The Commonwealth of Massachusetts

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August 4, 2017

Steven T. James
House Clerk
State House Room 145
Boston, MA 02133

William F. Welch
Senate Clerk
State House Room 335
Boston, MA 02133

Dear Mr. Clerk,

Pursuant to Section 154 of Chapter 46 of the Acts of 2015: Special Commission, Ovarian Cancer, please find enclosed a report from the Special Commission on Ovarian Cancer entitled "*Ovarian Cancer in Massachusetts: Report and Recommendations from the Massachusetts Special Commission on Ovarian Cancer*."

Sincerely,

Lea Susan Ojamaa, MPH
Chair, Special Commission on Ovarian Cancer
Massachusetts Department of Public Health

Charles D. Baker
Governor

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Ovarian Cancer in Massachusetts: Report and Recommendations from the Massachusetts Special Commission on Ovarian Cancer

August 2017

Massachusetts Department of Public Health

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SPECIAL COMMISSION ON OVARIAN CANCER STATUTORY LANGUAGE

Section 154 of Chapter 46 of the Acts of 2015: Special Commission, Ovarian Cancer

(a) There shall be a special commission relative to ovarian cancer in the Commonwealth. The commission shall consist of: the secretary of health and human services or a designee; the commissioner of public health or a designee; the commissioner of insurance or a designee; and 8 members who shall be appointed as follows: 2 members appointed by the senate president, 1 of whom shall be a person with or a survivor of ovarian cancer and 1 of whom shall be a medical specialist in ovarian cancer; 2 members appointed by the speaker of the house of representatives, 1 of whom shall be a person with or a survivor of ovarian cancer and 1 of whom shall be a medical specialist in ovarian cancer; and 4 members appointed by the governor, 1 of whom shall be a person with or survivor of ovarian cancer, 1 of whom shall be a medical specialist in ovarian cancer, and 2 of whom shall be members of the public with demonstrated expertise in issues relating to the work of the commission.

(b) The commission shall study and report on the following: (i) establishing a mechanism to ascertain the prevalence of ovarian cancer in the Commonwealth and, to the extent possible, collecting statistics relative to the timing of diagnosis and risk factors associated with ovarian cancer; (ii) determining how to best effectuate early diagnosis and treatment for ovarian cancer patients; (iii) determining any unmet needs of persons with ovarian cancer and those of their families; and (iv) providing recommendations for additional legislation, support programs and resources necessary to meet the unmet needs of persons with ovarian cancer and their families.

(c) The commission shall file its report and recommendations with the clerks of the senate and the house of representatives and the senate and house chairs of the joint committee on public health by December 31, 2015.

ACKNOWLEDGMENTS

The Massachusetts Special Commission on Ovarian Cancer would like to acknowledge the following individuals for their assistance in providing valuable information for the preparation of this report.

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EXECUTIVE SUMMARY

Ovarian cancer is the deadliest of the gynecologic cancers.[1] It is the eighth most common cancer among women and the fifth leading cause of cancer-related death among women.[2] Women of all ages can develop ovarian cancer, and it is more likely to occur in older women. The main risk factors of ovarian cancer include having a *BRCA* or other high-risk gene mutation; having a family history of ovarian, breast, colon, or endometrial cancer; endometriosis; and increasing age.

Factors that decrease risk include oral contraceptive use, parity, and tubal ligation. **In Massachusetts, 60% of ovarian cancer cases are diagnosed at a late stage, and this percent is even greater for non-Hispanic black women.[3] The national survival rate for women diagnosed at a late stage is just 29%.[4]** Ovarian cancer has a high rate of recurrence and once recurred is almost always incurable; treatment resistance is a major problem for ovarian cancer patients.[5] Symptoms of ovarian cancer are generally subtle and are often mistaken for other medical complaints. Thus, education about symptoms is essential. Ovarian cancer patients treated by gynecologic oncologists have better outcomes than patients treated by gynecologists. Patients have a range of unmet needs, especially for women living far from Boston.

Collection of *BRCA* gene mutation carrier status by the Massachusetts Cancer Registry (MCR) is important to determine if patients are being tested for *BRCA* status as well as to identify patient and family risk status for ovarian and other cancers. **There is a critical knowledge gap among both the general public and primary care providers concerning ovarian cancer symptoms, risk factors, and use of the US Preventive Services Task Force (USPSTF) guidelines and screening tools to determine genetic risk.** Lack of knowledge among primary care providers is concerning because they are usually women's first point of contact in the health care system and are necessary for specialist referrals. Primary care providers' lack of knowledge translates into potential missed opportunities to identify women at risk and/or appropriately diagnose women with ovarian cancer.

Educational programs to integrate risk assessment screening into primary care could improve early diagnosis and outcomes. By increasing awareness and knowledge about aspects of care it is possible that women with ovarian cancer will experience better outcomes. While each patient has a unique experience with ovarian cancer, there are three periods of time during which women tend to have more unmet needs: just after diagnosis and before treatment begins, after treatment ends when there is a strong fear of recurrence, and living with chronic ovarian cancer. Patients and families face a range of unmet needs, including ones related to psychosocial support, financial strain, service accessibility, and physical changes.

It is essential to decrease the incidence of ovarian cancer diagnoses, diagnose women at earlier stages, and provide support for patients and families to increase their quality of life. The uniqueness of ovarian cancer, along with documented racial and ethnic disparities, makes it particularly important to research, raise awareness, and increase knowledge.

The Commission identified the following recommendations tied to the three charges outlined in Section 154 of Chapter 46 of the Acts of 2015.

Charge i: Recommendation for Statewide Collection of Data

1) Explore a statewide mechanism for collecting *BRCA1* and *BRCA2* gene mutation carrier status for all ovarian cancer patients.

Charge ii: Recommendations for Early Diagnosis and Treatment

PROVIDER EDUCATION

2) Educate primary care providers, gynecologists, medical oncologists, and gynecologic oncologists to increase their awareness and knowledge of ovarian cancer and to effect clinical practice changes for reducing delays in diagnosis.

   Key messages should include:
   - Recognize that there is no reliable early detection or screening test,
   - ask about and listen to patients' answers about their symptoms (specifically ask about bloating, pelvic or abdominal pain, difficulty eating or feeling full quickly, and urinary urgency or frequency),
   - understand family history and genetic risk factors,
   - conduct risk assessment screening within all primary care practices and refer women at high risk for ovarian cancer to a genetic counselor for counseling and evaluation for testing,
   - refer ovarian cancer patients to a genetic counselor for counseling and testing and to a gynecologic oncologist for treatment, and
   - advise on the use of palliative care and integrative therapies that promote a higher and more comfortable quality of life.

