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# **BREAST CANCER ACTION PLAN FOR KENTUCKY**

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Report to Governor Paul E. Patton  
by the  
Kentucky Breast Cancer Task Force



June 30, 1999



**Governor's Mansion  
Frankfort, Kentucky 40601**

**Message from the First Lady**

The many thousands of Kentucky women who have had breast cancer, and the estimated 2800 women in Kentucky who have developed breast cancer within the current year, know that it is a disease which affects not only the individual woman, but also her family, her friends and the community in which she lives. It is not just a medical problem, it is a social problem. It is a problem that must be addressed by our society as a whole.

In order to do so, Governor Paul E. Patton established a Breast Cancer Task Force in July, 1998, to address both the medical and the social issues, and requested that we present him with an action plan for dealing with this major health problem. Task Force members were selected to provide effective representation of both lay and professional viewpoints, of both the private and public sectors, and the concerns of breast cancer survivors as well as geographic representation. However, although each person brought to the Task Force their opinions as well as their information gained from dealing with the disease in one capacity or another, and although there was spirited discussion of all the issues with which the Task Force dealt, the final set of proposed recommendations and actions represents the consensus of all Task Force members. As an indication of this agreement, I am pleased to note that each member has signed this report. Finally, I would like to express my thanks to Dr. Gilbert Friedell, the Executive Director of the Task Force, to Dr. Linda Linville and Ms. Connie Sorrell of the Kentucky Cancer Program, Co-Directors of the Task Force staff, and to members of the Task Force who were exceptional in their devotion to this project and their commitment of time and energy in the development of this report.

It is our hope that the information presented in this report will move Kentucky forward in its attack against a disease that strikes the women of this Commonwealth.

A handwritten signature in cursive script that reads "Judi Patton".

Judi Patton  
Chair, Governor's Task Force on Breast Cancer



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## Foreword

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With the establishment of this Task Force, Governor Paul E. Patton has given us an unusual opportunity to assess the current state of breast cancer control in Kentucky; to identify the elements that are missing and needed in order to have an optimal statewide breast cancer control program; and to present him with an action plan which, if carried out, will reduce breast cancer incidence, morbidity, and mortality. The committed and enthusiastic leadership of Chair Judi Patton and the diverse membership of the Task Force, representing a broad range of health care personnel, breast cancer survivors, and lay people from across the Commonwealth, have been particular strengths in this effort.

The Task Force documented many accomplishments in both public and private sectors over the past decade. Kentucky was one of the first states to enact legislation requiring third-party coverage of screening mammography and to fund free or low-cost screening for low-income women through the Kentucky Department for Public Health. The Commonwealth established a population-based cancer registry to collect, manage, and analyze data on breast cancer and other cancers—an essential element for assessing the level of cancer problems and our progress in addressing these problems. Since 1991, a higher proportion of breast cancer cases have been diagnosed and treated in early rather than later stages—a trend which should lower breast cancer mortality rates. At the same time, treatment has become less radical and equally or even more effective. These achievements are impressive, but much remains to be done.

We need to expand our databases on screening mammography and the diagnostic and therapeutic services that are utilized following abnormal mammograms. This information, coupled with data from an expanded Kentucky Cancer Registry, will help us better inform and educate health care professionals and the general public, allocate public and private resources to the areas of greatest need, and evaluate the effectiveness and cost of interventions.

We need to improve our dissemination of relevant and understandable breast cancer information to the public and to encourage optimal two-way communication between patients and their health care practitioners. Some of the recommended steps are the inclusion of breast health information in school health education programs and the integration of appropriate information on the clinical and psychosocial aspects of breast cancer into the curricula of medical, nursing, and allied health schools.

Finally, we need to make available and accessible to all women in Kentucky the screening, diagnostic, therapeutic, and rehabilitation services necessary to reduce mortality rates from breast cancer. Meeting these challenges will require maximum effort from both the private and the public sectors.



