
**Federal Ovarian Cancer Action Strategy
Report
(FOCAS)**

Resource on Federal Legislation and Programs Affecting
Ovarian Cancer



2009

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I. Executive Summary

This document is the first *Federal Ovarian Cancer Action Strategy Report (FOCAS)* to help ovarian cancer advocates and supporters understand the federal government's infrastructure, processes and programs. Most importantly, the report explains the role of federal funding to support ovarian cancer research initiatives. The Ovarian Cancer National Alliance's overarching goals include advancing research, improving health care practice and expanding a national, collaborative ovarian cancer advocacy movement.

The U.S. federal programs supporting ovarian cancer include:

- Ovarian Cancer Control Initiative (OCCI)
- Johanna's Law: The Gynecologic Cancer Education and Awareness Act of 2007 within the Centers of Disease Control and Prevention (CDC)
- Specialized Programs of Research Excellence (SPOREs)
- Clinical trials and research projects
- The prospective Biomarkers Research Centers of Excellence at the National Cancer Institute (NCI)
- The Department of Defense Ovarian Cancer Research Program (OCRP)

To improve the lives of women with or at risk of developing ovarian cancer, these programs must receive continued and increased funding — the Alliance is calling on you, the advocate, to help work for research and awareness that saves women's lives.

After reading the FOCAS Report, you should gain a thorough understanding of how federal legislation and funding affect research and policies for ovarian cancer. In addition, the brief descriptions of current ovarian cancer programs will provide you with key information about how your advocacy efforts have influenced ovarian cancer research and programs. With this background, the importance of your role in advocacy will be clear.

For more information or questions, please visit the Ovarian Cancer National Alliance at www.ovariancancer.org, e-mail at ocna@ovariancancer.org or call 202-331-1332/ toll free at 886-399-6262.

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II. Why Advocate for Ovarian Cancer Research and Awareness?

“Never doubt that a small group of thoughtful, committed citizens can change the world. Indeed, it is the only thing that ever has.”¹

—Margaret Mead

Advocacy is essential for supporting and furthering ovarian cancer policies and research. Advocacy efforts to promote research are critical to improve the quality of life for women with ovarian cancer or at risk for the disease. Proactive support will help advance the Alliance’s goals of supporting federal research on ovarian cancer .

Advocacy is defined as the act of pleading or arguing in favor of something— a cause, idea or policy.² Policy-makers are influenced by the opinions they receive regarding proposed legislative action, making well-educated, articulate and passionate ovarian cancer advocates a valued and effective resource to influence policies. **It is your right and responsibility to become involved in health policy advocacy.**

The Ovarian Cancer National Alliance, its Partner Members and other advocates have made headway for a brighter future for women with or at risk of the disease. For example, in 2007 President Bush signed legislation supporting gynecologic cancer education and awareness— Johanna’s Law— which would not have happened without the dedication of ovarian cancer advocates. The Ovarian Cancer National Alliance encourages advocates to continue voicing their support for research that makes a significant difference in the lives of women with ovarian cancer or at risk of getting the disease.

1 Johnson Lewis, Jone. (2008). Margaret Mead quotes. Retrieved on April 29, 2008, from http://womenshistory.about.com/cs/quotes/a/qu_margaretmead.htm.

2 Merriam-Webster Online (2008). Advocacy. Retrieved on May 20, 2008 at <http://www.merriam-webster.com/dictionary/advocacy>.

III. Role of the U.S. Federal Government in Ovarian Cancer

A. Structure of Congress³

Each year, the U.S. Congress determines funding levels for the upcoming fiscal year, making it critical for advocates to urge their congressional members to support ovarian cancer programs annually. Congress appropriates funds as part of the budget process. Even if funding has been authorized through legislation, funds must be allocated through annual appropriation bills to release money for the policy or program to take effect.

[See: Appendix A]

Congress maintains all of the federal government's legislative power. Congress is divided into two houses of elected officials – the Senate and the House of Representatives. The Senate consists of 100 Senators, two from each state, on six-year terms. The House consists of 435 members on two-year terms.

The Senate and the House are equal partners in the federal government, yet also hold unique powers. Specifically, the Senate approves treaties and presidential appointments. All revenue-raising and appropriations bills originate in the House. Each Congressional term is two-years — the 111th Congress will span 2009 to 2010.

³ Johnson, C. (1998). How our laws are made. *U.S. Government Printing Office Washington: 1998*. Retrieved on April 9, 2008 at http://frwebgate.access.gpo.gov/cgi-bin/getdoc.cgi?dbname=105_cong_documents&docid=f:sdo14.pdf.

B. Policy-making

Bills and proposals can be introduced by any member of either house of Congress. Each bill must go through several steps prior to becoming a public law. After a bill is introduced, committees and subcommittees will review it and hold hearings. During this process, amendments can be made at any point. The full house has the power to accept or reject bills. After a bill or proposal is approved in one house, it is sent to the other for a similar review process, where it can be passed, rejected or amended. Once both houses have voted to pass the bill, it is submitted to the President to either 1) sign into law or 2) veto, sending it back to Congress with objections.

In general, there are two main types of legislation: *authorizing legislation* and *appropriations legislation*.

- An authorizing bill provides a federal agency with the authority to conduct programs and authorize funds by recommending spending levels.
- An appropriations bill provides the legal authority needed to spend or obligate U.S. Treasury funds.

Funding authorization does not necessitate appropriation; Congress must provide specific funding in the subsequent appropriations bill.

