Sources of Cancer Research Funding in the United States

Michael McGeary and Michael Burstein

INTRODUCTION

BACKGROUND

More than 1.2 million Americans will be diagnosed with cancer this year, and nearly half will die from cancer within five years. About 565,000 will die this year, which makes cancer the second leading cause of death after heart disease. In addition to causing severe pain and suffering for patients and their families and friends, cancer has substantial economic costs: about $37 billion in direct health care costs and another $70 billion in loss of productivity due to morbidity and mortality.[1]

Research has long been one response to the toll of cancer—research on its causes and development, on how to cure, or better yet, prevent it, and on ways to improve the quality of life of those who are dying from it and who survive it. This effort has been complicated by the fact that cancer is not one disease but many. Although all cancers have in common the phenomenon of uncontrolled cell growth, they differ significantly in their cause, location, age of onset, susceptibility of population groups, severity, treatments, and aftereffects.

The National Cancer Institute (NCI) was the first categorical institute of the National Institutes of Health (NCI), established in 1937, and it has always been the biggest institute. The War on Cancer launched by National Cancer Act of 1971 greatly increased the priority of cancer research in the federal budget, and the Act established a model of public-private cooperation built around a nationwide network of research laboratories and cancer centers.

Overall mortality from cancer stopped increasing about 1991 and has fallen since then.[2] Much of the decrease can be attributed to the greater understanding of causal factors (e.g., smoking and lung cancer in men), better preventive measures (e.g., screening for breast, cervical, colorectal, and stomach cancers), and more effective treatments (e.g., for childhood leukemia, Hodgkin's disease, and testicular cancers).

CHANGING FEDERAL ROLE

The big ramp-up of federal funding at the beginning of the War on Cancer made NCI the largest source of support for cancer research, accounting for nearly two-thirds of funding from all sources in 1974. Over time, however, the funding base has broadened. Although NCI's budget has increased steadily over the years, to $2.9 billion for FY 1999, it is evident that other sources of funding have expanded even more, especially over the past two decades. Pharmaceutical companies, which did little cancer research in the early 1970s, have steeply increased their research budgets. Biotechnology, a relatively new industry created by advances in basic biomedical research, is pursuing cancer and other diseases, fueled by billions of dollars in venture

capital and stock proceeds. Members of the Pharmaceutical Research and Manufacturers Association (PhRMA), the largest pharmaceutical and biotechnology firms, reported spending about $1.4 billion on cancer research in 1997.[3] The recent proliferation of advocacy groups for specific diseases and their use of innovative fund-raising strategies, and the rise of cause-related marketing in corporate giving, are raising unprecedented amounts of charitable dollars for biomedical research.

The National Cancer Policy Board (NCPB), which commissioned this paper, is funded by NCI, CDC, the American Cancer Society, and private firms[4] to address national issues in cancer research, cancer care, and cancer prevention. NIH, especially through NCI, supports more academic, openly published research on cancer than any other single source, but additional funding sources are growing in importance. At several meetings in 1998 and 1999, the National Cancer Policy Board decided to gather information about who funds cancer research in the United States, as background for any subsequent analysis of cancer research policy and to help identify issues. NCI is just one partner—and no longer the majority funder—in the national cancer research enterprise (although it is the largest single institution and has the broadest scope). More and more, NCI's planning and priority setting (and those assessing their appropriateness and effectiveness) need to take into account the activities of others to ensure that there is overall balance in the national cancer program.

DATA ISSUES

The focus is on funding for research, broadly defined, including not just support of research projects but also support of the research infrastructure, including facilities, equipment, and research training. This counts all types of research, not just basic biomedical research conducted in laboratories. Thus we include clinical research, population-based research (e.g., epidemiology), health services research (e.g., outcomes and effectiveness) and social and behavioral research on risk factors and on intervention strategies. The Board asked the authors to exclude education and outreach activities and public-health service programs (but to include research on better ways to inform and educate the public and to improve public health measures, such as trials of smoking cessation programs).

The data presented in this paper were obtained from secondary sources and are subject to several caveats. First, they are not complete for all sectors, and many reports are not detailed. The pharmaceutical industry's largest trade organization, PhRMA, for instance, surveyed its members for how much they spend on cancer research, but there is no detail on types of research or types of cancer targeted. The biotechnology industry does not systematically collect information on research spending by disease. It is difficult to identify all of the private philanthropy and individual gifts and bequests going to cancer research across the country, because of the diffuse and decentralized nature of this funding, although in the aggregate it may be substantial. There is also no central reporting of state funding for cancer research.

Second, there may be some double-counting, although we have been able to account for some of it and believe it is minimal. Most of the funding of cancer research by private voluntary health organizations comes from individuals, but some comes from grants to those organizations (and so might be counted as foundation or government funding as well as spending by the private voluntary health organization). In some cases, part of the R&D expenditures of a pharmaceutical

or biotech company comes from a partner company and could be counted as R&D by two or more firms, although PhRMA eliminates double-counting where it can.

Third, a substantial amount of "cancer research" is so basic that its actual relevance to cancer is hard to predict. This can work in two directions. Cancer research has often benefited understanding of other disorders (e.g., the study of cancer viruses that proved directly relevant to HIV infection), and research on other conditions can illuminate cancer (e.g., studies of Hepatitis viruses and their connection to liver cancer). Basic research is included here if the funders intended it to contribute to better understanding of and ways to deal with cancer. Readers should keep in mind, however, that a broadly diversified national research enterprise may be as important, or more so, in the conquest of cancer over the long haul than the fraction of the medical research budget devoted specifically to cancer.

Fourth, 1997 was chosen as the comparison year, because it is the most recent year for which there are statistics on funding by most of the sources, such as industry and philanthropic foundations. The cancer research enterprise is growing rapidly, especially in certain sectors (e.g., biotechnology, cancer-specific voluntary organizations, and foundations). The balance among sectors may have shifted further in just the past two years, although federal funding of cancer research has also increased strongly. The prostate cancer program at the Department of Defense was just beginning in 1997, and since then, an ovarian cancer program has been added. NCI received a larger than average budget increase for FY 1999.

