TOWARD A CURE

A RARE DISEASE LEADS TO BIG DISCOVERIES
Understanding Diamond Blackfan Anemia

ALSO
Preserving fertility for patients undergoing cancer treatment
Dear Friends,

Working toward a cure begins with change – something that affects the field of oncology at an accelerating rate.

Rapid advances in cancer screening, prevention, genetics, molecular biology, imaging, diagnosis and treatment all contribute to a medical evolution that prompted us to unify and enhance the health system’s cancer activities beneath the banner of the North Shore-LIJ Cancer Institute more than two years ago.

With access to the vast resources of the North Shore-LIJ Health System, the Cancer Institute participates in and helps advance findings of clinical import in cancer research and treatment. More than 10,000 patients have participated in our clinical research to spur progress in the field. Now, 200 dedicated Cancer Institute doctors – from the laboratory bench, diagnostic and imaging staff, oncology clinicians and research physicians – work to improve every aspect of cancer care. Furthermore, a long-standing relationship with the National Cancer Institute (NCI) enhances the depth and scope of our program, as does our receiving a recent grant from the prestigious NCI Community Oncology Research Program – one of only 46 awarded in the country.

*Toward a Cure* highlights North Shore-LIJ Cancer Institute initiatives that touch our patients’ lives and contribute to the pursuit of new avenues of healing. We welcome your readership and look forward to your comments.

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Schedule an appointment with the North Shore-LIJ Cancer Institute: (855) 858-8550.
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Oncofertility and Beyond

Life After Cancer: Preserving Fertility

Defeating a patient’s cancer and preserving the quality of life afterwards is always the goal of the North Shore-LIJ Cancer Institute. For women and men still in their reproductive years, that means the Institute works to ensure that the treatments designed to defeat the disease, don’t jeopardize fertility and the dreams they have for their lives after cancer.

Avner Hershlag, MD, chief of the North Shore-LIJ Health System’s Center for Human Reproduction, knows that for individuals in their reproductive years, the critical issues of diagnosis, prognosis and treatment also include fertility preservation. “It’s important to let the patient know that there usually exists a realistic chance to have a baby.”

Developments in in-vitro fertilization (IVF) have paralleled advances in cancer treatment, allowing reproduction to remain a viable option for many cancer survivors. The current process for tissue freezing (cryopreservation), known as vitrification, yields excellent results for both eggs (oocytes) and embryos. Vitrified embryos have a better than 95 percent freeze-thaw survival rate, and a pregnancy-generating potential that is comparable to that of fresh embryos.

TIME IS OF THE ESSENCE

Before the patient begins treatment for cancer, there is usually a window of opportunity to take steps to preserve fertility. At North Shore-LIJ, collaboration between the Center for Human Reproduction and the Cancer Institute is key. “The referral process is quick,” Dr. Hershlag explained. “We see patients referred to us from the Cancer Institute within a week.”

Frozen embryos or eggs must first begin with the harvesting process. A reproductive endocrinologist uses fertility drugs to stimulate the ovaries to produce multiple eggs at once rather than the one egg a woman’s body normally produces in one cycle (the number and quality of the eggs retrieved are heavily dependent on the women’s age.) After eight to 13 days of medication, the eggs can be retrieved. “If a woman is going to be treated for breast cancer, there is usually time for two cycles, but with other cancers, starting treatment is more urgent. We must let the oncologist be...
Avner Hershlag, MD, Jasmine D’Alessandro, RN, and Hong Ang, an embryologist, identify a frozen embryo about to be thawed.

our guide.” Eggs or embryos are then frozen and implanted following the conclusion of treatment. Even if chemo-induced menopause is permanent, there is a good likelihood that IVF will be successful after cancer treatment is completed.

While there is debate about whether tamoxifen, often prescribed for 10 years after breast cancer, can be discontinued for two years so that a woman can carry her own child, a gestational carrier also remains an option for those who are concerned about stopping the medication for the two-year period.

If a man is concerned about preserving fertility, a sperm lab is located at the Center for Human Reproduction. If long-term storage is required, the specimens are sent to a sperm bank. The good news for men is that if cancer surgery is scheduled, for testicular cancer, for example, multiple specimens can be obtained in a short time. Further, sperm production is renewed after treatment in many cases.