The Ovarian Cancer National Alliance submits “Dear Colleague” letters to Congress to gain support from members on specific levels of appropriations in the larger appropriations bill. The “Dear Colleague” letters are an important vehicle for mobilizing Congress to pass legislation to appropriate funds for ovarian cancer.

Every February, the President releases a budget proposal. Congress may adhere more or less closely to the President’s proposed budget, depending on the relationships between the two bodies. Appropriations bills are derived from the amount of money allocated in the Budget Resolution. All appropriations bills should be passed by the beginning of the new Fiscal Year (FY), which begins in October of the preceding year. Fiscal Year 2010 (FY10) is October 1, 2009 to September 31, 2010.

C. Congressional Committees Involved in Ovarian Cancer Policy

There are key committees in both the Senate and House for ovarian cancer and other health issues. The table below provides a list of committees in both chambers of Congress.

Senate	House of Representatives
Appropriations Committee: the committee that controls the federal purse strings and determines funding for all government functions.	Appropriations Committee: the committee that controls the federal purse strings and determines funding for all government functions.
Labor, Health and Human Services Appropriations Subcommittee (LHHS): the subcommittee that determines funding for federal agencies, including the Departments of Health and Human Services, Labor, Education and their sub-agencies (e.g. National Institutes of Health, National Cancer Institute, Centers for Disease Control and Prevention).	Labor, Health and Human Services Appropriations Subcommittee (LHHS): the subcommittee that determines funding for federal agencies, including the Departments of Health and Human Services, Labor, Education and their sub-agencies (e.g. National Institutes of Health, National Cancer Institute, Centers for Disease Control and Prevention).
Defense Appropriations Subcommittee: the subcommittee that determines funding for the Department of Defense Ovarian Cancer Research Program.	Defense Appropriations Subcommittee: the subcommittee that determines funding for the Department of Defense Ovarian Cancer Research Program.
Health, Education, Labor, and Pensions (HELP): the authorizing committee with jurisdiction over all non-Medicare and non-Medicaid health care issues (e.g. Johanna’s Law).	Energy & Commerce Committee: Health Subcommittee: the authorizing committee with jurisdiction over all non-Medicare and non-Medicaid health care issues (e.g. Johanna’s Law).

IV. U.S. Federal Government Divisions Supporting Ovarian Cancer

A. The Department of Health and Human Services

Under the Department of Health and Human Services (HHS), both the Centers for Disease Control and Prevention (CDC) in Atlanta, Ga., and the National Cancer Institute (NCI), a part of the National Institutes of Health (NIH) in Bethesda, Md., support ovarian cancer research and educational programs. The CDC and NCI direct important research and awareness efforts that greatly contribute to our nation's ability to combat ovarian cancer.

1. Centers for Disease Control and Prevention

a. Ovarian Cancer Control Initiative (OCCI)

As part of the Ovarian Cancer National Alliance's efforts to prevent suffering and decrease mortality from ovarian cancer, advocating for enhanced federal investment in the CDC's Ovarian Cancer Control Initiative (OCCI) is critical. Despite increased knowledge and treatments for many once-deadly cancers, ovarian cancer's risk factors, symptoms and causes are not well understood. Created by Congress in 2000, OCCI is tasked with coordinating and funding health activities leading to early detection and improving treatment options to enhance survivorship.

For FY09, the Ovarian Cancer National Alliance and our partners were successful in securing funding for OCCI of approximately \$5.5 million. OCCI was the only cancer-specific program in CDC to receive an increase in funds for FY08 and continues to be funded in the FY09 and FY10 appropriations bills. The benefits of OCCI's research cannot be fully realized unless the results are effectively translated into public health interventions. OCCI must continue to receive adequate funding to translate research results for health care providers and women and increase the public's knowledge on ovarian cancer's symptoms.

b. Johanna's Law: The Gynecologic Cancer Education and Awareness Act of 2007

Unanimously passed by the 109th Congress and enacted in early 2007, Johanna's Law will provide authorization of up to \$16.5 million for awareness and education

through a national public service campaign that includes written materials and public service announcements. The law calls for campaigns to educate women and health care providers on the signs and symptoms of gynecologic cancers. In the case of ovarian cancer, symptoms are often missed, dismissed, misdiagnosed or only diagnosed in the disease's late stages.

In FY08 and FY09, Johanna's Law was appropriated \$6.5 million. The Ovarian Cancer National Alliance requests that Congress fully fund Johanna's Law by appropriating \$10 million in FY10.

As part of Johanna's Law, the CDC launched the *Inside Knowledge: Get the Facts About Gynecologic Cancer* campaign to raise awareness of the five main types of gynecologic cancer: ovarian, cervical, uterine, vaginal and vulvar. Campaign and educational messages were created following review of gynecologic cancer educational materials and guidance from a panel of experts including gynecologic oncologists, gynecologists, other medical practitioners; health and behavioral scientists; and representatives of nonprofit and advocacy organizations committed to raising awareness of gynecologic cancers.⁴

2. National Cancer Institute

The National Cancer Institute provides funding for ovarian cancer research and has created programs supporting awareness and research for the disease. Advocates must work to increase NCI funding to support and expand NCI efforts to reduce cancer incidence and mortality and advance important research and awareness efforts that contribute significantly to the battle against ovarian cancer.