These constraints on the data mean that the statistics presented in this paper are rough estimates. We believe they are in the right ballpark, however, and thus useful for informational and policymaking purposes. Underestimates may have occurred, because it is impossible to capture the full extent of private sector activity, especially state and local philanthropy and industry research. We also probably did not capture all cancer research support by federal agencies outside the Department of Health and Human Services or by state governments. On the other hand, we have probably included some double-counting and small amounts of non-research activities (e.g., public information, education, and outreach programs) that inflate the figures.

PLAN OF THE PAPER

There are two parts to this paper. The first reports on funding of cancer research by source—e.g., NCI, other NIH, other federal, industry, foundations, voluntary organizations, etc. The second compares the current pattern of funding with earlier estimates by NCI in 1971, 1974, 1981, and 1984.

I

FEDERAL FUNDING

NCI is the largest single provider of funds for cancer research, but other institutes and departments and agencies provide substantial amounts. DOD, for example, has become a major source of funds in recent years for research on breast and prostate (and more recently, ovarian) cancers.

NCI

NCI reports on cancer research spending ($2.4 billion in FY 1997) and also estimates how much it spends on several particular types of cancer, including brain and CNS cancer, breast cancer, cervical cancer, colorectal cancer, Hodgkin's disease, leukemia, liver cancer, lung cancer, melanoma, Non-Hodgkin's lymphoma, ovarian cancer, prostate cancer, and uterine cancer (Table 1).

Table 1. NATIONAL CANCER INSTITUTE
RESEARCH DOLLARS FOR VARIOUS CANCERS FY 1992 - FY 2000
(in millions)

	1992 Actual	1993 Actual	1994 Actual	1995 Actual	1996 Actual	1997 Actual	1998 Actual	1999 Estimate	2000 President's Budget
AIDS	$165.7	$173.0	$213.0	$217.7	$225.4	$224.7	$225.9	$235.4	$240.1
Brain and CNS	32.5	40.5	41.7	43.0	41.6	46.1	54.3	58.2	59.6
Breast Cancer	145.0	211.5	267.6	308.7	317.5	332.0	348.6	388.0	407.5
Cancer Prevention & Control	114.9	112.6	153.9	205.0	226.0	231.9	254.7	277.7	299.4
Cervical Cancer	30.7	42.2	42.3	45.5	51.6	55.8	58.0	62.1	63.6
Clinical Trials	314.5	326.8	339.0	384.8	393.8	417.6	478.1	498.1	512.2
Colorectal Cancer	69.2	74.2	83.1	96.5	98.0	103.2	121.0	130.0	133.1
Hodgkins Disease	6.7	6.8	6.7	7.8	8.0	8.1	8.3	9.1	9.3
Leukemia	64.6	74.2	77.7	77.5	79.3	91.2	103.4	106.5	109.0
Liver Cancer	30.7	37.5	37.9	38.0	31.4	35.3	38.1	40.8	41.8
Lung Cancer	76.3	92.9	106.4	113.9	119.4	132.4	139.8	146.8	150.3
Melanoma	24.8	29.8	33.4	31.8	36.0	43.3	50.3	54.8	56.1
Non-Hodgkins Lymphoma	33.4	40.1	38.7	39.7	49.9	52.7	57.1	62.2	63.7
Ovarian Cancer	20.7	32.5	33.5	33.9	36.5	41.7	40.8	44.0	45.0
Prostate Cancer	31.4	51.1	56.1	64.3	71.7	82.3	86.9	130.0	136.5
Uterine Cancer	7.8	6.3	7.2	7.7	8.1	8.1	12.2	12.9	13.2
Total NCI	1,947.6	1,978.3	2,076.2	2,129.4	2,254.9	2,389.1	2,527.5	2,903.3	2,972.9

SOURCE: NCI Financial Management Branch (www.nci.nih.gov/admin/fmb/areas.htm)

A large amount of detailed information is available on what NCI funds, right down to the specific research projects, and the results are published in the open scientific literature. NCI reviews its strategic research plan with the research community each year and publishes it.[5] In FY 1997, in terms of research target, NCI spent about 29 percent of its budget on cancer causation, 15 percent on cancer biology, 6 percent on detection and diagnosis research, and 29 percent on treatment research. About 10 percent was spent on research on better approaches to cancer prevention and control, and another 10 percent went for infrastructure (core grants for cancer centers, fellowships, traineeships, and other human resource development activities, and facility construction). By mechanism of support, about 24 percent of the NCI budget went to traditional

investigator-initiated grants (R01s) and 43 percent to other types of research grants and contracts, 2 percent for fellowships, 17 percent to intramural research, 10 percent to cancer prevention and control research, and 4 percent to administration.

Other NIH

NCI is by no means the sole NIH funder of cancer research at NIH. The National Heart, Lung, and Blood Institute, for example, supports cancer research through its programs for lung diseases and blood diseases. The National Institute of Environmental Health Sciences includes cancer in its research on biological responses to environmental agents. Since cancer affects every organ and system, and each age group, every NIH institute and most centers support some cancer-related research.

Each institute and center reports on how much it spends on cancer research. NCI is the biggest contributor, but other institutes contributed $372 million (13.5 percent of the NIH total) in FY 1997 (Table 2).