In short, if steps are taken before treatment, for many patients today there is life with children after cancer.
Following the Trail of a Rare Disease

May Lead to BIG Discoveries

A rare disease, Diamond Blackfan anemia was first described in 1936. It became a nearly-40-year pursuit for a hematologist at Cohen Children’s Medical Center of New York. Today, it is leading doctors and researchers in the North Shore-LIJ Cancer Institute and the Feinstein Institute for Medical Research to some important discoveries in what causes certain cancers.
Diamond Blackfan anemia (DBA) was named after the two Boston physicians who understood it clinically in 1938. Jeffrey Lipton, MD, PhD, chief of hematology/oncology and stem cell transplantation at Cohen Children’s, first heard of it in 1978. Stemming from his interest in scientific approaches to understanding diseases, he was intrigued. It has become his life’s work.

In DBA, while white cells and platelets are essentially normal, the red blood cells fail. A patient typically presents as an infant under the age of one with severe anemia. Over the years, a number of causal theories were proposed. Immunological derivation was the prevailing thought for a time, but in the nineties the basic pathophysiology of DBA was nailed down: Dr. Lipton and his team showed that the red cells’ demise (apoptosis) was programmed into their DNA, which is true of almost all inherited bone marrow failure disorders.

A lack of patients frustrated Dr. Lipton in his study of DBA. Only five to 10 cases occur in 1 million births in the US and Canada – 20 to 40 new patients born each year. He understood the classical diagnosis, which was anemia, but he was not able to observe how individual patients might depart from that definition. In 1991, he suggested to a fellow in his division, Adrianna Vlachos, MD that she might take a look at DBA. Now as an attending hematologist and clinical researcher in the
Bone Marrow Failure Program, Dr. Vlachos has made DBA her life’s work, too. She set up and maintains the Diamond Blackfan Anemia Registry, which contains more than 700 cases from North America and all over the world.

Looking at the biological and clinical pieces of the puzzle in parallel, Drs. Lipton and Vlachos came to understand that DBA was inherited as an autosomal dominant; in other words, only one parent with the gene could cause the problem. More than half the cases, however, were spontaneous mutations. They also discovered parents with DBA who were only mildly affected or not affected at all. Thus the expression was quite variable, with the same mutation but very different manifestations.

In 2005, experts from around the world met at a consensus conference chaired by Drs. Lipton and Vlachos. A consensus paper published three years later discussed the risk of bone marrow transplantation and which patients were appropriate candidates, as well as the side effects of corticosteroids and red cell transfusions; the paper led to improved therapies. (About 40 percent of patients can be maintained on corticosteroids, and the remainder treated with regular transfusions or transplants. Most young children who receive a transplant under age 10 usually will begin to produce the transplanted red blood cells, although he or she is not cured of DBA.)

Thanks to the important lab work of Niklas Dahl, MD, of the Rudbeck Laboratory at Uppsala University Children’s Hospital in Sweden, it came to be understood that in patients for whom there is a known mutation, DBA is caused by a ribosomal protein haploinsufficiency. Deletions later described by the Lipton/Vlachos team, in addition to mutations, of the known genes associated with DBA (about a dozen) account for an additional percentage of cases making a genetic diagnosis available today in 70 percent of patients. DBA is currently defined not only as a condition of red blood cell failure but also in terms of a high prevalence of birth defects, growth issues, metabolic bone disease and cancer.

Iron overload in patients receiving transfusions has become the major cause of death, supplanting unsuccessful transplants. (Patient/donor matching is now much improved.) Every transfusion contains 250 to 300mg of iron. Since the iron cannot be utilized without red cell production, it all goes into storage in the liver, endocrine organs and heart. Many DBA patients don’t store iron in the normal way, and it is disproportionately deposited in the heart, leading to heart failure. Drugs are available to treat this silent killer, but patients require careful monitoring, with specific MRI scans and/or liver biopsies.

At first, most of the observed cancer cases were leukemia. As the years passed and the DBA Registry grew, however, a true picture of the excess of cancer cases in DBA patients versus the general population emerged. It now appears that the ratio of osteosarcomas is 30 to one, observed to expected, and they are occurring in younger patients. There is an increased incidence of leukemia and myelodysplastic syndrome, and statistical significance has been achieved for colorectal cancer with breast cancer not far behind.

