SPECIAL INSERT:
The proposed cancer center at Yale-New Haven Hospital
A MESSAGE FROM THE PRESIDENT

At my tenure at Yale-New Haven Hospital draws to a close, I am in a unique position to look back at our storied history and imagine what lies ahead in Yale-New Haven Hospital’s future. I find myself thinking of the thousands of faces and friendships, the medical milestones, the sometimes daunting challenges, and the many accomplishments our organization has achieved. And the changes—the many, many changes.

Despite the constant changes in healthcare, the charity and philanthropy that was the impetus for the very first voluntary hospitals in this country—including the fourth one, Yale-New Haven—is still very much evident in every caregiver and all those who support their work in this hospital. The extraordinary people here have been the richest part of my career experience.

Among Yale’s many accomplishments during these past 36 years, the construction of two major facilities has had some of the most profound effects on how we deliver care. The South Pavilion, built in 1982, enabled us to unify the clinical departments, consolidate all operating rooms, medical records and radiology services and provide the most modern intensive care units to date. The Children’s Hospital, built in 1993, enabled us to consolidate healthcare for women and children and provide a child-sensitive environment for our pediatric patients.

We have worked hard to ensure financial stability during a turbulent era in healthcare. While I am proud of the physical growth and financial stability that have contributed to our success, I feel we have made significant strides in the areas of patient safety and quality of care. Our efforts to improve clinical outcomes and to measure our progress in meeting those who have been driven by our strong commitment to our patients. In doing so, we have looked outside the industry to quality programs such as OHS and Institute. Yale-New Haven Hospital and its exceptional medical staff, caregivers and other dedicated staff members.

Joseph A. Zacek, President and CEO

One of the most difficult issues following a cancer diagnosis is choosing where to get treated. Although many people are successfully cured of their cancer and many others live for decades after their diagnosis, cancer remains a life-threatening, complex set of diseases that can best be treated by a team of specialists in an advanced practice setting. Where you first receive care is critically important since the course of the disease may be defined by its initial treatment. "You only get that first chance to cure a cancer once," said Dr. Yung H. Son, M.D., who heads Yale-New Haven Hospital’s department of therapeutic radiology. "If that first effort fails, the chance of curing a recurrence is significantly lower." Receiving the right treatment from the start can notably increase a patient’s chance for a cure.

A study in the Journal of the American Medical Association (JAMA) showed that mortality rates were 40 to 80 percent lower for cancer patients in hospitals that had the most experience performing particular surgical procedures. In-depth experience in treating specific kinds of cancers can have a dramatic effect on a patient’s chances for a cure.

You will want to choose a medical center known for constantly pushing the boundaries of what can be done through medical research and advanced clinical practice. Specialties at advanced practice hospitals employ the latest proven treatment methods, use state-of-the-art technology and adopt new patient care programs to treat the whole patient, not just the disease. Specialists at advanced practice hospitals employ the latest proven treatment methods, use state-of-the-art technology and adopt new patient care programs to treat the whole patient, not just the disease.

In 2005, over 3,000 patients will come to Yale-New Haven Hospital for cancer treatment. Yale-New Haven has been recognized as being one of the top 25 hospitals for the treatment of cancer by U.S. News & World Report, and the Yale Cancer Center is one of a select network of 39 comprehensive cancer centers in the nation designated by the National Cancer Institute.
ENDURING CANCER WITH COURAGE AND HUMOR - When Lynne DelGrande was diagnosed with ovarian cancer, she made the brave decision to not be controlled by her disease or treatment. Her unconventional approach kept her family and caregivers in stitches. by Katie Fischer; photography by Harold Shapiro

CANCER: The Basics - Every day, about 46 people in Connecticut, 12 of whom live in the New Haven area, are diagnosed with cancer. Here are things you should know about screening and diagnosis for some of the most prevalent kinds of cancer. by Judith Lindquist

TREATING CANCER: The New Frontier - Not only do different kinds of cancer respond differently to various treatments, the individual patient's genetics may affect how well a specific treatment might work on his or her cancer. by Judith Lindquist

COMMUNITY RESOURCES: Yale-New Haven Hospital & Yale Cancer Center - Because cancer strikes everyone, community services such as Check It Out, Seeds of Prevention and the Connecticut Breast and Cervical Cancer Early Detection Program are helping people get the information and prevention options they need.

LEARNING ABOUT CANCER: Patient Education and Support Programs - When facing a chronic disease, patients, families and friends need all the emotional help they can get. YNHH provides a wide variety of free education and support programs for people dealing with all kinds of cancers.

THE PROPOSED CANCER CENTER at Yale-New Haven Hospital - Yale-New Haven Hospital's plans for a new comprehensive cancer center on Park Street will not only consolidate all of the existing cancer services into a single building, but will facilitate advances in cancer care and bring countless other benefits to the city and state.

BONE MARROW TRANSPLANTATION: A teenager gets a rare, second chance at life - Acute myeloid leukemia threatened to take Chrystal Torres' life when she was only 14 years old. It took a new, high-risk procedure at YNHH to save her. by Kathy Linthicum; photography by Robert Crum

GENETIC COUNSELING FOR CANCER - The information obtained from genetic testing can have a profound impact on an individual's life. Yale Cancer Center's cancer genetic counseling program provides services to individuals at high-risk for hereditary cancer syndromes due to their personal or family histories of cancer.

THE HERO'S CLINIC: Empowering childhood cancer survivors - As many as two-thirds of childhood cancer survivors experience late side-effects of the disease or its treatment that don't become apparent until later. Dealing with those late effects is becoming an increasingly important focus of cancer care.

WHAT YOU DON'T KNOW CAN HURT YOU: Early detection program provides safety net for women - The Connecticut Breast and Cervical Cancer Early Detection Program at Yale-New Haven offers mammograms and Pap smears free of charge for medically underserved women over age 40.

THE TOMMY FUND - The Tommy Fund raises awareness, funds and hope for children with cancer and their families - in memory of a little boy who won the heart of a region more than 50 years ago.

TENDER CONNECTIONS: Spiritual support while living with cancer - YNHH's religious ministries helps patients get in touch with their own religious traditions and spiritual understandings as a source of strength on their journey with cancer. by Judith Lindquist
Enduring Cancer with courage and humor

Lynne DelGrande keeps a file of inspirational sayings in her bedroom desk drawer. Among her pearls of wisdom is “courage needs a friend,” a particularly fitting motto for a woman whose unconventional approach to living with cancer makes people laugh.

Diagnosed with ovarian cancer in October 2003, just one week after her father died, Lynne admits to having ignored the signs and symptoms that something in her body was not right: constipation, bloated stomach, insomnia. For the next six months, Lynne came to Yale-New Haven Hospital (YNHH) for chemotherapy to shrink a 16-centimeter tumor on her right ovary before it could be surgically removed. A playful person by nature, Lynne came up with an unusual way to get through her illness and months of treatment.

“It all began when my sister, Karen, showed up at my house and presented me with a bag full of wigs, oversize glasses, plastic noses and goofy gadgets and gnomes,” said Lynne. “I guess she thought the dress-up clothes would be an improvement over my bald head.”

While the bag of costumes was intended to provide Lynne with a little comic relief, Lynne’s creative juices were just starting to flow. Over the ensuing months, Lynne developed a repertoire of outfits and characters that became her trademark. Each time she came to YNHH for treatment, Lynne assumed a new identity, donning colorful wigs, masks, eyewear and headbands with funny attachments.

“The costume I liked best was the Six Flags Amusement guy,” said Lynne’s patient, Tom Rutherford, M.D., gynecologic oncologist at YNHH and associate professor at the Yale School of Medicine. “She had that one down to a tee. She had everyone in stitches.”

Lynne’s family—which included four other siblings—was quick to participate in her charade. From sending offbeat greeting cards to drawing an abdominal roadmap for surgeons to follow during Lynne’s operation, the silliness served as a much-needed distraction.

“Lynne had everyone in the OR laughing when they saw the roadmap on her belly,” said Dr. Rutherford. Lynne’s operation, called a surgical debulking, involved the removal of the tumor, ovaries, uterine cervix and fallopian tubes.

Following her surgery, Lynne met her match in a patient named Suzanne, a kindred spirit who enjoyed the distraction and mischief of masquerading with Lynne throughout the hospital to the delight, amusement and bewilderment of patients and staff.