⁴ Department of Health and Human Services. Centers for Disease Control and Prevention. (2008). Gynecologic cancer: inside knowledge campaign. Retrieved on March 26, 2008 from <http://www.cdc.gov/cancer/knowledge/>.

a. Specialized Programs of Research Excellence

The Specialized Programs of Research Excellence (SPOREs), funded through federal grants, focus on translational research for specific organ sites, such as the ovaries, which aim to turn scientific discoveries into applicable solutions or treatments for cancer. The programs are typically four-year grants and can be renewed. NCI's Division of Cancer Treatment and Diagnosis (DCTD) oversees the SPOREs program.⁵

Today, four SPORE programs exist for ovarian cancer research: the University of Texas, MD Anderson Cancer Center (Houston, TX), Fox Chase Cancer Center (Philadelphia, PA), Fred Hutchinson Cancer Research Center (Seattle, WA) and the Dana-Farber/Harvard Cancer Center (Boston, MA). The centers are up for grant renewals periodically and must compete for continued SPORE funding.

b. Gynecologic Oncology Group

NCI supports the Gynecologic Oncology Group (GOG) which promotes clinical and basic research for gynecologic malignancies, including cancers of the ovaries, uterus, cervix, vagina and vulva. GOG seeks to improve the quality of patient care through coordinating clinical trials and publicly providing research results.⁶

⁵ U.S. National Institutes of Health. (2008), National Cancer Institute. SPOREs specialized programs of research excellence: ovarian spores. Retrieved on April 1, 2008 from <http://spores.nci.nih.gov/current/ovarian/ovarian.html>.

⁶ Gynecologic Oncology Group. (2008). Homepage. Retrieved on April 1, 2008 from <http://www.gog.org/index.html>.

c. Clinical Trials

Clinical trials test early research findings to improve methods of prevention, screening, early diagnosis and treatments for cancers. Clinical trials are available to women at all stages of ovarian cancer, from newly diagnosed to recurrent cancers. Details regarding various clinical trial results are located on NCI's Web site. The Web site provides detailed results of ovarian cancer clinical trials results from 2000 to 2008. NCI needs to continue clinical trials to bring the benefit of research to patients and women at risk of ovarian cancer.⁷

Women interested in participating in ovarian cancer clinical trials can receive more information by visiting the Ovarian Cancer National Alliance Clinical Trials Matching Service powered by EmergingMed on the [Ovarian Cancer National Alliance's Web site](#).⁸

d. Ovarian Cancer Research Projects

NCI supports more than 600 active research projects on ovarian cancer in its cancer research portfolio database. As advocates, it is important to support the continuation of existing research projects as well as research projects that explore new ideas that may reveal scientific discoveries impacting the lives of women with or at risk of ovarian cancer.⁹

7 U.S. National Institutes of Health. (2008). National Cancer Institute. Ovarian cancer trial results. Retrieved on February 25, 2008 from <http://www.cancer.gov/clinicaltrials/results/ovarian?keyword=any+ovarian&page=1>.

8 Ovarian Cancer National Alliance – Clinical Trials, available at <http://www.ovariancancer.org/index.cfm?fuseaction=Page.viewPage&pageId=526>.

9 U.S. National Institutes of Health (2008). National Cancer Institute. The cancer research portfolio: database of cancer research projects, funding opportunities, and resources. Retrieved on April 1, 2008 from <http://researchportfolio.cancer.gov/index.jsp>.

B. The Department of Defense: Ovarian Cancer Research Program

Since 1997, Congress has appropriated funds for the Department of Defense (DoD) Ovarian Cancer Research Program (OCRP), which is modeled after the successful Breast Cancer Research Program created in 1992. The program funds multidisciplinary research efforts that investigate innovative methods of studying early detection, screening and treatment of ovarian cancer as well as attract new investigators to the fields.

Some of the OCRP breakthroughs include discovery of biomarkers for early stage ovarian cancer, mutations of the breast cancer 1 gene (BRCA 1) and breast cancer 2 gene (BRCA 2) that cause cells to divide rapidly or uncontrollably resulting in ovarian cancer, development of an animal model to study disease, and the identification of new biomarkers with the potential to improve early detection.

The potential application of these medical breakthroughs requires increased funding to sustain ongoing research and move the breakthroughs from the laboratory to the patient.

OCRP was appropriated \$10 million for FY08 and \$20 million in FY09. The Ovarian Cancer National Alliance calls upon Congress to provide \$30 million to the program in FY10.

[See: Appendix E]

V. Ovarian Cancer Statistics

According to the American Cancer Society, an estimated 21,500 new cases of ovarian cancer will be diagnosed in American women in 2009. Approximately 14,600 women will die from the disease in 2009.¹⁰

From 2000 to 2004, 72,529 women died from ovarian cancer. Among white females, there were 65,133 deaths and among black females, there were 5,841 deaths.¹¹ The age-adjusted death rate was 8.9 per 100,000 women per year between 2000 and 2004.¹²

The age-adjusted incidence rate (diagnosis of new ovarian cancer cases) was 13.5 per 100,000 women of all races from 2000 to 2004. The highest age-adjusted incidence rate was among white women at 14.3 per 100,000 women. This is followed by an age-adjusted incidence rate of 11.5 per 100,000 women among Hispanic women.¹³

Ovarian cancer is the eighth most common cancer among women, excluding non-melanoma skin cancers. However, ovarian cancer ranks fifth in cancer deaths among women of all races, accounting for more deaths than any other cancer of the female reproductive system. Ovarian cancer is the fourth leading cause of cancer-related death for white women, according to the Centers for Disease Control and Prevention.¹⁴

10 American Cancer Society. (2009).

11 U.S. National Institutes of Health (2008). Surveillance epidemiology and end results (SEER): cancer of the ovary. National Cancer Institute. Retrieved April 7, 2008, from http://seer.cancer.gov/csr/1975_2004/results_single/sect_a_table.03_2pgs.pdf.

