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ONE HUNDRED ELEVENTH CONGRESS

# Congress of the United States

## House of Representatives

COMMITTEE ON ENERGY AND COMMERCE

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### MEMORANDUM

March 19, 2010

**To: Members of the Subcommittee on Health**

**Fr: Democratic Staff of the Subcommittee on Health**

**Re: Subcommittee Hearing on NCI Cancer Research**

On Tuesday, March 23, 2010, at 2:00 p.m. in room 2322 Rayburn House Office Building, the Subcommittee on Health will hold a hearing entitled "NCI Cancer Research: Today's Progress; Tomorrow's Challenges." The hearing will examine the National Cancer Institute's (NCI) cancer research efforts.

### I. BACKGROUND

In 2009, cancer was the second leading cause of death in the United States and by the end of this year could surpass heart disease as the leading cause of death.<sup>1</sup> Estimated new cases of cancer in 2009 numbered 1.48 million.<sup>2</sup> Over 560,000 Americans were estimated to die from cancer in 2009, accounting for one of every four deaths in this country. The American Cancer Society (ACS) estimates that slightly less than one in two men will develop cancer in their lifetime.<sup>3</sup> For women, the lifetime risk of developing cancer is approximately one in three.

In 2006, the top ten most common cancers were (measured in rates per 100,000): prostate, female breast, lung and bronchus, colon and rectum, corpus and uterus, bladder, non-

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<sup>1</sup> National Center for Health Statistics, *Leading Causes of Death: 2006* (Apr. 17, 2009) (online at [www.cdc.gov/nchs/FASTATS/lcod.htm](http://www.cdc.gov/nchs/FASTATS/lcod.htm));

National Cancer Institute, *Connecting the Nation's Cancer Community: An Annual Plan and Budget Proposal Fiscal Year 2010* (2009) (online at [plan.cancer.gov/index.htm](http://plan.cancer.gov/index.htm)).

<sup>2</sup> American Cancer Society, *Cancer Facts and Figures: 2009* (2010) (online at [www.cancer.org/downloads/STT/500809web.pdf](http://www.cancer.org/downloads/STT/500809web.pdf)).

<sup>3</sup> *Supra* note 2.

Hodgkin lymphoma, melanomas of the skin, kidney and renal pelvis, and ovarian.<sup>4</sup> Lung and bronchus, prostate, female breast, colon and rectum, pancreas, ovary, leukemias, non-Hodgkin lymphoma, liver and intrahepatic bile duct, and esophagus were the ten tumor sites with the highest death rates.

Rare and deadly cancers also pose special challenges with respect to detection, diagnosis, and treatment. Depending on the number of individuals with a particular form of cancer, and the likelihood of survival five years after diagnosis, a cancer can be categorized as rare, deadly, both, or neither.

There is no consensus definition of rare cancers. The Orphan Drug Act (P.L. 97-414) and Rare Disease Act of 2002 (P.L. 107-280) define a rare disease or condition as one that “affects less than 200,000 persons in the United States.” The National Cancer Institute (NCI) has previously defined a rare cancer as one with an incidence rate of less than 40,000 Americans per year.<sup>5</sup> Cancers with five-year survival rates under 50% are considered to be among the deadliest cancers; these include cancers of the lung and bronchus, pancreas, stomach, ovary, liver and intrahepatic bile duct, brain, myeloma, and esophagus.<sup>6</sup> NCI defines high mortality cancers as those with a five-year survival rate of approximately 25% to 30% or less.<sup>7</sup>

## **II. RESEARCH EFFORTS AT THE NATIONAL CANCER INSTITUTE**

### **A. Current NCI Research Activities and Authorities**

NCI is one of 27 institutes and centers that make up the National Institutes of Health (NIH) and is the principal institute for cancer research. Research conducted and supported by NCI is credited with tremendous progress against cancer, including the decrease in the rate of cancer deaths over the past decade and decline in new cancer cases since 1999.<sup>8</sup> In 2008, there were over 11 million cancer survivors in the United States, due in part to advances in our understanding of the causes of cancer, as well as the development of new technologies to prevent, detect, diagnose, and treat it.<sup>9</sup>

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<sup>4</sup> Centers for Disease Control and Prevention, *United States Cancer: 2006 Top Ten Cancers* (2009) (online at [apps.nccd.cdc.gov/uscs/](http://apps.nccd.cdc.gov/uscs/)).