“We all loved it when Lynne and Suzanne made the rounds in their kooky outfits,” said Linda Como, a medical assistant in the gynecology oncology unit. “She and Suzanne really livened up the unit,” said Reverend Peg Lewis, director of religious ministries. “They were determined, especially Lynne, not to be controlled by their disease or treatment.”
The Early Detection Program at Yale-New Haven Hospital, created by Peter Schwartz, M.D., chief of the division of gynecologic oncology, was established in 1990 to identify ovarian cancer in its early stages when it is highly curable. The program includes genetic counseling for women, like Lynne’s sister Karen, who have a first-degree relative (a mother or a sister) previously diagnosed with ovarian cancer.

"Early detection is critical because ovarian cancer is highly curable in its earliest stages," said Dr. Schwartz. Unfortunately, most women — about 70 percent — are not diagnosed until the disease has spread to the upper abdomen (Stage III) or beyond the abdominal cavity (Stage IV). "Our ovarian cancer early detection program is actively working on new techniques to identify ovarian cancer in its earliest stages. To this end, we have some very exciting developments using proteomic research techniques (the study of proteins in the bloodstream) to identify women who have early ovarian cancer."
"Peter Schwartz is the innovator behind many of the state-of-the-art gynecologic oncology treatments that have become the standard of treatment throughout the world today," said Dr. Rutherford, who noted that Dr. Schwartz introduced the use of chemotherapy prior to surgery in the management of advanced-stage ovarian cancer.

"Fifteen or 20 years ago, if you had ovarian cancer, especially advanced-stage cancer, we'd take you to the OR, and you'd probably end up in the intensive care unit with a real rocky post-op course. Giving chemotherapy before surgery to women with extremely advanced ovarian cancer helps destroy cancer cells and reduce the amount of cancer," said Dr. Rutherford.

"Despite the need to return to YNHH for even more aggressive therapy with its unpleasant side effects, Lynne continued to maintain her trademark fashions and high spirits. "Lynne's playful attitude and humor were important in helping her cope during a stressful time," said Pat Scholl, M.S.W., a social worker on the gynecology/oncology unit. "She helped others as well as herself."

YNHH's caregivers recognize that emotional support is an important component to patient care. Individual and group support help cancer patients and their families cope with the diagnosis of cancer.

"Having cancer and going through all of the horrible treatments is not fun," said Lynne. "I know it's very serious. But you can choose how you deal with it, and I think humor helps take the edge off, not only for you but also for your family and extended support group."

"She continued, "It's kind of hard to call a person and say, 'How are you today?' when you know the person has cancer. The zany hair or mask helps to bridge that and helps you act silly rather than sick. If you dwell on being sick, you're not going to get better because you have no hope — and you have to keep the hope."

"Lynne freely admits that, 'Yep, we could have problems, but this is what I have today; this is where we'll go today, and I'm going to make the best of it'" said Dr. Rutherford.

"When I received my diagnosis, I would do my crying in the shower, and I still do sometimes. There's something more cathartic about doing it there and it doesn't disrupt family time."

"From the get-go, I've had the fear that I could become my disease. That, perhaps, is the strongest motivation for me: to survive, I can not and will not let this happen."

Every day, about 46 people in Connecticut, 12 of whom live in the New Haven area, are diagnosed with cancer. And every day, an estimated 19 Connecticut residents — five from New Haven — die of cancer. Connecticut has the 4th highest rate of cancer in women, the 2nd highest rate of breast cancer in women, and the 11th highest rate of cancer in men.

Approximately 9,500 new cases of cancer will be diagnosed in children under 14 this year. This year, about 1,370,000 new cancer cases will be diagnosed, and about 570,000 Americans are expected to die of cancer.

Cancer isn't one single disease; it is many diseases with one key factor in common: Somewhere in the body, the natural process of new cells dividing to replace those that have died spirals out of control. Cells proliferate at a fierce rate, causing an unnatural growth. If that growth continues, other organs and body processes are affected and sometimes shut down.

The good news is that cancer deaths have declined about 1 percent a year since 1999, thanks to earlier detection, more effective prevention efforts and better treatments.

According to the National Cancer Institute, approximately 9.8 million Americans (3.5 percent of the population) with a history of cancer were alive in 2001, the latest year for which we have data. According to the American Cancer Society, about 1.3 million new cancer cases are expected to be diagnosed in 2009, including the following estimates for some of the most prevalent kinds of cancer:

- Prostate: 232,090
- Breast: 212,930
- Lung: 172,570
- Colon: 104,950
- Lymphoma: 63,740
- Melanoma: 59,580

Cancer: The Basics
WHAT YOU SHOULD KNOW: Screening and diagnosis.

Thousands of lives have been saved by detecting cancer at its earliest, most treatable stage. Yale-New Haven Hospital has a full range of the latest in cancer diagnostic services, including screening and diagnostic mammography, ultrasound, MRI, PET scanning, needle biopsy, surgical biopsy and pathology programs for all types of cancer. Sometimes, more than one diagnostic test is necessary to provide your cancer specialist with complete information. Screening guidelines and diagnostic methods for some of the most common cancers follow.

**Diagnosing Breast Cancer**

**Screening Guidelines:**

Combining mammography with clinical breast exams and self-exams is the best way to detect breast cancer early. The American Cancer Society recommends that women age 40 and older have screening mammograms every year. Women at increased risk of developing breast cancer because of family history or other reasons should talk with their doctors about the benefits of starting mammograms when they are younger.

**Mammography** — Mammograms are special x-rays that can detect small growths or microcalcifications in the breast even before they can be felt by hand. If the results of your mammogram are not conclusive, you may have to have a diagnostic mammogram, an ultrasound or a breast biopsy.

**MRI (Magnetic Resonance Imaging)** — MRI can detect breast cancer; however, because it is more costly and lacks professional standards for widespread use, MRI is not recommended in breast cancer screening.

**ULTRASOUND** — Ultrasound uses high-frequency sound waves to create an image of a part of the body. Ultrasound can be used to evaluate breast health. Radiologists use ultrasound technology to see whether a breast lump is filled with liquid (a cyst) or is solid. Cysts and solid tumors can require further testing, either through needle aspiration, needle biopsy or surgical biopsy.

**DIAGNOSTIC MAMMOGRAM** — During a diagnostic mammogram, special x-ray images are taken in greater detail of an area that looked abnormal on a screening mammogram. About 10 percent of women who undergo screening mammograms will be referred for a diagnostic mammogram. The diagnostic mammogram is used to decide if:

- The area is normal and the patient can continue with annual screenings.
- The area should be watched and an additional mammogram performed in a few months.
- Additional testing, such as biopsy, is necessary.

**SURGICAL BIOPSY** — Surgical biopsies are performed under either local or general anesthesia. Surgeons remove the lump or area of concern, then send it to the pathologists for examination. Removal may involve a needle localization before undergoing surgery. This involves inserting a needle/wire combination into the breast in the suspicious area. X-ray films are then taken to be certain that the correct area is localized. Though the procedure is more invasive than needle biopsy, the advantage is that the lump or area of concern is removed.

**BREAST BIOPSY, NEEDLE BIOPSY (MAMMOGRAM)** — Fine needle aspiration, stereotactic core needle biopsy, MRI localizations, as well as ultrasound-guided breast biopsies are performed on an outpatient basis at the Yale-New Haven Breast Center. During the stereotactic core needle biopsy, using an x-ray for guidance, a physician inserts a thin needle into the suspicious area and withdraws one or more samples of tissue. The sample is then analyzed under a microscope by pathologists to determine if cancer is present. The procedure takes about an hour and avoids surgical biopsy for select patients.

The Yale-New Haven Breast Center provides women with convenient appointments, rapid diagnosis and treatment and access to the most up-to-date technology and latest research protocols. Patients receive personal, friendly, confidential care that is designed to meet the needs of the whole patient, not just the disease.

Services include the following specialties: breast surgery, breast imaging (including screening and diagnostic mammography, breast ultrasound, breast MRI and breast biopsy services), reconstructive surgery, pathology, medical oncology, radiation oncology and genetic counseling. To learn more, call 203-785-3328 or visit www.yalenewhavenbreastcenter.org. You can also choose to have a mammogram from one of the center's three mammography imaging sites. The center's radiologists and technologists are highly experienced and have advanced credentials in mammography and radiography. Because of the high-quality care offered, the center has been accredited by the American College of Radiology (ACR). This accreditation means the mammography equipment and the technologists performing mammography exams meet the standards of excellence established by the ACR.

