

# NCI Legislative Update

## National Cancer Advisory Board

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Relations

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# Legislative Activities

Appropriations Status

Hearings and Briefings

Legislation of Interest

## FY 09 Appropriations Status

- FY 2009 Appropriations cycle began Feb. 4 with the announcement of the President's Budget
  - NIH - \$ 29.3 Billion
  - NCI - \$ 4.8 Billion
- House Action Scheduled
  - Subcommittee Markup June 19
  - Full Committee Markup June 25
- Senate Action
  - Subcommittee Hearing July 16

# FY 08 Appropriations

## War Supplemental Spending Bill

- Senate version
  - Domestic spending attached
  - \$400 million to NIH
  - Passed Senate May 22
- House version
  - Domestic spending NOT included
  - Passed House May 15

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## Senate Cancer Hearing

- Cancer: Challenges and Opportunities in the 21<sup>st</sup> Century
- Conducted by Senate HELP Committee on May 8
- Sens. Kennedy and Hutchison announced their intention to introduce legislation

## Goals of Potential Cancer Bill

- Remove barriers currently hindering progress in cancer research and treatment
- Improve access to early detection measures and cancer care
- Reduce disparities in cancer treatment
- Increase enrollment in clinical trials
- Encourage additional opportunities for cancer research and more cooperative cancer research

# Breast Cancer and Environment

- House Energy & Commerce, Subcommittee on Health held hearing on May 21 to receive input on 2 bills (HR 1157 and HR 758)
- Witnesses
  - Panel 1 - Dr. Deborah Winn, DCCPS/NCI
  - Panel 2 - Fran Visco (President, NBCC); Dr. Lyerly (Director, Duke Cancer Center); Sheryl Crow
  - Panel 3 – Kristen Zarfos (St. Francis Breast Health Center); Alva Williams (Survivor)

## Breast Cancer and Environment

- Purpose of hearing – to hear opinions about specific provisions of legislation
- NIH/NCI does not SUPPORT House or Senate bill – but does not OPPOSE Senate bill
- Lack of support due to “disease-specific”
- Specific provisions of Senate bill
  - NIH has ability to use discretion as to whether to follow recommendations of Breast Cancer Environment Research Panel
  - Seen to preserve peer review

## Director's Meetings

### With Appropriations Subcommittee Members

- Rep. Walsh (R-NY, Ranking Member)
- Rep. McCollum (D-MN)
- Rep. Simpson (R-ID)

### With New Members

- Rep. Tsongas (D-MA)
- Rep. Boyda (D-KS)

## Congressional Events – NCI Staff

- Dr. Croyle – Moderated panel on IOM Report, “Cancer Care for the Whole Patient: Meeting Psychosocial Needs” on March 31
- Dr. Helman – Spoke about NCI blood cancer research at Leukemia Lymphoma Society event on April 8
- Dr. Kohn – Participated in NJ town hall meeting on women’s health with Rep. Rodney Frelinghuysen (R-NJ) on April 14
- Dr. Fagan spoke about smoking cessation to the Congressional Black Caucus on April 15
- Dr. Fine briefed Congressional staff on brain cancer research on April 23

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## Legislation of Interest

- ✓ Genetic Information Nondiscrimination Act (GINA)
- ✓ Conquer Childhood Cancer Act
- ✓ SBIR/STTR Reauthorization Act
- ✓ Pediatric, Adolescent, and Young Adult Cancer Survivorship and Quality of Life Act

## Genetic Information Nondiscrimination

- HR 493 Introduced in the House by Rep. Slaughter (D-FL) on Jan. 16, 2007
  - Passed the House in April, 2007; sent to Senate
  - Amended and passed by Senate in April, 2008
  - Returned to House where it passed May 5
  - **Signed by President on May 21 (PL 110-233)**

## GINA – Key Provisions

- Prohibits discrimination in **health insurance**
  - May not adjust premium or contribution amount based on genetic information
  - May not require individual or family to undergo genetic tests
  - May not request, require or purchase genetic information
  - Authorizes a penalty for failure to comply by
    - Basing eligibility on genetic information
    - Basing exclusion of preexisting condition

## GINA – Key Provisions

- Prohibits **employment** discrimination on basis of genetic information
  - May not limit, segregate, or classify employees based on genetic information
  - May not request, require or purchase employee's genetic information
  - Must treat genetic information as confidential medical record
  - May disclose in certain circumstances, such as, health researcher, court order, certify FMLA

## GINA – Key Provisions

- Establishes Study Commission
  - To review developing science of genetics
  - Make recommendations to Congress
  - Six years after enactment (2014)
- Addresses “Genetic Services” in clinical trials
  - Potential for discrimination exists based on mere action of requesting genetic test
  - Assumption could be made that a participant has a genetic disorder
  - Bans discrimination based on genetic services, as with genetic information

National Cancer Institute

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*visit our website: <http://legislative.cancer.gov/>*

U.S. DEPARTMENT  
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