12 American Cancer Society. (2008). Detailed guide: ovarian cancer: what are the key statistics?. Retrieved on April 7, 2008 from http://www.cancer.org/docroot/CRI/content/CRI_2_4_1X_What_are_the_key_statistics_for_ovarian_cancer_33.asp?sitearea=.

13 U.S. National Institutes of Health (2007). National Cancer Institute-Surveillance Research Program. SEER surveillance, epidemiology and end results: cancer of the ovary. Retrieved on April 7, 2008 from http://seer.cancer.gov/statfacts/html/ovary.html?statfacts_page=ovary.html&x=16&y=16.

14 U.S. Cancer Statistics Working Group. *United States Cancer Statistics: 1999–2004 Incidence and Mortality Web-based Report*. Atlanta: U.S. Department of Health and Human Services, Centers for Disease Control and Prevention and National Cancer Institute; 2007. Retrieved on April 7, 2008 from <http://apps.nccd.cdc.gov/uscs/Table.aspx?Group=3f&Year=2004&Display=n>.

Every woman is at risk of developing ovarian cancer. Approximately 32 percent of women who are diagnosed with ovarian cancer are 54 or younger. However, ovarian cancer develops mainly in older women, with approximately 68 percent of women diagnosed at 55 or older. It is slightly more common in white women than black women. A woman's risk of developing invasive ovarian cancer during her lifetime is one in 72; and her lifetime chance of dying from invasive ovarian cancer is one in 95.

About three out of four women with ovarian cancer survive at least one year after diagnosis. Almost half of women with ovarian cancer are still alive at least five years after diagnosis. Women younger than 65 who are diagnosed with ovarian cancer have better five-year survival rates than older women.

If ovarian cancer is found and treated before the cancer spreads outside the ovary, the five-year survival rate is 93 percent. While an optimistic percentage, only 19 percent of all ovarian cancer is found at this early stage. The overall five-year survival rate for 1996 to 2004 was 46 percent according to SEER data in 17 geographic areas. Five-year relative survival rates by race were 46 percent for white women and 39 percent for black women.¹⁵

An survey conducted by the Ovarian Cancer National Alliance in 2007 shows that the majority of ovarian cancer survivors saw more than one doctor before being diagnosed. According to the survey, approximately 40 percent of women were treated for other conditions prior to a diagnosis of ovarian cancer. Women report being treated for a vast number of other conditions including gas, constipation, colon or bowel blockage, menopause (post and peri), flu, bladder or urinary infection, gall bladder problems, irritable bowel syndrome, diverticulitis, ovarian cysts, fibroid tumors, endometriosis, colitis, depression, GERD, liver problems, upper respiratory infection, anemia, kidney stones, back problems, lupus, a sexually-transmitted disease and age.

¹⁵ U.S. National Institutes of Health (2007). National Cancer Institute-Surveillance Research Program. SEER surveillance, epidemiology and end results: cancer of the ovary. Retrieved on April 7, 2008 from <http://seer.cancer.gov/statfacts/html/ovary.html>.

In 2007, a consensus statement by leading ovarian cancer organizations, universally identifies common symptoms of ovarian cancer, include 1) bloating, 2) pelvic or abdominal pain, 3) difficulty eating or feeling full quickly, and 4) urinary symptoms (urgency or frequency).¹⁶ Several other symptoms have been commonly reported by women with ovarian cancer. These symptoms include fatigue, indigestion, back pain, pain with sexual intercourse, constipation and menstrual irregularities. However, these symptoms are not as useful in identifying ovarian cancer because they are also found in equal frequency in women who do not have ovarian cancer.

[See: Appendix D]

Historically ovarian cancer was called the “silent killer” because symptoms were not thought to develop until the chance of cure was poor. However, recent studies have shown this term is untrue and that the following symptoms are much more likely to occur in women with ovarian cancer than women in the general population. These symptoms include:

- **Bloating**
- **Pelvic or abdominal pain**
- **Difficulty eating or feeling full quickly**
- **Urinary symptoms (urgency or frequency)**

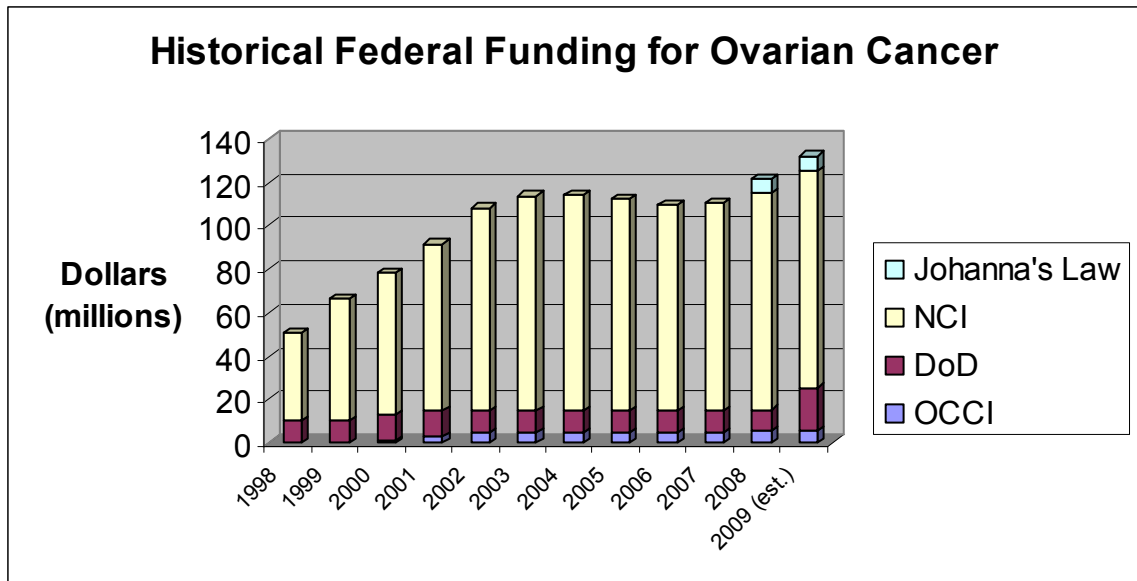
Women who have these symptoms almost daily for more than a few weeks should see their doctor, preferably a gynecologist. Prompt medical evaluation may lead to detection at the earliest possible stage of the disease. Early stage diagnosis is associated with an improved prognosis.

