

2003 State of the State
of Gynecologic Cancers

First Annual Report to the Women of America





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About the Society of Gynecologic Oncologists (SGO) and the Gynecologic Cancer Foundation (GCF)

The Society of Gynecologic Oncologists (SGO) is a national medical specialty organization of physicians who are trained in the comprehensive management of women with malignancies in the reproductive tract. Its purpose is to improve the care of women with gynecologic cancer by encouraging research, disseminating knowledge to raise the standards of practice in the treatment and prevention of gynecologic malignancies, and cooperating with other organizations interested in women's health care, oncology and related fields.

The Society's membership is primarily comprised of gynecologic oncologists, as well as other related medical specialists such as medical oncologists, radiation oncologists and pathologists. SGO members provide multidisciplinary care including chemotherapy, radiation therapy, supportive care and surgery.

For more information about the SGO and the field of gynecologic oncology, please visit www.sgo.org or contact the Society at 312.644.6610.

The Gynecologic Cancer Foundation (GCF) was established by SGO in 1991 as a not-for-profit charitable organization to raise funds to support philanthropic programs to benefit women who have, or who are at risk for developing, a gynecologic cancer.

The mission of the Gynecologic Cancer Foundation is to ensure public awareness of gynecologic cancer prevention, early diagnosis and proper treatment, as well as to support research and training related to gynecologic cancers. GCF advances this mission by increasing public and private funds that aid in the development and implementation of programs to meet these goals.

For more information about GCF, its educational materials or research grants, please visit www.wcn.org/gcf or contact Executive Director Karen Carlson by phone at 312.644.6610 or by e-mail at Karen_Carlson@sba.com. For additional information on gynecologic cancers or a referral to a gynecologic oncologist, please call the toll-free GCF Information Hotline at 800.444.4441.

GCF is a 501(c)(3) non-profit organization under the U.S. Internal Revenue Code.

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A Letter to the Women of America

September is Gynecologic Cancer Awareness Month — a time for women to learn about gynecologic cancers and focus on the simple steps they can take to maintain their gynecologic health.

This year, to further empower the women of America with the latest information about gynecologic cancers, the Gynecologic Cancer Foundation (GCF) is proud to share with you the first annual *State of the State of Gynecologic Cancers* — a snapshot of our current knowledge about gynecologic cancers, and an expression of our hope to prevent these diseases in the future.

The Gynecologic Cancer Foundation was established by the Society of Gynecologic Oncologists (SGO) in 1991 as a not-for-profit charitable organization to support philanthropic programs that benefit women who have, or are at risk for developing, a gynecologic cancer. Its mission is to ensure public awareness of gynecologic cancer prevention, early diagnosis and proper treatment as well as to support research and training related to gynecologic cancers.

While I am pleased to say that the report highlights many exciting advances in the fight against gynecologic cancers, many challenges still remain. For example, while diagnosis and treatment techniques are becoming more refined and accurate, we still have more than 80,000 women diagnosed each year in the U.S. with a gynecologic cancer.¹ And, with approximately 26,000 of these women dying from these cancers each year,² we know there is much work left to do before we achieve our goal of eliminating these diseases.

Therefore, to provide a clear view of the state of gynecologic cancers in this country, we have focused on the most common types that affect the most women: cervical cancer, ovarian cancer (epithelial and stromal cell/germ cell), uterine cancer (endometrial and uterine sarcomas), vaginal cancer and vulvar cancer. In future reports, we may also choose to examine rare gynecologic cancers such as fallopian tube cancer, as scientific advances present more information and encouraging news about these cancers.

Medical advances however, are only part of this fight to diagnose, effectively treat and ease the impact of gynecologic cancers on women. SGO is actively advocating for passage of significant federal legislative initiatives that will improve the lives of those suffering from many types of cancer, and these are summarized below:

- *Johanna's Law: The Gynecologic Cancer Education and Awareness Act of 2003*, to be introduced by Representative Sander Levin (D-MI) and Representative Kay Granger (R-TX), would authorize a national gynecologic cancer early detection and awareness campaign directed at women and their physicians.
- *Providing Annual Pap Tests to Save Women's Lives Act of 2003* (S. 416), introduced by Senator Olympia Snowe (R-ME), would provide for annual screening coverage of Pap smears and pelvic exams under the Medicare program.