The four mammography imaging sites include the following:

- 800 Howard Avenue, New Haven
- 150 Sargent Drive, New Haven
- Yale-New Haven Shoreline Medical Center, Guilford
- The YNHH mammography van (Bethel), which travels throughout southern Connecticut. For more information about the van services and schedule, call 203-688-6800.
Diagnosing Colorectal Cancer

Fecal occult test - The fecal occult test is a valuable diagnostic tool for detecting colorectal cancer. The test picks up small amounts of blood in the stool. If positive, it indicates that something in the digestive tract may need further investigation. You can have this test done in your physician's office.

Sigmoidoscopy or Colonoscopy - During a sigmoidoscopy, your physician uses a miniature scope inserted into the lower part of the bowel to examine the inside of the last part of the colon for growths or abnormalities. Small growths, called polyps, can be removed quickly and without major surgery. Since polyps can become cancerous over time, removing them is the most important step in preventing the development of colon cancer. Removed polyps are tested to see if they are benign or malignant. A colonoscopy is essentially the same procedure, except the doctor uses a longer tube to examine the entire colon.

Lower GI Series - During this test, the patient is first given a barium enema. Then x-rays are taken, with the barium highlighting the inside of the colon. Sometimes air can be carefully inserted into the colon, making small lesions easier to see. This is called a double contrast barium enema. Only a double contrast barium enema is sensitive enough to be used for screening.

Surgical Biopsy - Surgical biopsies are performed under general anesthesia at the hospital or in your doctor's office. Surgeons remove a sample of tissue from a tumor and send it to the pathologist for examination. Sometimes, if the tumor is small enough, the surgeon can remove it completely during this procedure.

Diagnosing Lung Cancer

Lung cancer is not usually diagnosed in the early stages, so it is important to discuss any changes you notice with your doctor. Some of these symptoms can be caused by a number of conditions - not necessarily cancer - but they should be checked by your physician. Changes to watch for include:

- Persistent cough
- Sputum streaked with blood
- Chest pain
- Shortness of breath
- Reversing lung infections, i.e., pneumonia or bronchitis
- Fatigue, loss of appetite, weight loss

CT or CAT Scan - Your doctor may order additional x-rays, such as a CAT scan (computer assisted tomography), that show the lung in more detail.

Thoracoscopy - This procedure, performed under general anesthesia, involves surgically opening the lung to remove a tissue sample. The mediastinum, the area between the lungs, may also be examined. The procedure may require an overnight hospital stay.

Mediastinoscopy - A more invasive procedure, this involves making an incision into the chest and inserting a bronchoscope through the opening to check for any signs of cancer.

Sputum Testing - Your doctor may test your sputum for the presence of cancer cells. This sample is examined by a pathologist under a microscope, a process called cytology.

Bronchoscopy - During this procedure, your physician uses a miniature scope inserted into the lung to examine the inside of the lung. He or she may take a small tissue sample to be analyzed.

Needle Aspiration - If the area of concern is not accessible by bronchoscopy, your doctor may perform a needle aspiration. Using x-ray guidance to locate the area, a needle is inserted through the chest and a small sample is removed for examination.
DIGITAL RECTAL EXAM — Most prostate cancers form in the back part of the prostate gland and can be felt during a digital rectal examination (DRE) yearly. Men at high risk, such as African Americans and men who have a first-degree relative (father, brother or son) diagnosed with prostate cancer at an early age (younger than age 65), should begin testing at age 45. Men at even higher risk (because they have several first-degree relatives who had prostate cancer at an early age) could begin testing at age 40.

THE PSA TEST — The PSA test is a valuable diagnostic tool, which can detect changes in the prostate even before they can be felt by digital examination. That’s good news, because when detected early, prostate cancer is very treatable. You can have this test done in your physician’s office.

The PSA test measures a protein made by prostate cells. When cancer is present, the prostate cells produce more of this protein. There is no specific normal or abnormal PSA level; however, the higher a man’s PSA level, the more likely it is that cancer is present. Because various factors can cause PSA levels to fluctuate, one abnormal PSA test does not necessarily indicate a need for other diagnostic tests. If PSA levels continue to rise over time, other tests may be needed.

TRUS (Trans Rectal Ultrasound) — If further tests are needed, your physician may perform a transrectal ultrasound. Ultrasound uses high-frequency sound waves from a probe placed in the rectum to create an image of the prostate gland on a video screen. The test is relatively painless and quick. This test is used in conjunction with a needle biopsy of the prostate and is very useful in helping physicians detect any abnormal growths in the prostate, even those too small to be felt by a rectal exam.

BLOOD SCREENING — Advances in technology have made it possible to screen blood samples for protein patterns specific to head and neck cancer. Researchers have developed a classification system using these protein patterns that was able to successfully distinguish between cancer patients and healthy smokers with an accuracy of 80 to 92%.

ORAL CDX — A new way to test for oral cancer before a biopsy is called Oral CDx. A doctor or nurse uses a small brush to gather cell samples of a suspicious area. The specimen is then sent to a lab for computer analysis. In a recent study of 945 patients, Oral CDx detected all cases of oral cancer correctly, even when dentists didn’t suspect the presence of cancer from a lesion.

DIAGNOSIS — Head and neck cancer is diagnosed by a combination of a medical history, physical examination, various imaging studies (CAT scans, MRI scans) and biopsies of the tumor. A biopsy is the only sure way to confirm whether a suspected lesion is cancer. A surgeon removes tissue and submits it to a pathologist who examines it under a microscope to check for abnormal or malignant cells.

One of the real dangers of this cancer is that in its early stages, it can go unnoticed. It can be painless, and little in the way of physical changes may be obvious. When people do go to their doctors they may complain of a lump in their neck, a sore on the tongue, difficulty or pain with swallowing, hoarseness, ear pain or bleeding from a sore in the mouth. How far advanced the cancer is often depends on its site.

The most common symptoms of head and neck cancer include:

- Any sore in the mouth or throat that does not heal within two weeks
- Neck or jaw pain that radiates to the ear
- Abnormal growth in the mouth
- Lump in the neck that remains for more than two weeks
- Chronic cough or hoarseness
- Sore throat that does not improve
- Difficulty swallowing food or liquids
- Coughing up blood
TREATING CANCER: The New Frontier.

Surgery, radiation and chemotherapy remain the mainstays of cancer treatment, but these treatments have been revolutionized by technological advances that result in less-invasive surgery, more targeted radiation delivery and more effective drugs. In addition, a better understanding of tumor genetics and physiology has made it possible to customize some treatments to target specific types of tumors. Although early visions of cancer therapy often assumed that cancer was a uniform disease susceptible to an all-purpose magic bullet, we now know that cancer is a heterogeneous family of diseases. Not only do different kinds of cancer respond differently to various treatments, the individual patient's genetics may affect how well a specific treatment might work on his or her tumor.

**Surgery**

The experienced and skillful cancer surgeons at NYUH often use surgery as the first course of treatment to remove cancerous tumors and tissues. Improved instrumentation allows surgeons to operate with greater precision and, when possible, use smaller incisions that allow patients to recuperate faster. Many procedures can now be performed on an outpatient basis, allowing patients to return home the same day.

**Radiation Therapy**

Half of all cancer patients at NYUH are treated with radiation therapy. Depending on the type and extent of cancer, radiation therapy can be used alone or in combination with other treatments, such as surgery or chemotherapy. Physicians sometimes use radiation therapy to shrink tumors before surgery. There are two forms of radiation therapy: external and internal. Most patients have external radiation therapy, but some patients have both types.

**What's new in cancer surgery?**

**THE GAMMA KNIFE** — A remarkable tool, the gamma knife allows surgeons to operate on abnormal areas of the brain and surrounding tissues without making an incision. Using a technique called stereotactic radiosurgery, it is designed to precisely target and destroy certain benign and malignant brain tumors as well as some head and neck cancers such as nasopharyngeal cancer and ocular melanomas, using highly focused gamma rays. Patients experience minimal pain and, in most cases, can resume their regular activities within a day or two after treatment.

**LASER SURGERY** — A highly focused, powerful beam of light energy, laser surgery is used to cut through tissue or to vaporize cancers of the cervix, larynx (voice box), liver, rectum or skin. Laser surgery, also called photocoagulation, is often used to relieve symptoms resulting from large tumors pressing on the windpipe or esophagus, which may cause problems with breathing or eating.