This report addresses the aforementioned issues and others that are closely related. There are 18 specific recommendations and a large number of action items under each recommendation. Some of the recommendations and related actions should be implemented as soon as possible. Others call for the collection of additional information and/or further analysis of existing databases. A few issues need further definition and/or clarification. For example, what process should be used to get standards of care adopted by health care practitioners, and how should compliance with these standards be assessed?

Because additional time will be needed to carry out these tasks, we have requested that the Governor extend the Task Force for an additional year. We propose to utilize the expertise which Task Force members have gained over the past year, along with that of selected consultants, to fully respond to the Governor's original charges by July 2000.

I would like to express my deep appreciation to First Lady Judi Patton for her admirable and committed leadership of the Task Force. Colleagues in the Kentucky Cancer Program, Linda Linville and Connie Sorrell, have my gratitude for their great skill and tremendous investment of time and energy in staffing the Task Force. This report would not have been possible without them. I also would like to thank Joyce Beaulieu and Jennifer Galland for their excellent research services, Tom Kean and Karin Hohman for serving as primary consultants and expert facilitators at our meetings, and Martha McKinney for serving as a consultant and scientific writer. Finally, I wish to commend and thank the Task Force members for their exceptional commitment to this project. Their enthusiasm and high levels of participation have greatly facilitated the development of this report. In truth, it is their report!

A handwritten signature in black ink that reads "G. H. Friedell". The signature is written in a cursive, flowing style.

Gilbert H. Friedell, M.D.  
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## Executive Summary

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Breast cancer is the most commonly diagnosed cancer and the second leading cause of cancer-related death among Kentucky women. Risk for breast cancer increases with age. Each year, three-quarters of the new breast cancer cases diagnosed in Kentucky occur among women over age 50, and half of all new cases occur in women over age 65. To reduce breast cancer mortality rates among women of all ages, screening mammography services must be readily available and accessible, women diagnosed with breast cancer must receive optimal treatment, and provisions must be made for continuity of care across all stages of the disease.

The critical need to address breast cancer mortality and related issues prompted Governor Paul E. Patton to establish the Kentucky Breast Cancer Task Force. An Executive Order issued in February 1998 instructed the Task Force to assess and make recommendations to the Governor on the following:

- Effectiveness and adequacy of educational inreach/outreach programs throughout the state, including an inventory of such programs and the materials and approaches used;
- Availability, accessibility, quality, utilization, and outcomes of public and private breast cancer screening and treatment services, including continuity of care and rehabilitation;
- Adequacy of health insurance coverage with regard to breast cancer-related issues;
- Services needed and received by uninsured and underinsured women with breast cancer;
- Availability and allocation of state and federal dollars for breast cancer and areas of need; and
- Availability and utilization of data from private and public sources on breast cancer screening, diagnosis, treatment, and outcomes.

The Governor appointed Judi Patton, First Lady of the Commonwealth, to chair the Task Force and Dr. Gilbert Friedell, Director Emeritus of the Markey Cancer Center, to serve as Executive Director. At the Governor's request, the Kentucky Cancer Program assumed responsibility for Task Force coordination and management. Task Force members included radiologists, medical oncologists, radiation therapists, surgeons, and other practicing physicians; nurses; breast cancer survivors; local/county public health officials; medical social workers; and representatives of the Kentucky Department for



Public Health, American Cancer Society, Health Kentucky, Inc., Kentucky African Americans Against Cancer, the Kentucky Breast Cancer Advisory Committee, the Kentucky Breast Cancer Coalition, the Kentucky Medical Association, local breast cancer coalitions, and the health insurance community. National experts on mammography registries, breast cancer prevention and education, and clinical treatment guidelines served as Task Force consultants.

The Task Force held meetings in October and December 1998 and in February and April 1999. At the October inaugural meeting, Task Force members established four work groups to gather preliminary information on breast cancer prevention, early detection, treatment, and quality-of-life services. After completing these tasks, members divided into five new work groups to examine public education, breast cancer screening and treatment, health insurance coverage, supportive services and palliative care, and data/research needs. Each work group met several times and communicated by conference call between meetings. Their collective activities culminated in the adoption of 18 recommendations and 60 proposed actions.