3) Review curricula for training programs (physicians, physician assistants, nurse practitioners) for inclusion of ovarian cancer elements. Recommend existing programs and resources that can be added to curricula.

PATIENT EDUCATION

4) Increase ovarian cancer patient awareness and education regarding the standard of care for treatment, the insurance appeal process of non-covered standard of care, and the importance of clinical trials at all stages of treatment.

GENERAL PUBLIC EDUCATION

5) Provide education to the general public (with a focus on women) to increase awareness and knowledge of ovarian cancer risk factors and symptoms and to clarify misconceptions to help reduce delays in diagnosis.

Charge iii: Recommendations for Support

6) Promote Massachusetts-specific resources and support services for ovarian cancer patients.

I. AIM OF REPORT

The aim of this report is to provide recommendations for reducing the burden of ovarian cancer in the Commonwealth of Massachusetts. Based on the Commonwealth's Special Commission on Ovarian Cancer statutory language, the recommendations enclosed in this report focus on the following charges: (i) establish a mechanism to ascertain the prevalence of ovarian cancer in the Commonwealth and, to the extent possible, collect statistics relative to the timing of diagnosis and risk factors associated with ovarian cancer; (ii) determine how to best effectuate early diagnosis and treatment for ovarian cancer patients; (iii) determine any unmet needs of persons with ovarian cancer and those of their families; and (iv) provide recommendations for additional legislation, support programs and resources necessary to meet the unmet needs of persons with ovarian cancer and their families. These recommendations are incorporated throughout charges i through iii.

II. METHODS

The Massachusetts Commission on Ovarian Cancer convened for the first time on October 4, 2016 and four more times (November 8, 2016, February 15, 2017, April 7, 2017, and May 24, 2017). The Department of Public Health (DPH) engaged JSI Research and Training Institute, Inc. (JSI) to support the work of the Commission. JSI provided Commission members with agendas and accompanying materials in advance of the meetings and co-facilitated them with DPH. JSI also conducted background research and literature reviews on various aspects of ovarian cancer, and held interviews with all Commission members in order to prepare this report. Members shared their expertise diagnosing, treating, and providing support to ovarian cancer patients; experiences as ovarian cancer patients/survivors or caregivers; and understanding of health insurance coverage for ovarian cancer.

III. LANDSCAPE OF OVARIAN CANCER

Ovarian cancer is the deadliest of the gynecologic cancers.[6] It is a particularly important cancer to research and understand, as several unique features contribute to its low survival rate. The absence of a valid screening test and lack of obvious symptoms lead to frequent late stage diagnoses—almost two-thirds of ovarian cancer cases are diagnosed at a late stage, in which there is a 29% survival rate.[7] Greater public awareness, health care provider education, treatment research, and patient support can improve the lives of women in Massachusetts who suffer from ovarian cancer and contribute to earlier diagnoses of new cases when ovarian cancer is much more curable.

INCIDENCE, MORTALITY, AND RACIAL/ETHNIC DISPARITIES

Ovarian cancer is the eighth most common cancer among women and the fifth leading cause of cancer-related death among women.[8] The ovarian cancer incidence rate (number of new cases during a specified time period) in Massachusetts between 2009 and 2013 was 11.9 per 100,000 women, which was similar to the national incidence rate during the same time period (11.6 per 100,000).[9,10] This means that in this

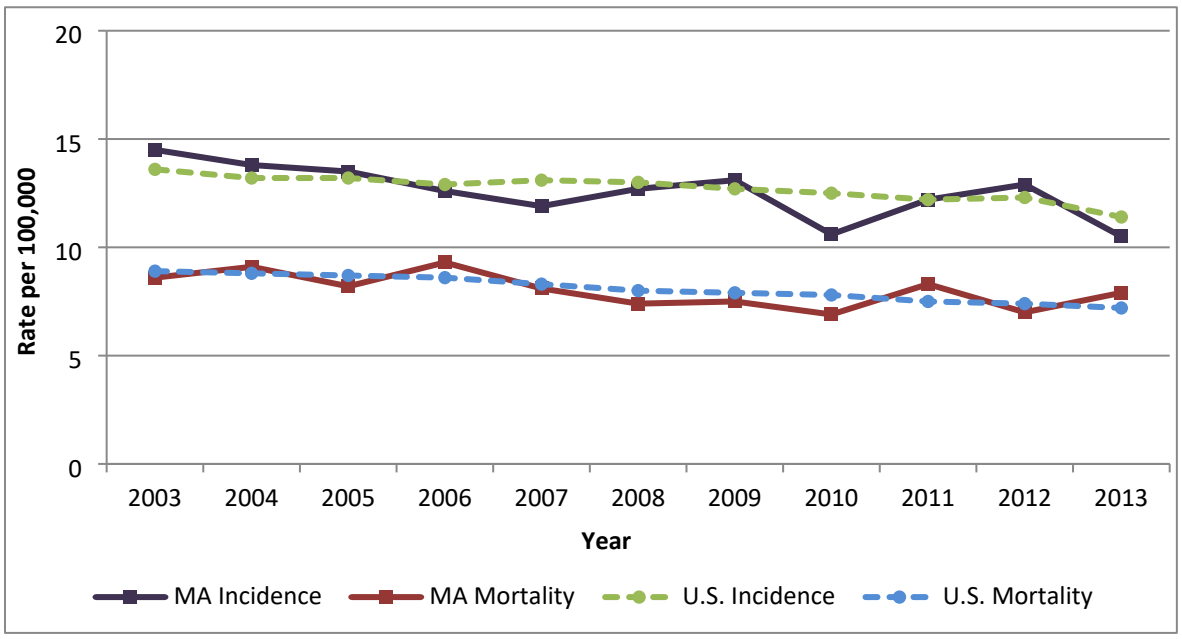
time period, 2,492 women (an average of 498 per year) were diagnosed with ovarian cancer in Massachusetts.