**MOHS SURGERY** — A technique to remove certain skin cancers by shaving off one layer of skin at a time until examination under a microscope reveals that all the cells are normal. This technique is used when the extent of a cancer is not known or when as much healthy tissue as possible needs to be preserved as in cancers on the head and face.

**CRYOSURGERY** — Uses liquid nitrogen spray or a very cold probe to freeze and kill abnormal cells. This technique is sometimes used to treat precancerous conditions such as those affecting the cervix. Cryosurgery is also being studied as a treatment of some cancers such as those of the prostate.

**EXTERNAL RADIATION** — One type of machine that delivers external radiation is called a linear accelerator. NYUH has three state-of-the-art linear accelerators. Some technical variations of external beam radiation are stereotactic radiosurgery (gamma knife), high-dose three-dimensional radiation therapy, intensity-modulated radiation therapy and intraoperative radiation therapy. These types of radiation therapy are highly specialized and used in very specific settings.

**INTERSTITIAL RADIATION THERAPY** — A technique using radioactive sources to deliver high energy to a tumor, sparing healthy tissue. These radioactive sources can be removed after the proper dose is reached, or in some cases are left permanently, as with I-125 for prostate cancer.

**INTENSITY MODULATED RADIOTHERAPY (IMRT)** — While conventional radiotherapy delivers large homogenous blocks of radiation to a target area, intensity modulated radiotherapy (IMRT) uses digital diagnostic imaging, computers and specialized software to match the radiation beam precisely to the shape of the tumor. IMRT fires a series of miniature "beamlets" that may vary in direction and/or intensity. As a result, therapy is less damaging to healthy tissue. IMRT is ideal for prostate cancer, some head and neck tumors and others that are near important body parts such as the brain, lung and spinal cord.

**INTERCAVITARY RADIATION** — Used most commonly in gynecological cancers, such as cancer of the uterus. In this procedure, radioactive sources are placed into applicators that are positioned into the uterus, while the patient is under anesthesia. These are left in place for 48-72 hours and then removed.
ANTIANGIOGENESIS DRUG
Among the new cancer fighters are the antiangiogenesis drugs, which keep tumors from growing and nutrient vessels to survive. They first degrade healthy tissue, looking for blood vessels to tap for these essentials. Eventually, they start to grow their own capillaries and vessels. Angiogenesis inhibitors prevent tumors from building those pipelines.

CHEMOTHERAPY
Chemotherapy is the use of chemicals to promote the destruction of cancer cells on a selective basis. Chemotherapy is used for a variety of purposes:

- To cure a specific cancer;
- To control tumor growth when cure is not possible;
- To shrink tumors before surgery or radiation therapy;
- To relieve symptoms, such as pain; and
- To destroy microscopic cancer cells that may be present after the known tumor is removed by surgery (called adjuvant therapy). Adjunct therapy is given to prevent a possible cancer recurrence.

ON THE LEADING EDGE OF THERAPY
Scientists are working to improve the treatment of cancer by developing more sophisticated, less invasive surgical techniques, new chemotherapy agents and biologic therapies, and by improving the precision of computer-targeted radiotherapy. The following are new therapies for cancer that show promise for the future.

- GENE THERAPY — Researchers are studying several ways to treat cancer using gene therapy. Some approaches target healthy cells to enhance their ability to fight cancer. Other approaches target cancer cells, to destroy them or prevent their growth.

- HORMONE THERAPY — Certain hormones normally produced by the body may actually encourage the growth of certain cancer cells. To counter this, cancer patients may receive drugs that decrease the amount of hormones produced in the body or block the action of the hormones. Sometimes, the glands that produce the hormones are removed.

- BONE MARROW AND STEM CELL TRANSPLANTATION — Bone marrow, spongy material found inside bones, produces white and red blood cells and platelets. Marrow contains the stem cells that can reproduce all types of blood cells. Bone marrow and/or stem cells are collected before a patient undergoes high-dose chemotherapy, which kills most of the bone marrow and stem cells in addition to the cancer cells, leaving the patient vulnerable to infection and bleeding. Giving the patient back stem cells helps the body to make new immune cells.

- IMMUNOTHERAPY — The immune system, which fights off common colds and flu, may also help fight off cancer cells. The goal of immunotherapy and biotechnology are to activate the body's immune system so that it will recognize and kill cancer cells. These techniques have been successful against renal (kidney) malignancies and several other types of cancer.

- BIOLOGIC THERAPY

Gene therapy — Researchers are studying several ways to treat cancer using gene therapy. Some approaches target healthy cells to enhance their ability to fight cancer. Other approaches target cancer cells, to destroy them or prevent their growth.

Hormone therapy — Certain hormones normally produced by the body may actually encourage the growth of certain cancer cells. To counter this, cancer patients may receive drugs that decrease the amount of hormones produced in the body or block the action of the hormones. Sometimes, the glands that produce the hormones are removed.

Bone marrow and stem cell transplantation — Bone marrow, spongy material found inside bones, produces white and red blood cells and platelets. Marrow contains the stem cells that can reproduce all types of blood cells. Bone marrow and/or stem cells are collected before a patient undergoes high-dose chemotherapy, which kills most of the bone marrow and stem cells in addition to the cancer cells, leaving the patient vulnerable to infection and bleeding. Giving the patient back stem cells helps the body to make new immune cells.

A new cancer center:
Yale-New Haven Hospital's fourth pavilion.
New cancer center to bring community benefits

A host of community benefits will accompany Yale-New Haven Hospital’s proposed cancer center - consistent with the community benefits resolution passed by the New Haven Board of Aldermen in 2004. After numerous discussions with organizations and representatives from throughout the New Haven community, YNHH developed a plan to address issues as diverse as housing, public health, education, parking, traffic, job training and youth programs - in addition to the $7 million+ the hospital already provides each year in community health programs.

As part of its cancer center project, the hospital will provide $150,000 a year for three years to create a home rehabilitation program to be administered by the Hill Development Corporation (HDC), and will also give HDC property in the Hill neighborhood to help build one new house and renovate two others. The hospital will be funding a community liaison position for three years to address community access to construction and permanent jobs associated with the cancer center and will work with its contractors to set aside construction trades apprenticeships for New Haven residents and to increase the number of paid internships at the hospital for high school students.

YNHH has also pledged a $500,000 grant to the new Courtland Seymour Wilson Library in the Hill neighborhood to purchase books, annual college scholarships for New Haven students interested in pursuing medical careers, daycare support for low-income families in the Hill and $150,000 in grants for existing youth programs in the city.

We have worked with Yale-New Haven Hospital to address critical city needs in the past and this program underscores their ongoing commitment to extend that role in the future for the benefit of all.

David Aharano
Executive Director
HDC Development Corporation

"This exciting facility has the potential to change the face of cancer research and to translate the essence of innovation to clinical care. That transformation could mean a difference in the lives of thousands of people in Connecticut and throughout the country."

Richard C. Levin
President, Yale University

We view this as an incredibly positive and comprehensive program.

Everett Boice Kimber
President Emeritus
New Haven Clergy Association

In addition to the essential health benefits the cancer center will bring New Haven and Connecticut citizens, the project will provide major economic benefits. To begin with, the three-year building project will provide 350 construction jobs at its peak. When the cancer center opens in the fall of 2008, it will create about 400 new, permanent jobs, a number that will increase to 525 within three years as patient demand grows. The project -- the cancer center plus the proposed parking garage and retail office building -- could add approximately $6 million a year in revenue for the city of New Haven in new PILOT (Payment In Lieu of Taxes) payments and property tax revenue. In addition, New Haven will receive more than $4 million in building permit fees. A recent study by the Connecticut Economic Resource Center (CERC) indicated that the full economic impact of the cancer center would exceed $1 billion.

As part of the building project, Yale-New Haven Hospital has committed to a $1.9 million community investment program that would provide support for key priorities identified by the community such as affordable housing, education, daycare, youth programs and jobs. While the cancer center is the largest economic development project ever proposed in New Haven and one of the largest in the state, it requires no city or state funding. Financing will come from the hospital's current resources, from fundraising and from bond financing.
New cancer center to bring community benefits

A host of community benefits will accompany Yale-New Haven Hospital's proposed cancer center - consistent with the community benefits resolution passed by the New Haven Board of Aldermen in 2004. After numerous discussions with organizations and representatives from throughout the New Haven community, YNH developed a plan to address issues as diverse as housing, public health, education, parking, traffic, job training and youth programs - in addition to the $7 million the hospital already provides each year in community health programs.