Table 2. NATIONAL INSTITUTES OF HEALTH
CANCER RESEARCH BY INSTITUTE, FY 1997-FY 1999
(in millions of dollars)

	FY 1997 Actual	FY 1998 Estimate	FY 1999 Estimate
NCI	2,389.0	2,547.3	2,776.3
NHLBI	57.6	59.8	67.5
NIDR	16.4	17.3	19.8
NIDDK	33.4	36.5	39.4
NINDS	17.9	18.7	24.5
NIAID	43.1	44.4	47.9
NIGMS	22.6	24.4	30.4
NICHD	10.3	11.0	11.9
NEI	8.6	9.2	9.5
NIEHS	84.4	89.4	94.8
NIA	12.2	12.7	15.0
NIAMS	5.3	5.7	6.2
NIDCD	2.9	3.1	4.3
NIMH	4.3	3.8	4.1
NIAAA	2.7	2.0	2.5
NINR	3.6	4.3	4.6
NHGRI	17.1	22.2	30.2
NCRR	25.9	29.8	37.9
FIC	0.6	0.6	0.7
NLM	0.0	0.0	4.5
TOTAL NIH	2,760.7	2,941.2	3,231.8

SOURCE: NIH Office of Financial Management

Again, there is much information on the research that is funded, and the results are generally published in the open literature.

Other Department of Health and Human Services Agencies (DHHS)

DHHS reports to Congress each year how much it spends on a number of areas of "health," including cancer, in the so-called "Moyer Materials" requested by the House and Senate Appropriations Committees. The Board also obtained a license and used the RaDiUS (Research and Development in the United States) database developed by the RAND Corporation to explore the types of cancer research activities engaged in by each agency by identifying all intramural and extramural projects or tasks in which the word "cancer" appears in the abstract.

- The Centers for Disease Control and Prevention (CDC) estimated it spent $185 million on cancer-related R&D programs in FY 1997. The categories included breast and cervical cancer ($139.7 million), cancer registries ($22.3 million), other chronic diseases ($8.1 million), infectious diseases ($450 thousand), environmental health ($1.7 million), and occupational safety and health ($12.7 million). Not all are research programs. For example, the breast and cervical cancer program is an early detection program aimed at underserved populations. Deleting this program and assuming the rest of the activities are research or research-related (e.g., registries) would leave $45.3 million. According to RaDiUS, the National Institute for Occupational Safety and Health was supporting research grants with titles such as "Respiratory carcinogenesis in uranium miners;" "Cancer mortality in minority workers;" and "Time-related factors in radiation cancer dose response."

- AHCPR estimated it spent $3.9 million on research on health costs, quality, and outcomes related to cancer (out of a research budget of $95 million). According to RaDiUS, there were extramural projects with such titles as "Developing effective breast cancer risk information;" "Cost effectiveness of MRI breast screening;" "Treatment choices and outcomes in prostate cancer;" "Care, costs, and outcomes of local breast cancer treatments;" "Risk factors of early unscheduled visits in cancer patients;" and "Cancer screening of low income and minority women." Some projects with a larger scope in which cancer was included were "Measuring quality by achievable benchmarks of care;" and "Optimal policies for clinical lab quality control."

- HCFA spends enormous amounts on cancer—$16.7 billion in FY 1997—but mostly on medical services and care. HCFA has a relatively small program of research, demonstrations, and evaluation projects ($44 million in 1997) to develop, test, and implement new health care financing and payment policies and to evaluate the impact of HCFA programs on beneficiaries, providers, states, and other customers and partners. It focuses on costs, access, quality, services delivery models, and financing and payment approaches.[6] Although past HCFA research has included "Mammography Services Paid by Medicare in 1994-1995," and "Predicting the Costs of Hospitalization for Cancer Care,"[7] RaDiUS did not identify any cancer-related HCFA research in 1997 and so we did not count any funding for cancer research from HCFA that year.

- DHHS did not report cancer-specific research supported by FDA, although the RaDiUS search turned up a number of intramural research projects that FDA conducts in support of its mission of regulating the public health through science-based standards. They included "Flow and image cytometry in B cell lymphocytic leukemia;" "Molecular genetics of common and familial B-cell lymphocytic leukemia;" "Interleukins and their receptors in tumor biology;" "Molecular mechanisms governing B and T cell differentiation and neoplasias" (Gene Therapy Program); several studies of the EGF/ERBB supergene family in ovarian carcinoma (Cytokine Biology Program); "Preclinical models for testing of biological cancer therapeutics;" and "IL-2 and IP-10 as regulators of angiogenesis" (Hematologic Products Program).

Other Federal Agencies

According to RaDiUS, ten federal departments and agencies funded at least one project or activity with the word "cancer" in its abstract or title in FY 1997. Of the 9,888 specific projects, 5,905 were funded by DHHS. Most of the rest were reported by the Department of Veterans Affairs (VA) (2,912) and DOD (859). The remaining 212 (2 percent) were scattered among the other seven agencies. Some of these are not actually cancer-related. Some of the VA hits, for example, are drug trials in which having cancer is a disqualifying condition. On balance, however, these numbers likely underestimate the number of cancer research studies or activities funded by federal agencies (some will use other terms instead, such as neoplasm, carcinogenesis, leukemia, or carcinoma). The balance among them seems reasonable, however, and may be used as a rough guide as to how much funding the other agencies are providing for cancer research.

VA. Interpreting VA's funding for cancer research is problematic. VA's own appropriation for health research was $262 million in 1997, but it performed or sponsored $932 million in research.[8] Many of the nearly 3,000 cancer studies it is carrying out in its network of 99 veterans medical centers across the country are Stage I, II, and II drug trials that being done on a reimbursable basis for a pharmaceutical firm or with an NCI grant, or they are clinical studies of risk or outcome that compare normal populations with these with cancer and other diseases and with those over 65 (because VA is an excellent setting for multi-center research in these populations). More than 60 percent of VA's research funding came from outside sources in 1997—grants from other federal agencies, DOD reimbursements, grants from voluntary agencies, clinical income, and industry funding. This funding is already counted as part of the research budgets of NCI and other NIH institutes and of private firms sponsoring clinical trials.

