

Lobby Day | April 2009

Talking Points: The 21st Century Cancer ALERT Act

In March, Senators Edward M. Kennedy (D-MA) and Kay Bailey Hutchison (R-TX) introduced the 21st Century Cancer ALERT Act (S. 717) in the U.S. Senate. Senators Dianne Feinstein (D-CA), Barbara Mikulski (D-SD) and Tim Johnson (D-SD) have also agreed to cosponsor the bill. **ALERT** stands for **A**ccess to **L**ife-saving **E**arly Detection, **R**esearch and **T**reatment:

- **Early Detection** — The ALERT Act **emphasizes prevention and early detection**. It promotes the discovery and development of biomarkers to detect cancers at the earliest possible stage when cancer is most treatable, as well as access to existing technologies for underserved populations.
- **Research** — The ALERT Act **strengthens cancer research** by promoting public-private partnerships and collaboration between government agencies. The bill also focuses on translational research so new discoveries in the laboratory make their way to patients as quickly as possible.
- **Treatment** — The ALERT Act **improves access to treatments and cancer care** by expanding access to clinical trials and patient navigation services, promoting coordination of cancer care, and strengthening the oncology workforce.

WHY DO WE NEED THE 21st CENTURY CANCER ALERT ACT?

- In 1971, the United States declared war on cancer. Despite momentous strides and life-saving advances since then, the fundamental goal of the war — to diminish death and suffering from cancer — has not been fully realized. The U.S. must reignite the war on cancer and remove barriers to discovering and delivering the cures for cancer.
- Cancer costs the U.S. \$219 billion each year and claims more than 560,000 lives — almost 1,500 a day. The disease inflicts incalculable physical pain and emotional distress on cancer patients and their families. Forty percent of Americans will be diagnosed with cancer at some point in their lives; 1.4 million new cases will be diagnosed this year alone.
- There are racial, ethnic, geographic and socioeconomic disparities in access to cancer care. Underserved populations lack access to basic health care services like cancer screening, and are more likely to be diagnosed at later stages and receive lower standards of care. Uninsured cancer patients are 60 percent more likely to die than those with health insurance.

FEATURES OF THE CANCER ALERT ACT

EARLY DETECTION:

- **Biomarkers:** The Cancer ALERT Act encourages collaboration between federal agencies and the private sector to develop biomarkers for the early detection of cancer. We know the importance of early detection for cancers of the breast, colon and prostate. But many cancers still do not have effective early detection methods. One of the most promising avenues is research on biomarkers, which may alert clinicians that cancer may be developing in a patient's body. Biomarkers can also allow treatments to be tailored to an individual person or tumor and reduce the risk of side effects.

- **Mobile Medical Vans:** The Act provides grants for mobile medical vans to conduct cancer screening and prevention education activities in underserved communities.
- **Colorectal Screening & Treatment:** The Act authorizes grants to states for colorectal cancer screenings for underserved populations, modeled after the National Breast and Cervical Cancer Early Detection Program, including a pathway to Medicaid for treatment.
- **Tobacco Cessation:** The Act directs states to offer tobacco cessation medications and counseling to pregnant women enrolled in Medicaid.

RESEARCH:

- **Collaboration:** The Cancer ALERT Act will help maximize the national investment in cancer research by encouraging federal agencies that conduct cancer research to cooperate, including the National Cancer Institute and other institutes of the National Institutes of Health, Food and Drug Administration, Centers for Disease Control and Prevention, and Department of Defense. We must ensure the brightest minds in government, the private sector and the non-profit community are collaborating and sharing information.
- **Translational Research:** We must not only discover, but *deliver* the cures for cancer. The Act has a focus on translational research, which is vital. We must make sure the diagnostic tests, devices and treatments discovered and improved by scientists in the laboratory are delivered to patients as quickly and safely as possible.
- **National Biorepository Network:** The Act encourages the establishment of a national network of biorepositories, which will help investigators pool resources, recognize economies of scale and ultimately enhance the drive toward personalized medicine. The bill also helps ensure adequate protections for patient privacy.
- **Food and Drug Administration:** The Act encourages the FDA to improve its processes for review and approval of cancer diagnostic tests, devices and treatments, with the goal of getting new and improved technologies to patients as quickly and safely as possible. This is increasingly important as our reinvention of cancer research yields new technologies and treatments.
- **Focus on Childhood Cancers:** The Act authorizes grants for research on the causes of health disparities in childhood cancer survivorship and evaluates follow-up care for childhood cancer survivors.
- **Focus on Rare & Low Survival Cancers:** The Act enhances research into rare cancers and cancers with low survival rates by including such cancers in the Cancer Genome Atlas, as a focus of the Early Detection Research Network and establishing targeted research grants. (Rare cancers are defined as those with an incidence rate of less than 15 cases per 100,000, or fewer than 40,000 new cases per year. Low survival cancers are those with a 5-year survival of less than 50 percent.)