¹ American Cancer Society. Cancer Facts & Figures, 2003. Available at: www.cancer.org/docroot/STT/stt_0.asp. Accessed September 3, 2003.

² Ibid.

- *The Access to Cancer Clinical Trials Act* (H.R. 2021), introduced by Representative Deborah Pryce (R-OH), would require all private health insurance plans to cover routine costs of cancer patients who qualify to participate in a cancer clinical trial.
- *The Cancer Survivorship Research and Quality of Life Act of 2003* (S. 1101/H.R. 2741), introduced by Senator Kay Bailey Hutchinson (R-TX) and Representative Roger Wicker (R-MS), would authorize funds to the Office of Cancer Survivorship within the National Cancer Institute to study the long-term and short-term physical, psychological, social and economic effects of cancer.
- *The Cancer Testing, Education, Screening and Treatment Act* (H.R. 1868), introduced by Representative Maxine Waters (D-CA), would establish a program to provide cancer screenings and treatment for minorities and other populations served by public health centers.
- *The Quality Cancer Care Preservation Act* (S. 1303/H.R. 1622), introduced by Senator Sam Brownback (R-KS) and Representative Charlie Norwood (R-GA), would adjust current Medicare reimbursement policies that allow overpayment for cancer chemotherapy drugs and underpayment for essential care needs of cancer patients.
- *The Access to Cancer Therapies Act of 2003* (S. 1037), introduced by Senator Olympia Snowe (R-ME), would provide Medicare coverage for all oral anticancer drugs.

In addition to these efforts, state legislatures are actively engaged across the country in legislative action affecting women’s health and are working to do their part to improve lives through better access to medical care and support systems.

We are very grateful to the physician members of the SGO for their contributions to and support of this important report.

Finally, we hope that women find the *State of the State of Gynecologic Cancers* to be a source of valuable information and encouragement. We plan to publish this report every year to keep women apprised of the latest information available about these cancers — from those who are specially trained to treat them. While significant advances can be found in these pages, the most critical lesson for women remains the importance of early and regular gynecologic screening. With this in mind, we hope women will get screened annually for gynecologic cancers and remind their network of family and friends to do the same. With each positive action a woman takes to protect herself, the more we will accomplish in this journey to fight gynecologic cancers.

Sincerely,



Karl C. Podratz, M.D., Ph.D.
Chairman
The Gynecologic Cancer Foundation

Commonly Asked Questions

What are gynecologic cancers?

Gynecologic cancers are the uncontrolled growth and spread of abnormal cells originating in the female reproductive organs, including the cervix, ovaries, uterus, fallopian tubes, vagina and vulva.

What causes gynecologic cancers?

Biomedical research has discovered that some classes of genes, called oncogenes and tumor suppressor genes, promote the growth of cancer. You can acquire abnormal function of these genes during life (e.g., through smoking, aging, environmental influences) or you can inherit gene mutations from your parents or grandparents. In one instance — cervical cancer — cancer is caused by a sexually transmitted virus.

Can gynecologic cancers be prevented?

Diet, exercise and lifestyle choices play a significant role in the prevention of cancer. Additionally, knowing your family history can increase your chance of early diagnosis and can help you take action toward prevention. Screening and self-examinations conducted regularly can result in the detection of certain types of gynecologic cancers in their earlier stages, when treatment is more likely to be successful and a complete cure is a possibility.

Who should treat gynecologic cancers?

Gynecologic cancers should be treated by a cancer specialist, such as a gynecologic oncologist. A gynecologic oncologist is a board-certified obstetrician/gynecologist who has an additional three to four years of specialized training in treating gynecologic cancers from an American Board of Obstetrics and Gynecology-approved program. This subspecialty program provides training in the biology and pathology of gynecologic cancers, as well as in all forms of treatment for these diseases, including surgery, radiation, chemotherapy and experimental treatments.