One major focus of VA research is the array of chronic diseases and conditions that are common among veterans, including cancer.[9] In its fall 1996 grant review cycle, VA awarded 143 grants to intramural and extramural investigators. The 22 awards for cancer research received 14.5 percent of the funding.[10] These included several large initiatives: VA's part of the multi-agency "Prostate cancer intervention versus observation trial" (PIVOT) and a study of colorectal cancer screening, and several smaller projects, including a study of patient involvement in prostate cancer treatment decisions and a clinical trial of a diagnostic method, 18-F-Fluorideoxyglucose positron emission tomography (PET) imaging in patients with solitary pulmonary nodules.

A rough estimate of total VA cancer research funding can be derived by assuming that 14.5 percent ($39 million) of VA's overall federal appropriation for research of $272 million in 1997 was for cancer research.

DOD. In 1992, Congress began to earmark funding for breast cancer research in the DOD budget. The appropriation for the breast cancer research program was $100 million in FY 1997. Another $12.5 million was appropriated to fund computer-aided decision support systems, research on computer-aided diagnosis, and establishment of an advanced cell detection center. Also in 1997, Congress appropriated $38 million for prostate cancer research.[11] (Ovarian cancer was added in 1998.)

The RaDiUS search turned up fewer than 20 projects in other parts of DOD. For example, the Air Force's Armstrong Laboratory carries out research on radiation hazards in aerospace operations, which funded several projects in FY 1997 (e.g., "Endpoints of chronic irradiation of cancer-prone mice" and "Long-term life expectancy radiation effects"). An Army program on environmental quality technology funded several studies of the genetic damage caused by environmental chemicals. A tri-service Defense Women's Health Research program funded a study of the clinical feasibility of digital mammography.

The DOD total is about $160 million ($150.5 million for the Congressionally mandated breast and prostate cancer programs and the rest for the studies of radiation effects, chemical carcinogenesis, and other topics of interest to the armed forces).

EPA, DOE, NASA, NSF, Commerce, and USDA. These agencies each support some cancer research, but together the funding would be relatively small. RaDiUS picked up 212 projects with the word cancer in the abstract in these agencies, or 2 percent of the total. EPA, for example, supports some cancer-related projects as part of its program of research supporting the development of air, water, and other environmental standards. DOE also supports a number of cancer-related research projects, although half of the ones identified by RaDiUS are reimbursed work done for other federal agencies. DOE research focuses on the effects of radiation on humans and the uses of radiation in treating cancer. NASA is supporting several studies that would make use of the space station to study the effects of microgravity on the production of anti-cancer drugs and vaccines. NSF funds basic biology research.[12]

If we assume that fewer than 200 of them are actually about cancer, but they are only half the number of the projects we would find with a more detailed search, and they cost $200,000-250,000 on average a year (but not all are just about cancer), these agencies would be funding between $50 million and $100 million a year in cancer research.

INDUSTRY FUNDING

Information on industrial funding is difficult to determine because of proprietary concerns, and because the industry associations do not want to impose too great a reporting burden on their members.

Pharmaceutical Industry

The Pharmaceutical Research and Manufacturers of America (PhRMA) conducts an annual survey of its members, which are the large U.S. pharmaceutical companies and most of the largest biotechnology companies. PhRMA companies have greatly increased their funding of research and development over the past decade, surpassing NIH/ADAMHA research funding about 1992. In 1997, PhRMA members reported total spending on R&D to be $18.9 billion, nearly twice as much as in 1990 in constant (i.e., inflation-adjusted) dollars.[13]

In 1997 PhRMA surveyed member companies on how much they spent in cancer R&D—$1.4 billion. That included work on some 316 drugs and vaccines in various stages of development and a growing investment in basic research.[14]

A recent PhRMA survey found that cancer therapies are also the leading category of biotechnology products in development. PhRMA reported that 140 pharmaceutical and biotechnology companies were in the process of testing 350 new biotechnology medicines, including 151 for cancer.[15]

Biotechnology Industry

The Biotechnology Industry Organization (BIO) reported R&D spending by biotechnology firms totaling $9.0 billion in 1997, 14 percent more than in 1996.[16] BIO does not report amount of funding by disease, only the number of companies working on a particular disease. The numbers of companies working on products by type of cancer were:[17]

Breast Cancer	68
Colon Cancer	25
Leukemia	35
Liver Cancer	17
Lung Cancer	45
Ovarian Cancer	27
Prostate Cancer	56
Stomach Cancer	4
Kidney Cancer	16
Skin Cancer	16

Most of the largest biotechnology firms—eight of the 10 largest, for example—belong to PhRMA and are included in $1.4 billion R&D total reported by that organization for 1997. The two large firms that do not belong to PhRMA are Chiron and Immunex, which had R&D expenditures of $296.5 million and $109.3 million, respectively.[18]. The next problem is to determine how much, if any, of that research was on cancer. Chiron provides a table on its Internet site showing that four of its 13 therapy projects, none of its eight vaccine projects, and one of its seven diagnostic projects concern cancer (5 of 28 total).[19]

There were nearly 1,300 biotech companies in 1997, most of them small (one-third have fewer than 50 employees, two-thirds fewer than 135 employees). R&D expenditures per employee in the 10 largest firms were nearly $100,000, but presumably that amount was less in most firms. Still, total research spending by the almost 1,200 biotech firms below the top 100 may

have been substantial in the aggregate. There remains a difficult problem of estimating how much was for cancer research.

Another way to proceed is to look at some of the firms working specifically on cancer drugs and vaccines. EntreMed reported spending $9.0 million in 1997, Oncormed (now GeneLogic) $0.8 million, and Oncogene Sciences (now OSI Pharmaceuticals) $16.9 million.

For now, pending a firm-by-firm analysis of R&D spending and judgment of how much was for cancer in each case, we believe it would be conservative to add $200 million to the PhRMA total for cancer-specific R&D among the non-PhRMA biotechnology companies (roughly 20% of the Chiron and Immunex R&D budgets, or $80 million, plus $50 million for the cancer-specific biotech firms such as EntreMed, plus $70 million among the remaining 1,100-1,200 companies).

