treatment services, on site or by referral. Their medical staff must be board certified in the major medical specialties, including oncology where applicable.

Clinical research is required if the program accepts 750 or more analytic cases annually. All facilities in this category hold at least weekly cancer conferences. Two other hospitals are approved in the Community Hospital Cancer Programs category (CHCP): Princeton Community Hospital and City Hospital Inc.

Currently available information about radiation oncology services in the state is vague and can be misleading. Preliminary data, gathered by the West Virginia Hospital Association, indicate 17 locations that offer some type of radiology service. However, the association presently is unable to identify the extent of radiation oncology services offered or the type of equipment used at these locations. It would be useful for patients and their healthcare providers to more easily identify locations of licensed linear accelerators and treatment simulators.

The West Virginia State Medical Association identifies 24 oncologists in 11 counties. There are fewer than 50 certified oncology nurses in the state. There is one Oncology Nursing Society chapter in West Virginia; it is based in Morgantown. There is hospice service in only 22 West Virginia communities.

Convenient access and proximity to health-related services often influence their use by patients. West Virginia—with its mainly rugged, mountainous terrain that features small, isolated communities and winding secondary roads—presents many transportation challenges, especially for the almost two-thirds of the population that live in rural communities with fewer than 2,500 residents. Currently there is no inventory of available services or centralized coordination of patient transport. Because current transportation efforts often depend on volunteers, they may not be readily available or reliable. Patients and their families would benefit from a more coordinated approach to this issue. A similar situation exists regarding patient housing, though at some of the larger facilities there is some limited housing assistance for patients undergoing active treatment.

In a recent survey of 287 Lincoln County residents, about 49 percent of respondents said they traveled 16 miles or more to reach a doctor or healthcare provider. About 29 percent of respondents said they had to rely on others for transportation to and from their provider. About 59 percent of respondents reported that lack of a vehicle or driver was the biggest barrier to access to health care. The survey was conducted as part of a study by the Center for Rural Health and the Appalachian Transportation Institute, two agencies affiliated with Marshall University.

Access to Care Goal and Objectives

Four-Year Goal:	**Increase access to care and support services for cancer patients and survivors.**

Objective I:

Assess the availability of services and the regional distribution of cancer care facilities.

Strategies:

1. Identify all cancer treatment programs throughout the state.

Primary Facilitators: West Virginia Cancer Registry, Mountains of Hope Patient Care and Survivorship Subcommittee, West Virginia Chapter of the American College of Surgeons, Community Hospital Comprehensive Cancer Program, West Virginia Hospital Association, West Virginia Medical Association

Community Linkages: Appalachia Cancer Network community coalitions

2. Identify specific populations and geographic areas in need of additional cancer-related services.

Primary Facilitators: West Virginia Bureau for Public Health Comprehensive Cancer Control Program, Mountains of Hope Patient Care and Survivorship Subcommittee, West Virginia Center for Rural Health, Rural Health Education Partnership Program, West Virginia Hospital Association, West Virginia Cancer Registry

Community Linkages: Appalachia Cancer Network community coalitions

Objective II:

Identify the barriers to care for patients and survivors in West Virginia.

Strategies:

2. Assess trends from transportation studies conducted over the past five years.

Primary Facilitators: West Virginia Bureau for Public Health Comprehensive Cancer Control Program, Mountains of Hope Patient Care and Survivorship Subcommittee, West Virginia Department of Transportation, Appalachian Regional Commission, Center for Rural Health, Appalachian Transportation Institute (Marshall University)

3. Survey cancer patients, family members, healthcare providers and cancer survivors regarding barriers to care.

Primary Facilitators: West Virginia Bureau for Public Health Comprehensive Cancer Control Program, Mountains of Hope Patient Care and Survivorship Subcommittee, West Virginia Primary Care Association, West Virginia Chapter of the American College of Surgeons, West Virginia Rural Health Education Partnerships, West Virginia Medical Association, West Virginia Nurses Association, American Cancer Society, NCI Cancer Information Service

Community Linkages: Cancer patients, Appalachia Cancer Network Community Coalitions, Breast and Cervical Cancer Screening Program Cancer Information Specialists

Objective III:

Develop a Mountains of Hope work group to determine measures for increasing access.

Strategies:

1. Develop a comprehensive report based on the above sources of information.

Primary Facilitators: West Virginia Bureau for Public Health Comprehensive Cancer Control Program, Mountains of Hope Patient Care and Survivorship Subcommittee

Community Linkages: Cancer survivors

2. Identify appropriate partners to address access issues.

Primary Facilitators: West Virginia Bureau for Public Health Comprehensive Cancer Control Program, Mountains of Hope Patient Care and Survivorship Subcommittee, Center for Rural Development, American Cancer Society

Community Linkages: cancer survivors

Diagnosis and Treatment

While the state of West Virginia remains committed to assisting communities in providing a "coordinated, community-based continuum of care," there are many challenges to achieving that goal. Reasonable access to diagnostic and treatment services remains an elusive goal for many West Virginians. In 1998 almost 91 percent of all West Virginia counties still had some portion identified by the federal government as "medically underserved" (WV Rural Health Plan 1998). Physician shortages in rural areas have been a consistent problem for West Virginia. Almost 30 percent of the state's population does not have access to a primary care provider; in 1998 there were 122 unfilled requests for primary care physicians for rural underserved areas (West Virginia Rural Health Plan 1998).

Information about the availability of oncologic diagnostic and treatment services in West Virginia is sometimes misleading. While the PDQ database lists 15 cancer treatment programs, only three of these provide the full range of pediatric and adult treatment modalities, and only four provide access to clinical trials. Only one hospital, West Virginia University's Ruby Memorial, does bone marrow transplants. The West Virginia Hospital Association database lists thirty-six hospitals with oncology services; however, approximately one-third of the list is made up of small, rural facilities with extremely limited on-site services. Even patients seen at some larger community hospitals are referred to larger facilities for some diagnostic and treatment services; these programs are often located far from the patient's home.