16 American Cancer Society. (2008) What are the key statistics about ovarian cancer? Retrieved on March 24, 2008 from http://www.cancer.org/docroot/CRI/content/CRI_2_4_1X_What_are_the_key_statistics_for_ovarian_cancer_33.asp?sitearea=.

VI. Appendices

Appendix A: Overview of U.S. Federal Dollars Spent on Ovarian Cancer Programs

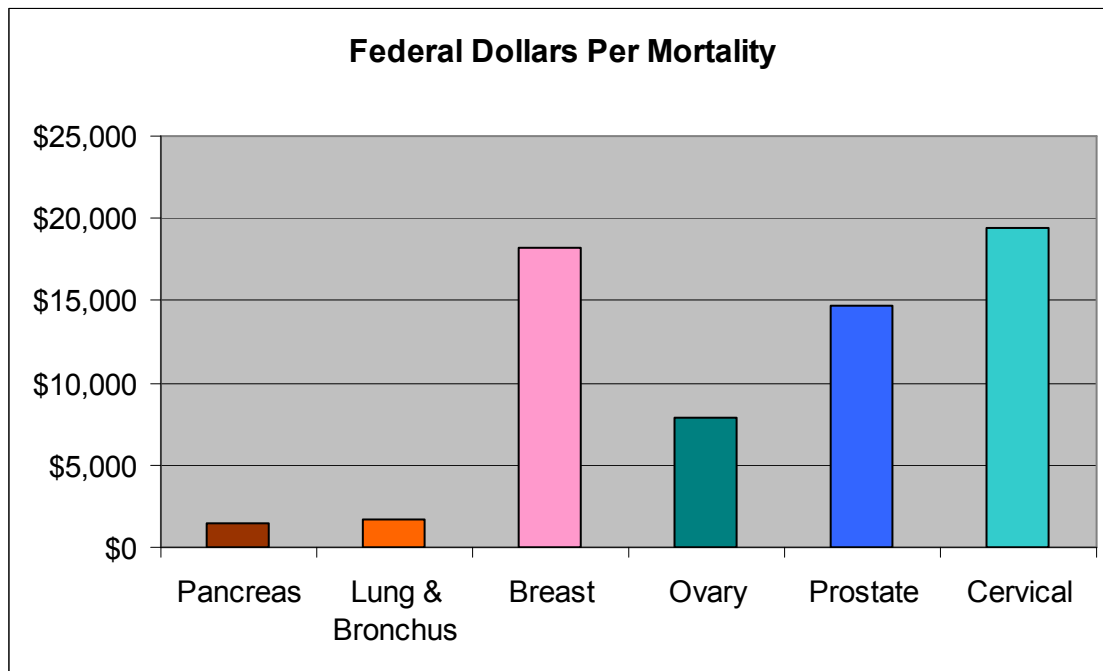
Graph 1



This graph displays the distribution of U.S. federal funding to government entities for ovarian cancer. The National Cancer Institute is allocated the most funds. Johanna’s Law was first funded in FY08.