FOUNDATIONS

Spending by non-profit foundations is tracked by the Foundation Center, including three types of foundations: independent endowments and funds, corporate giving foundations, and community-based donors. Serious limitations are placed on this data, because it is gathered and presented by the Foundation Center as an aid to those looking for grants, not as a tool for those trying to determine the aggregate amounts that foundations spend on a particular purpose, such as cancer research. Nevertheless, as the largest available source of information on foundation grants, we have chosen to use its data, subject to appropriate caveats.

Two Foundation Center reports are used here.

1. The annual report, *Foundation Giving*, reports the number and amount of foundation grants by broad category. According to the 1998 edition of *Foundation Giving*, foundations awarded grants totaling $13,836.1 million in 1996, of which 16.2 percent ($2,241.4 million) was for health purposes.

2. The Center also produces an annual *Foundation Grants Index*, which includes detailed information on grants of more than $10,000 made by a sample of 1,016 foundations. Approximately 800 of the foundations in the sample are among the largest 1,000 foundations in the country. The other 200 are drawn from the more than 41,000 remaining foundations. Thus, the *Foundation Grants Index* aims to provide a representative sampling of foundations, but it is weighted heavily towards larger donors. Although the sample includes only 2.4 percent of all foundations, they account for more than half of all grant dollars awarded yearly.

The grants in the *Foundation Grants Index* are categorized by subject, one of which is "Health." "Cancer research" is a sub-category of "Health." In 1996, the last year for which there is fairly complete reporting, the foundations in the sample awarded $1,179,670,000 in grants for health purposes.[20] More detailed data in the *Foundation Grants Index* are available on CD-ROM. According to this database, grants made to U.S. institutions for cancer research totaled $31,144,733 in 1996, or 2.6% of the total funding of health grants.

To estimate the amount of grants for cancer research by all foundations, we extrapolated from the sample in the *Foundation Grants Index* to the full set of foundations by assuming that about 2.6 percent of the funding of all health grants was for cancer research:

Total 1996 foundation "health" grants:	$2,241,400,000
Foundation-funded "cancer research" (2.6% of total health grants)	$58,276,000

The next step was to estimate the total in 1997. The annual compound rate of growth in funding for cancer research from 1994 to 1996 in the *Foundation Grants Index* was 2.7 percent. Assuming that it grew another 2.7 percent from 1996 to 1997, foundation grants for cancer research totaled $59, 849,000 in 1997.

HOWARD HUGHES MEDICAL INSTITUTE (HHMI)

HHMI has a unique status as a "medical research institute." It contributes a large amount to the national biomedical research effort; its annual medical research budget was more than $400 million in 1999, roughly comparable in spending to a mid-sized NIH institute.

It is difficult to estimate how much HHMI spends on cancer-related research. It supports people, not projects. The approach is to try to pick the best scientists and let them decide what research to do. HHMI staff know how their support is distributed among broad fields of science, for example, genetics, structural biology, etc., but because they do not allocate funding by disease, HHMI does not count funding by disease area.

The president of HHMI says if he had to make a ballpark guess, at least 25 percent of what HHMI investigators are doing is directly or indirectly related to cancer (he estimated about $110 million, or 27 percent, of the current annual budget for medical research of about $400 million).[21] It could be more depending on how much basic research is counted. For example, HHMI supports a lot of work on cell cycle control, all of which could be deemed cancer related. Some investigators are working on cancer directly, for example, Bert Vogelstein's work on colon cancer. But every cancer researcher knows that cancer is a problem of cell cycle control, and HHMI devotes a significant fraction of its budget to studying molecular and cellular growth and regulatory factors.

Estimating 27 percent of HHMI's 1997 research budget of $352 million yields approximately $95 million for HHMI cancer-related research that year.

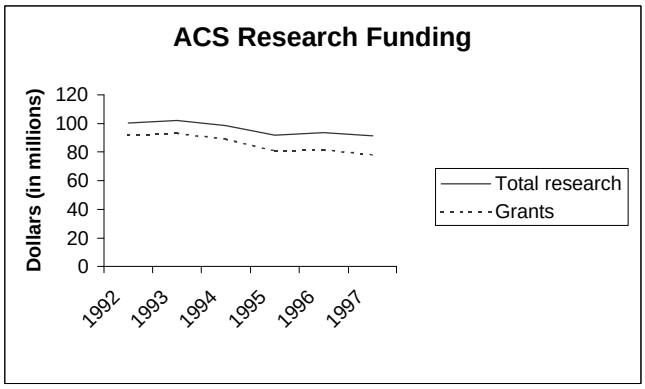
VOLUNTARY HEALTH ORGANIZATIONS

Voluntary health organizations, which collect donations from the general public, provide an important source of funding not only for research, but also for outreach and prevention programs, as well as for patient treatment services. The American Cancer Society, based in Atlanta, has long been the largest such organization devoted to cancer, but recent years have seen a proliferation of other groups, many of which are growing. The analysis below is not comprehensive, because a complete listing of cancer funding groups is not available.

American Cancer Society (ACS)

The ACS is the nation's largest cancer charity, receiving approximately $427 million in donations in 1997, and it is the largest single non-government funder of cancer research in the United States. As shown below, ACS's research budget has contracted in recent years, but it still represents a significant amount of support—$91.1 million in 1997 (Figure 1). In addition to its peer-reviewed extramural research grants, the ACS also funds intramural epidemiology research as well as intramural psychosocial and behavioral research.

Figure 1. Support of Cancer Research by American Cancer Society, 1992-1997



Year	Total research budget	Grants
1992	$100,243,000	$91,902,000
1993	102,266,000	93,223,000
1994	98,283,000	89,024,000
1995	92,153,000	80,860,000
1996	93,384,000	81,721,000
1997	91,119,000	78,159,000

Source: American Cancer Society Annual Reports, 1993-1997

Leukemia Society of America (LSA)

LSA is the second largest volunteer cancer charity, behind the ACS, collecting $57 million in funds in 1997. Although its efforts are aimed explicitly at leukemia, lymphoma, and myeloma, much of its grant funding goes toward basic cancer research, especially since the aforementioned cancers are often model systems.