The ovarian cancer mortality rate for Massachusetts between 2009 and 2013 was 7.5 per 100,000 women, which means that 1,690 women died from ovarian cancer during this time period (an average of 338 per year).[11] The Massachusetts mortality rate was slightly lower than the national 2014 mortality rate, which was 8.8 per 100,000 women.[12]

While both national and Massachusetts ovarian cancer incidence and mortality rates have slightly decreased over the past many years (2.0% decrease per year for national incidence rate, 2.1% decrease per year for national mortality rate, and 2.2% decrease per year for Massachusetts incidence and mortality rates, see Figure 1), the reasons for this trend are not clear and the need for improved earlier diagnosis, treatment, and support is pressing.[13,14]

One implication of lower mortality rates is that some patients are living with the cancer and its effects for longer. Some also develop chronic ovarian cancer, which means the cancer does not completely go away, and they need continued and often constant treatment. The five-year survival rate has increased over the past three decades; in 1975 the national five-year survival rate for women with ovarian cancer was 33.7%, whereas in 2008 that rate was 46.2%.[15] This means that with the increase in median survival time, more resources are necessary to support these patients.

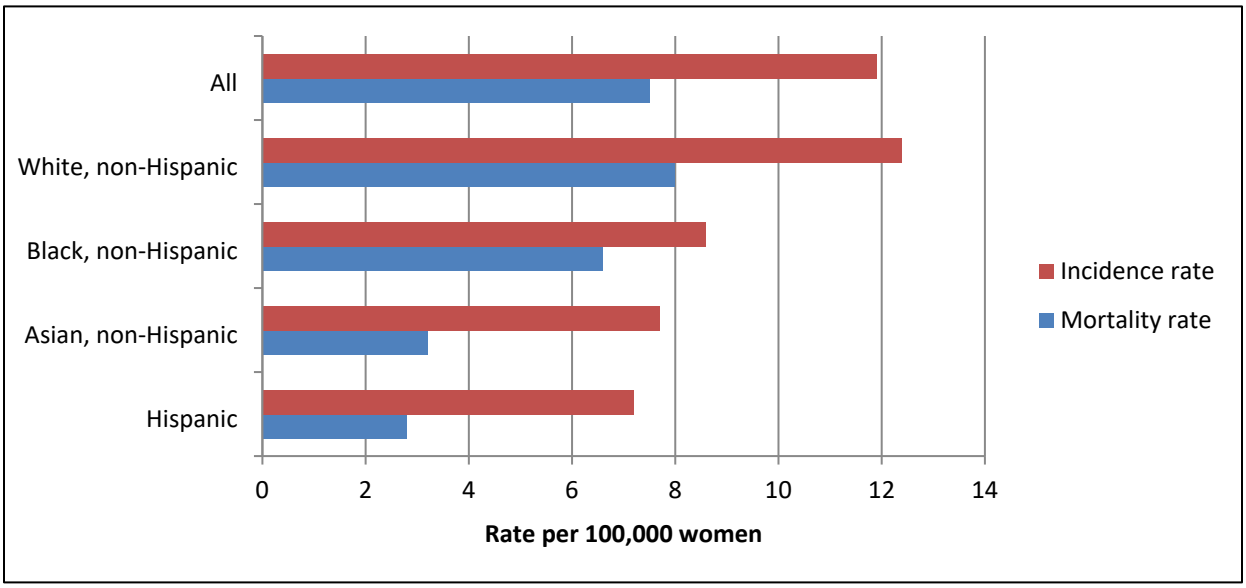
Figure1: Ovarian Cancer Incidence and Mortality Rates In MA and U.S., 2003–2013[16,17,18]



There are racial and ethnic disparities within the overall incidence and mortality rates among women diagnosed with ovarian cancer in Massachusetts. Figure 2 shows the incidence and mortality rates in Massachusetts between 2009 and 2013, broken down by four racial/ethnic groups. Non-Hispanic white women had the greatest incidence and mortality rates for ovarian cancer compared to other racial/ethnic groups. The mortality rates for non-Hispanic whites and non-Hispanic blacks did not differ significantly from each other, although they both differed significantly from the rates for non-Hispanic Asian and

Hispanic women. Although both the incidence and mortality rates were highest among the non-Hispanic white population, the mortality-to-incidence ratio was higher among non-Hispanic black women compared to non-Hispanic white women (0.79 versus 0.64).[19] This means that of women diagnosed with ovarian cancer, there is a greater likelihood that a black woman will die compared to a white woman. The reasons for this appear to be multifaceted. Several studies indicate that differences in rates of treatment with guideline-recommended care may account for part of this disparity with broader social factors also playing a role.[20,21,22] Further Massachusetts-specific evaluation is warranted.

Figure 2: Incidence and Mortality Rates in Massachusetts by Race/Ethnicity, 2009–2013



Women of all ages can develop ovarian cancer. Between 2009 and 2013, the median age at diagnosis in both Massachusetts and in the United States was 63 years old, which means that half of women were younger than 63 when diagnosed with ovarian cancer and half were older.[23,24] Although the median age at diagnosis was the same in Massachusetts and in the United States, women ages 55–64 years old nationally were most likely to develop ovarian cancer, whereas in Massachusetts women ages 75–79 years old had the highest incidence rate.[25,26] When initiating programs and resources for women with ovarian cancer, it is important to consider the unique kinds of treatment and support that women of different ages need.

RISK FACTORS, GENETICS, AND SCREENING

Ovarian cancer is associated with several risk factors. Well-confirmed factors that increase risk include being a *BRCA* or other high-risk gene mutation carrier, having endometriosis (a disorder in the uterus), a family history of ovarian, breast, colon, or endometrial cancers, and older age. Factors that are correlated with decreasing the risk of ovarian cancer include oral contraceptive use, parity (the condition of having given birth), and tubal ligation (surgical sterilization) (Figure 3).[27,28] Regarding risk for ovarian cancer, research is currently being conducted on the effects of removing the fallopian tubes as a way to reduce ovarian cancer risk, as some ovarian cancer originates in the fallopian tube.[29]

Figure 3: Risk Factors of Ovarian Cancer

Factors that **Increase** Risk	Factors that **Decrease** Risk
BRCA or other high-risk gene mutation carrier	Oral contraceptive use
Endometriosis	Parity
Family history of ovarian, breast, colon, or endometrial cancers	Tubal ligation
Increasing age	

One of the biggest predictors of developing ovarian cancer is whether a woman is a *BRCA1* or *BRCA2* gene mutation carrier. These genes produce tumor-suppressor proteins and, when mutated, cells are more likely to develop alterations that can lead to cancer because the mutated genes cannot produce the necessary repairs. Mutations in *BRCA1* and *BRCA2* genes account for approximately 15% of ovarian cancers overall.