Clinical trials are one of the most important methods of finding better ways to prevent and treat cancer. Clinical trials test many types of treatments: new drugs, new approaches to other therapies, new combinations of treatments or new methods such as gene therapy. Most of today's most effective standard treatments are based on previous study results. Clinical trials may also answer important scientific questions and suggest future research directions. Because of progress made through clinical trials, many people treated for cancer are now living longer.

There are no hard data as to why so few West Virginians participate in clinical trials. However, the anecdotal evidence points to several possibly relevant factors. First, as previously noted, the PDQ lists only four locations in the state that participate in trials. Patients would need to arrange for travel and housing. There is evidence that many West Virginians cannot afford these expenditures, even when their health insurance covers some of these costs. Other reasons include the lack of physicians' awareness and knowledge of the clinical trial process and not presenting trials as a treatment option. Additionally, patients are often reluctant to leave their current doctor or the area. The CIS has a current initiative to educate providers and patients about clinical trials. Current research is exploring whether cultural barriers specific to the state also inhibit participation in clinical trials.

Diagnosis and Treatment Goal

Four-Year Goal:	**Ensure the highest quality diagnosis, treatment and care are available to all West Virginians.**

Objective I:

Identify gaps in high-quality cancer diagnosis and treatment in West Virginia.

Strategies:

1. Come to consensus around what constitutes "high quality" cancer diagnosis and treatment.

Primary Facilitators: West Virginia Bureau for Public Health Comprehensive Cancer Control Program, Mountains of Hope Patient Care and Survivorship Subcommittee, NCI Cancer Information Service, American Cancer Society, North Central West Virginia Chapter of the Oncology Nursing Society, Center for Health Ethics and Law, West Virginia Chapter of the American College of Surgeons, Leukemia and Lymphoma Society, Office of Facility Licensure and Accreditation (OFLAC), American Lung Association, Susan G. Komen Breast Cancer Foundation, West Virginia Association of Radiologists, West Virginia Pharmacy Board, West Virginia Medical Board, National Cancer Institute

Community Linkages: Cancer patients and survivors

2. Assess public and patient perception of what constitutes "high quality."

Primary Facilitators: West Virginia Bureau for Public Health Comprehensive Cancer Control Program, Mountains of Hope Patient Care and Survivorship Subcommittee, NCI Cancer Information Service, American Cancer Society, West Virginia University Prevention Research Center, Mary Babb Randolph Cancer Center, Appalachia Cancer Network, West Virginia Breast and Cervical Cancer Screening Program

Community Linkages: Cancer patients and public representatives

3. Develop and endorse a culturally appropriate "Patient's Guide" for distribution to every newly diagnosed cancer patient in West Virginia.

Primary Facilitators: West Virginia Bureau for Public Health Comprehensive Cancer Control Program, Mountains of Hope Patient Care and Survivorship Subcommittee, NCI Cancer Information Service, American Cancer Society, West Virginia University Prevention Research Center, Mary Babb Randolph Cancer Center, Appalachia Cancer Network, West Virginia Breast and Cervical Cancer Screening Program

Community Linkages: West Virginia Primary Care Association, West Virginia hospitals, Appalachia Cancer Network Community Coalitions, West Virginia University Extension Service, West Virginia senior centers

4. Increase public, patient, and provider awareness about clinical trials.

Primary Facilitator: NCI Cancer Information Service, Mary Babb Randolph Cancer Center, Appalachia Cancer Network, West Virginia Bureau for Public Health Comprehensive Cancer Control Program, Mountains of Hope Patient Care and Survivorship Subcommittee, West Virginia Breast and Cervical Cancer Screening Program, American Cancer Society

Community Linkages: West Virginia Primary Care Association, West Virginia hospitals, Appalachia Cancer Network Community Coalitions, West Virginia University Extension Service, West Virginia senior centers

Pain Control and End-of-Life Issues

Access to high-quality cancer care is inclusive across a continuum of care from pre-birth to natural death. Pain control and end-of-life care are important but often neglected aspects of this continuum. The goals of Healthy People 2010 are to (1) improve the quality of life and years of healthy living and (2) eliminate health disparities. All people are entitled to enhanced quality of life until the very moment of their death. Healthy dying is a natural part of healthy living.

West Virginians have recently expressed dissatisfaction with, and a desire to improve, the current provision of end-of-life care. A series of community dialogue meetings were held across the state in 1999 as part of the West Virginia Initiative to Improve End-of-Life Care (funded through July 2002 by the Robert Wood Johnson Foundation, the West Virginia Humanities Council, the Claude Worthington Benedum Foundation, and the Project on Death in America.). West Virginia is among only 17 states to receive such funding. During these community dialogues, residents identified several needs: greater attention to advanced care planning (including where death occurs), greater access to palliative care and hospice services, and greater attention to pain management at the end of life. Adequate end-of-life care must focus on the needs of family and friends as well as on the needs of patients. The literature documents the negative health effects of death and dying on survivors. The Initiative to Improve End-of-Life Care also surveyed pharmacists, physicians, nurses, and social workers across the state. Most healthcare professionals rated end-of-life care in West Virginia as only fair.

Several challenges to improving end-of-life care are pronounced in West Virginia. They include a larger proportion of elderly living in rural areas and a higher percentage of deaths from chronic disease than in other states.

West Virginia has the highest median age of all states at 37.7 years and ranks fifth in the nation in the percentage of the population over the age of 65. According to the 1990 U.S. Census, the aging population represented 15 percent (268,897) of the total population. By the year 2020, this number is expected to reach 345,000, a 28 percent increase.

West Virginia is the second most rural state in the country with 64 percent of its population living in rural areas. Most of the state's elderly reside in rural areas, even though its ratio of urban to rural elderly does increase with age. The ratio is .78 for the 65^{+} age group, .82 for the 75^{+} group, and .91 for the 85^{+} group. Referrals to hospice are low, and reimbursement to hospices for care of patients in rural areas is well below the costs. The reality is that many older adults confront barriers to obtaining healthcare services and resources such as hospices and nursing homes.