Studying a disease with a predisposition to cancer that affects a small segment of the population, in the clinic and the lab, has led two pediatric hematologist/oncologists and their research team to the brink of understanding some of the possible causes of cancer. Cancer strikes about 2,500 children a year. Many more adults are diagnosed – for example, 200,000 adult women with breast cancer and 200,000 adult men with prostate cancer. Clearly, the impact of any potential discoveries could be huge.

In laboratory studies at the Feinstein Institute for Medical Research, led by Lionel Blanc, PhD, assistant investigator at the Center for Oncology and Cell Biology, Laboratory of Developmental Erythropoiesis; and Brian Dulmovits, a medical student, the “DBA team” has modelled DBA in mouse embryos and emulated defective bone growth. Additional work will create DBA mutations in bone tissue of live mice and likely generate bone cancer (osteosarcoma) – linking the human DBA cancer predisposition to an experimental model. The hope is to define the molecular events leading to cancer and develop rational treatment for this and other cancers that effect children as well as adults.
PHYSICIAN PROFILE:

Harry Raftopoulos, MD
The prospects are much brighter today for many lung cancer patients. Indeed, cancer patients in general.

“Promising advances have grown exponentially, especially in the last several years,” said HarryRaftopoulos, MD, codirector of the Lung Cancer Center of Care. He has witnessed rapid changes in the detection, diagnosis and treatment of lung malignancies, especially since 2007, when he joined the North Shore-LIJ Cancer Institute. For instance:

* Early detection has improved survival for high-risk patients like smokers.
* Advances in biotechnology have spurred rapid evolution in chemotherapy for lung tumors.
* Genomic profiles can lead to more specific (targeted) therapy.
* Patients now benefit from less-invasive surgical techniques and radiation therapy modalities that reduce side effects.

It wasn't always so. "Back in the 1990’s, lung cancer patients only occasionally entered the oncology clinic,” Dr. Raftopoulos said. “But most were referred directly to hospice because there were no more treatment options.”

He chose to specialize in this challenging field because he believed he could make a difference. It has become his life’s work.

A REVERSAL BEGINS

After graduating from University of the Witwatersrand Medical School in Johannesburg, South Africa, Dr. Raftopoulos came to Manhattan for his residency and fellowship. His international clinical exposure afforded him the insight that oncologists offered limited therapies and little hope to lung cancer patients.

“Now, on the other hand, lung cancer can be a chronic, treatable condition,” Dr. Raftopoulos said. “For instance, targeted agents can help patients with Stage 4 disease to live five years after diagnosis.”
Furthermore, he added, “We are discovering more therapies related to genetic mutations.” Previously thought to have reached a dead end, immune therapy is gaining extreme momentum with new medications that appear to be active across multiple tumor types.

Dr. Raftopoulos leads the Lung Cancer Center of Care’s participation in such developments, working with National Cancer Institute cooperative groups to better define therapy. In addition to state-of-the-art treatment protocols, the center also offers promising agents in development via clinical research. Several such agents have shown to prolong survival for patients with advanced disease and are now FDA-approved and commercially available.

To improve lung cancer patients’ quality of life, Dr. Raftopoulos leads research to develop more effective antiemetics, to ease side effects. He also cochairs the Respiratory Symptoms Study Group of the Multinational Association of Supportive Care in Cancer, which seeks to define and measure dyspnea, as well as the association’s Infection/Myelosuppression Study Group.

“With cautious optimism, I can say that we may be closing in on lung cancer,” said Dr. Raftopoulos.

The Lung Cancer Center of Care battles the complexity and risks of lung cancer with a strategic marshalling of skilled personnel and specialized resources. Under the codirection of Dr. Raftopoulos and Lawrence Glassman, MD, multidisciplinary team members who are adept in the most advanced technology and fluent in the latest research bring their expertise to bear for the benefit of each lung cancer patient.

- Research, including new therapeutic approaches, is integral to the program. Each individual treatment plan incorporates the latest findings whenever it can benefit the patient.