BRCA1 and *BRCA2* mutations cause women to have a substantially greater risk of developing ovarian cancer. (Women with these gene mutations also have a substantially greater risk of developing breast cancer.) While approximately 1.3% of women in the general population will develop ovarian cancer, 39% of women with a *BRCA1* mutation and 11–17% of women with a *BRCA2* mutation will develop ovarian cancer by age 70.[30] Research indicates that other genetic mutations may also be associated with a greater likelihood of developing ovarian cancer.[31] One such mutation causes Lynch syndrome; women with this syndrome have about a 9–12% risk of developing ovarian cancer.[32]

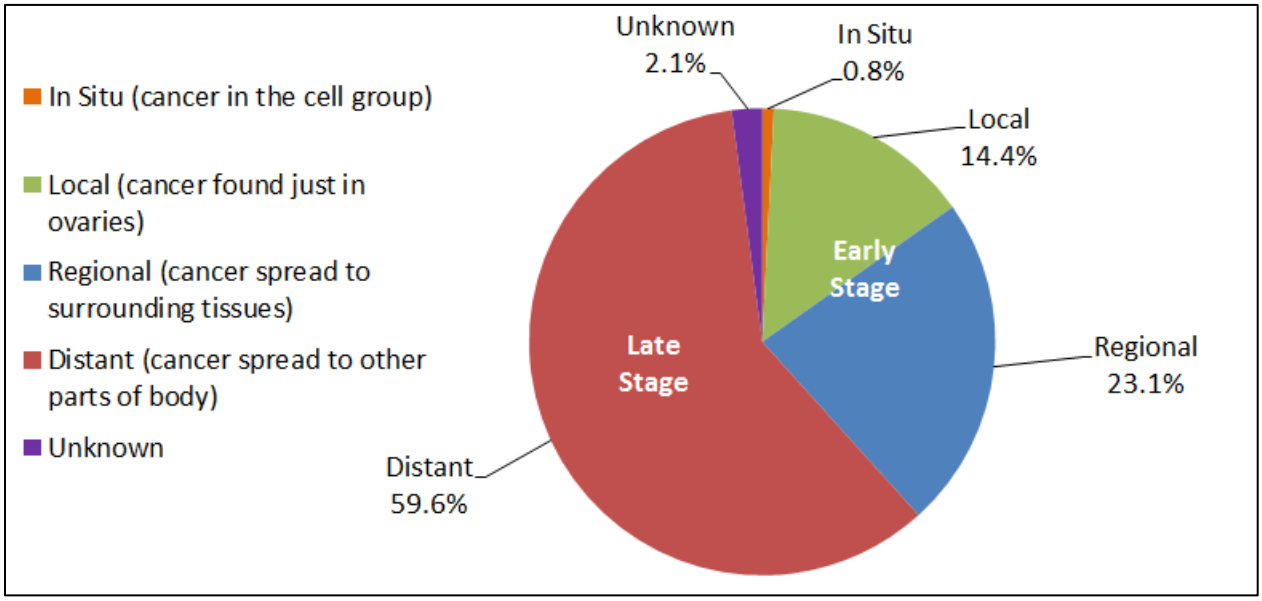
Although women can undergo genetic testing to determine if they are at greater risk of developing ovarian cancer due to *BRCA* genetic mutations, there is no reliable screening mechanism to detect ovarian cancer early. While researchers and medical providers used to believe that a CA125 test—a blood test that measures the amount of the protein CA125—could be used to detect ovarian cancer at an early stage, recent research has determined that this is not a valid screening test for ovarian cancer.[33] This lack of screening is one of the reasons that ovarian cancer is difficult to detect early.

UNIQUE FEATURES OF OVARIAN CANCER

There are several unique aspects of ovarian cancer that make it particularly important to research and raise awareness about. First, ovarian cancer is typically diagnosed at a late stage, thus contributing to its low survival rate.

In Massachusetts between 2009 and 2013, approximately 60% of cases were diagnosed at a distant stage, meaning that the cancer had spread to parts of the body beyond the ovaries. Twenty-three percent of the cases were diagnosed at the regional stage, where the cancer had spread to surrounding tissue beyond the ovaries, and just over 14% of ovarian cancer cases were diagnosed at the local stage, where the cancer was found only in the ovaries.[34] The local and regional stages are considered an early stage, whereas the distant stage is considered a late stage (Figure 4).

Figure 4: Ovarian Cancer in Massachusetts by Stage at Diagnosis, 2009–2013



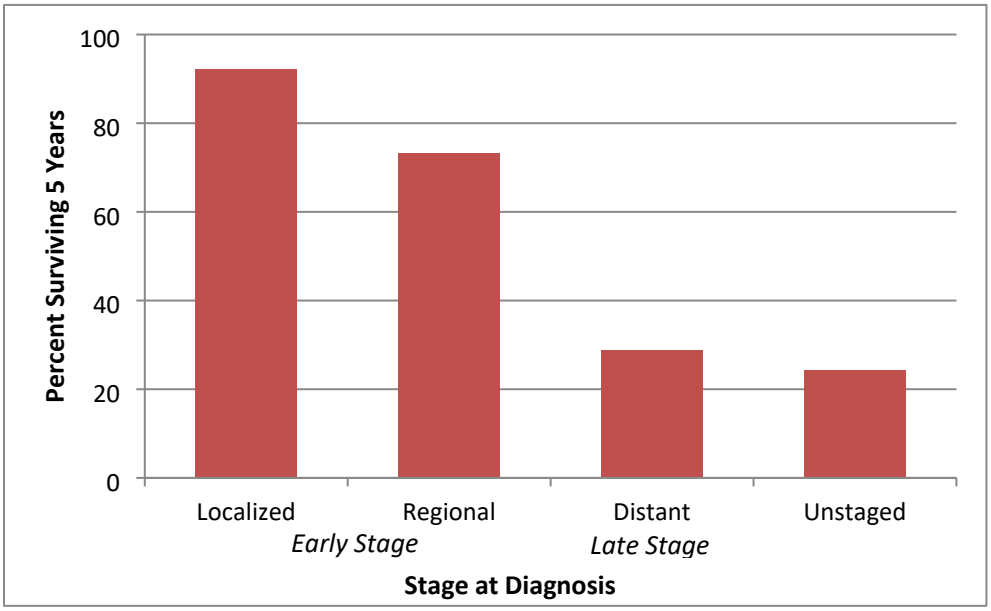
Across racial and ethnic groups, disparities exist in the percentage of women diagnosed at each stage. While just under 54% of non-Hispanic white women were diagnosed in the distant stage in Massachusetts between 2009 and 2013, almost 71% of non-Hispanic black women were diagnosed at the distant stage. The percentages of non-Hispanic Asian women and Hispanic women were lower than that of non-Hispanic white women.[35]