National data have indicated that people prefer to die in the comfort of their own homes, surrounded by loved ones. In West Virginia in 1997, out of a total of 20,872 deaths, 10,243 people died in a hospital and 4,917 died at home. Only 11.3 percent of the

individuals who died in their homes had hospice services, a figure that remains 35 percent below the national average of 17 percent. Only 2 percent of nursing home residents received hospice care in 1997.

The Center for Health Ethics and Law at the West Virginia University Robert C. Byrd Health Sciences Center has been the lead organization for the West Virginia Initiative to Improve End-of-Life Care. The Center for Health Services and Outcomes Research of the CAMC Health Education and Research Institute is the lead organization for data collection and analysis for this project.

The initiative is a statewide, multidisciplinary, comprehensive and public participatory effort to improve all aspects of end-of-life care for the citizens of West Virginia. The initiative consists of the following organizations:

Bureau of Senior Services
West Virginia Department of Health and Human Resources Guardianship Commission
West Virginia Boards of Medicine and Pharmacy
West Virginia State Medical Association
West Virginia State Bar
Hospice Council of West Virginia
West Virginia Health Care Association
West Virginia Hospital Association
West Virginia Council of Home Health Agencies
West Virginia Network of Ethics Committees
West Virginia Cancer Pain Initiative
West Virginia Humanities Council
West Virginia Rural Health Education Partnerships
West Virginia Chapter of the National Association of Social Workers
Center for Health Ethics and Law
West Virginia University Schools of Medicine, Nursing, and Pharmacy
West Virginia School of Osteopathic Medicine
Marshall University School of Medicine
CAMC Health Education and Research Institute
West Virginia University Health Center for Pain Management
Professional Anesthesia Services, Inc.
Northern West Virginia Pain Management Center
Catholic Diocese of Wheeling-Charleston
Synod of the West Virginia-Western Maryland Evangelical Lutheran Church in America
West Virginia Council of Churches
West Virginia University Departments of Public Administration and Social Work;
American Association of Retired People
Legal Aid Society Long-term Care Ombudsman Program
South Central West Virginia AIDS Network

The West Virginia Initiative to Improve End-of-Life Care has seven task forces to develop the mechanisms to meet the 2010 objectives. The seven task forces are Funding and Finance, Professional Education, Palliative Care Delivery Systems, Cultural and Spiritual, Policy, Community Visioning, and Survey and Needs Assessment. Various programs that will contribute to meeting the 2010 objectives have already been put in place:

- Education—various programs, including a media campaign, to educate healthcare professionals and the public about end-of-life care.
- Financing—establish more complete and efficient financial coverage for end-of-life care. Change the Medicaid disincentive to bringing hospice care into long-term care facilities and develop a model hospice benefit for managed care.
- Palliative Care Delivery Systems—facilitate the development of palliative care teams in hospitals, long-term care facilities, and communities.
- Policy—educate the state legislature about pertinent policy issues related to end-of-life care, including decision-making and pain management.
- Public Discussion—foster a statewide dialogue around the issues of death and dying and increase the comfort of citizens in addressing end-of-life issues.
- Statewide Resources—develop a toll-free information number (1-877-209-8086) and Website (www.wvinitiative.org) to serve as resources for patients, families, and healthcare professionals; monitor and share the latest developments in end-of-life care.

The West Virginia Center for Health Ethics and Law and the West Virginia Initiative have proposed to the West Virginia Legislature that a West Virginia Center for Palliative Care and Hospice be established as a statewide resource to meet the end-of-life objectives of Healthy People 2010 and the 2000-2002 State Health Plan. This center will help ensure a long-range approach to meeting the objectives and serving the healthcare professionals and citizens of West Virginia.

Pain Control and End-of-Life Issues Goal and Objectives

Four-Year Goal:	**Ensure each West Virginia cancer patient has access to treatment and resources that allow for optimal pain control and end of life support.**

Objective I:

Collaborate with the West Virginia Pain Initiative and West Virginia Initiative to Improve End-of-Life Care.

Strategies:

1. Recruit members of the West Virginia Pain Initiative and the West Virginia Initiative to Improve End-of-Life Care to join the Mountains of Hope Coalition and jointly develop a plan of action and recommendations for cancer patients.

Primary Facilitators: Mountains of Hope Patient Care and Survivorship Subcommittee, American Cancer Society, Mary Babb Randolph Cancer Center, West Virginia University Center on Aging, Center on Health Ethics and Law, End of Life Initiative, Council of Churches, West Virginia Hospice Council, American Association of Retired People

Community Linkages: Cancer survivors, senior centers, Area Agencies on Aging

2. Assess public and patient perceptions and expectations of cancer-related pain and preferences concerning the end of life.

Primary Facilitators: Mountains of Hope Patient Care and Survivorship Subcommittee, West Virginia Pain Initiative, End of Life Initiative, American Cancer Society, Appalachia Cancer Network, Benedum Community Cancer Education Programs, West Virginia University Prevention Research Center, West Virginia University Department of Community Medicine, West Virginia University Center on Aging, West Virginia Hospice Council, Bureau of Senior Services, American Association of Retired People

Community Linkages: Cancer survivors, senior centers, Area Agencies on Aging, West Virginia University Extension Agents, home health nurses, Appalachia Cancer Network Community Coalitions, West Virginia Breast and Cervical Cancer Screening Program Cancer Information Specialists

3. Endorse and promote recommendations on cancer pain and end-of-life issues to the public, patients and providers.

Primary Facilitators: West Virginia Bureau for Public Health Comprehensive Cancer Control Program, West Virginia Breast and Cervical Cancer Screening Program, Appalachia Cancer Network, American Cancer Society, Benedum Community Cancer Education Programs, West Virginia University Prevention Research Center, Charleston Area Medical Center, West Virginia Pain Initiative, End of Life Initiative, Mary Babb Randolph Cancer Center, West Virginia Hospice Council, American Association of Retired People, West Virginia Council of Home Health Agencies, Council of Churches, local ministerial associations, Center on Aging, Bureau of Senior Services, West Virginia University School of Medicine, West Virginia University School of Pharmacy, West Virginia University School of Nursing, Leukemia and Lymphoma Society, American Lung Association

Community Linkages: Pharmacists, cancer survivors, senior centers, Area Agencies on Aging, West Virginia University Extension agents, home health nurses, Appalachia Cancer Network Community Coalitions, West Virginia Breast and Cervical Cancer Screening Program Cancer Information Specialists

Care and Survivorship References and Resources

Cancer Facts and Figures 2001. 2001. American Cancer Society, Inc.