- To address the discomfort from the disease and the side effects of its treatment, staff members keep abreast of the most current pain-management therapies via ongoing consultations with North Shore-LIJ palliative care physicians, nurses and social workers.

- Physicians, interns and fellows confer regularly to analyze the implications of late-breaking research and treatment developments and explore innovative projects to further enhance care.

- Specialists collaborate, deliberate new findings and provide updates on complicated cases at regular Thoracic Tumor Board meetings.
Lake Success Expansion: Total Care Under One Roof

Today, cancer treatment is multidisciplinary. A single patient often receives care from several specialists, including a medical, surgical and/or radiation oncologist, depending on the type of cancer and the treatment course.

To provide more convenient access to more comprehensive care, the North Shore-LIJ Cancer Institute is investing $175 million to open and expand cancer services throughout the New York metropolitan area, continued on next page ...
Above, center and bottom: Part of the Center for Advanced Medicine, the Monter Cancer Center recently doubled in size to 80,000 square feet.

From left: Louis Potters, MD, co-executive director of the North Shore-LIJ Cancer Institute and chair of radiation medicine for the North Shore-LIJ Health System; Brett Cox, MD, chief of brachytherapy; Sherin Joseph, chief radiation therapist; and Kerry-Ann Brown, RN, oncology research nurse.

From left: Charles Conte, MD, chief of surgical oncology, and James Sullivan, MD, associate chair of surgery for the North Shore-LIJ Health System.
Increasing patients’ access to world-class care close to home.

A primary example of the North Shore-LIJ Cancer Institute’s investment in multidisciplinary care is the newly completed, $84 million expansion at the health system’s Center for Advanced Medicine (CFAM) in Lake Success. Home to the Cancer Institute, CFAM is one of the largest cancer programs in the New York metropolitan area. Few East Coast facilities offer as much variety of up-to-the-minute technology in one location that allows tailored, streamlined care.

CFAM was already home to diagnostic radiology, breast imaging, urology and ambulatory surgery services. Now with an additional 93,000 square feet, CFAM serves as the new home of all ambulatory hematology/oncology, chemotherapy and radiation oncology services offered by North Shore University Hospital and Long Island Jewish (LIJ) Medical Center.

**Radiation Medicine**

Much of CFAM’s new space is the $45 million, 30,000-square-foot headquarters for the North Shore-LIJ Department of Radiation Medicine, which was previously across the street at LIJ.

“The move gave us the opportunity to invest in the latest technology in the field,” said Louis Potters, MD, chair of radiation medicine and co-executive director of the North Shore-LIJ Cancer Institute. Those investments include:

- the Gamma Knife Perfexion, a single-session option for patients who need additional treatment with chemotherapy, radiation therapy or brain surgery;
- three TrueBeam linear accelerators, each equipped with new Calypso systems (known as GPS for the Body), Cone-Beam CT Scanning, VisionRT, treatment gating and ExacTrac imaging;
- a comprehensive brachytherapy program – one of the busiest in the nation – providing a full range of temporary and permanent implant techniques;
- stereotactic radiosurgery and stereotactic body radiation therapy;
- intensity-modulated radiation therapy; and
- image-guided radiation therapy.

“Our radiation medicine program is grounded in evidence-based care, quality and safety and the most supportive and compassionate care as possible for our patients,” Dr. Potters said. “Our program of ‘Smarter Radiation Oncology’ has been trend-setting.”

**The Monter Cancer Center**

Also part of CFAM, the Monter Cancer Center recently doubled in size to about 80,000 square feet, making it the destination for a wide range of coordinated ambulatory hematology/oncology and chemotherapy treatment services. Amid soft light and live greenery, patients receive leading-edge treatment in private chemotherapy bays, plus immunotherapy, hormone therapy or targeted therapy treatments, as needed.

The Monter Cancer Center is home to the Division of Medical Oncology. Led by 35 elite, disease-oriented specialists, multidisciplinary teams care for patients with all types of cancers, ranging from common cancers such as lung, breast, colorectal, and prostate cancers and lymphomas to far less common cancers such as bone marrow failure/MDS and sarcomas.