A late-stage diagnosis is associated with lower survival rates. In the United States between 2006 and 2012, the five-year survival rate for ovarian cancer diagnosed at the local stage was 92.1%. Ovarian cancer diagnosed at the regional stage had a five-year survival rate of 73.1%, and in the distant stage the five-year survival rate was just 28.8% (Figure 5).[36]

Moreover, the recurrence rate for ovarian cancer is very high. Approximately 70% of patients diagnosed with ovarian cancer suffer a recurrence, which means that the cancer returns after a period of remission. The chance of the cancer recurring is correlated with the stage at which it is diagnosed: patients diagnosed in an early stage have approximately a 10% chance of recurrence, whereas patients diagnosed at a late stage may have up to a 90% chance of recurrence.[37] Furthermore, most women diagnosed with late-stage ovarian cancer will face multiple episodes of recurrent disease, with shorter intervals between as the recurrences repeat.[38] Ovarian cancer at this stage is almost always incurable, and treatment resistance is a major problem for ovarian cancer patients.[39]

It is also important to note that there are women who suffer from chronic ovarian cancer. They fall into neither the survivorship or recurrence stages, and they must go through multiple cycles of surgery, chemotherapy, radiation, and clinical trials throughout their lives.

Figure 5: Survival Rates by Stage of Diagnosis in the United States, 2006–2012



One major reason for late-stage diagnosis for women with ovarian cancer is that the symptoms associated with ovarian cancer are generally subtle and are often mistaken for other medical complaints. Although ovarian cancer used to be called the "silent killer" due to its supposed lack of symptoms, recent research has shown that the following symptoms are more likely to occur in women with ovarian cancer than in the general population:

- bloating,
- pelvic or abdominal pain,
- difficulty eating or feeling full quickly, and
- urinary urgency or frequency.[40,41]

When these symptoms are persistent or represent a change from normal, they can be associated with ovarian cancer. However, because these symptoms mirror those of other benign conditions, cancer is often not detected until a late stage. Therefore, education and awareness about ovarian cancer symptoms for providers, as well as for the general public, are essential.

Another aspect of ovarian cancer that differentiates it from many other cancers is the process by which it is diagnosed and treated. Research has shown that there are different outcomes for women with ovarian cancer based on the type of surgeon who treats them. Women with ovarian cancer who are treated by a gynecologic oncologist have a higher chance of survival compared to patients treated by general gynecologists.[42,43] One reason for this is that gynecologic oncologists have been trained for the specific and complex surgery that ovarian cancer often requires, even for women who are diagnosed in an early stage. Additionally, because ovarian cancer has many different types of histology, meaning it is not just one cancer, providers must have the expertise to determine the treatment necessary for the specific type of cancer. It is therefore necessary to encourage and enable all patients to be treated by a gynecologic oncologist rather than a gynecologist.

PATIENT NEEDS

As with all cancers, patients have a range of needs from diagnosis through post-treatment. Due to ovarian cancer's high rate of recurrence and severity of treatment, women with ovarian cancer often have a great need for psychosocial support. Several local and national organizations focus on research, advocacy, and support for ovarian cancer patients and their families. Additional resources may be helpful to increase education and awareness about ovarian cancer, promote research to improve treatment, and support women and families affected by ovarian cancer and should be available across the Commonwealth.

KEY POINTS

- Ovarian cancer is the eighth most common cancer among women and the fifth leading cause of cancer-related death among women. Compared to other gynecologic cancers, ovarian cancer is the deadliest.[44]
- The mortality-to-incidence ratio of ovarian cancer is higher for non-Hispanic black women, meaning there is a greater likelihood that a black woman will die of ovarian cancer compared to a white woman.
- Women of all ages can develop ovarian cancer. The risk increases with age.
- The main risk factors of ovarian cancer include being a *BRCA* or other high-risk gene mutation carrier, having a family history of ovarian, breast, colon, or endometrial cancer, endometriosis, and increasing age. Factors that decrease risk include oral contraceptive use, parity, and tubal ligation.
- 60% of ovarian cancer cases are diagnosed at a late stage, and this percent is even greater for non-Hispanic black women. The survival rate for women diagnosed at a late stage is just 29%.
- Symptoms of ovarian cancer are non-specific and subtle, making it difficult to diagnose, and education about symptoms is essential.
- Ovarian cancer patients treated by gynecologic oncologists have the best outcomes.

IV. COMMISSION CHARGE AND RECOMMENDATIONS

Charge i: Establish a mechanism to ascertain the prevalence of ovarian cancer in the commonwealth, and, to the extent possible, collect statistics relative to the timing of diagnosis and risk factors associated with ovarian cancer.

Reporting of ovarian cancer cases is required under Massachusetts General Laws, Chapter 111, Section 111B: Malignant disease and benign brain-related tumor registry, reports. This law is implemented by regulation under Chapter 105, Code of Massachusetts Regulation, Section 301.000: Cancer Registry.

The Massachusetts Cancer Registry (MCR) is managed by DPH and is a population-based registry that collects, reviews, and analyzes information on all newly diagnosed cases of ovarian cancer throughout the Commonwealth. Reporting facilities are required to report case-level data to the MCR within 180 days of diagnosis or first date of patient interaction. Data elements that are captured for ovarian cancer include:

- Patient identifiers and demographics
- Provider and facility identifiers

- Cancer identification and date of diagnosis
- Extent (stage) and type (histology) of disease at diagnosis
- Type and date of first treatment that includes surgery (or reason for no surgery) and chemotherapy and radiation
- Other information as necessary to ensure completeness

Data elements are revised periodically in accordance with national cancer registration standards and Commonwealth-specific requirements. The MCR provides de-identified case data to federal cancer registries as part of national reporting.

Data collected and analyzed provide important information for monitoring the impact of ovarian cancer and are also used when designing and evaluating cancer prevention and control programs. The MCR issues reports that provide information on statewide incidence and mortality, and also publishes special publications that contain statistical data or current public health issues related to cancer.