Better health for West Virginia: Affordable health coverage for West Virginia Families. January 2001. Recommendations for 2001. West Virginia Community Voices Partnership in collaboration with the Healthy Kids Coalition and the American Friends Service Committee.

Breast cancer screening: health professional summary. May 2001. PDQ database. National Cancer Institute.

Braden J, Beauregard K. 1994. *Health Status and Access to Care of Rural and Urban Population*. Agency for Health Care Policy and Research (No. 94-0031).

Brown, ML, Hodgson TA, Rice DP. 1996. Economic impact of cancer in the United States. In: Schottenfeld D, Fraumeni JF, Editors. *Cancer Epidemiology and Prevention*. 2nd edition. Oxford University Pres.

Cancer in West Virginia: Incidence and Mortality 1993-1998. Charleston, WV: West Virginia Department of Health and Human Resources. Division of Surveillance and Disease Control. W.V. Cancer Registry, March, 2001.

Cancer in West Virginia: Incidence and Mortality 1993-1997. November 1999. Charleston, WV: West Virginia Department of Health and Human Resources. Division of Surveillance and Disease Control. W.V. Cancer Registry.

Cervical cancer screening: health professional summary. November 2000. National Cancer Institute.

Cervical cancer prevention: patient summary. August 2000. PDQ Database. National Cancer Institute.

Deering MJ. 1996. Consumer health information demand and delivery: Implications for libraries. *Bulletin of the Medical Library Association* 84:209-216.

Eichholzer M. et al. 1996. Prediction of male cancer mortality by plasma levels of interacting vitamins: 17 year follow-up of the prospective Basel study. *International Journal of Cancer* 66:145-150.

Emanuel EJ, Fairclough DL, Slutsman J, Alpert H, Baldwin D, Emanual L. 1999. Assistance from family members, friends, paid care givers, and volunteers in the care of terminally ill patients. *The New England Journal of Medicine* 341(13):956-963.

Facing Forward: A Guide for Cancer Survivors. National Cancer Institute, April 2001.

Frame, JN et al. 2001. Developing a rural colorectal screening program. *Oncology Issues* 16:12-16.

Friedman GD et al. 1991. Case-control study of screening for prostate cancer by digital rectal examinations. *Lancet A.* 337:1526-1529.

Fromer MJ. 2000. New emphasis on colorectal cancer screening with launch of last month's national colorectal cancer awareness month. *Oncology Times* 22:40-41.

Grann PH et al. 1994. Prospective study of plasma fatty acids and risk of prostate cancer. *Journal of the National Cancer Institute*. 86:281-286.

Greenlee RT et al. Cancer statistics 2000. *CA: A Cancer Journal for Clinicians* 50:7-33.

Greenlee RT et al. Cancer statistics 2001. *CA: A Cancer Journal for Clinicians* 51:15-36.

Hall HI et al. 2000. Breast and cervical carcinoma mortality among women in the Appalachian Region of the U.S., 1976-1996. *Cancer* 89:1593-1602.

Houts PS et al. 1984. Nonmedical costs to patients and their families associated with outpatient chemotherapy. *Cancer* 53:2388-2392.

Houts, PS et al. 1986. Unmet psychological, social, and economic needs of persons with cancer in Pennsylvania. *Cancer* 58:2355-2361.

Houts PS et al. 1988. Unmet needs of persons with cancer in Pennsylvania during the period of terminal care. *Cancer* 62:627-634.

Institute of Medicine, Committee on Care at the End of Life. 1997. Field MJ and Cassell CK, eds. *Approaching Death: Improving Care at the End of Life*. Washington D.C.: National Academy Press.

Liff JM, Show WH, Greenberg, RS. 1991. Rural urban differences in the stage at diagnosis: Possible relationship to cancer screening. *Cancer* 67:1454-1459.

Lindau ST et al. 2001. Improving rates of cervical cancer screening and pap smear follow-up for low-income women with limited health literacy. *Cancer Investigator* 19:316-23.

Mammography. June 26, 1992. *Morbidity and Mortality Weekly Report* 41(25):454-459.

Mandelblatt J, Gopaul I, Westreich M. July 18, 1986. Gynecological care of elderly women: another look at Papanicolaou Smear Testing. *Journal of the American Medical Association* 256(3):367-371.

Miller D. May 18, 2001. Census shows we're older still. *Charleston Gazette*. Charleston, WV.

Monroe AC, Ricketss TC, Savitz LA. 1992. Cancer in rural versus urban populations: a review. *Journal of Rural Health* 8:312-220.

Moody-Ayers SY, Wells CK, Feinstein AR. 2000. Benign Tumors and "early detection" in mammography-screened patients of a natural cohort with breast cancer. *Archives of Internal Medicine* 160:1109-1115.

Morton MS, Griffiths K, Blacklock N. 1996. The preventive role of diet in prostate disease. *British Journal of Urology* 77:481-493.

National Cancer Institute. Division of Cancer Prevention and Control. 1990. Surveillance Program. Unpublished data.

National Rural Health Association. May 1999. Access to healthcare for the uninsured in rural and frontier America. NRHA. Internet (accessed 15 May 2001).

The National Strategic Plan for the Early Detection of Breast and Cervical Cancers. 1994. Department of Health and Human Services. Atlanta: Centers for Disease Control and Prevention.

Newberger EC, Curry AE. Educational attainment in the United States (Update): Population characteristics. United States Census Bureau.

North Carolina Cancer Control Plan. May 1996. North Carolina Department of Environment, Health, and Natural Resources: Advisory Committee on Cancer Coordination and Control.

Porter PL et al. 1999. Breast tumor characteristics as predictors of mammographic detection. Comparison of interval-and screen-detected cancers. *Journal of the National Cancer Institute* 91:2020-2028.