Monter Cancer Center service highlights include:

- A vast clinical trials program with new agents and novel treatment options. We offer studies initiated by our physicians, National Cancer Institute cooperative groups and other organizations.
- The only adult bone marrow and stem cell transplant program accredited by Foundation for the Accreditation of Cellular Therapy (FACT) on Long Island, Queens and Brooklyn – one of the largest in the metro New York area.
- Oncology nurse navigators to coordinate patient care.
- Supportive oncology care and pain management.
• A full complement of patient support services, including nutritional counseling, oncology social work and support groups.

**THE BRAIN TUMOR CENTER AND SURGICAL ONCOLOGY**

CFAM now also houses surgical oncology services and the Brain Tumor Center.

North Shore-LIJ Cancer Institute oncologic surgeons specialize in the surgical management of rare and complex tumors, regularly treat patients that other centers can’t – as well as more common malignancies. They are adept at techniques that lead to improved outcomes and faster post-surgical healing, such as robotic surgery; laparoscopic and minimally invasive surgery; and the NanoKnife, including irreversible electroporation (IRE) for pancreatic cancer.

The oncologic surgeons perform more than 2,000 procedures annually, including for the gastrointestinal tract, including the colon and rectum; the digestive system, including hepatobiliary and pancreatic; kidney and bladder; breast; the endocrine system, including the thyroid and parathyroid; reproductive systems; chest and lung; and skin (melanoma).

The Brain Tumor Center, a collaboration between the North Shore-LIJ Cancer Institute and Cushing Neuroscience Institute, offers comprehensive treatment for benign and malignant tumors of the brain, from preoperative evaluations through post-operative, in-hospital management. The center has relocated its consultation and outpatient services to CFAM from North Shore University Hospital. The new location fosters closer teamwork between clinicians and researchers to develop personalized treatment options.

Brain Tumor Center staff members are a uniquely collaborative team of neurosurgeons, neuro-oncologists and radiation oncologists who offer up-to-date evaluations and personalized treatments for patients with brain tumors. Areas of expertise include stereotactic neurosurgery, skull base surgery, minimally invasive endoscopic surgery and stereotactic radiosurgery.

**“ONE-STOP SHOPPING”**

“Our vision is to create a ‘cancer campus’ here at CFAM,” said George Raptis, MD, vice president of oncology network services and associate chief of hematology/oncology at North Shore University Hospital and LIJ Medical Center. “As the various oncological specialties become technically more demanding and more sophisticated, we realize that we can deliver the best, most compassionate care if we work as a team, with all of our services in close proximity. At a very vulnerable time in their lives, patients with cancer should not have to travel to distant addresses, perhaps in different towns, to coordinate their care. The care should be centered around them.”

The advantages of “one-stop shopping” for cancer services are very clear, according to Dr. Potters. All appointments – physician visits, scheduled treatments and meetings with providers of support services – are under the CFAM roof. Patients and physicians benefit from “a central location that is much more conducive to collaborating on cases and coordinating care,” according to Dr. Potters.

The North Shore-LIJ Cancer Institute’s programs and services provide care for the whole person – not just clinically, but also emotionally, socially and psychologically – to enhance the quality of life. The commitment to enhancing the patient experience is carried through in the new space, with amenities that range from the streamlined check-in and check-out procedures, to the modern exam and treatment rooms, and spacious, private changing rooms augmented by skylights and contemporary art.

“Integrated comprehensive care is just better,” said Daniel Budman, MD, co-executive director of the North Shore-LIJ Cancer Institute and chief of hematology/oncology. “Our centralized location is much more conducive to case collaboration and coordination. Our patients feel the difference.”
Around the Network

The North Shore-LIJ Cancer Institute spans from Manhattan and Staten Island into Queens and Long Island. This regional continuum of care continues to expand with new facilities and added services, providing more patients with convenient access to the area’s cancer specialists.

The Cancer Institute at Lenox Hill Hospital offers comprehensive breast, thoracic and head/neck oncologic surgery services. Furthermore, it recently broadened the scope of its radiation oncology services by installing New York City’s first TomoTherapy unit (see photo on next page), which offers efficient, highly customized, focused radiation for patients with difficult-to-treat cancers. Also part of the expansion:

- Intrabeam intraoperative radiotherapy, which can eliminate the need for a post-operative course of radiation by delivering a concentrated dose while the patient is still in the operating room.