COLLECTION OF BRCA GENE MUTATION CARRIER STATUS

As stated in the *Landscape* section, being a *BRCA1* or *BRCA2* gene mutation carrier is a well-confirmed risk factor that causes women to have a substantially greater risk of developing ovarian cancer. Hereditary ovarian cancer is most often caused by *BRCA* gene mutations. The Society of Gynecologic Oncology, the National Comprehensive Cancer Network, and other national and international professional organizations state that all women with ovarian cancer should receive genetic counseling and be offered genetic testing, even in the absence of a family history.[45,46]

BRCA gene mutation carrier status is not collected by the MCR. Collection and analysis of this information in ovarian cancer patients through a population-based method will provide state-specific information about the burden of ovarian cancer with a genetic component. Additionally, not only does identification of *BRCA* status in patients allow for identification of other cancer risks, but it also provides valuable information to inform other family members about their cancer risk and offers options for testing and risk-reducing surgery that would decrease their risk of cancer.

Further, collecting *BRCA* gene mutation status will provide important information about the number of ovarian cancer cases that are <u>not</u> being tested and why (e.g., testing not offered, patient did not follow through with testing, health insurance barrier). Collection and analysis of *BRCA* gene mutation carrier status and related information by the MCR will lead to better-informed clinical strategies and interventions to help improve lives.

KEY POINT

- Collection and analysis of *BRCA* gene mutation carrier status by the Massachusetts Cancer Registry is important to determine if patients are being tested for *BRCA* status as well as to identify patient and family risk status for ovarian and other cancers.

Recommendation for Statewide Collection of Data

1) Explore a statewide mechanism for collecting *BRCA1* and *BRCA2* gene mutation carrier status and related information for all ovarian cancer patients. Types of information to collect may include:

- Personal and family history of cancer
- Type and date of *BRCA* test ordered
- *BRCA* test results
- Type and date of other high-risk genetic mutation testing, if applicable
- Test results of other high risk genetic mutation testing
- Reason (s) not tested
- Insurance status and type

Charge ii: Determine how to best effectuate early diagnosis and treatment for ovarian cancer patients.

EARLY DIAGNOSIS

Ovarian cancer is challenging to diagnose due to the vague nature of symptoms and no current reliable screening tool. Thus, the vast majority of cases are diagnosed at a late stage with accompanying low survival rates.[47] Early-stage diagnosis is associated with a much improved prognosis and is critical to reducing the burden of ovarian cancer. The lack of awareness and knowledge of ovarian cancer for individual women, the general public, and health care providers contributes to late-stage diagnoses.

GENERAL PUBLIC

Research indicates that awareness of ovarian cancer risk factors and symptoms, combined with a lack of understanding of impact, is low. Additionally, many women do not discuss ovarian cancer or vague abdominal symptoms they are experiencing with their healthcare providers as part of their routine gynecologic health care. The reasons for this vary, but include:

- not wanting to bother their healthcare providers with vague symptoms
- feeling embarrassed to talk about these symptoms
- believing that symptoms will just go away
- not trusting their providers

Another reason cited is providers that do not bring up the topic of ovarian cancer with their patients. Furthermore, a common misconception among women is that a Pap test is useful in screening for ovarian cancer; however, it is only useful for cervical cancer screening. Therefore, women mistakenly believe a negative Pap test means they don't have ovarian cancer. [48,49,50]

HEALTH CARE PROVIDERS

While detection of ovarian cancer in an early stage is correlated with higher survival rates, there is currently no effective screening tool to help diagnose ovarian cancer early. While not as effective as an early diagnosis screening tool, health care providers can promote early-stage diagnoses by having a strong understanding of the symptoms associated with ovarian cancer, as well as through referring high-risk patients to geneticists for counseling and genetic testing.

A consensus on the signs and symptoms of ovarian cancer has emerged over time, though primary care providers still lack knowledge about them. The Gynecologic Cancer Foundation, the Society of Gynecologic Oncologists, and the American Cancer Society authored a consensus statement in 2007 regarding symptom recognition and prompt medical evaluation, preferably by a gynecologist, to help lead to detection at the earliest stage of cancer.[51] It is important that health care providers gain a stronger understanding of ovarian cancer symptoms so that they can better diagnose patients early.

In addition to symptom awareness, genetic counseling referrals can help promote early diagnosis for ovarian cancer patients. The U.S. Preventive Services Task Force (USPSTF), an independent panel of experts in primary care and prevention that develops evidence-based recommendations for clinical preventive services, recommends genetic counseling and evaluation for *BRCA* testing among individuals with high-risk family histories. The USPSTF recommends several validated questionnaires to determine if, based on family history of breast, ovarian, or other types of *BRCA*-related cancer, a patient should be referred to a genetic counselor for further evaluation.

While these questionnaires exist, several studies indicate that there is a lack of knowledge among primary care providers regarding ovarian cancer risk factors, including the genetic principles necessary to collect family history and identify individuals at risk for *BRCA* gene mutations. Although gynecologists also lack knowledge in this area, they do have a higher rate than primary care providers for adhering to the USPSTF recommendations for identifying high-risk women to refer to genetic services.[52,53,54,55]

More education of providers will contribute to their better understanding of ovarian cancer symptoms, risk factors, genetics, and implementation of the USPSTF guidelines. During interviews, Commission members praised one educational program called “Survivors Teaching Students: Saving Women’s Lives” developed by the national Ovarian Cancer Research Fund Alliance. The program’s goal is to help future health care providers diagnose ovarian cancer more quickly. It trains ovarian cancer survivors and caregivers to educate medical and nursing students by sharing their stories and relaying facts about ovarian cancer. The program is active in 34 states, including in Massachusetts (currently implemented only at Tufts Medical School).

KEY POINTS

- There is a critical knowledge gap among both the general public and primary care providers concerning ovarian cancer symptoms, risk factors, and use of the USPSTF guidelines to determine genetic risk.
- Lack of knowledge among primary care providers is concerning because they are usually women’s first points of contact in the health care system and are necessary for specialist referrals.
- Primary care providers' lack of knowledge translates into potential missed opportunities to identify women at risk.
- Educational programs and policies to integrate risk assessment screening into primary care could improve early diagnosis and outcomes.

TREATMENT

The course of ovarian cancer treatment is determined by the stage at which the cancer is diagnosed. In general, complete treatment involves both surgery and multiple cycles of chemotherapy. Surgery can be significant and extreme requiring complex cytoreductive surgical techniques. Chemotherapy can be rigorous and necessitate hospitalization. Intraperitoneal chemotherapy (injection of the drugs into the abdominal cavity) is now considered a preferred treatment in addition to regular intravenous (IV) chemotherapy.[56,57]

TYPE OF PHYSICIAN WHO PERFORMS SURGERY

One major factor that affects the survival rate of women being treated for ovarian cancer is the type of physician who performs the surgery. The National Comprehensive Cancer Network, which provides evidence-based practice guidelines, recommends that ovarian cancer surgery and staging be done by a gynecologic oncologist as a standard of care. As stated in the *Landscape* section, research has shown that patients who are treated by gynecologic oncologists tend to fare better or much better than those treated by gynecologists or general surgeons and additionally have a greater survival rate.[58,59, 60] Gynecologic oncologists have been trained for the specific and complex surgery that ovarian cancer often requires and have skill sets with complex cytoreductive surgical techniques.