Prostate cancer screening: health professional summary. March 2001. PDQ Database. National Cancer Institute.

Prostate cancer and prevention: patient summary. January 2001. PDQ Database. National Cancer Institute.

Remington P, Lantz P, Phillips JL. 1990. Cervical cancer deaths among older women: implications for prevention. *Wisconsin Medical Journal* 89:32-34.

Ries LAG, Eisner MP, Kosary CL, Hankey BF, Miller BA, Clegg L, Edwards BK (eds.). 2000. *SEER Cancer Statistics Review: 1973-1997*. National Cancer Institute. Bethesda, MD.

Rodgers CC. 1997. *Changes in the Older Population and Implications for Rural Areas*. U.S. Department of Agriculture. Rural Development Research Report No. 90.

Scardino PT. 1989. Early detection of prostate cancer. *Advances in Urologic Ultrasound* 16:635-655.

Screening for colorectal cancer—United States, 1997. February 19, 1999. *Morbidity and Mortality Weekly Report* 48:116-121.

Self-reported use of mammography among women aged 40 years old or older—United States, 1989 and 1995. October 10, 1997. *Morbidity and Mortality Weekly Report* 46(40):937-941.

State-specific prevalence of selected health behaviors by race and ethnicity-Behavioral Risk Factor Surveillance System, 1997. March 24, 2000. *Morbidity and Mortality Weekly Report* 49:1-60.

Stommel M, Given CW, Given B. 1991. The cost of cancer care to families. Working paper. Family Care Study, Department of Family Practice, Michigan State University.

Tessaro IA et al. 2000. Adapting a natural (lay) helper model of change for worksite health promotion for women. *Health Education Research Theory and Practice* 15:603-614.

Tilden VP, Tolle SW, Garland MJ, Nelson CA. 1995. Decisions about life-sustaining treatment. *Archives of Internal Medicine* 155:633-638.

Tolle SW. 1998. Care of the dying: clinical and financial lessons from the Oregon experience." *Annals of Internal Medicine* 128(7):567-568.

Tringali CA. 1986. The needs of family members of cancer patients. *Oncology Nursing Forum* 13:65-70.

United States Census 2000. U.S. Census Bureau.

West Virginia Breast and Cervical Cancer Screening Program. May 2001. Noncompeting continuation application, year 11. West Virginia Department of Health and Human Resources. Office of Maternal, Child and Family Health.

West Virginia County Health Profiles-2000. (Internet) West Virginia Bureau for Public Health. Charleston, WV: West Virginia Department of Health and Human Resources, Revised 1997. Accessed July 3, 2001.

West Virginia Health Care Authority. 1999. Unpublished data. Charleston, WV: West Virginia Health Care Authority.

West Virginia Rural Health Plan. January 1998. West Virginia Department of Health and Human Services.

West Virginia - Specific Focus Area: End of Life. 2001. in *West Virginia Healthy People 2010*. West Virginia Bureau for Public Health.

West Virginia State Health Plan 2000-2002. January 2000. West Virginia Health Care Authority. Charleston, WV: West Virginia Health Care Authority.

West Virginia Vital Statistics 1998. January 2000. West Virginia Bureau for Public Health. Charleston, WV: West Virginia Department of Health and Human Resources.

What you need to know about prostate cancer. 2000. U.S. Department of Health and Human Services. National Institutes of Health. National Cancer Institute.

The Coalition seeks to build a strong network of community volunteers, survivors and providers working together on public awareness, legislative action and funding for priority cancer issues.

VII

Advocacy

The Mountains of Hope Coalition advocates on behalf of cancer related issues, making sure that these matters get the public attention, the legislative action, and the funding they deserve. The Coalition, through a combination of direct lobbying and grassroots advocacy, keeps cancer high on the agendas of key decision makers.

Direct Lobbying

The Coalition relies upon the ACS, one of its founding members, to promote its direct lobbying efforts. When appropriate, ACS lobbyists work to enact, modify, or halt passage of legislative proposals at all levels. The ACS also encourages West Virginians to have face-to-face meetings with legislators or public officials and to prevail upon them to consider a specific position. Under the ACS's mandate for responsible advocacy, direct lobbying has been used very effectively at the state level in West Virginia where, in recent legislative sessions, the following actions were taken:

- Passage of the state's first smokeless tobacco tax (including pipe tobacco and cigars);
- Passage of legislation to ban bidis, the flavored, unfiltered, imported cigarettes that contain three times the nicotine and tar as domestic tobacco products;
- Passage of a resolution to study whether health insurers should be required to pay for routine medical costs associated with clinical trials;
- Passage of the Breast and Cervical Treatment Act, making West Virginia one of only three states to submit a business plan to implement this important new federal program; and
- Establishment of the Patient's Bill of Rights allowing an individual to sue his or her HMO if it refuses to send a claim through to a review board.

Efforts were also made to require retailers to place tobacco products behind the counter and to require vendors to be licensed to sell tobacco products. This license could be suspended or revoked if a vendor continually sold tobacco products to children. Unfortunately, neither of these bills passed.

Grassroots Advocacy

The Coalition focuses much of its efforts on encouraging and promoting grassroots advocacy. The goal of community-based advocacy is to allow any individual to become an advocate in the war on cancer. While direct advocacy means face-to-face contact, grassroots advocacy can be accomplished in a variety of ways, including letter-writing, making a phone call, sending an e-mail, or any other means of communication with the general public, legislators, and other key decision makers. The WVBPH, another of the Coalition's founding members, often takes the leadership role in promoting community-based efforts by providing advice and education to local groups and helping to coordinate the efforts of related statewide entities such as the Tobacco, Nutrition, Physical Activity and the Healthy People 2010 coalitions. Through the creation of a strong network of community volunteers, survivors, and providers, Coalition members have worked together to heighten public awareness, to impact legislative action and to urge funding for priority cancer issues. Examples of previously successful grassroots advocacy efforts include the establishment of both the state's comprehensive Cancer Registry and the West Virginia Breast and Cervical Cancer Diagnostic and Treatment Fund. With the establishment of a Mountains of Hope Advocacy Work Group, the Coalition believes even more can be done to keep the membership informed and actively working for

- increased investments for cancer research and programs;
- increased access to cancer care, prevention, and awareness programs;
- reduced disparities among minority and medically underserved populations;
- reduction and prevention of suffering from tobacco-related illnesses; and
- heightened public and professional support for Mountains of Hope: The West Virginia Comprehensive Cancer Coalition.