How are gynecologic cancers treated?

Gynecologic cancers are treated by using one or more of the following options: surgery, radiation therapy, chemotherapy and experimental treatments. The choice of therapy depends on the type and stage of the cancer.

Who is at risk?

Any woman is at risk for developing a gynecologic cancer. Each year, approximately 83,700 women in the United States are diagnosed with cancers affecting the reproductive organs.³

³ American Cancer Society. Cancer Facts & Figures, 2003. Available at: www.cancer.org/docroot/STT/stt_0.asp. Accessed September 3, 2003.

Cervical Cancer

State of Cervical Cancer

Cervical cancer is cancer that begins in the cervix, the part of the uterus or womb that opens to the vagina. Cervical cancer is caused by abnormal cellular changes in the cervix and is the only gynecologic cancer that can be prevented by regular cervical cancer screening. It usually affects women between the ages of 30 and 55.

Symptoms: Symptoms include bleeding after intercourse, excessive discharge and abnormal bleeding between periods, although often there are no symptoms.

Risk factors: Failure to receive regular cervical cancer screening often eliminates the opportunity for early diagnosis. Persistent high-risk human papillomavirus (HPV) infection has been shown to be the cause of virtually all cervical cancers, although other risk factors include smoking, HIV infection and early age of first intercourse.

Screening/Prevention: Over the last 50 years, routine use of the Pap test to screen for cervical cancer has reduced deaths from the disease by 74 percent.⁴ A Pap test is the standard way physicians check to see if there are any cell changes that might cause concern. The Pap test involves looking at a sample of cells from the cervix under a microscope to see if there are any cells that are abnormal. It is a good test for finding not only cervical cancer cells, but also cells that might become cancerous in the future. Usually, health care providers perform the Pap test as part of a routine pelvic exam. In March 2003, the Food and Drug Administration (FDA) approved a new approach to cervical cancer screening for women 30 years of age and older — the use of the Hybrid Capture II HPV test in conjunction with the Pap test. This test combines a Pap test with the test for cancer-causing, or high-risk, HPV.

Incidence: In 2002, about 4,100 women died from cervical cancer in the U.S.⁵ An estimated 12,200 will be diagnosed in 2003.⁶ Between 1955–1992, cervical cancer mortality rates declined on average about 2 percent per year in the U.S.⁷

Advances in Cervical Cancer

Using modern technologies, scientists, physicians, engineers and others are working together to create rapid advances in the field of cervical cancer prevention, screening and treatment. Never before has there been such a rapid rate of discovery in this field.

⁴ American Cancer Society. Detailed Guide: Cervical Cancer. *What are the Key Statistics for Cervical Cancer?* Available at: www.cancer.org/docroot/CRI/CRI_2_3x.asp?dt=8. Accessed September 3, 2003.

⁵ American Cancer Society. Cancer Facts & Figures, 2002. Available at: www.cancer.org/docroot/STT/stt_0.asp. Accessed September 3, 2003.

⁶ American Cancer Society. Detailed Guide: Cervical Cancer. *What are the Key Statistics for Cervical Cancer?* Available at: www.cancer.org/docroot/CRI/CRI_2_3x.asp?dt=8. Accessed September 3, 2003.

⁷ Ibid.

One of the most exciting advances in cancer prevention was reported in the past year — the first major clinical trial of an HPV vaccine. The reported vaccine is designed to protect against HPV 16 infection, the most common virus type in cervical cancers. More than 750 women who had never been exposed to HPV 16 were given the vaccine. A second group received a placebo. After an average of 17 months of follow-up, none of the women in the vaccine group developed a lasting HPV 16 infection compared to 41 women in the placebo group. This report brings us one step closer to the day when routine vaccination will prevent most cases of cervical cancer. Several groups are now working on combination vaccines to protect against HPV 16 along with other common HPV virus types that cause cervical cancer and genital warts. This is an early and major advance in preventing HPV infection and cervical cancer.