<sup>5</sup> National Cancer Institute, *EGRP Hosts Workshop on Understudied Rare Cancers* (2005) (online at [epi.grants.cancer.gov/Conference2/summary.html#OS2](http://epi.grants.cancer.gov/Conference2/summary.html#OS2)).

<sup>6</sup> National Cancer Institute, *Surveillance Epidemiology and End Results (SEER) Data* (2010) (online at [www.seer.cancer.gov](http://www.seer.cancer.gov)).

<sup>7</sup> NIH Office of Rare Diseases Research (ORDR) and Division of Cancer Prevention, NCI Workshop, *Rare Cancers with High Mortality: Challenges for Cancer Prevention and Treatment* (2009) (online at [rarediseases.info.nih.gov/files/Rare\\_Cancers\\_Agenda\\_DEC09.pdf](http://rarediseases.info.nih.gov/files/Rare_Cancers_Agenda_DEC09.pdf)).

<sup>8</sup> National Cancer Institute, *The U.S. National Cancer Institute* (July 6, 2009) (online at [www.cancer.gov/cancertopics/factsheet/NCI/NCI](http://www.cancer.gov/cancertopics/factsheet/NCI/NCI)).

<sup>9</sup> *id.*

NCI's responsibilities include: (1) conducting and promoting cancer research; (2) reviewing and approving grant applications to support research on the causes, diagnosis, treatment, and prevention of cancer; (3) collecting, analyzing, and disseminating the results of cancer research conducted in the United States and abroad; (4) providing training and education in cancer diagnosis and treatment; and (5) overseeing the National Cancer Program.<sup>10</sup> The National Cancer Program is the vehicle for conducting and supporting research, training, dissemination, and other activities related to cancer. Through the National Cancer Act of 1971, Congress strengthened NCI's ability to combat cancer.<sup>11</sup> Among other provisions, this legislation authorized NCI's submission of an Institute budget directly to the President.

NCI cancer research spans the continuum of scientific discovery – from “bench to bedside.” These steps include: (1) making discoveries in a laboratory (basic research); (2) building on this research to develop innovations to prevent, detect, diagnose, and treat disease (translational research); and (3) testing the safety and efficacy of these innovations (clinical research).<sup>12</sup>

## **B. Recent Innovations and Future Activities in NCI Cancer Research**

Looking ahead, one area of great promise in cancer treatment is “personalized medicine” – treatment that is based on the genetic material (genome) of a patient's tumor. This will allow for targeted cancer therapies based on the individual profile of the patient's tumor, maximizing the benefit of treatment while minimizing side effects, e.g., toxicity.

In 2005, following the completion of the Human Genome Project, NCI and its sister institute, the National Human Genome Research Institute, launched the Cancer Genome Atlas (TCGA). TCGA is the largest single effort to apply genomics science to cancer. TCGA project goals are to: (1) sequence the genomes of specific cancers; (2) identify alterations in genes associated with cancer; and (3) differentiate cancer subtypes.<sup>13</sup> In its three-year pilot phase, TCGA focused on three cancers that account for over 210,000 cancer cases and 190,000 cancer deaths each year: glioblastoma (brain cancer), lung cancer, and ovarian cancer. These cancers were selected on the basis of human material (biospecimen) availability that met project requirements, as well as poor clinical outcomes for those diagnosed. Recent data from the glioblastoma research have identified four distinct subtypes of this cancer, an important

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<sup>10</sup> *id.* note 8.

<sup>11</sup> National Cancer Institute, *The National Cancer Act of 1971* (2010) (online at [legislative.cancer.gov/history/phsa/1971#bill](http://legislative.cancer.gov/history/phsa/1971#bill)); The National Cancer Act of 1971 (P.L. 92-218).

<sup>12</sup> *id.* note 8.

National Cancer Institute, *What is a Clinical Trial?* (Apr. 8, 2008) (online at [www.nci.nih.gov/clinicaltrials/learning/what-is-a-clinical-trial](http://www.nci.nih.gov/clinicaltrials/learning/what-is-a-clinical-trial)).