Advocacy Goals and Objectives

Four-Year Goal:	**Create a strong network of community volunteers, survivors and providers working together on public awareness, legislative action and funding for priority cancer issues.**

Goal I: Use the Breast Cancer Diagnostic and Treatment Fund model to provide financial aid to low-income colorectal, lung and prostate cancer patients.

Objective I:

Create a Mountains of Hope Advocacy Work Group.

Strategy:

1. Identify and prioritize advocacy issues.

2. Keep the coalition abreast of national advocacy issues.

Objective II:

Link West Virginia to national issues and efforts.

Strategy:

Affiliate the Advocacy Work Group with the Intercultural Cancer Council, National Pain Initiative, Oncology Nursing Society, Susan G. Komen, etc.

Objective III:

Link the Advocacy Work Group to community coalitions for rapid mobilization and information dissemination.

Strategy:

The Advocacy Work Group will train members of the VNN to work with media, interface with local political groups (and legislators), and move action items forward in their own communities.

Goal II: Support efforts to significantly increase cigarette and other tobacco product taxes as a deterrent to youth smoking.

Goal III: Lobby to fully implement the Breast and Cervical Cancer Treatment Act .

Goal IV: Advocate to reduce chemotherapy and other treatment-related costs for low-income people.

Goal V: Lobby to pass a resolution that ensures costs related to clinical trials will be fully covered by insurance and lowered for low-income people without insurance coverage.

Appendix A

Mountains of Hope Affiliates

American Association of Retired People
American Cancer Society
American Lung Association
Barker, Frederick MD
Braxton County Health Department
Brooke County Health Department
Carl Johnson Medical Center
Charleston Area Medical Center
- Health Education and Research Institution

Coalition for a Tobacco-FreeWest Virginia
Greenbrier Valley Cancer Center
HBA Cytology Center
Health Access Free Clinic
James Tiger Morton Catastrophic Illness Commission
Kanawha-Charleston Health Right
Kanawha County EncorePlus
Kanawha County Schools
Kanawha Hospice Care, Inc.
Leukemia and Lymphoma Society
Lincoln County Primary Care Center
Marion County Health Department
Marshall University
- Joan C. Edwards School of Medicine

McDowell Rural Health Advisory Council
NCI Cancer Information Service
Mineral County Health Department
Mingo County Health Department
Mission West Virginia
Myers Clinic
National Association of Social Workers
North Central Appalachia Cancer Network
Ohio County Health Department
Pennsboro Medical Center
Preston-Taylor Community Health Center
Prezybysz, Thomas MD
Raleigh-Boone Medical Center
Ritchie County Primary Care Association
St. Mary's Hospital
Strategic Health Services, Inc.
Susan G. Komen Breast Cancer Foundation
Thomas Memorial Hospital
Tygart Valley Total Care Clinic
Upper Kanawha Medical Center
Valley Health System
Weirton Medical Center
Wellness Council of West Virginia
West Virginia Board of Examiners (Registered Professional Nurses)
West Virginia Breast and Cervical Cancer Screening Program
West Virginia Bureau for Public Health
- Office of Epidemiology and Health Promotion
  - Comprehensive Cancer Program
  - Healthy People
  - Physical Activity Program
  - Cancer Registry
- Office of Maternal, Child and Family Health
  - Breast and Cervical Cancer Screening Program

West Virginia Cancer Registrars Association
West Virginia Health Right
West Virginia Healthy People 2010
West Virginia Hospice Association
West Virginia Hospital Association
West Virginia Initiative to Improve End of Life Care
West Virginia Insurance Commission
West Virginia Medical Institute
West Virginia Primary Care Association
West Virginia Public Employee Insurance Agency
West Virginia Rural Health Education Partnership
West Virginia School of Osteopathic Medicine
West Virginia State Medical Association

West Virginia University
- Betty Puskar Breast Care Center
- Center on Aging
- Center for Health Ethics and Law
- Extension Service
- Mary Babb Randolph Cancer Center
- School of Dentistry
- School of Medicine
- School of Nursing
- School of Pharmacy

West Virginia University Hospitals, Inc.
West Virginia University Prevention Research Center
Wheeling Hospital
Williamsburg Health Clinic
Y.W.C.A. of Charleston

Appendix B

Mountains of Hope Mission Statement

The mission of Mountains of Hope, the West Virginia Comprehensive Cancer Control Coalition, is to provide leadership by facilitating and coordinating statewide and community-level collaboration to reduce the human and economic impact of cancer in West Virginia.

Appendix C

Mountains of Hope Values Statements

The value statements listed below are not in any priority order.

- All members' opinions are valued equally and we recognize that what each member has to contribute is valued equally.
- We value making decisions together.
- We operate with human courtesy and respect. We value integrity.
- We serve the people and communities of West Virginia, not ourselves or our agencies.
- We value speaking with one voice as a coalition while recognizing that we may have opposing viewpoints.
- It is OK to make mistakes–we learn from them.
- We value ethical organizational practices.
- We value and uphold our commitments and will be accountable for them.
- We value each others' time.
- We resolve conflicts and work towards solutions.
- We value our mission and goals.
- We value and seek diversity within our coalition.
- We seek first to understand, then to be understood.
- We value the idea that we can make a difference and measure our accomplishments.
- We value compassion and our actions reflect our commitment to reducing human suffering due to cancer.