Significant changes also have taken place in the area of cervical cancer screening, as new research continues to find ways to make screening more accurate and cost effective. Recent advances include the new liquid-based Pap tests that improve detection of some cervical abnormalities. Automated Pap tests, which are designed to remove the human error involved in reading Pap slides, are still under development. HPV testing in combination with Pap results has changed the way many clinicians screen women age 30 and older and the way doctors interpret certain Pap abnormalities. Possible new screening approaches include direct visualization and the use of specialized light sources to illuminate areas of precancerous change. Lastly, there is a large effort to eventually replace the regular Pap test (that looks for visible abnormal cells) with a “molecular Pap test” that would identify abnormal genetic changes in the cells, perhaps before the cells look cancerous or precancerous.

Progress also is apparent in treatments for invasive cervical cancers. A significant advance has been made in developing fertility-sparing surgery for a few women with early-stage cervical cancer. The treatment removes the cervix while preserving the upper uterus. Pregnancy outcomes are still being studied, but this past year brought small, yet hopeful, reports of safe and successful pregnancies.

Ovarian Cancer: Epithelial

State of Epithelial Ovarian Cancer

Ovarian cancer, the sixth most common cancer (other than skin cancer) among women,⁸ usually arises on the surface of the ovary in the epithelial cells. About 85 percent of ovarian cancers are epithelial ovarian cancers.⁹

Symptoms: Symptoms include unusual changes or discomfort, such as pressure or fullness in the pelvis, abdominal bloating, or changes in bowel and bladder patterns, which are constant and progressive.

Risk factors: The risk of epithelial ovarian cancer increases with age, especially around the time of menopause. A family history of epithelial ovarian cancer is one of the most important risk factors. Infertility and not bearing children are also risk factors, while pregnancy can decrease the risk of developing epithelial ovarian cancer.

Screening/Prevention: Currently, there is no widely available screening test for epithelial ovarian cancer. Some prevention measures for epithelial ovarian cancer include pregnancy and birth control pill use.

Incidence: Ovarian cancer ranks fifth in cancer deaths among women and causes more deaths than any other cancer of the female reproductive system.¹⁰ In 2003, it is estimated that more than 25,000 new cases will be diagnosed and approximately 14,000 women will die from ovarian cancer in the U.S.¹¹

Advances in Epithelial Ovarian Cancer

During recent years, a series of significant advances have taken place in the management of patients with advanced ovarian cancer. Years ago, one study established that the combination of two drugs, platinum agents and a taxane, worked better than chemotherapy combinations previously used to treat ovarian cancer. This combination brought new hope for women with the disease, but much work lies ahead for this deadly cancer. Recent studies have looked at the controversial role of maintenance therapy (after a woman with ovarian cancer completes her first set of chemotherapy treatments), and at the role of additional surgery for women whose initial surgery results were not optimal.

An important ongoing research trial also is examining the treatment results for women with ovarian cancer if one of three newer drugs, liposomal doxorubicin, topotecan or gemcitabine,

⁸ American Cancer Society. Detailed Guide: Ovarian Cancer. *What are the Key Statistics About Ovarian Cancer?* Available at: www.cancer.org/docroot/CRI/CRI_2_3x.asp?dt=33. Accessed September 3, 2003.

⁹ American Cancer Society. Detailed Guide: Ovarian Cancer. *What is Ovarian Cancer?* Available at: www.cancer.org/docroot/CRI/CRI_2_3x.asp?dt=33. Accessed September 3, 2003.

¹⁰ American Cancer Society. Detailed Guide: Ovarian Cancer. *What are the Key Statistics About Ovarian Cancer?* Available at: www.cancer.org/docroot/CRI/CRI_2_3x.asp?dt=33. Accessed September 3, 2003.

¹¹ Ibid.

is added to the standard platinum and taxane chemotherapy. More than 2,500 women have participated in this study, which likely will be completed sometime in 2004. Final study results probably will not be known for about two years following the end of the study.