In 1997, LSA awarded $14.7 million in research grants, up from $14. 2 million in 1996.[22]

Association for the Cure of the Cancer of the Prostate (CaP CURE)

CaP CURE spent more $16 million in 1997 on 85 peer-reviewed research projects at medical centers and universities, a Gene & Family Studies Consortium, a Therapy Consortium, a Nutrition Project, and special awards.[23]

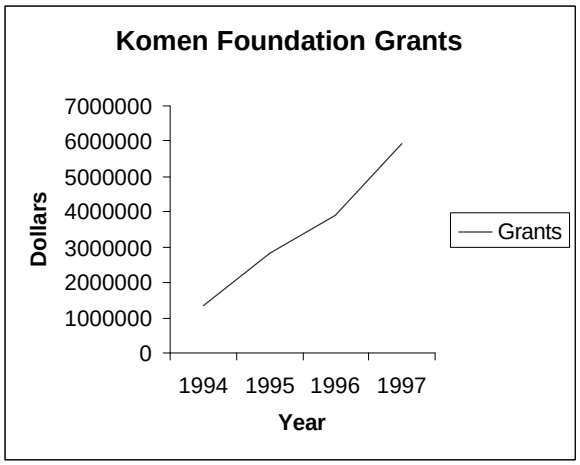
American Institute for Cancer Research

In 1997, AICR awarded grants for research into diet, nutrition, and cancer totaling $5.8 million.

Susan G. Komen Breast Cancer Foundation

The Komen Foundation, founded in 1982, is a relative newcomer among volunteer health organizations. Despite its youth, however, it is the nation's largest funding organization dedicated to breast cancer, and the fourth largest cancer charity in 1996, behind ACS, LSA, and the American Institute for Cancer Research.[24] In 1997, Komen awarded $5.9 million in peer-reviewed research grants. Moreover, as shown in Figure 2, below, it has seen tremendous growth since 1994. This growth is likely the result of increased success on the part of breast cancer advocacy groups in garnering public support.

Figure 2. Research Funding by Susan G. Komen Breast Cancer Foundation, 1994-1997



Source: Susan G. Komen Breast Cancer Foundation

Additional volunteer groups raising funds for cancer research include:

- Cancer Research Foundation of America (grants awarded for basic research relating to cancer prevention): $1.6 million (1997)

- National Foundation for Cancer Research (grants awarded for basic cancer research at the molecular and sub-molecular level): $4.2 million (1997)

The funding data presented above represent a small sampling of moneys available from volunteer health organizations of varying sizes. There are, however, approximately 900 cancer charities registered with the Internal Revenue Service, who reported taking in more than $4 billion in 1996.[25] It is not known how much goes for research as opposed to other activities, such as education and services. As noted above, ACS received $427 million in donations and budgeted

$91 million for research in 1996. The Komen Foundation received $13 million and awarded $3.9 million in research grants.

The organizations identified above together provided about $116 million for research. There are many cancer charities, and it would be conservative to estimate they contributed at least $150 million in 1997.

STATE GOVERMENT

Several states appropriate funds directly to cancer centers. They include Texas ($125 million in1997 for M.D. Anderson) and New York ($32 million for Roswell Park).

In addition, some states have recently established cancer research programs. In 1993, for example, California enacted the University of California-Wide Breast Cancer Research Program funded from the state tobacco tax. The goal of the program is to fund breast cancer research that complements rather than duplicates research funded by the federal government and other agencies. Funding priorities in 1996 included etiology, pathogenesis, new approaches to prevention, early detection, and innovative models of care and treatment modalities. Research awards are based on scientific merit as determined by peer review panels. The 1997 budget was $14.7 million and funded 66 projects in 24 California research institutions (the 1999 budget is $17.4 million).[26]

In 1996, California enacted another cancer research program focusing on prostate and ovarian cancer, funded with state general revenues administered by the state health department. The start-up budget for 1996-1997 was $2 million, and increased to $25 million for 1997-1998. California has two other state-funded programs that support cancer research: University of California Tobacco-Related Disease Research Program and University of California-Wide AIDS Research Program.

The Illinois Department of Public Health administers a breast and cervical cancer program established in 1994 with a budget of about $350,000 a year from general funds and state income tax check-off contributions. Massachusetts has a breast cancer research grant program established in 1993 funded at $2.5 million a year. The New Jersey Commission on Cancer Research established in 1985 is funded by a cigarette tax and “conquer cancer” license plate fee that brings in about $1.25 million a year. In 1996 it began to administer a breast cancer research fund supported by a state income tax check-off that brings in $200,000 a year. New York started a breast cancer research and education program in 1996 funded by a state income tax check-off that brought in about $500,000 in FY 1997. The Pennsylvania Department of Health is just beginning a breast cancer and cervical cancer research program created in 1997 with funds from an income tax check-off and private donations. All these programs use peer review (some of the smaller programs fund proposals that were approved but not funded by larger agencies such as NCI for lack of funds).[27]

Other state-funded programs using peer review that support cancer research include:[28]

- Nebraska Cancer and Smoking Disease Research Program
- Texas Advanced Research Program/Advanced Technology Program
- Arizona Disease Control Research Commission

There are probably more such programs, but there is no central registry that tracks them. We estimate a total of $200 million from state revenues but this figure could grow with further investigation.