This report summarizes key issues affecting the quality, accessibility, and outcomes of breast cancer screening and care. Specific recommendations and proposed actions follow each issue, along with a listing of data/information needs. The Task Force's priorities for implementation are as follows:

## **First Priority**

- Establish an integrated, ongoing public information program to foster a high degree of knowledge among women of all ages about breast cancer risks, early detection, treatment options, and quality-of-life issues.
- Provide all women ages 40 and older with access to screening mammography in accordance with current American Cancer Society guidelines.
- Develop strategies to improve the availability and accessibility of breast cancer screening services and to increase screening mammography rates in geographic areas with high proportions of late-diagnosed breast cancers and among subgroups of women with lower screening rates (e.g., African American women; women with less than 12 years of education; women who are non-English-speaking; and women who are low-income, uninsured, and/or • 70 years).
- Promote universal adherence to professionally-accepted standards of care for breast cancer early detection, diagnosis, treatment, and rehabilitation.



- Improve linkages among existing data sources, expand the Kentucky Cancer Registry to include initial and follow-up treatment data from physicians' offices, and establish new data sources (e.g., a statewide mammography registry) consistent with a data analysis plan based upon Task Force recommendations.
- Link breast cancer patients with information and services that will help them effectively navigate the cancer care continuum.
- Provide all breast cancer patients with access to funded sources of treatment.
- Establish an ongoing mechanism for monitoring implementation of Task Force recommendations, identifying emergent problems, and updating recommended actions.

## **Second Priority**

- Encourage all health professionals to use professionally-accepted pain management assessments and palliative care protocols when caring for breast cancer patients.
- Activate the Kentucky Department for Public Health breast cancer screening fund for uninsured and underinsured women with support from grants, private donations, the sale of specialty license tags, and/or financial contributions denoted on individual income tax returns.
- Evaluate the economic impact of breast cancer prevention strategies, early versus late-stage diagnosis, and alternative approaches to treatment and rehabilitation in Kentucky.

## **Third Priority**

- Increase clinical research on breast cancer prevention, detection, diagnosis, treatment, and rehabilitation. Encourage studies on the psychological and social implications of genetic testing.
- Inform breast cancer patients, family members, and caregivers about available counseling and support services and facilitate access to these services.
- Provide insurance coverage and other resources to reduce financial barriers and facilitate universal access to breast cancer early detection, treatment, rehabilitation, support, and hospice services.



- Encourage in-state self-insured companies and in-state branches of out-of-state companies to provide screening mammography coverage in accordance with current American Cancer Society guidelines.
- Prohibit insurance, employment, and other forms of discrimination against women with breast cancer and women who are considered to be at “high risk” for breast cancer because they have requested or received genetic testing.
- Encourage the Health Care Financing Administration to extend hospice eligibility to all patients who could benefit from these services, regardless of life expectancy.
- Examine variations in charges for breast cancer services across Kentucky, taking into account stage of disease at diagnosis, the quality of services provided, the availability of free services, and other cost-related factors.

## Recommendations & Actions Requiring Legislative Support

- **Recommendation:** Prohibit insurance, employment, and other forms of discrimination against women with breast cancer and women who are considered to be at “high risk” for breast cancer because they have requested or received genetic testing.
- **Recommendation:** Activate the Kentucky Department for Public Health breast cancer screening fund for uninsured and underinsured women with support from grants, private donations, the sale of specialty license tags, and/or financial contributions denoted on individual income tax returns.
- **Action:** Provide the state match needed to obtain federal grants for screening medically indigent women.
- **Action:** Fund the Kentucky Cancer Registry to expand treatment data collection.
- **Action:** Fund the Kentucky Cancer Program to explore the feasibility of establishing a mammography registry.
- **Action:** Fund the Kentucky Cancer Program to oversee the development of a statewide strategic plan for public education and outreach, coordinate statewide activities that emanate from this plan, and organize an implementation phase to move the Task Force recommendations forward.