Another important area of interest is the evaluation of treatments that cause fewer side effects. One interesting agent under study is Xyotax (CT2103). Investigators hope this agent will be at least as effective as the current first-line agent paclitaxel, but will cause less hair loss and nerve damage. Other promising agents include novel molecular therapeutics that specifically target cancer cell growth, restrict the blood supply to a growing tumor, or block metastasis, but do not have the side effects associated with chemotherapies.

Future promising research for ovarian cancer will focus on further development of therapies targeting cell signals and enzyme pathways that are part of ovarian cancer cells, but not part of healthy body cells. Research in this area is in the early stages however, it is considered the new frontier where potential therapeutic, maintenance and prevention strategies exist.

Ovarian Cancer: Stromal Cell and Germ Cell

State of Stromal Cell and Germ Cell Cancer

Stromal cell cancer starts in the stromal cells of the ovary — cells that produce female hormones and form the tissue that holds the ovaries together. Germ cell cancer starts in the cells that form eggs in the ovary.

Symptoms: Stromal cell and germ cell cancers can cause pain or discomfort at the beginning stages. Stromal cell tumors can secrete hormones like estrogen or testosterone, and cause symptoms of abnormal uterine bleeding and facial hair growth.

Risk factors: There are no known risk factors for stromal cell and germ cell cancer.

Screening/Prevention: There are no known prevention measures for stromal cell and germ cell cancer.

Incidence: Only about 5 percent of ovarian cancers are stromal cell cancers and 15 percent of ovarian cancers are germ cell cancers.¹² Stromal cell cancers are the most common hormonally active tumors.¹³ Germ cell cancer is usually found in adolescent girls and young women between the ages of 16 and 20. Both stromal cell and germ cell cancers usually affect one ovary and most often are found at early stages.

Advances in Germ Cell Ovarian Cancer

The challenge for the future management of germ cell tumors spans the spectrum of this disease from those with the best prognosis to those with the worst prognosis. To save the lives of the small number of young women who die early from germ cell tumors, we must find ways to identify the extremely aggressive types of this cancer.

The remarkable athletic success of Lance Armstrong, who survived a widely metastatic male germ cell cancer, highlights the importance of avoiding the damaging effects of chemotherapy. The most common treatment for germ cell tumors is a three-drug combination called BEP, which contains bleomycin, etoposide, and cisplatin.

Unfortunately, this successful and effective treatment can lead to scarring in the lungs, leukemia years later in 1 percent to 2 percent of patients, a painful decrease in nerve sensation and chronic anemia. Avoiding these lifelong consequences of treatment while saving lives is the challenge for this disease in the next decade. A soon-to-be-launched Children's Oncology Group study will

¹² American Cancer Society. Detailed Guide: Ovarian Cancer. *What is Ovarian Cancer?* Available at: www.cancer.org/docroot/CRI/CRI_2_3x.asp?dt=33. Accessed September 3, 2003.

¹³ Women's Cancer Network. *Ovarian Cancer Statistics*. Available at: www.wcn.org/interior.cfm?diseaseid=8&featureid=1. Accessed September 3, 2003.

look at the possibility of eliminating the use of chemotherapy in select germ cell tumors. After initial surgery, participants will be intensely monitored using examinations and biochemical markers, and given chemotherapy only if evidence of a recurrent tumor is found.

Advances in Stromal Cell Ovarian Cancer

These malignancies are among the rarest of the ovarian cancers and fortunately, often the least aggressive. The most common stromal malignancy is granulosa cell tumor.

Many granulosa cell tumors occur in young girls, who usually receive an excellent prognosis for eliminating these tumors. A second form of the tumor can occur in a wide range of ages, but most commonly in women in their 60s and 70s. The unique feature of this cancer is its tendency for late recurrence, sometimes 10 or even 15 years after initial surgery. The discovery of the tumor marker, inhibin, has helped with monitoring some patients for recurrence of this cancer.

The slow-growing behavior of granulosa cell tumor is unique in gynecologic malignancy. Solving the molecular biology of its delayed growth may open new avenues for the treatment of this cancer or other cancers.