INDIVIDUAL GIFTS AND BEQUESTS

People with large fortunes often set up foundations, but many people of smaller net worth make donations or earmark part of their estates to go to local charities, including cancer research institutions. There is no good way to track this, although some perspective may be gained from looking at sources of funding of some of the cancer research centers. According to cancer center directors discussing an early draft of this report at National Cancer Policy Board meeting, most of their funding comes from the sources already identified—e.g., NCI and other NIH institutes, other federal research programs, ACS, and other voluntary organizations and foundations. Additional local sources of funding might one or more of the following: income from endowment; gifts and donations from individuals and businesses; funds from parent institutions (universities and medical centers); indirect cost recovery; and clinical income.

Cancer center directors report that these privately raised funds, although relatively small, are important because they are flexible. They can be used for parts of the cancer research enterprise that research project grant funds cannot be used for, such as supporting new investigators until they can win a peer-reviewed grant, carrying an established investigator between external grants, and funding promising but risky research until there are enough results to submit a grant application.

SUMMARY

According to the information we have been able to gather from secondary sources, including estimates where information is incomplete, spending on cancer research amounted to more than $5 billion in 1997, of which NCI provided $2.4 billion (Table 3).

Table 3. Sources of Funding of Cancer Research, 1997

(millions of dollars)

FUNDER	AMOUNT
Federal, total	**$3,060**
National Cancer Institute	2,389
Other National Institutes of Health Institutes	372
Other Department of Health and Human Services Agencies	49
Other Federal Departments and Agencies	250
Industry, total	**1,600**
Pharmaceutical Research and Manufacturers Association	1,400
Biotechnology Industry Organization	200
Nonprofit Organizations	**305**
Foundations	60
Howard Hughes Medical Institute	95
Voluntary Organizations	150
State Programs	**200**
Local Sources	**
TOTAL	**5,165**

** Unknown

II

In this section, the current distribution of sources of funding is compared with earlier years. NCI collected information on all federal and nonfederal sources of cancer research funding during the first decade of the National Cancer Plan established by the War on Cancer Act in 1971 (Table 4).

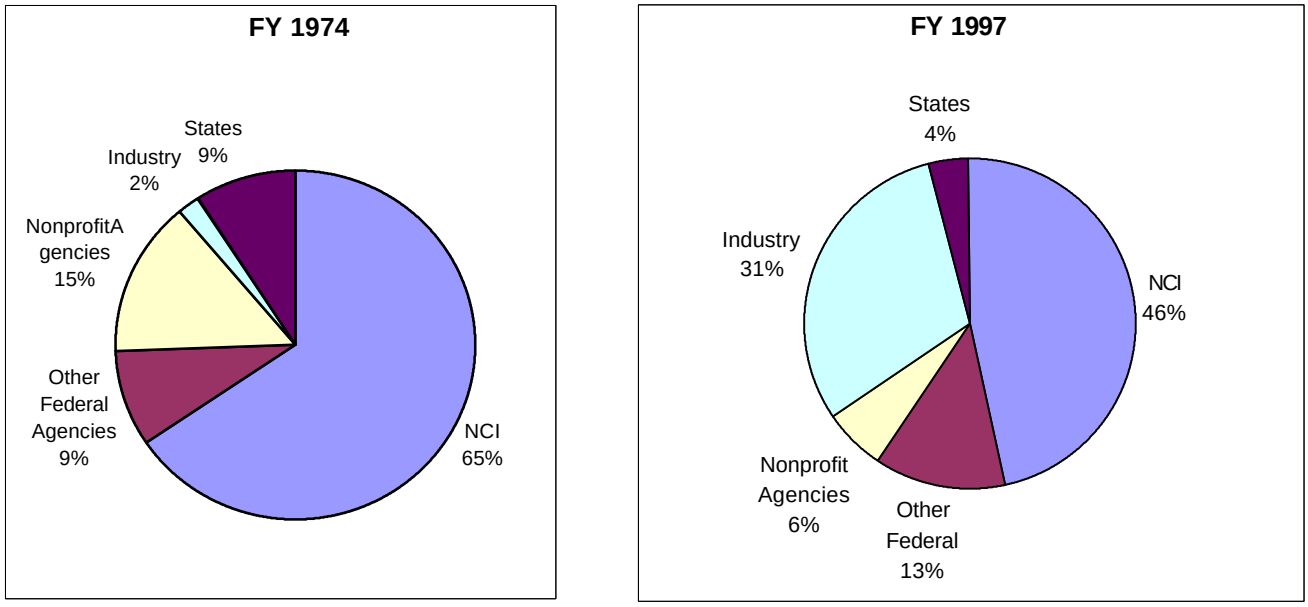
Table 4. SOURCES OF CANCER RESEARCH FUNDING
SELECTED YEARS, 1971-1997 (millions of 1997 dollars)

	FY 1971	FY 1974	FY 1981	FY 1984	FY 1997
NCI	817	1,781	1,698	1,597	2,389
Other Federal	281	239	422	412	671
NIH	NA	94	146	245	372
DHHS	NA	6	45	38	49
Other	NA	139	232	128	250
Nonprofits	366	397	364	331	305
Voluntary Agencies/Foundations	366	397	362	326	305
Labor	0	NA	2	4	NA
Industry	53	48	498	443	1,600
States	299	254	259	279	200
TOTAL	1,816	2,720	3,242	3,061	5,165

SOURCES: For 1971-1984, annual plans of National Cancer Program prepared by NCI; for 1997, see Table 4.
NOTE: Constant dollar conversions made using the GDP deflators in OMB, *Historical Tables, Budget of the United States Government: Fiscal Year 2000*, Washington, DC, U.S. Government Printing Office, 1998: Table 10.1.

In 1974, after the initial buildup of federal funding in the War on Cancer, NCI accounted for nearly two-thirds of all funding of cancer research in the United States. By 1997, NCI was the source of less than half of all funding (46 percent). Industry's share increased from 2 percent in 1974 to 31 percent in 1997.

Figure 3. Share of cancer research funding, 1974 and 1997



CONCLUSION

NCI remains the single largest funder of cancer research, and it has a highly diversified program. Industry is a fast-growing source of research funding, most of which is spent on in-house research but some of which supports university research. Industry research is more applied and has relatively shorter time horizons.