Stephanie Bernik, MD, left, leads the Comprehensive Breast Center of the North Shore-LIJ Cancer Institute at Lenox Hill Hospital.

continued on next page ...
Using a construction crane, the Cancer Institute recently installed Manhattan’s first TomoTherapy unit at Lenox Hill Hospital.

Dennis Kraus, MD, director of the Center for Head and Neck Oncology at Lenox Hill Hospital, is on the team of specialists that offers patients minimally invasive endoscopic surgery.

From left: Radiation oncologists Anuj Goenka, MD, and Jed Pollack, MD, at the newly opened Radiation Medicine Department at the North Shore-LIJ Cancer Institute at Lenox Hill Hospital.
Contrast-enhanced spectral mammography, which significantly enhances breast cancer detection and reduces the time between testing and diagnosis.

More brachytherapy options, such as high-dose-rate brachytherapy, radioembolization, intravascular brachytherapy and total body irradiation.

The North Shore-LIJ Cancer Institute at Staten Island University Hospital is the cornerstone of cancer care for the community, providing radiation oncology, surgical oncology and uro-oncology services. The Florina Rusi-Marke Comprehensive Breast Center offers diagnosis and treatment, which a cadre of specialists that includes breast surgeons, medical, surgical and radiation oncologists, radiologists, pathologists and plastic and reconstructive surgeons.

Glen Cove Hospital’s Don Monti Cancer Center treats a wide range of cancers and blood disorders in a convenient, community-based setting. The multidisciplinary program offers patients medical oncology, hematology, radiation medicine (including a new linear accelerator), surgical oncology, imaging, pathology, certified oncology nursing, nutrition, rehabilitation, education and community outreach, and the opportunity to participate in clinical trials. The Commission
The North Shore-LIJ Cancer Institute at Huntington offers a full range of care at its ambulatory site, including CyberKnife noninvasive radiation therapy, medical oncology, radiation oncology and infusion services. The center coordinates care with Huntington Hospital surgical oncology specialists in breast, colorectal, gastrointestinal and gynecologic cancer and neuro-oncology. Huntington Hospital is accredited by the National Accreditation Program for Breast Centers and the American College of Surgeons and a Joint Commission-designated Palliative Care Advanced Center of Excellence.

North Shore Radiation Therapy, CyberKnife of Long Island in Smithtown deploys noninvasive radiation therapy to treat all malignancies, new and recurrent – for instance, head/neck, brain, lung, prostate and liver cancer, plus tumors of the spine, pancreas and rectum – without complications or side effects. It also provides patients with medical and surgical oncology services.

Now under construction, the North Shore-LIJ Cancer Institute at Great South Bay is a $34 million, 40,000-square-foot outpatient cancer center. It will provide diagnostic imaging, radiation medicine, medical oncology, surgical oncology and outpatient chemotherapy. It will also offer patients the opportunity to participate in advanced clinical trials.

Among the specialists at North Shore-LIJ Cancer Institute at Huntington are, rear from left: Richard Byrnes, MD, Barbara Livingson, RN, NP, John Ames, MD, Magdalena Petryk, MD, and Janna Andrews, MD. Front from left: Michael Buchholtz, MD, Heather Zinkin, MD, and Erna Busch-Devereaux, MD.
Kanti Rai, MD, right, chief of CLL research, discusses promising research with Nicholas Chiorazzi, MD, center/left, head of the Karches Center for CLL Research at the Feinstein Institute for Medical Research with members of the lab research team.
North Shore-LIJ Cancer Institute’s clinical research focuses on several areas:

1. early drug development
2. clinical trials initiated by investigators or sponsors such as the National Cancer Institute (NCI) or pharmaceutical companies.
3. quality of life and supportive care studies
4. population studies such as cancer screening or prevention in high-risk individuals.

More than 10,000 individuals have participated in North Shore-LIJ’s oncology research, which dates back almost 30 years. The studies span everything from new drugs in cell culture, to innovative treatments and analyzing the long-term benefits of smoking cessation.