Uterine Cancer: Endometrial

State of Endometrial Cancer

Most uterine cancers begin in the lining of the uterus (endometrium) after menopause, when a woman's menstrual cycle ends and the endometrium flattens out. This type of uterine cancer, endometrial cancer, occurs when cells in the endometrium become cancerous and begin to invade the myometrium, the muscle of the uterus.

Symptoms: Warning signs include any bleeding after menopause or irregular vaginal bleeding before menopause.

Risk factors: Risk factors include obesity, hypertension, diabetes, inappropriate estrogen use, tamoxifen use and late menopause. Women who have not been pregnant also have a slightly higher risk for endometrial cancer. A high risk for endometrial cancer can be inherited in some families.

Screening/Prevention: Currently, other than yearly pelvic exams, there are no screening tests for endometrial cancer that are recommended on a routine basis. A woman may lower her risk for developing endometrial cancer by exercising regularly and eating a healthy diet. Keeping blood sugar and blood pressure under control also helps lower the risk. Women with unexpected postmenopausal bleeding or heavy, prolonged or unexpected bleeding during the menstruating years should have an endometrial biopsy to check for endometrial cancer. A Pap test does not screen for endometrial cancer.

Incidence: Endometrial cancer is the most common cancer of the female reproductive organs.¹⁴ In 2003, an estimated 40,100 new cases will be diagnosed and 6,800 women will die from uterine cancer.¹⁵

Advances in Endometrial Cancer

A link between excess estrogen and endometrial cancer has been clear for some time. Now the mechanisms behind this association are being unraveled, along with the role of the counterbalancing female hormone, progesterone. Recent research has caused both doctors and women to ask more questions about the risks and benefits of hormone medications. The emerging detailed understanding of the actions of the two female hormones will ultimately help doctors and women decide when and how hormone medications promote health, and reduce the risk for endometrial and other hormone-related cancers.

Some endometrial cancers behave much more aggressively than most, and one of the current challenges is identification of these aggressive cancers so that an appropriately aggressive

¹⁴ American Cancer Society. Detailed Guide: Endometrial Cancer. *What are the Key Statistics for Endometrial Cancer?* Available at: www.cancer.org/docroot/CRI/CRI_2_3x.asp?dt=11. Accessed September 3, 2003.

¹⁵ Ibid.

treatment plan can be prescribed. Many researchers believe the secret to identifying these aggressive cancers lies in understanding the genetic makeup of tumors. New studies have identified several genes that may be useful in identifying the endometrial cancers that are most likely to spread and recur. Changes in two genes called “p53” and “PTEN” may not only signal aggressive tumors, but also may be instrumental in the future development of drugs to combat this cancer.

Genetic research also is helping doctors and researchers understand the cause of familial endometrial cancers. Many women are familiar with the concept that some families carry a high risk for change in the BRCA1 or BRCA2 genes, which causes a high risk for breast cancer. Familial endometrial cancer is much the same, with some families having a damaged form of a gene called HNPCC, causing a high risk for colon and uterine cancers. As with the two genes p53 and PTEN mentioned above, researchers are very hopeful that an understanding of what has gone wrong to cause the cancer will help lead to new ways to fight the cancer.

Uterine Cancer: Uterine Sarcomas

State of Uterine Sarcomas

Uterine sarcomas are a type of uterine cancer in which cancer cells form in the muscle of the uterus (leiomyosarcoma) or its connective tissue (endometrial stromal sarcoma) instead of the lining (endometrium). Additionally, some women develop mixed tumors that contain elements of malignant endometrial and stromal cells (carcinosarcomas). These tumors account for less than 5 percent of all uterine cancers, but behave much more aggressively than their more common counterparts (endometrial cancers).

Symptoms: Abnormal vaginal bleeding is the most common symptom in women with uterine sarcomas. Leiomyosarcomas can produce pelvic pain or pressure. In addition, fibroids that grow rapidly, especially during the post-menopausal period, should raise the suspicion of a leiomyosarcoma.