TREATMENT:

- **Clinical Trials:** The Cancer ALERT Act improves awareness and expands access to clinical trials by requiring coverage of routine care costs for clinical trials, both through employer-provided health plans and Medicare. The thousands of pioneers who participate in the clinical trials process improve future cancer treatment options for millions. Yet, while more than 1.4 million Americans are diagnosed with cancer each year, fewer than 5 percent will participate in an approved clinical trial.
- **Patient Navigation:** The Act reauthorizes the Patient Navigation Act through FY2015; it is currently set to expire at the end of FY2010. Patient navigators are trained, culturally sensitive health care workers who provide support and guidance to cancer patients through the cancer care continuum.

- **Coordination of Cancer Care:** The Act creates a demonstration project within Medicare to reimburse providers for coordinating the cancer care patients receive during treatment and coordinating care after treatment has concluded.
- **Complete Recovery Care:** The Act improves “complete recovery care,” or the treatment of the secondary effects of cancer like psychosocial, neurocognitive and physical effects, by coordinating the activities of the federal agencies that provide such services and other stakeholders.
- **Oncology Workforce:** The Act ensures a stable workforce for the future by supporting retired nurse military officers to work as nurse faculty and commissioning a study to identify oncology workforce gaps.

ADDITIONAL INFORMATION: Responding to FAQs and Concerns

- ***The bill doesn't go far enough; it should be more aggressive.***

The bill's leading sponsors, Senators Edward Kennedy and Kay Bailey Hutchison, committed from the beginning to develop a bipartisan bill. The bipartisan bill that was introduced in March represents a delicate balance struck after much negotiation. The sponsors are working to make refinements to the legislation to address questions and concerns expressed by members of both parties, as well as the broader cancer community, while maintaining the balance needed for bipartisan support.

- ***How much will it cost? There is no price tag.***

Additional funding will be required for provisions like establishing a national network of biorepositories, implementing the colorectal cancer screening and treatment program and reauthorizing the patient navigator program. The sponsors' first goal was to agree on the policy. Now the bill is being shared with the Congressional Budget Office and affected agencies like the National Cancer Institute to assess the costs for each of the provisions.

- ***Is this bill endorsed by others in the cancer community?***

The cancer community is generally supportive of the bill, and more than 30 organizations have endorsed the bill. Some organizations would like to see certain provisions strengthened, such as those dealing with clinical trials, smoking cessation within Medicaid and comprehensive cancer care planning services. If you encounter recommendations or concerns about specific provisions — either during your Hill visits or anytime thereafter — please pass the information along to Senior Policy Advisor Matt Moore (972.701.2021, mmoore@KomenAdvocacy.org) for follow-up.

- ***How does this bill fit within the broader health reform debate?***

Senator Kennedy is one of the leaders of health reform in Congress, and he has committed to moving the ALERT Act in advance of the health care reform effort. Both Senators Kennedy and Hutchison consider the ALERT Act a top priority and believe we must knock down barriers to discovering and delivering the cures for cancer, an area that might not receive close enough attention if wrapped into the overall health care reform effort. Some broad access-related provisions that were discussed early in the process of developing the ALERT Act were not included, both for jurisdictional reasons and because they could more appropriately be addressed through health care reform.