Appendix A (cont): Ovarian Cancer Funding History

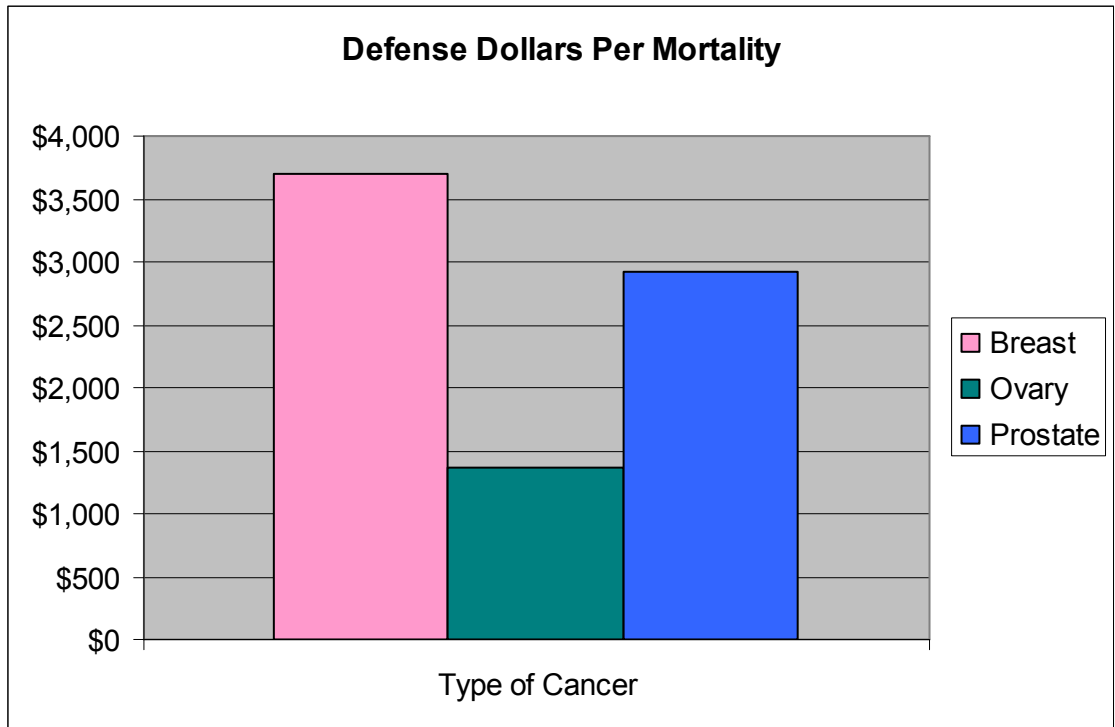
Graph 2



The graph displays research dollars spent per cancer-specific death. It includes both federal and Department of Defense dollars. For instance, federal research dollars are approximately \$7,493 per ovarian cancer death. By comparison, federal research dollars are approximately \$18,076 per breast cancer death. Defense research dollars for FY2009 are approximately \$1370 per ovarian cancer death. By comparison, defense research dollars are approximately \$3,694 per breast cancer death and \$2,924 per prostate cancer death.

Appendix A(con't)

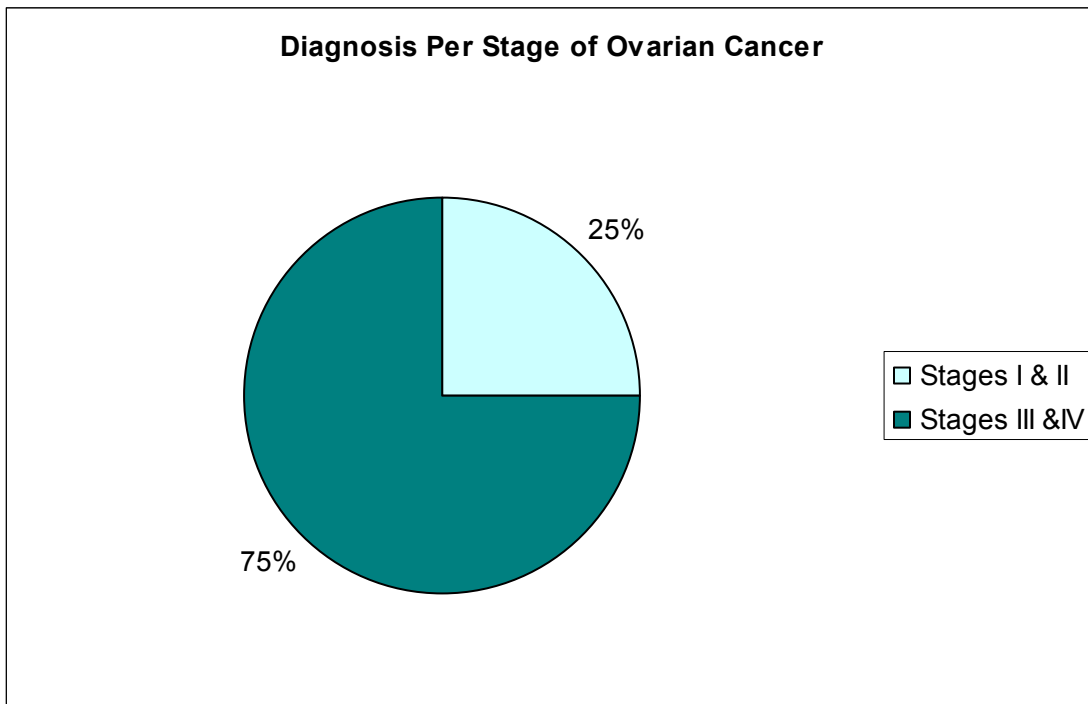
Graph 3



This graph further displays the differentiation of DoD spending per cancer-specific death.