Risk Factors: Sarcomas have been reported to occur more frequently in women with a history of previous pelvic radiation therapy. In addition, these rare tumors appear to occur more commonly in African-American women than in Caucasians.

Screening/Prevention: Due to their rarity, there is no proven effective screening method for these cancers. In addition, there are no methods of prevention available for this disease.

Incidence: There are approximately 40,100 cases of uterine cancer annually, and sarcomas comprise 2 percent to 4 percent of these cases.¹⁶

Advances in Uterine Sarcomas

Because of the rarity of these tumors, advances in screening and prevention may be slow. However, several treatment advances have occurred in the areas of surgery and chemotherapy. In general, initial surgery for uterine sarcomas consists of a hysterectomy with removal of the fallopian tubes and ovaries as well as sampling of lymph nodes. Two large clinical series in the past year show that the most common type of sarcoma, called leiomyosarcoma, rarely spreads to lymph nodes. This finding is important because it will help some women avoid lymph node removal at the time of surgery.

Chemotherapy has been used as part of treatment for patients with sarcomas, but effectiveness has been limited. Most recently, a promising new combination of gemcitabine and docetaxel has been demonstrated to have a response rate twice as high as most previous combinations. This promising therapy currently is being evaluated in patients with early-stage leiomyosarcoma to see if it can prevent recurrence.

¹⁶ American Cancer Society, Detailed Guide: Uterine Sarcoma. *What are the Key Statistics for Uterine Sarcoma?* Available at: www.cancer.org/docroot/CRI/CRI_2_3x.asp?dt=63. Accessed September 3, 2003.

Over the past year or two, a cautionary note also has emerged regarding uterine sarcomas. Reports from both Europe and the United States suggest there is an increased risk for uterine sarcomas in women who use the anti-breast cancer drug tamoxifen. It is clear that the number of breast cancer recurrences prevented is many times greater than the number of sarcomas caused by this agent, and no woman should stop taking her tamoxifen solely because of this risk. But women and their doctors should be aware of the risk, and as always, women who use tamoxifen should be sure to report any abnormal vaginal bleeding.

Vaginal Cancer

State of Vaginal Cancer

Vaginal cancer is cancer that starts in the vagina, usually in the epithelium (lining). It is usually diagnosed in elderly women with abnormal bleeding and treated with radiation.

Symptoms: Vaginal cancer, especially early or precancerous vaginal cancer, may not produce any symptoms.

Risk factors: Risk factors for vaginal cancer include advanced age (age 60 and older), HPV infection and cervical cancer.

Screening/Prevention: There are currently no screening methods to detect vaginal cancer; however, many early cases of vaginal cancer or precancerous conditions can be diagnosed through routine pelvic exams. There is no known way to prevent vaginal cancer, but women should be aware of certain risk factors, like HPV infection.

Incidence: Vaginal cancer is very rare. An estimated 2,000 women will get vaginal cancer this year.¹⁷ Vaginal cancer accounts for about 3 percent of cancers of the female reproductive system.¹⁸

Advances in Vaginal Cancer

Because of its rarity, large studies investigating the prevention and treatment of vaginal cancer have not been done. However, lessons can be derived from the growing body of information about HPV's association with many vaginal cancers. For instance, risk-reduction measures such as stopping smoking and treating early precancerous HPV-related lesions are important.

Although precancerous areas of the vagina and very early-stage invasive carcinoma of the vagina may be treated with surgery, most cases of invasive vaginal cancer are treated with radiation. Early diagnosis is therefore important to minimize the need for radical surgery and radiation therapy. Pap tests can detect vaginal cancer, but in the past, the need for Pap tests after a woman has had a hysterectomy has been unclear. New guidelines from the American Cancer Society and the American College of Obstetrics and Gynecology state that women who had precancerous changes on the cervix at the time of hysterectomy should continue to get Pap tests to screen for vaginal cancer and pre-cancer. After three consecutive normal tests, these women are advised that they can discontinue screening. Women with no cervical abnormalities can discontinue Pap tests immediately after a hysterectomy. With these

¹⁷ American Cancer Society, Detailed Guide: Vaginal Cancer. *What are the Key Statistics for Vaginal Cancer?* Available at: www.cancer.org/docroot/CRI/CRI_2_3x.asp?dt=55. Accessed September 3, 2003.