Recently, the NCI recognized the Cancer Institute’s research with a five-year, $4.1 million Community Oncology Research Program grant to study large patient populations.

On the following pages, find examples of our ongoing trials.

continued on next page ...
Clinicians like oncologist Tom Bradley, MD, left, work with trial participants.
A Pilot Study Treatment of Malignant Tumors Using [18F] Fluorodeoxyglucose [FDG]

This Phase 1 study is investigator-initiated based on the work of Doru Paul, MD, a medical oncologist at the Monter Cancer Center, and supported by seed funds from the Cancer Institute. It hypothesizes that [18F] [FDG], a radioactive diagnostic material used for PET scans, can be used safely and effectively, in high doses, as a therapeutic agent in patients with advanced, stage IV, small-cell lung tumors and lymphomas that failed standard-of-care treatment. The rationale for using high doses is that most malignant lesions have increased glucose metabolism, which is mirrored by an increased uptake of FDG. Since FDG cannot be metabolized within the cell-like glucose, it is effectively confined within the cancer cells. Thus, FDG, given at higher than diagnostic doses, is potentially a novel form of targeted therapy for tumors with increased FDG uptake.

This small study (about 10 subjects to be enrolled) is a collaborative effort of the Cancer Institute, the North Shore-LIJ Department of Radiation Medicine and the Department of Nuclear Medicine.

An Open-Label, First-in-Human Study of the Safety, Tolerability, and Pharmacokinetics of VX-970 in Combination With Cytotoxic Chemotherapy

The hypothesis, by the investigators at the Cancer Institute, is that this new compound, VX-970 (manufactured by Vertex Pharmaceuticals, which also sponsors the trial), will inhibit a critical pathway essential for cancer cells to repair damage from chemotherapy. The North Shore-LIJ Cancer Institute, the Dana-Farber Cancer Institute in Boston and the Ohio State University Comprehensive Cancer Center are the three sites that will be studying the effect of VX-970 administered with cisplatin in this phase 1 study.

Dr. Raftopoulos is the principal investigator of this study and the first patient was enrolled at the Monter Cancer Center. The total number of patients who will be enrolled is dependent on side effects of treatment.

READ MORE on the following pages how cancer trial participation has made a difference for Abe Bernstein and Shira Gittleman.
Abe Bernstein

In his "trophy room" of his home.
After a skiing excursion in Utah, Abe Bernstein noticed his glands were swollen. When the swelling wouldn’t go away, he visited his primary care physician, who sent him for a biopsy. The diagnosis: chronic lymphocytic leukemia (CLL).

Mr. Bernstein visited a specialist, who told him: “You should go to LIJ and see Kanti Rai. He taught us everything we know about CLL.” Mr. Bernstein took that advice and met with Dr. Rai, chief of CLL research at LIJ Medical Center and one of the most respected names in the field.

Mr. Bernstein was not in a good place. When CLL is first diagnosed, active surveillance is usually the recommended approach, but Dr. Rai told Mr. Bernstein that his blood numbers indicated it was time to start chemotherapy. In response, the veteran track and field athlete and recent participant in the USA Track and Field Masters Outdoor Championships said, “I told him I couldn’t start immediately because I was going heli-skiing in British Columbia.”

Dr. Rai replied, ‘People with your numbers aren’t able to get out of bed, and you’re going heli-skiing?”

Mr. Bernstein began treatment with rituximab, fludarabine and cyclophosphamide, and went into remission with no side effects after four of the customary six chemotherapy sessions. During his three-year remission, he continued his athletic endeavors. He won the 400m and 800m meets in the 70-to-74 age group at the Canadian Masters Track and Field Championship and nearly duplicated that feat in his bracket at the 2012 Huntsman World Senior Games in Utah by winning the 400m and taking second in the 800m.

But CLL can be tricky. Four years after his diagnosis, Mr. Bernstein relapsed. He underwent the same treatment. It was again successful – but this time, his remission lasted only a year. When the CLL returned, it did so with a vengeance. Mr. Bernstein’s lymph nodes were so swollen that he was unrecognizable. He was convinced his time had come.