The philanthropic sector is also large and growing fast. At the national level, ACS is still the largest private cancer-specific fundraiser for cancer research, but it is being joined by a growing number of new organizations raising funds for education, research, and services for specific cancers. At the regional, state, and local levels, cancer research centers attract funding from local charities and individual donors. The charitable sector also provides funding for buildings and equipment and other necessary infrastructure that federal agencies tend not to fund. The states will be in a position to become much larger sources of funding, if they choose to allocate some or all of the revenues from the tobacco settlement to cancer research.

NCPB, in its role as adviser to NCI on national cancer policy, should take these national developments into account when considering policy issues affecting NCI. At the beginning of the War on Cancer, NCI was necessarily the dominant institution. Today, it is no longer the majority funder, and the relative role of other sectors is growing.

NCPB should also be cognizant of the division of labor among the sectors in what they spend their funds on, and the implications that these different roles may have in NCI planning and priority setting. NCI and other NIH institutes generally want to avoid funding work that industry would fund anyway. Private nonprofit agencies play an important role in filling in gaps in federal funding, for example, funding of facilities, new researchers, and of established researchers between federal grants.

[1] American Cancer Society, *Cancer Facts and Figures, 1998*. Available at <www.cancer.org>. The relative survival rate for cancer, after adjustment for other mortality factors (e.g., heart disease, accidents, etc.), is 58 percent. Also, these figures do not include diagnoses of basal or squamous cell skin cancer, which will total more than a million additional cases of cancer this year.
[2] P. Cole and B. Rodu, Declining cancer mortality in the United States, *Cancer* 1996;78:2045-2048; J.C. Bailar III and H.L. Gornick, Cancer undefeated, *New England Journal of Medicine* 1997;336:1569-1574 (Table 1).
[3] *New Medicines in Development for Cancer: 1997 Survey*, PhRMA, June 1997, at <www.phrma.org/charts/c_c97.html>.
[4] At the time of this report, additional Board funding had been provided by Abbot, Amgen, Inc., and Hoechst Marion Roussel, Inc.
[5] The latest, *The Nation's Investment in Cancer Research: A Budget Proposal for Fiscal Year 2000*, is available at <wwwosp.nci.nih.gov/NCIWEB/planning.htm>.
[6] For an overview of HCFA's current program, see Research and Demonstration Grants Available from the Health Care Financing Administration, available at <www.hcfa.gov/ord/prioriti.htm>.
[7] Reports with these titles are available from the National Technical Information Service (PB98-120611 and PB90-205295, respectively).
[8] See summary of budgetary resources in Office of Research & Development (ORD)/VA, *Improving Health Care for Veterans, 1997 Annual Report*, also at <www.va.gov/resdev/>.
[9] See ORD/VA, "Programs and Services," at <www.va.gov/resdev/ps/psidx.htm>, ORD/VA, "Designated Research Areas for an Integrated Program of Research" (working paper, February 1, 1998), and ORD/VA, *Improving Health Care for Veterans, 1997 Annual Report*, also at <www.va.gov/resdev/>.
[10] J. R. Fuessner, *Refining Research Priorities: New Initiatives Meeting Veterans Needs*. Washington, DC: Department of Veterans Affairs, 1997.
[11] Detailed information can be found at <cdmrp.army.mil/>.
[12] NCI-funded cancer centers, for example, were awarded $28 million in NSF grants in FY 1997.
[13] *1997 Industry Profile*, PhRMA, March 1997. Pharmaceutical R&D increased to $24.0 billion in 1999, 2.4 times more than in 1990. See *1999 Industry Profile* at <www.phrma.org/publicatons/industry/profile99/index.html>.
[14] *New Medicines in Development for Cancer: 1997 Survey*, PhRMA, June 1997, at <www.phrma.org/charts/c_c97.html>. According to the most recent survey, the number of cancer medicines in development has increased to 354. See, *New Medicines in Development for Cancer: 1999 Survey*, PhRMA, May 1999, at <www.phrma.org/cancer/index.html>.
[15] "1998 survey, 350 biotechnology drugs in development," PhRMA, available at <www.phrma/org/charts/biointro.html>.
[16] "Some Facts About Biotechnology," available at <www.bio.org>.
[17] BIO did not report the total number of companies involved in cancer R&D in 1997; in 1996 BIO reported that 256 biotech companies were working on cancer therapies/cures.
[18] From SEC filings. The Chiron total is exclusive of $79.5 million in R&D paid for by third parties.
[19] See <www.chiron.com/research/pipeline/static.html >.
[20] *The Foundation Grants Index, 1998*. The Foundation Center, New York, NY.
[21] Telephone conversation between Purnell Choppin, President, Howard Hughes Medical Institute, and Michael McGeary, November 20, 1998.
[22] "Fiscal Year Functional Expenses," Leukemia Society of America, available at <www.leukemia.org/docs/annual_report/fc_financ.html>.

[23] *CaP CURE: Portraits of Progress: Report 1997/1998*. Association for the Cure of Cancer of the Prostate.
[24] *American Cancer Society 1998 Competitive Analysis*. Atlanta, GA: Michelson & Associates, Inc. [1998].
[25] Ibid.
[26] Telephone conversation between Marion Kavanaugh-Lynch, Director, California Breast Cancer Research Program, University of California-San Francisco, and Michael McGeary, December 16, 1998. See also annual reports on website of California Breast Cancer Research Program: <www.ucop.edu/srphome/bcrp/>.
[27] Based on information from Marion Kavanaugh-Lynch, Director, California Breast Cancer Research Program, University of California-San Francisco, who hosted a meeting of breast cancer research funders in July 1998.
[28] These programs were identified from a list of peer-reviewed funding sources of the NCI cancer centers program, along with ACS, University of California-Wide Breast Center Research Program, and other programs listed above.