As part of its cancer center project, the hospital will provide $150,000 a year for three years to create a home rehabilitation program to be administered by the Hill Development Corporation (HDC), and will also give HDC property in the Hill neighborhood to help build one new house and renovate two others. The hospital will be funding a community liaison position for three years to address community access to construction and permanent jobs associated with the cancer center and will work with its contractors to set aside construction trades apprenticeships for New Haven residents and to increase the number of paid internships at the hospital for high school students.

YNH has also pledged a $50,000 grant to the new Courtland Seymour Wilson Library in the Hill neighborhood to purchase books, annual college scholarships for New Haven students interested in pursuing medical careers, daycare support for low-income families in the Hill, and $150,000 in grants for existing youth programs in the city.

New cancer center to bring financial benefits

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Zaccagnino:
A legacy of building and programmatic growth

When Joseph A. Zaccagnino, president and chief executive officer of Yale-New Haven Hospital, retired this fall, the hospital campus looked very different than the day he first set foot in the hospital. Zaccagnino began his career at Yale-New Haven as an administrative fellow, after receiving a Master’s of Public Health degree in hospital administration from Yale University School of Medicine in 1970. His distinguished career spanned more than 35 years – including 14 years as executive vice president and chief operating officer and 14 years as president and chief executive officer, and his tenure was marked by physical renewal and programmatic growth of the hospital.

Zaccagnino led the development of such critical initiatives as the construction of the South Pavilion in 1982; the creation of the Children’s Hospital in 1993; and the formation of the Yale New Haven Health System in 1997 with the addition of Bridgeport and Greenwich hospitals, as well as an affiliation with Weserly Hospital in Rhode Island. In 2000, YNHH acquired the Yale Psychiatric Institute and opened the Yale-New Haven Psychiatric Hospital. Most recently YNHH opened an ambulatory satellite emergency and diagnostic and treatment facility in Guilford, Connecticut. Zaccagnino led the critical planning and state certificate-of-need stages of the proposed cancer center at Yale-New Haven Hospital.

“This has been such an incredible and humbling experience, both personally and professionally,” said Zaccagnino. “I have had the privilege of working with outstanding staff and together we have created a major medical center hospital that delivers among the finest medical care available in America to increasing numbers of patients each year. I know I am leaving this hospital in talented, committed and capable hands. I look forward to the day the new cancer center opens.”

"Integrating cancer patient services with the introduction of new cancer treatments in one building specifically designed for cancer care will provide a true center of excellence.”

Joseph A. Zaccagnino, President and CEO of Yale-New Haven Hospital

| Milestones during President Zaccagnino’s YNHH career |
|---|---|---|---|---|---|---|---|---|---|
| 1970 | Joseph A. Zaccagnino begins his career at YNHH | 1993 | Opened the Children’s Hospital at New Haven; and the Yale-New Haven Psychiatric Hospital | 2000 | Yale-New Haven Hospital acquired the Yale Psychiatric Institute and opened the Yale-New Haven Psychiatric Hospital | |
| 1978 | Began his career at Yale-New Haven as an administrative fellow | 1996 | Signed affiliation agreement with YNHH and Greenwich Hospital | 2004 | Expanded the new YNHH Childcare project to serve 570 children |}

Community Resources:
Yale-New Haven Hospital & Yale Cancer Center

The Cancer Information Service (CIS) at the Yale Cancer Center has both a partnership and a research program. The CIS Partnership Program for New England brings cancer information to people who may have difficulties seeking health information because of educational, environmental, language or other barriers. It also strives to increase partners’ awareness that cancer health disparities are a major public health problem where the burden of cancer falls disproportionately on certain racial, ethnic and socioeconomic groups. By pooling resources and working together, the CIS and its partners are able to create programs with wider reach and greater impact for our region.

The CIS Research Program – for New England, New York, New Jersey, Pennsylvania, Delaware, Michigan, Indiana and Ohio – is working and partnering with national and regional researchers across the research continuum from capacity building through dissemination and diffusion. The CIS is a highly utilized quality source of current cancer information, and, thus, it is a particularly good laboratory in which to conduct cancer communication research. Staffed by specially trained information specialists, the CIS provides toll-free telephone service in English and Spanish (1-800-4-CANCER), offering personalized attention to each caller and answering questions about cancer prevention, screening, diagnosis, treatment and research.

Check It Out is an educational program on breast and testicular cancer aimed at high school students. A joint effort by the Yale Cancer Center, Yale-New Haven Hospital, the American Cancer Society and the Jewish women’s organization Hadassah, the program teaches students the proper techniques for performing breast and testicular self-examinations. The overall goal is to raise awareness and instill healthy habits at an early age.

Seeds of Prevention is a public awareness and education program. Focusing on cancer prevention through good nutrition, the program promotes an understanding of the value of healthful food, emphasizing the National Cancer Institute’s 5-A-Day Program. Vegetable seed packets, newsletters and other materials on nutrition are distributed in the spring in Connecticut elementary schools, at health fairs and at other community events.

The Connecticut Breast and Cervical Cancer Early Detection Program provides free mammograms and Pap tests for women aged 40 and older who do not have insurance or whose insurance does not cover these screenings. Yale-New Haven Hospital is one of 17 sites in Connecticut participating in the program, which receives state and federal funding.

Community Resources 19
Learning about cancer: patient education and support programs

Knowledge is power...
Learning how to live with cancer is one of the biggest challenges an individual can face.

The Yale Cancer Center offers several patient-related activities and programs that can help patients and their families cope.

The L.Y.B.B.Y. Basket (the "Look Your Best Basket at Yale") is a program that fosters self-esteem in men and women who are hospitalized with cancer and experience changes in appearance related to treatment. An extension of the "Look Good...Feel Better" program, the L.Y.B.B.Y. Basket provides turbans, caps, moisturizing lip balms and educational materials about expanded services to the inpatient oncology units.

Look Good...Feel Better is a free, national, public service program to help women, men and children deal with appearance changes that may occur as a result of cancer and its treatment. Participants attend hands-on workshops learning makeup techniques, scarf tying and wig and hair alternatives in a friendly and supportive environment. Individual consultations at participating salons are available through referrals.

The Connecticut Wig Bank, co-sponsored by the American Cancer Society, offers new and nearly new wigs and hairpieces to those patients with financial constraints who have hair loss because of chemotherapy and radiation treatment.

Supportive Care Services provide individual and group counseling, done in collaboration with oncology, social workers, psychiatry and hospital clergy. This is available for patients and families upon referral.

The Yale Patient Teaching Tools include self-care guidelines on symptom management such as hair loss, nausea, taste changes and low white blood counts and discharge instructions for patients after breast surgery, colostomy and urostomy teaching and sexual changes. Many of the educational materials are also written in Spanish.

For more information on any of these programs, contact Bonnie Indeck, patient services coordinator, at 203-688-6573.

Support Groups: caring for the whole patient

Cancer survivors and their families say that being cancer-free does not mean being free of cancer. Physical, psychological, social and financial needs persist, and survivors face a risk that the cancer will return. Support groups provide patients, families and friends with a continuing link to a compassionate resource whether they are facing a new cancer diagnosis or have been cancer-free for decades.

Oncology Parents' Support Group - first Thursday of the month, 7-9 p.m., New Canaan, L.C.S.W., at 203-688-7919.

Stem Cell Transplant Group - for patients who have had stem cell transplants, their families and other support persons, third Monday of the month; Contact: Bonnie Indeck at 203-688-6573, or Ann Conklin Walsh at 203-688-7298.

Teens' Support Group - for teenage cancer patients, same time as the Parents' Support Group, first Thursday of the month, 7 p.m. at Yale-New Haven Children's Hospital.

Women with Cancer: A Support Group - every other Thursday, 4-5:30 p.m., Yale Cancer Center; Contact: Pat Scholl, L.C.S.W., 203-688-5962, or Tish Knoll, R.N., Ph.D., 203-737-2357.
Bone Marrow Transplantation:
A teenager gets a rare, second chance at life

Chrystal Torres was 14 years old and should have been out playing soccer—not lying in a hospital room. She made up for lost time kicking a soccer ball in the hallways when she could and filling syringes with water to squirt the interns until they put on gowns to protect themselves. She was tough, and she had to be to face her disease: acute myeloid leukemia (AML), which had given her fevers, bruises and stomach aches and was about to disrupt her first years of high school.