Yet, many ovarian cancer patients are not treated by such specialists and, therefore, are receiving inadequate care. Moreover, the location and type of practice where patients are treated can have a bearing on the type of provider available. Patients at large, high-volume hospitals or facilities that are National Cancer Institute (NCI)-designated cancer centers are more likely to be treated by gynecologic oncologists.

Research outlines variable factors as to why ovarian cancer patients are not getting referred to gynecologic oncologists, but questions remain. One study found that clinicians less likely to refer patients to gynecologic oncologists included practitioners in rural locations, male physicians, family practitioners, solo practitioners, and practitioners with higher weekly patient loads.[61]

CLINICAL TRIALS

In addition to the type of provider that treats ovarian cancer patients, the type of treatment can also have an effect on patient outcomes. Clinical trials, which are research studies that explore whether certain treatments are safe and effective, can be a good treatment option for some patients. Many ovarian cancer patients are candidates for clinical trials, and greater awareness among patients at all stages about their availability is important.[62]A good starting point is the Clinical Trials website, a service of the US National Institutes of Health. It is a registry and results database of publicly- and privately-supported clinical studies of human participants from around the world. It is available at https://clinicaltrials.gov.

KEY POINTS

- All ovarian cancer patients, regardless of diagnosis stage, should understand the importance of being treated by a gynecologic oncologist and the value and importance of clinical trials as a treatment option.
- By increasing awareness and knowledge about these aspects of care it is possible that women with ovarian cancer will experience better outcomes.

Recommendations for Early Diagnosis and Treatment

PROVIDER EDUCATION

2) Provide education to primary care providers, gynecologists, gynecologic oncologists, and medical oncologists to increase their awareness and knowledge of ovarian cancer and to effect clinical practice changes for reducing delays in diagnosis.

Key messages should include: 1) recognize that there is no reliable early detection or screening test, 2) ask about and listen to patients' answers about their symptoms (specifically ask about bloating, pelvic or abdominal pain, difficulty eating or feeling full quickly, and urinary urgency or frequency), 3) understand genetic risk factors, 4) conduct risk assessment screening across all primary care practices and refer women at high risk for ovarian cancer to a genetic counselor for counseling and evaluation for testing, 5) refer ovarian cancer patients to a genetic counselor for counseling and testing and to a gynecologic oncologist for treatment, and 6) advise on the use of palliative care and integrative therapies that promote a higher and more comfortable quality of life.

Mechanisms could include:

- Hospital grand rounds
- Continuing medical education programs for physicians and physician assistants provided through the Massachusetts Medical Society, the Massachusetts Chapter of American College of Physicians, and other professional associations
- Continuing education unit programs for nurses and nurse practitioners provided through the Massachusetts Nurses Association and other professional associations

3) Review curricula for training programs (physicians, physician assistants, nurse practitioners) for inclusion of ovarian cancer elements. Make suggestions of existing programs and resources that can be added to curricula.

PATIENT EDUCATION

4) Increase ovarian cancer patient awareness and education regarding the standard of care for treatment (including the need to consult with a gynecologic oncologist), the insurance appeal process for non-covered standard of care, and the availability and importance of clinical trials at all stages.

GENERAL PUBLIC EDUCATION

5) Provide education to the general public (with a focus on women) to increase awareness and knowledge of ovarian cancer risk factors and symptoms and to clarify misconceptions to help reduce delays in diagnosis.

Mechanisms could include:

- A statewide public education campaign or a targeted campaign
- Educational programs (including peer-to-peer education) offered to groups in settings such as community health centers, retirement centers, faith-based and nonprofit agencies
- Educational information distributed to patients through health care provider offices

There are a number of organizations involved with ovarian cancer education that could be involved as stakeholders/partners. See Appendix.

Charge iii: Determine any unmet needs of persons with ovarian cancer and those of their families.

The journey that a patient experiences from the time of diagnosis with ovarian cancer to the period of survivorship, chronic cancer, or end of life is met with an array of needs. The ovarian cancer journey has several distinct phases, some that are associated with significant patient and family support and some that Commission members and research have identified as lacking support. While each patient has a unique ovarian cancer experience, there are some common trends regarding unmet needs. According to literature and Commission interviews, there are unmet needs, especially a lack of psychosocial support, at: 1) the period just after diagnosis before treatment begins, 2) the period after treatment ends when there is a strong fear of recurrence, and 3) when living with chronic ovarian cancer.

After diagnosis, which typically occurs in a late stage, ovarian cancer patients must understand the treatment plan and continuum of care that they are about to experience. The high percentage of late-stage diagnoses means that treatment decisions must often be made quickly, which can be stressful for many women and their families. Some research indicates that patients are faced with shock, fear, and a lack of information immediately following the initial diagnosis.[63] Several Commission members also noted a lack of communication between providers and patients and also between providers. This insufficient communication can contribute to a lack of information shared about patient resources and a lack of coordinated care.

Women also have significant unmet needs after treatment ends. Because of the high recurrence rate of ovarian cancer, especially in cases diagnosed at a late stage, fear of recurrence is particularly sharp. In several studies, the fear of the cancer spreading or returning was identified as a high-priority unmet need.[64,65,66] Commission members explained that because the intense support system that was in place during treatment goes away, patients are often left without necessary psychosocial support. Peer support groups, counseling, referrals to community resources, and dependable communication with health care providers can help women feel supported during these periods of uncertainty.

In addition to unmet psychosocial needs, ovarian cancer patients and their families may have other unmet needs, including ones related to service accessibility, financial stability, and physical changes. According to Commission members, the lack of available or reliable transportation, specifically for patients who live far away from Boston, can make it challenging to receive treatment and support. Financial strain can be especially significant for low-income women with ovarian cancer. Finally, after surgery, the immediate onset of menopause and inability for women to have children can result in a range of physical and emotional needs.

There are services, including psychosocial support, that exist to meet these needs, however ovarian cancer patients have difficulty learning about and accessing these services with no comprehensive resource guide available. A comprehensive guide of Massachusetts-specific resources would likely be referred to, and relied on, by women and their families suffering from ovarian cancer.