Appendix D

Mountains of Hope Steering Committee (September 2001 - June 2002)

Amy Reasinger Allen
NCI Cancer Information Service
Coalition Office: Vice Chair,
Patient Care and Survival Subcommittee

Pamela Brown
Mary Babb Randolph Cancer Center
West Virginia University
Founding Organization Representative

Sharon Cope
West Virginia Breast and Cervical Cancer Screening Program
Coalition Office: Vice Chair,
Early Detection Subcommittee

James Frame, MD
Oncology Services
Charleston Area Medical Center
Coalition Office: Coalition Chair

Anne Harmon
West Virginia University Center on Aging
Coalition Office: Chair, Patient Care and Survivorship Subcommittee

Diana Harrison
American Cancer Society Mid-Atlantic Division
Founding Organization Representative

Alan Holmes
West Virginia Bureau for Public Health
Founding Organization Representative

Carol Mangone
Mary Babb Randolph Cancer Center
West Virginia University
Coalition Office: Chair, Prevention Subcommittee

Gerard Oakley, MD
Joan C. Edwards School of Medicine
Marshall University
Coalition Office: Coalition Vice Chair

Leesa Prendergast
West Virginia University Prevention Research Center
Coalition Office: Vice Chair, Prevention Subcommittee

Robin Seabury
West Virginia Breast and Cervical Cancer Screening Program
Founding Organization Representative

Mountains of Hope Steering Committee (July 2002 -)

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* Representative, Founding Member

Appendix E

Mountains of Hope Bylaws

September 7, 2000

SECTION I: Mission/Purpose

A. **Mission Statement: The mission of the West Virginia Comprehensive Cancer Control Coalition is to provide leadership by facilitating and coordinating statewide and community level collaboration that reduces the human and economic impact of cancer in West Virginia.**

B. **Purpose: The purpose of the West Virginia Comprehensive Cancer Control Coalition is to develop and implement a comprehensive cancer control plan for the state. The Coalition will strive to ensure that all of West Virginia's Healthy People 2010 cancer objectives are addressed in the Comprehensive Cancer Control Plan.**

SECTION II: Membership

A. Membership Eligibility: Membership in the West Virginia Comprehensive Cancer Control Coalition is voluntary. Membership is open to all organizations who support the mission and purpose of the Coalition. An organization may choose multiple representatives (see voting membership). There are no membership dues.

B. **Voting Membership:** Each organization will be afforded one (1) vote. Membership will be based upon organizations. Organizations will appoint one representative to the Coalition. (Please note, exceptions may be made to provide individuals representing specific regional interests, such as the WVBCCSP Cancer Information Specialists, voting privileges. These exceptions will be determined by the Steering Committee.)

C. **Member Autonomy:** In order to protect each member's individual/organizational autonomy, their organizations will not be listed on the Coalition's letterhead. Participating individuals/organizations may be listed in source materials under the following sentence;

> Each individual/organization participating in the West Virginia Comprehensive Cancer Control Coalition supports efforts to reduce cancer in West Virginia, and selects and participates in those activities of the Coalition that support its own organizational objectives.

D. Values: The membership of the Coalition will operate under the organizational values listed in Appendix A.

SECTION III: Funds and Contributions to the Coalition

A. Acceptance: Upon approval by the Steering Committee, the Coalition may accept funds and contributions from individuals and corporations, through a designated fiscal agent. Coalition functions which incur costs may be offset by sponsorship from individuals or corporations, but acceptance of these funds by the Coalition does not constitute partiality or endorsement on the part of the Coalition. The Coalition shall not endorse any person, company, product or procedure which relates to cancer control or prevention without Steering Committee approval (see decision rules). The Coalition will forthrightly disclose to its membership and audiences any corporate contributions.

B. Management of Funds: The Director of the Lead Agency shall manage fiscal transactions and records of the Coalition. Quarterly financial statements should be prepared and presented to the Steering Committee. At the request of the Steering Committee, the Lead Agency Director will prepare other financial reports.

SECTION IV: Officers

A. Officers:

1. **Chair:** The duties of the Chair include presiding at all Coalition meetings, Steering Committee meetings and other functions of the coalition. The Chair must be elected from the membership of the Coalition.
2. **Vice-Chair:** In the absence of the Chair, the Vice-Chair presides at any coalition meeting or function. The Vice-Chair is also a member of the Steering Committee. The Vice-Chair must be elected from the membership of the Coalition.
3. **Committee Chair:** The duties of the Committee Chair include presiding over all committee meetings and ensuring information produced during committees meetings is reported to the Coalition in the manner prescribed by the Steering Committee. The Committee Chair is a member of the Steering Committee.
4. **Committee Vice-Chair:** In the absence of the Committee Chair, the Vice-Chair will preside over committee meetings. The Committee Vice-Chair is a member of the Steering Committee.

B. Terms: All officers are elected for two (2) year terms*. Elections will occur in the second half (January - June) of each year to ensure that new officers can begin their duties on July 1. Transition time between the election of officers and the operating year (July 1 through June 30) should be used for orientation, transfer of files, etc. In the event an officer is unable to complete his/her term, the Steering Committee shall appoint a replacement for the remainder of the unexpired term.
**In the first year of operation the Vice-Chairs will be elected for one (1) year terms. This will offset the terms of the Chairs and Vice-Chairs to ensure continuity among leadership. All Vice-Chairs elected after the initial operating year will serve two (2) year terms.*

SECTION VI: Committees

A. Standing Committees: The Coalition will operate three (3) standing committees. These committees are:

1. Prevention Committee
2. Early Detection Committee
3. Patient Care and Survivorship Committee

The Steering Committee may add Standing Committees from existing Ad Hoc Committees at the beginning of each operating year.

B. **Ad Hoc Committees:** Ad Hoc Committees may be convened at any time by the Steering Committee. Ad Hoc Committees will be considered by the Steering Committee at the request of Coalition membership.

C. Steering Committee: (See Section VII)

D. **Committee Membership:** Each coalition member is encouraged to serve on at least one (1) Standing Committee. Each committee member has one (1) vote on the respective committee on which they are serving. Members may express preference for committee assignments.

SECTION VII: Steering Committee

A. Purpose: The purpose of the Steering Committee is to provide direction to the Coalition on forming the West Virginia Comprehensive Cancer Control Plan. It is the responsibility of the Steering Committee to ensure that the activities of the Coalition are directed toward completion and implementation of the West Virginia Comprehensive Cancer Control Plan.