"When you’re a kid you can’t really comprehend a disease like this," Chrystal, now 22, said. "I’d never had to deal with illness in my family. I’d seen shows about children with cancer, and my first question was ‘Am I going to die?’"

She did get seriously ill. The year after her diagnosis filled with hospital stays, blood transfusions, spinal taps and chemotherapy, which left her nauseous and losing her hair. And after all that, she still faced a 50 percent chance of relapse. After three fruitless bone marrow drives and lots of prayers, the only answer seemed to be a mismatched related transplant, an experimental procedure that would use Chrystal’s mother’s stem cells for her transplant.

That’s when Barbara Sleight, M.D., a stem cell transplant specialist and an assistant professor at the Yale School of Medicine, stepped in and encouraged the family to allow Chrystal to be the first pediatric patient to undergo a mismatched related (haploidentical) transplant at YNHH. The hospital had been performing stem cell transplants with genetically-matched donors since 1993, and Dr. Sleight felt confident that the hospital had the expertise and the resources to give Chrystal this chance to live.

"Dr. Sleight walked us through everything," said Flo Torres, a registered nurse in the cardiac step-down unit at YNHH, who was initially ambivalent because she didn’t want her daughter to suffer any longer. She said, ‘Flo, you’ll be giving her life a second time.’"

Stem cells are able to recreate all blood and the immune system. When a patient’s stem cells become damaged due to diseases such as aplastic anemia or cancer, a stem cell transplant may be the only hope. Using stem cells that match the patient’s cells greatly reduces the risk of graft-versus-host disease (GVHD), the most dangerous complication of a transplant. GVHD occurs when the donor’s immune system attacks the recipient’s body tissues.

A transplant between a parent and a child or between siblings—even though they may be only half matched, is called a haploidentical mismatch transplant. In such a procedure, teamwork is essential, drawing upon the expertise of the hospital’s stem cell transplant colleagues, blood banking services and stem cell processing staff. The research protocol used for Chrystal’s transplant included a highly meticulous method of stem cell processing.

First the donor is given a drug that steers stem cells from the bone marrow into the peripheral blood where they are easier to remove. Then stem cell technologists carefully remove most of the T-lymphocyte, or T-cells. These cells are important because they fight germs, but they may also cause rejection of donor stem cells and other problems, including graft vs. host disease.

"Haploidentical transplants were first done for adults at Yale-New Haven, but the adults didn’t tolerate it well," said Dr. Sleight. "They had more pre-existing medical problems prior to transplant. The adults frequently died of infections, graft vs. host disease, relapse or other complications. Children’s immune systems recover much faster and their bodies are much healthier. In pediatrics, to date we have done three of these high-risk haploidentical transplants including Chrystal’s, and all have done remarkably well."

Flo Torres gladly donated her stem cells in three visits to the YNHH apheresis clinic. She sat in a lounge chair and watched TV while her cells were collected through sterile needles placed in both arms for four to six hours per day. "I used to call those days my spa days," Flo Torres said.
Some families go so far as to videotape the actual transplant and many patients think of the event as a second birthday. For Chrystal, the journey began with total-body irradiation to rid her body of leukemia cells and to disable her immune system and avoid rejection of the new cells. Her "second birthday" took place on two days, December 18 and 19, 1998. Flo Torres kissed the bags that held her donated stem cells and prayed over them. The actual procedure was anticlimactic—two blood transfusions that lasted a couple of hours each.

After the procedure, Chrystal spent two months isolated in a hospital room. Doctors, nurses and family members who visited wore masks to protect her from germs. The staff monitored her closely for complications. As expected, engraftment, evidence that donor stem cells are present within 10 days after the transplant, was expected, engraftment, evidence that donor stem cells are expected, engraftment, evidence that donor stem cells are expected in the hospital. Two primary nurses created a special care plan for Chrystal and led a team of core nurses who worked the plan around the clock. "They weren't even like nurses, they were like older sisters to me," Chrystal said.

The nurses made sure Chrystal practiced meticulous skin hygiene. They cleaned her mouth three times a day and provided social outlets to keep her from feeling isolated and depressed.

"We knew what she was going through and the stress she was under, so we let her get away with more than we usually would," said Carolyn Demsky, A.P.R.N., one of Chrystal's primary nurses. "We'd cover her mouth three times a day and provided social outlets to keep her from feeling isolated and depressed."

"Today Chrystal is doing well. It typically takes two years to get out of the woods after a bone marrow transplant, and last year Chrystal celebrated five years without cancer. To celebrate Chrystal's anniversary, her mother gave her a bracelet, ring and necklace from Tiffany's, and her college sorority sisters took her out to dinner.

Now, once a year, Chrystal returns to YNHH for a checkup in the HERO's clinic, one of 24 follow-up clinics throughout the country for childhood cancer survivors. She works as a pediatric patient care associate at YNHH, and she is studying nursing at Southern Connecticut State University with the goal of someday working at YNHH as a nurse for children suffering from cancer and its complications.

"At this point, I honestly don't remember a lot about what happened," Chrystal said. "Obviously it feels great because I got a second chance. If anything, it's made me stronger. I don't take life for granted."

Bone Marrow Transplantation

The genetic counseling service offers educational lectures and programs to medical and lay groups, and can provide clinical and technical support to research projects in the area of cancer genetics. Contact: Ellen Matloff, M.S., Director, Cancer Genetic Counseling Shared Resource Yale Cancer Center 203-764-8400 FAX 203-764-8401 ellen.matloff@yale.edu

Yale Cancer Center’s genetic counseling program for cancer provides services to individuals at high risk for hereditary cancers due to their personal or family histories of cancer. This program consists of three phases:

1) obtaining a detailed medical and three-generational family history;
2) calculating a personalized risk assessment, obtaining insurance authorization for testing and providing options for prevention, surveillance and genetic testing; and
3) coordinating and interpreting genetic testing and developing a management plan based on the test results.

Appropriate candidates include individuals who have a personal and/or family history of:

- Multiple relatives on the same side of the family with the same cancer or related cancers (i.e., breast/ovarian/pancreatic, pancreatic/ovarian, colon/uterine/ovarian)
- Cancer at an unusual young age (e.g., <50 for breast, <50 for colon)
- More than one primary diagnosis of cancer in the same person (e.g., multiple colon cancers, breast and ovarian cancer)
- Rare cancers such as male breast cancer, medullary thyroid cancer, etc.
- A known altered cancer-predisposing gene

Clinics are held at Yale-New Haven twice each week. Outreach clinics at Greenwich Hospital, Norwalk Hospital and Danbury Hospital are held monthly.

Yale Cancer Center
Yale University New Haven, Connecticut 06519

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As a 10-year-old with cancer, Juliana DeWitt was so traumatized by her illness she didn’t speak for three months. “I was in the fifth grade when I was diagnosed with cancer,” said Juliana. “Although my family, doctors and nurses tried to explain what was happening to me, I didn’t understand.” A stuffed rabbit named Peanuts, given to her by her grandfather, became her confidant. “My rabbit became my lifeline, helping me through all of my hospitalizations, a bone marrow transplant, and chemotherapy and radiation treatments.”

Curing childhood cancers has become one of modern medicine’s greatest success stories. Almost 80 percent of pediatric cancer patients live beyond the five-year milestone. As many as two-thirds of them, however, experience late side effects of the disease or its treatment that don’t become apparent until some time after the child is cured. Dealing with those late effects — second cancers, heart damage, learning impairments and fertility problems, among others — is becoming an increasingly important focus of cancer care.

For Juliana, now 19 and a survivor of acute lymphoblastic leukemia, the end of her cancer treatments marked the beginning of an entirely new set of health problems — avascular necrosis, a disease resulting from the temporary or permanent loss of the blood supply to the bones, and a secondary cancer of the muscle in her neck that had to be surgically removed. And she was recently diagnosed with diabetes.

“Long-term endocrine problems are the most common complications following cancer treatment,” said Stuart Weinzimer, M.D., assistant professor of pediatrics at Yale School of Medicine. The endocrine system is particularly sensitive to cancer therapies. Some late effects may include hormone disturbances that may cause short stature, disturbances of puberty and thyroid or fertility disorders.