Finally, while there is much focus on the medical treatments aimed at treating and curing patients, there is less emphasis on therapies and care that address the pain and discomfort associated with ovarian cancer. Research has shown that palliative care—care that is patient-driven and aims to relieve symptoms and stress—improves the quality of life of ovarian cancer patients and can also reduce the cost of treatment.[67] The advantages of palliative care are evident, and the American Society of Clinical

Oncology recommends that palliative care be included as a routine part of cancer care by the year 2020.[68] Commission members also identified palliative care and integrative therapies, such as yoga and massage for relaxation and acupuncture for management of pain and nausea, as beneficial components of the ovarian cancer journey. A greater emphasis on this type of care could benefit women suffering from ovarian cancer.

Currently, there are a number of groups both locally and nationally that provide resources, support, and advocacy for ovarian cancer patients and their families (see Appendix). However, as discussed above, certain needs remain unmet, and certain initiatives could improve the lives of ovarian cancer patients and their families.

KEY POINTS

- While each patient has a unique experience with ovarian cancer, three periods where there tend to be unmet needs include the period just after diagnosis before treatment begins, the period after treatment ends when there is a strong fear of recurrence, and living with chronic ovarian cancer.
- Patients and families face a range of unmet needs, including ones related to psychosocial support, financial strain, service accessibility, and physical changes.
- Palliative care and integrative therapies are valuable and should complement medical treatment.

Recommendation for Support

6) Promote Massachusetts-specific resources and support services for ovarian cancer patients. Essential information includes, but is not limited to, a list of gynecologic oncologists and NCI-designated Cancer Centers. Promotion may include the creation of a comprehensive guide.

Conclusion

Despite the fact that ovarian cancer is highly curable if diagnosed early, ovarian cancer causes more mortality in American women each year than all other gynecologic cancers combined. The absence of a valid screening test and a lack of obvious symptoms lead to frequent late-stage diagnoses with low survival rates. The uniqueness of ovarian cancer, along with documented racial and ethnic disparities, makes it particularly important to research, raise awareness, and increase knowledge about. Based on Commission meetings, Commission interviews, and background research, this report presents a series of recommendations that range from increasing statewide collection of key patient data; implementing educational programs for the general public, patients, and health care providers to increasing support for patients and families, including promoting Massachusetts-specific resources and support services for ovarian cancer patients and families. It is essential to decrease the incidence of ovarian cancer diagnoses, diagnose women at earlier stages, and provide support for patients and families to increase their quality of life. Massachusetts can accomplish these goals.

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APPENDIX: OVARIAN CANCER-RELATED ORGANIZATIONS AND RESOURCES

The list below is not inclusive of all organizations and hospitals that provide ovarian cancer education, support, advocacy, and other resources. It can be expanded as appropriate.

Name	Location	About the Organization*
American Cancer Society ***www.cancer.org***	National, with two Central New England Region chapters (Acton, MA and Framingham, MA)	Dedicated to eliminating cancer as a major health problem by preventing cancer, saving lives, and diminishing suffering through research, education, advocacy, and service.
Beth C. Wright Cancer Resource Center ***www.bethwrightcancercenter.org***	Ellsworth, ME	Offer hope, knowledge, and support to patients, their families, caregivers, and friends by providing information, social services, and compassion.
Cancer Connection ***www.cancer-connection.org***	Northampton, MA	Support people living with cancer through education, peer groups (including weekly gynecologic cancer support groups for patients and families), integrative therapies, and other programs to strengthen body and spirit.
Center for Gynecologic Cancers (Massachusetts General Hospital) ***www.massgeneral.org/cancer/services/centers/Gyn_cancers.aspx***	Boston, MA	Offer comprehensive care supported by surgical innovation, research, and clinical trials for gynecologic cancers including ovarian cancer.
Facing Cancer Together ***www.facing-cancer.org***	Newton, MA	Provide support, wellness, and educational services to anyone affected by cancer, regardless of their capacity to pay.
Facing our Risk of Cancer Empowered (FORCE) ***www.facingourrisk.org***	Tampa, FL	Improve the lives of individuals and families affected by hereditary breast, ovarian, and related cancers through research, support, and advocacy.
The Healing Garden ***www.healinggarden.net***	Harvard, MA	Provide integrative care through therapeutic services, educational programs, and a healing environment for anyone with a cancer diagnosis. Teach wellness education classes, promoting cancer prevention.

The Julie Fund for Women's Cancers ***www.juliefund.org***	Newton, MA	Impact key areas related to women's cancers, including research and funding, education, and non-medical support (including food, temporary housing, and transportation).
National Ovarian Cancer Coalition ***www.ovarian.org***	National, with local chapter (Arlington, MA)	Fight to prevent and cure ovarian cancer and improve the quality of life for survivors. Educate communities and provide information to newly-diagnosed patients, hope to survivors, and support to caregivers.
Ovarian Cancer 101 ***www.ovariancancer101.org***	Cotuit, MA	Fight ovarian cancer through education, support, and advocacy.
Ovarian Cancer Awareness Coalition ***www.ovariancancerawareness.org***	Greater Boston Area	Three organizations (Patricia Cronin Foundation, Dana-Farber/Brigham & Women's Cancer Center, and MA Department of Public Health) dedicated to fighting ovarian cancer.
Ovarian Cancer Research Fund Alliance ***www.ocrfa.org***	New York, NY and Washington, DC	Support and advocate for people affected by ovarian cancer. Promote research related to the causes, prevention, diagnosis, treatment, and cure for ovarian cancer.
Ovations for the Cure of Ovarian Cancer ***www.ovationsforthecure.org***	Framingham, MA	Dedicated to the pursuit of a cure for ovarian cancer by providing public education, patient emotional support, and research funding.
Patricia Cronin Foundation ***www.patsfriends.org***	Quincy, MA	Provide support to ovarian cancer patients, their friends, and families. Increase awareness and promote research on causes, diagnosis, and treatment of ovarian cancer.
SHARE Cancer Support ***www.sharecancersupport.org***	New York, NY	Create and sustain a supportive network and community of women affected by breast and ovarian cancers to share information, support, strength, and hope.
Susan F. Smith Center for Women's Cancers (Dana-Farber/Brigham and Women's Hospital) ***www.brighamandwomens.org/bwhcancer/dfcibwh_cancer_treatment.aspx?id=4294967626***	Boston, MA	Dedicated to providing compassionate care and personalized diagnosis, treatment, and support for every ovarian cancer patient and her family.

**Descriptions are drawn from organizations' websites.*