B. **Membership: The membership of the Steering Committee will consist of the following:**

1. The Coalition Chair (Serves as Steering Committee Chair)
2. The Coalition Vice-Chair (Serves as Steering Committee Vice-Chair)
3. The Chairs and Vice-Chairs of each Standing Committee
4. The appointed representative, or alternate, from each Founding Group (listed below)
    a. The WV Bureau for Public Health
    b. The WV Breast and Cervical Cancer Screening Program
    c. The American Cancer Society
    d. Mary Babb Randolph Cancer Center

C. **Voting: Each member of the Steering Committee will receive one (1) vote. Proxy votes are not allowed. Voting by mail, e-mail, or FAX will be permitted.**

D. Decision Rules: On all matters requiring a voting decision, the Steering Committee will require 80% of those members present to agree before any proposal is adopted. Prior to the debate of an issue/proposal, the Chair must specify a time limit for the debate. A vote may be taken at any time during this specified period of time. However, if by the end of the time allotted for debate, 80% of the members present cannot agree, the proposal is not accepted.

E. **Quorum: In order for a vote to be taken by the Steering Committee, one-half the membership of the Steering Committee must be present. Quorum may include alternate representatives. This must include either the Chair or the Vice-Chair of the Steering Committee.**

F. **Alternates: Steering Committee members representing the Founding Groups are encouraged to designate in writing one (1) alternate representative for occasions where the primary representative cannot attend meetings. The alternate is a voting member of the Coalition for the specific meeting in which the primary representative is not in attendance. The Vice-Chair of each Standing Committee will serve as the alternate for the Standing Committee Chair.**

G. **Meeting Schedules: The Steering Committee should meet monthly either via telephone conference call or face-to-face. Meetings are to be called by the Chair.**

SECTION VIII: Coalition Meetings

A. **Schedule of Full Coalition Meetings: Up to four (4) Coalition meetings may occur in any operating year, with a minimum of two meetings in one operating year. Meetings are called by the Chair. Membership must be given at minimum of thirty (30) days notice for all Coalition meetings. There should be no more than seven (7) months lapse between Coalition meetings.**

B. **Meeting Conduct: Meetings are to be conducted following the guidelines prescribed in *Robert's Rules of Order*.**

C. **Voting: All members present represent a Coalition quorum for voting purposes. Each voting member present is afforded one (1) vote. Voting will be conducted using anonymous ballots. No proxy votes will be allowed. (Voting by mail, e-mail, or FAX will be permitted** only for elections and awards nominations **using designated ballots received prior to the election date.)**

D. **Decision Rules: Decision making on all issues except general elections will require a minimum 80% of those members present to agree before any proposal is adopted. Prior to the debate of an issue/proposal, the Chair must specify a time limit for the debate. A**

vote may be taken at any time during this specified period of time. However, if by the end of the time allotted for debate, 80% of the members present cannot agree, the proposal is not accepted.

E. **Loss of Membership: Failure to attend any two (2) meetings in a row within one year may result in removal from the membership of the Coalition upon recommendation by the Steering Committee. All members are encouraged to inform the Chair of an expected absence. Membership will be reviewed annually by the Steering Committee.**

SECTION IX: Communications

A. **Media: The Coalition Chair or his/her appointee will act as media spokesperson for the Coalition. The Coalition will also compile and maintain a list of Source Experts to respond to information requests regarding specific cancer control topics.**

B. **Coalition Communications: Coalition staff will use mail and e-mail as the primary vehicles for communications to members. FAX and telephone may supplement mail/e-mail when necessary.**

SECTION X: Amendment of Bylaws

A. **Notice: Suggested amendments to these bylaws require written notice to the Steering Committee. The Steering Committee will consider each suggestion within sixty (60) days of its receipt.**

B. **Voting: These bylaws may be amended at Coalition meetings by an 80% majority of the voting members present.**

Appendix F

West Virginia Healthy People 2010 Cancer Objectives

- Reduce lung cancer deaths to a rate of no more than 59 per 100,000 West Virginia residents
- Reduce breast cancer deaths to no more than 21 per 100,000 West Virginia females
- Reduce prostate cancer-related deaths to 19.5 per 100,000 West Virginia males
- Decrease the number of persons who have had a sunburn with redness lasting at least 12 hours within the past 12 months
- Increase the proportion of adults who have received from a physician: counseling about tobacco use/cessation, diet modification, and cancer screening recommendations
- Increase to at least 95 percent the proportion of women aged 18 and older who have ever received a Pap test and to at least 85 percent those who received a Pap test within the preceding three years
- Attain a level of at least 50 percent of people aged 50 and older who have received a colorectal screening examination (fecal occult blood testing) within the preceding 1-2 years and increase to at least 40 percent those who have ever received proctosigmoidos copy
- Increase to 95 percent the expected number of cancer cases reported to the West Virginia Cancer Registry (WVCR) within 12 months of the close of the diagnosis year and publish incidence and mortality data within 18 months of the close of the diagnosis year
- Increase the number of cancer survivors who are living five years or longer after diagnosis of cancer

List of Acronyms

ACS	American Cancer Society
BRFSS	Behavioral Risk Factor Surveillance Survey
CDC	Centers for Disease Control and Prevention
CIS	Cancer Information Service
DHHS	Department of Health and Human Services
ICC	Intercultural Cancer Council
MBRCC	Mary Babb Randolph Cancer Center
NABCO	National Alliance of Breast Cancer Organizations
NCI	National Cancer Institute
NIH	National Institutes of Health
NOT	Not On Tobacco
OEHP	Office of Epidemiology and Health Promotion
PDQ	Comprehensive, computerized cancer information database of the NCI
PHNPAT	Public Health Nurses Physical Assessment Training Program
PRC	Prevention Research Center
SEER	Surveillance, Epidemiology and End Results
VNN	Volunteer Navigator Network
WVBCCSP	West Virginia Breast and Cervical Cancer Screening Program
WVBPH	West Virginia Bureau for Public Health
WVBRFSS	West Virginia Behavioral Risk Factor Surveillance Survey
YRBS	Youth Risk Behavior Survey

List of Tables and Illustrations