“I wish I’d known more about the medical complications of my cancer,” said 44-year-old Patsy Twohill, a survivor of childhood cancer, and now an employee at Yale-New Haven Hospital. Twohill was 13 years old when she was diagnosed with Hodgkin’s disease. It took 10 years to beat it with radiation and chemotherapy treatments and long hospital stays. “My high school years were the worst years of my whole life,” said Twohill.

At age 24, Patsy was finally feeling great and living a healthy and active lifestyle. She had become an avid golfer and ran four miles every other day. Twelve years later, Patsy’s health began to decline. She became easily fatigued, especially when she climbed stairs or hills and when she played golf. She gained weight. Her doctor told her she had adult-onset asthma.

“I never factored in Patsy’s medical history, nor did I order a chest x-ray to explore what might be causing Patsy’s condition. Instead, he treated Patsy with breathing treatments and steroids, which offered her temporary relief.

A month later, still feeling poorly, Patsy referred herself to the Winchester Clinic at YNHH where a chest x-ray revealed a weak, enlarged heart.

“Often this knowledge can literally save their lives.”

The science of identifying, understanding, preventing and treating late effects in childhood cancer survivors is an evolving field. Childhood cancer often requires aggressive treatments, including a combination of chemotherapy, radiation and surgery, at a time of life when bodies are growing and developing. Some survivors show no late effects from treatment while others have mild, moderate or even severe health problems. These health complications can develop during treatment or months, years or even decades later.
The HERO'S clinic, which opened in 2002, was developed for individuals who have survived childhood cancer for five or more years. It focuses on the prevention, detection, and treatment of complications from cancer treatment and it provides guidance and education to empower survivors to take steps to maximize their health, quality of life, and longevity.

For 20-year-old Allison Gaffey, who is a seven-year survivor of osteogenic sarcoma—one of the most common types of bone cancer—knowledge is power.

"I'm always eager to be involved in cancer research to advance the cause and to stay abreast of recent developments and current treatments," she said. Referred by her oncologist, Dr. Joseph McNamara, Allison was seen for the first time recently by Dr. Kadan-Lottick. Since her recovery from cancer, Allison has experienced mild hearing loss and developmental and attention-deficit disorder when she started college three years ago. She assumed she had difficulty starting college three years ago.

"It's important for you to know how to stay well and that includes a good health care screening. We want to give you extra attention because you've worked so hard to get here." Dr. Kadan-Lottick continued, "There's been a shift from 'Isn't it a miracle to survive childhood cancer?' to 'How do you live your life?' said Dr. Kadan-Lottick during Allison's initial screening.

At her appointment, Dr. Kadan-Lottick spent a lot of time going over Allison's history allowing time to discuss concerns, problems and risks followed by a physical examination. "You're in the prime of your life," said Dr. Kadan-Lottick during Allison's initial screening. It's important for you to know how to stay well and that includes a good health care screening. We want to give you extra attention because you've worked so hard to get here."

"Uncertainty is the greatest psychosocial stressor in cancer survivorship," said Sheila Santacroce, A.P.R.N., Ph.D., associate professor at the Yale School of Nursing and a HERO'S clinicist. "We help survivors manage their uncertainty by providing information about their cancer and its treatment, by monitoring them in the clinic and by offering health education that focuses on how to prevent or minimize potential late effects." The HERO'S clinic is at the forefront of research investigating some of the metabolic markers responsible for the physiological and psychological problems in childhood cancer survivors.

The HERO'S clinic is currently conducting studies related to late effects in childhood cancer survivors such as stroke, cardiac events, subsequent cancers and neuropsychological outcomes.

"This research is important because we are able to better provide treatment recommendations and identify the factors that may increase or decrease a patient's risk of developing a late effect," said Tara McPartland, M.S.W., M.P.H., a pediatric research coordinator in the department of pediatrics at the Yale School of Medicine. "This knowledge is critical in teaching patients how they can modify their lifestyle and health behaviors."

As the number of childhood survivors rises, it is becoming increasingly important for medical professionals to collect information on survivorship and the long-term effects of childhood cancer treatment, even extending into middle age and beyond.

"Medical outcomes research has moved along at a brisk rate," said Dr. Kadan-Lottick. "Two-thirds of childhood cancer survivors are doing great! Thirty-three percent however, will have a severe late medical complication that can be clinically silent unless caught early. The good news is that most of the complications are amenable to early screenings and treatment."

"The HERO'S clinic is a big benefit to all of our patients," said Dr. McNamara, an attending physician at Yale-New Haven Hospital. "Curing cancer comes at a cost—hormonal, orthopedic, psychosocial. We need the expertise of medical researchers in caring for these problems; the HERO'S clinic serves as a tremendous resource for all providers and institutions caring for cancer patients. We took to them to formulate a plan to cure and perhaps lessen the intensity of chemotherapy treatments and to reduce the likelihood of lifelong complications."
30 What You Don't Know Can Hurt You

early detection program provides a safety net for women

When Frances Raffone's telephone rang, she wasn't prepared for bad news. It was the doctor's office calling: a radiologist had found a suspicious spot on her mammogram. Raffone, who had just turned 50, was counting on a clean bill of health after her first checkup in years. A single mother of four, she had always spent any spare cash on her children's clothes, never her own medical care.

"I was really scared," said Raffone, who supports herself with a home-based sewing business and can't afford medical insurance. "Other than having kids, I had never been in the hospital. I'd never thought about it. I was always busy living my life."

Another mammogram led to a biopsy, which yielded some good news for Raffone: She did not have cancer. The experience shook her up so much, however, she hasn't missed a mammogram since. Now the Connecticut Breast and Cervical Cancer Early Detection Program at the Yale-New Haven Hospital (YNHH) Women's Center tours her experience as a reminder of the importance of such screenings.

"Early detection is the key to treating cancer successfully, and our goal is to make sure every woman has that chance — no matter what her income or insurance situation may be," said Patricia DeWitt, director of community health for YNHH and the Early Detection Program, and a breast cancer survivor herself.

"We find it disturbing that over the last 25 years, the incidence of breast cancer has shifted from affluent counties to poorer counties. We need to reach out to the women who may not be getting these tests, particularly African-American and Hispanic women who have the highest mortality rate of all racial and ethnic groups, and older women who may believe that screenings increase their risk of dying."

The Connecticut Breast and Cervical Cancer Early Detection Program at YNHH was established in 1996, with support from the Connecticut Department of Public Health and Center for Disease Control. In the past two years, it has provided mammograms and Pap smears for more than 400 women who are primarily 40 or older with no health insurance or with insurance that carries a high deductible or that does not cover the tests.

Women who have taken advantage of the program have incomes that average below $10,000; 92 percent have no insurance. Many don't fit the typical picture of poverty.

"I am one of those people who has fallen through the cracks even though I worked hard all my life, paid my taxes and raised my son," said Doris Alvarez, 61, a restaurant worker in Branford, who spent years trying not to think about how she was skipping mammograms. "I have no insurance. My restaurant offers insurance for $151 a month, and that's not economically sensible for me. The Early Detection Program has basically been my checkup."

While they are happy to help anyone they can, the Early Detection Program's staff is particularly concerned about low-income women in New Haven, the seventh poorest city in the nation, which has a high incidence of late-stage breast cancers consistent with its increasing poverty levels.

Sandra Hurd, R.N., case manager of the Early Detection Program, and Brenda Caullay, outreach educator, connect with women in their own neighborhoods — in churches, community centers, schools, senior centers, supermarkets and beauty salons. They pay particular attention to women who have difficulty accessing services at the clinic. That may include grandmothers who worry about taking two buses in inclement weather with grandchildren in tow; women who are Hispanic or newly arrived from Russia or Vietnam who may not understand free tests are available and those in low-paying jobs where schedules are drawn up at the last minute, making it difficult to commit to appointments.

Culture, age and genetics are factors too. Studies have found that older women are likely to ignore the need for mammograms. Another study of low-income African-American women shows they are more likely to miss appointments if they don't have symptoms.

Doctors have long known that breast cancer is an especially serious threat to African-American and Hispanic women. They are diagnosed less often than white women, and they have the highest mortality rate of any racial or ethnic group. Statistics have shown for more than four decades that African-American women are less likely to get breast cancer than white women but are more likely to die of the disease. Last year, a Yale University School of Medicine study showed that tumors of African-American women are nearly four times more likely to have a genetic mutation related to a more aggressive form of breast cancer than are the tumors of white women.