¹⁸ Ibid.

guidelines, Pap test screening after a hysterectomy will be used only for women at the highest risk for this rare cancer.

Several approaches are possible when radiation is needed for invasive vaginal cancer. Recent research has helped clarify the most effective combination of approaches, and has shown that some portions of the radiation treatments can be given quickly, over an hour or two, rather than over several hours or even days, making the treatments more convenient and comfortable for patients.

Vulvar Cancer

State of Vulvar Cancer

Vulvar cancer appears as lesions on the surface of the vulva or labia. It most often occurs on the inner part of the labia majora or labia minora.

Symptoms: Vulvar cancer symptoms include itching, burning, bleeding, pain or a new lump in the vulvar area.

Risk factors: Risk factors include diabetes, advanced age (age 70 and older) and chronic vulvar irritation. Women with HPV infection are also at risk.

Screening/Prevention: There is no known way to prevent vulvar cancer; however, regular Pap tests, pelvic exams and examination of the vulva for changes may lead to early detection. Self-examination with a mirror can help to identify early changes.

Incidence: Vulvar cancer is uncommon, representing only about 4 percent of all female reproductive organ cancers.¹⁹ This year, about 4,000 women will be diagnosed with vulvar cancer in the U.S.²⁰ Vulvar cancer is frequently cured, usually by surgically removing the vulvar lesions and the groin lymph nodes.

Advances in Vulvar Cancer

This disease is undergoing active and broad-based research, ranging from improved prevention to more effective, organ-preserving therapy. In some respects, however, the greatest challenge is getting women to seek medical attention in time. Too often, early disease-related symptoms are treated “over the phone” or simply ignored because of embarrassment. Campaigns to promote self-examination and increased awareness are currently advocated by women’s support groups. Better understanding and treatment of the disease’s pre-invasive state offers promise in earlier case identification and prevention.

When surgery is required for invasive vulvar cancer, new strategies are being studied to improve outcomes. “Sentinel node biopsy” is an important surgical technique that may help reduce problems associated with surgery for vulvar cancer. The “sentinel node biopsy” strategy also is being used in breast cancer and in malignant melanoma. If this technique is validated, it holds the promise of reducing after-surgery complications and identifying the earliest forms of spread.

One after-surgery complication, which can be a lifelong problem, is swelling in the leg in which lymph nodes have been removed. The Gynecologic Oncology Group recently launched

¹⁹ American Cancer Society. Detailed Guide: Vulvar Cancer. *What are the Key Statistics for Vulvar Cancer?* Available at: www.cancer.org/docroot/CRI/CRI_2_3x.asp?dt=45. Accessed September 3, 2003.

²⁰ Ibid.

a study using a new tissue sealant in an effort to reduce this complication, as well as to reduce infection, inflammation and problems with wound healing following vulvar cancer surgery.

Another area of active research is the optimal treatment of women with advanced disease. Recent experience using radiation and chemotherapy prior to surgery has allowed most women with advanced disease to undergo less invasive and frequently organ-sparing surgery. In fact, in some women, vulvar cancers completely disappeared so that no additional surgery was required. The extent to which chemotherapy adds to tumor regression is currently being studied in randomized trials.

Acknowledgements

We would like to thank the following members of the Society of Gynecologic Oncologists (SGO) for contributing to the *State of the State of Gynecologic Cancers* first annual report. These individuals generously shared their knowledge and expertise regarding the latest information and advances in gynecologic cancers to make this report as accurate and timely as possible. Many of these physicians and gynecologic cancer specialists are actively involved in clinical practice and research to develop innovative treatments for gynecologic cancers.

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For more information about women's cancers, visit
GCF's Women's Cancer Network Web site:

www.wcn.org

Log on for a confidential risk assessment to learn about
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