<sup>13</sup> National Human Genome Research Institute, *The Cancer Genome Atlas* (Jan. 12, 2010) (online at [www.genome.gov/17516564](http://www.genome.gov/17516564)).

discovery that will assist in determining optimal treatments for diagnosed patients.<sup>14</sup> NIH will expand TCGA to study 20 other cancers over the next few years. These cancers have not yet been decided upon.

In 2009, NCI launched the cancer Human biobank (caHUB). caHUB will serve as a national repository of biological materials and associated data. This initiative will further TCGA and other groundbreaking cancer research by ensuring the availability of high-quality human biospecimens.

Other NCI initiatives include the cancer Biomedical Informatics Grid (caBIG), an information network that facilitates the secure collection, organization, sharing, and analysis of data associated with cancer research. Nanotechnology is also facilitating progress in the early detection, diagnosis, and treatment of cancer.<sup>15</sup> Nanotechnology is the creation of incredibly small but useful materials, devices, and systems that can monitor and manipulate biological processes at the molecular level.

### **III. THE NATIONAL CANCER INSTITUTE'S BUDGET**

President Obama's FY 2011 Budget requests \$5.26 billion for NCI, an increase of \$163 million over FY 2010 appropriations.<sup>16</sup> The American Recovery and Reinvestment Act of 2009 allocated \$1.26 billion in supplemental NCI funding for FY 2009 and FY 2010. The majority of this funding – \$845.6 million – was obligated in FY 2009.

In FY 2008, the most recent year for which tumor site-specific funding levels are available, NCI's total budget was \$4.83 billion.<sup>17</sup> Breast cancer was funded at \$572.6 million, followed by prostate cancer (\$285.4 million), colorectal cancer (\$273.7 million), lung cancer (\$247.6 million), and leukemia (\$216.4 million). The deadliest cancers, other than lung cancer, received far less funding: Brain and central nervous system cancer received \$153.7 million; ovarian cancer received \$100.0 million; pancreatic cancer received \$87.3 million; liver cancer received \$74.2 million; myeloma received \$41.5 million; and stomach cancer received \$12.4 million.

It is important to note, however, that tumor site-specific funding levels are not an exhaustive representation of NCI's research investment. For example, investments in initiatives such as TCGA are expected to provide valuable information for all forms of cancer. TCGA, like

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<sup>14</sup> National Cancer Institute, *The Nation's Investment in Cancer Research: Connecting the Nation's Cancer Community (An Annual Plan and Budget Proposal for Fiscal Year 2011)* (2010) (online at [plan.cancer.gov/](http://plan.cancer.gov/)).

<sup>15</sup> National Cancer Institute, *NCI Alliance for Nanotechnology in Cancer* (2010) (online at [nano.cancer.gov/learn/understanding/](http://nano.cancer.gov/learn/understanding/)).

<sup>16</sup> National Institutes of Health Office of Budget, *Institute/Center Submissions: National Cancer Institute* (2010) (online at [officeofbudget.od.nih.gov/insti\\_center\\_subs.html](http://officeofbudget.od.nih.gov/insti_center_subs.html)).

<sup>17</sup> National Cancer Institute, *The NCI Annual Fact Book* (2009) (online at [obf.cancer.gov/financial/factbook.htm](http://obf.cancer.gov/financial/factbook.htm)).

other newer NCI initiatives, reflects the Institute's interest in expanding beyond the current understanding of cancers by organ site to better understand genetic changes that drive cancer as a whole.

#### **IV. WITNESSES**

The following witnesses have been invited to testify:

##### **Panel One:**

**Anna D. Barker, Ph.D.**  
Deputy Director  
National Cancer Institute

##### **Panel Two:**

**Robert S. DiPaola, M.D.**  
Member  
Science Policy & Legislative Affairs Committee  
American Association of  
Cancer Research  
Director, Cancer Institute of New Jersey

**Megan Gordon Don, M.H.S.**  
Chair  
The Deadly Cancer Coalition  
Director of Government Affairs  
Pancreatic Cancer Action Network

**Kristin Fitzgerald**  
Naperville, Illinois

**Ellen Sigal, Ph.D.**  
Chair and Founder  
Friends of Cancer Research