"We need more studies that look at distinct ethnic groups," said Bruce Haffty, M.D., vice chairman of therapeutic radiology for the Yale University School of Medicine, who is conducting a separate study looking at racial differences in early-onset breast cancer in African-American and Korean women. "There is still a lot to learn about the different ways their breast cancer develops," he said.

Meanwhile, Hurd and Caullay are trying to teach their patients about the importance of preventative health care. It can be a difficult challenge. "Sometimes, whether or not you go to the doctor is based on how you were raised," said Raffone. "My parents never believed in doctors, and I was an ostrich — you know, you stick your head in the sand. You think what you don't know won't hurt you."

Hurd and Caullay get right on the phone to women even when they have missed appointments two or three times. Raffone became more committed to the program when the staff invited her to join a weekly exercise walk for patients and staff. Now she says she will never miss another mammogram. "I've always thought that if you're alive you should have medical care regardless of what your income is," Raffone said. "Getting this care makes me feel justified."
The S.A.L.O.N. Project: Testing women on their own turf

Twice a year, clients at Hair's Kay Beauty & Barber Salon, LLC, in New Haven gather at the salon to sip a cup of tea, laugh a little and relax. Then, one by one, they go outside to the Yale-New Haven mammography van for their annual test.

"It's all about taking care of women - mind, body and spirit," said Karaine Holness, the salon owner who has hosted these events for three years. She makes appointments for clients to get mammograms on the van and has helped the hospital track down women who need repeat mammograms.

Holness is one of the most devoted participants in S.A.L.O.N. (Strategic Alliance for Learning, Outreach and Networking), a collaborative outreach program funded by the Connecticut affiliate of the Susan G. Komen Breast Cancer Foundation. The primary goal of S.A.L.O.N. is to provide breast health education, increase breast cancer awareness and provide breast-screening services for underserved women over age 40.

Robin Zingales, R.N., former case manager of the Connecticut Breast and Cervical Cancer Early Detection Program, came up with approaching African-American and Hispanic women in a familiar environment because she was concerned they were reluctant and fearful of going to such a large delivery system for mammograms as the YNHH Women's Center.

After enlisting seven beauty salons, outreach staff moved on to churches, supermarkets, Salvation Army outlets and community centers. They sought out Hispanic women at the Fair Haven Clinic, located in New Haven's heavily Hispanic neighborhood.

"Fear is still a big problem among women," said Holness. "Many of them are afraid they will hear bad news, so we talk to them, and it adds dignity to the whole thing. You may not be able to save the world, but if you can save one person, that's good."

Karaine Holness (right) and a couple of her supporters show off the literature they share with clients. Jennifer Scarlett (left) is the owner of Jenny's Beauty Salon in New Haven, and Yvonne Jackson is Holness' mother and a stylist at Hair's Kay Salon.

"You may not be able to save the world, but if you can save one person, that's good."

Karaine Holness (salon owner) and buds for the S.A.L.O.N. project (above)

The Tommy Fund for Childhood Cancer

In memory of a little boy who won the heart of a region

The Tommy Fund for Childhood Cancer was established in 1953 in honor of Tommy Mondzierski, who died of cancer that same year - just two weeks before his fifth birthday. Before his death from acute leukemia, Tommy managed to garner the attention of an entire state, including a local fire department that knew of his passion for firemen and fire trucks. To help Tommy's family pay for his medical care, members of the fire department from Tommy's hometown of New Britain raised nearly $1,000, and, after Tommy's death, they raised an additional $8,000 for statewide leukemia research at Yale University.

More than 30 years later, in 1986, a group of parents of children with cancer and their caregivers at Yale-New Haven Hospital revived the Tommy Fund for Childhood Cancer with the help of New Haven firefighters.

Fundraising and awareness-raising activities, including golf tournaments and a family day road race, help support the work at Yale-New Haven Children's Hospital, the Yale School of Medicine and the Yale Cancer Center. The fund helps support the medical care of children with blood disorders and malignancies, as well as the care of families throughout a child's illness, and research and teaching in the field of childhood cancer.

Through the generosity and support of both individuals and corporations, the Tommy Fund for Childhood Cancer has been able to make a compelling difference in the lives of children and their families at Yale-New Haven Children's Hospital.

To learn more about the work of the Tommy Fund, please contact us at 1-800-974-5559 or read about us online at www.tommyfund.org.
Tender Connections: spiritual support while living with cancer

Faith and spirituality are strong allies when it comes to coping with cancer, according to Reverend Peg Lewis, director of Yale-New Haven Hospital’s religious ministries department. “A diagnosis of cancer moves people to search below the surface of life.”

In the course of our daily lives, we rarely acknowledge our own mortality, but cancer brings that reality front and center. Whether a patient is confronting a rigorous course of treatment for a newly diagnosed disease or facing the end of his or her life, some fundamentally human questions emerge: What does my life mean? Did I do something to bring this on myself? How will my life be changed by this disease? What happens to me when I die? How will my children cope when I’m gone? Where is God in all of this for me?

“Our role as hospital chaplains is to help patients get in touch with their own religious traditions and spiritual understandings as a source of strength as they progress on their journey of life with cancer,” said Rev. Lewis. “Even though cancer is increasingly a chronic disease and less of a death sentence, the disease still gets people very focused on what is most important in their lives – relationships with loved ones and transcendental meanings. Religious and spiritual beliefs give patients and their families a source of courage and conviction at a time when it’s easy to feel helpless.”

Chaplains connect with patients in many ways. “If patients indicate an interest in spirituality when they’re admitted, the system generates a referral to our department,” Rev. Lewis explained. Other caregivers, such as nurses and social workers, also refer patients. “And sometimes, I’ll just see someone who looks like she needs to talk,” she added. “I call these my holy spirit referrals.”

The YNHH religious ministries department oversees eight certified full-time chaplains, several part-time chaplains and four to six chaplain interns who serve the spiritual needs of patients 24 hours a day, seven days a week. They represent a variety of religious traditions. “We also have a multi-faith network in the community we can call upon when we have a patient with a tradition that we’re not able to match with a chaplain on staff. This is an essential resource for an institution whose diverse employee and patient populations include Christians, Muslims, Jews, Buddhists and Hindus, among others.” The department staff averages more than 21,000 visits to patients each year.

“Patients’ concerns are often linked to where they are in their journey. Patients who have just been diagnosed are often thinking about the fact that their time may be limited. They’re trying to figure out what are the most important things for them to be doing. In addition, recently diagnosed cancer patients are often awestruck at how wonderful everyday life is. They have a heightened sensitivity to the world and are feeling very connected to nature and very grateful for their friends and family.

“My role is to include the people I’ve talked with in my prayers, so I ask them what they would like me to pray for on their behalf.” People become very quiet at this point. They are often moved to tears and reach to find their deepest want. Sometimes, they ask for recovery; sometimes they pray for the well-being of their family; sometimes for peace and an end to the suffering of others. They have a heightened sensitivity to the world and are feeling very connected to nature and very grateful for their friends and family.

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“Many patients will tell me they are not afraid of death, but they are afraid of dying. They may have concerns about pain and other symptoms, and I’m able to alleviate those concerns with a referral to our palliative care specialists who are very skilled at managing those symptoms.
Rev. Peg Lewis

"I meet God in these patients and their families. These are people at their most vulnerable, undergoing significant transitions. I may not know them long, but I can know them deeply. It is a great privilege to sit down and listen to patients and their loved ones explore uncharted territory, whether it’s a new diagnosis or the end of life. They share their realizations and thoughts about what they hope for, what scares them most, what they treasure above all else."

One woman told me she did not want to talk about dying, but she brought me a tape recording of John Rutter’s Requiem, and we talked about death in the language she chose—music.

"Often patients will talk about how very difficult it will be to find the words to say goodbye to those they love. I can help by letting them rehearse these conversations with me. It’s hard to articulate just how tender and awe-inspiring these encounters can be."

Peg Lewis has been practicing pastoral care at YNHH for 18 years; nearly all of that time has been spent working with oncology patients.
The war against cancer

The war against cancer is a national endeavor... a Yale–New Haven medical center mission... and, above all else, a personal battle. It requires deep and constant investments – personal, institutional, financial and emotional. It requires both fortitude and support on many levels. Your support can help Yale–New Haven Hospital support the patients who come here with hope for care and cure.

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