Appendix B: Ovarian Cancer Statistics and Graphs

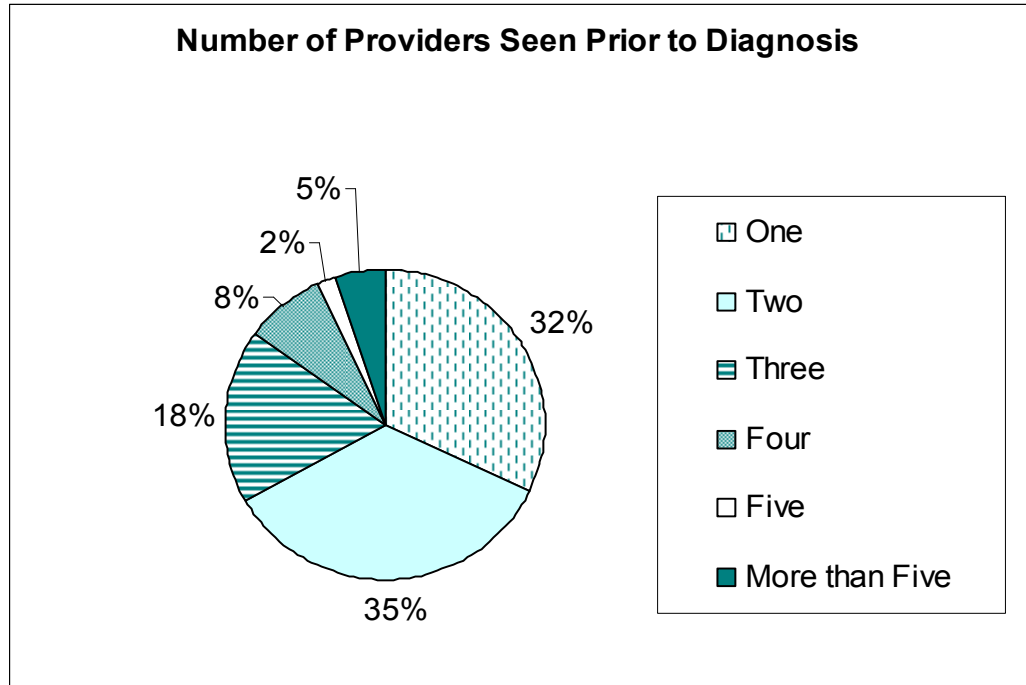
Graph 1



This graph displays the percentage of ovarian cancer cases diagnosed according to cancer stage. Unfortunately, 75 percent of diagnoses are in later stages of ovarian cancer. This may be attributed to lack of screening methods and no effective early detection test.

Appendix B (con't)

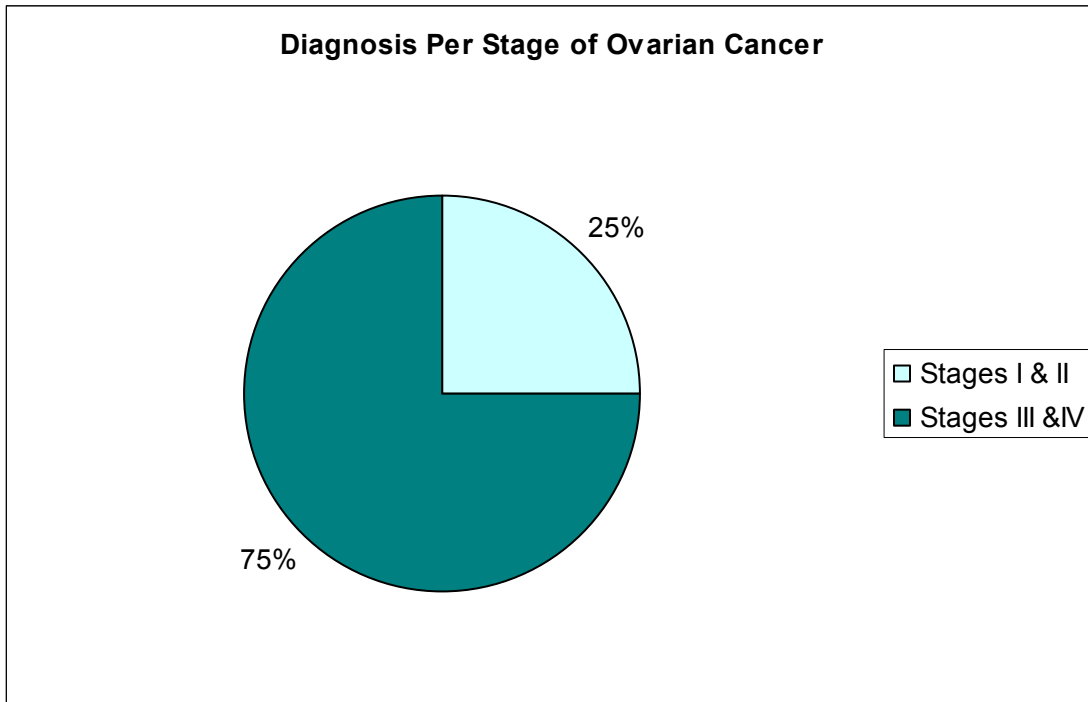
Graph 2



In 2007, the Alliance conducted a patient survey regarding the number of providers women see prior to diagnosis. This graph explains the number of various health care providers women visit before being diagnosed with ovarian cancer. Ovarian cancer has symptoms that can be easily confused with other medical problems, which may explain why women visit many providers.

Appendix D: Ovarian Cancer Statistics and Graphs

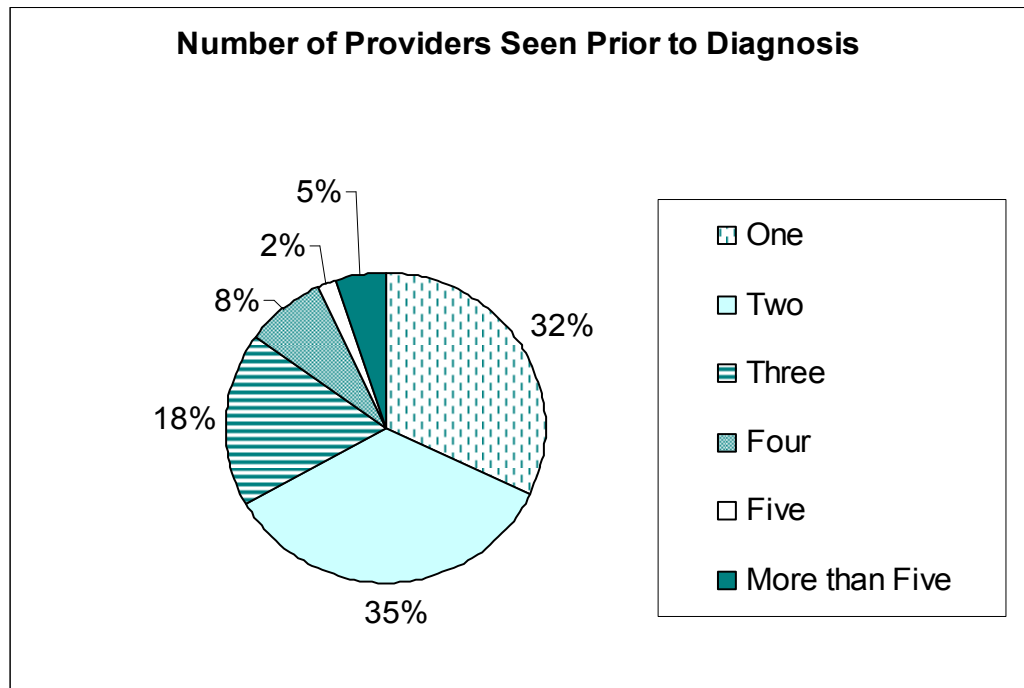
Graph 3



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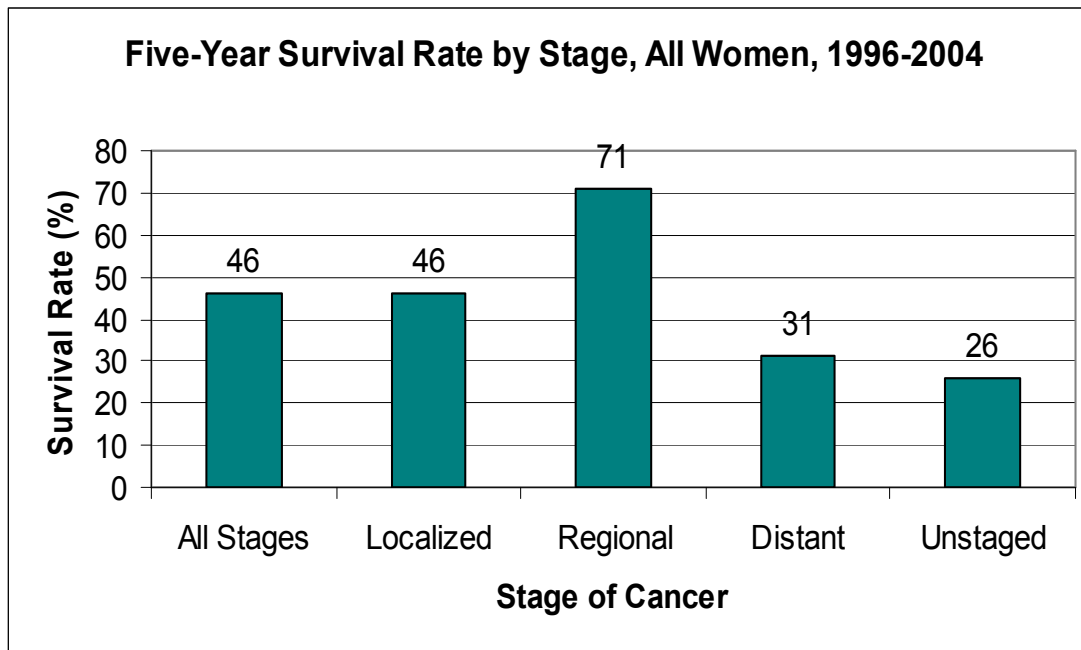
Appendix D (con't)

Graph 4



In 2007, the Ovarian Cancer National Alliance conducted a patient survey regarding the number of providers women see prior to diagnosis. This graph explains the number of various health care providers women visit before being diagnosed with ovarian cancer. Ovarian cancer has symptoms that can be easily confused with other medical problems, which may explain why women visit many providers.

Appendix B (con't)

Graph 5¹⁷

The graph displays the relative five-year survival rate by stage. The earlier ovarian cancer is diagnosed commonly correlates with longer survivorship. However, recurrence rates are high at any stage of ovarian cancer. For instance, even cancer found in Stage 1 has estimated 70 percent recurrence rate.

¹⁷ Cancer Statistics Review, 1975-2004 Surveillance Epidemiology and End Results, National Cancer Institute http://seer.cancer.gov/cgi-bin/csr/1975_2004/search.pl#results.

Appendix C: Estimated Numbers of Ovarian Cancer Cases and Deaths by State, 2009

(Note: * <50 cases or deaths)

STATE	CASES	DEATHS
Alabama	330	270
Alaska	*	*
Arizona	450	290
Arkansas	190	130
California	2,390	1,580
Colorado	340	210
Connecticut	290	180
Delaware	70	50
Dist. Of Columbia	*	*
Florida	1,560	970
Georgia	580	400
Hawaii	90	50
Idaho	100	50
Illinois	820	600
Indiana	420	340
Iowa	210	170
Kansas	190	150
Kentucky	280	210
Louisiana	280	210

Maine	120	70
Maryland	420	260
Massachusetts	540	350
Michigan	740	520
Minnesota	390	240
Mississippi	170	140
Missouri	400	290
Montana	80	50
Nebraska	120	90
Nevada	180	120
New Hampshire	110	60
New Jersey	680	540
New Mexico	140	90
New York	1,530	970
North Carolina	630	430
North Dakota	*	*
Ohio	820	580
Oklahoma	260	170
Oregon	300	220
Pennsylvania	1,070	760
Rhode Island	90	60
South Carolina	310	210

Tennessee	430	310
Texas	1,420	890
Utah	140	90
Vermont	50	*
Virginia	530	380
Washington	510	340
West Virginia	150	120
Wyoming	*	*

Note: These estimates are offered as a rough guide and should be interpreted with caution. State estimates may not add to U.S. totals due to rounding and exclusion of state estimates of fewer than 50 cases.

American Cancer Society, 2009