That’s when Dr. Rai told him that he had been accepted into a federal drug trial for ibrutinib. Thirty days after beginning treatment, Mr. Bernstein’s condition improved significantly and he could resume his track training. He entered the 75+ 100m Masters race at the Penn Relays, the oldest and biggest track meet in the US. Before 50,000 people, just 90 days after beginning the trial, Mr. Bernstein took home a bronze medal.

Today, Mr. Bernstein’s numbers are normal. He will continue his ibrutinib regimen indefinitely. “I consider that race the greatest I ever ran,” he said. “It was an affirmation of life. With the help of my doctors at the North Shore-LIJ Cancer Institute, I intend to outrun CLL.”
She Joined Clinical Trials for Her Daughter’s Generation

With a family history of breast cancer, Shira Gittleman was conscientious about getting an annual mammogram.

But when her husband lost his job and the family’s health coverage, she missed a year. In November 2011, when her husband had a new job and new insurance coverage, the West Hempstead resident went to her doctor right away for a mammography prescription, and then booked an appointment.

“During the exam, I could tell that something was going on. The technicians were very friendly, and then all of a sudden they stopped talking,” Ms. Gittleman said. “A day later, my doctor called and said she had some news and she needed to see me right away.”

The news was that the exam had found something suspicious, and her doctor wanted her to see a breast surgeon. The surgeon ordered a biopsy, which revealed Stage 1, triple-negative breast cancer. This meant that the breast cancer cells had tested negative for hormone epidermal growth factor receptor 2 (HER-2), estrogen receptors (ER) and progesterone receptors (PR), and would not respond to targeted therapies. Triple-negative breast cancer, which comprises about 10 to 20 percent of breast cancers, tends to be more aggressive, so time was of the essence.

Ms. Gittleman needed to make a decision: Should she undergo a mastectomy or lumpectomy?

While she grappled with this decision, Ms. Gittleman’s internist recommended she consult with Lora Weiselberg, MD, of the North Shore-LIJ Cancer Institute.

“Dr. Weiselberg spent a lot of time with me,” Ms. Gittleman said. “She told me that since I would definitely receive chemotherapy and radiation, either a lumpectomy or a mastectomy would be appropriate. I was reluctant to undergo major surgery and face the long recovery, so I chose a lumpectomy.”

Ms. Gittleman’s surgery went smoothly. She underwent subsequent chemotherapy at the Monter Cancer Center. During an exam prior to treatment, Dr. Weiselberg asked if Ms. Gittleman would participate in a study sponsored by the National Cancer Institute of Canada (NCIC), “Assessment of Cognitive Function in Breast Cancer and Lymphoma Patients Receiving Chemotherapy at Pre-Treatment, Post-Treatment and at Six-Month Follow-up.”

“I was happy to be able to participate and help advance cancer research,” said Ms. Gittleman. Chemotherapy was challenging, but she got through it. When she finished chemo and began to undergo radiation treatment, Dr. Weiselberg asked if Ms. Gittleman would participate in “A Phase III Randomized Trial of Metformin Versus Placebo on Recurrence and Survival in Early Stage Breast Cancer,” sponsored by the NCIC. Ms. Gittleman again said yes. That trial is ongoing.

Her treatment over, Ms. Gittleman says she feels well. “I am glad to have been offered the opportunity to participate in two trials,” Ms. Gittleman said, “and potentially to help women of my daughter’s generation who might be faced with breast cancer. It’s a small contribution I can make.”
From right: Shira Gittleman with her daughter, Millie, who was an important member of her support team during her treatment and recovery.
TOWARD A CURE  Making a Gift

Trustee F.J. McCarthy with his wife, Kelly.
A recent bout with prostate cancer gave F.J. McCarthy, a trustee of the North Shore-LIJ Health System, a rather unexpected opportunity to experience the competence and caring of the system’s physicians and support staff first-hand, from an operating room and a hospital bed.

The velocity of the rise of Mr. McCarthy’s PSA (prostate-specific antigen) test (2.7 in April 2011, 4.7 in September and greater than 6 in December) was significant enough that his primary physician in Bay Shore, where he lives, sent him to urologist Louis Kavoussi, MD, of the Cancer Institute’s Prostate and Genitourinary Cancer Center, who also serves as chair of urology for the North Shore-LIJ Health System.

“For my cancer, he recommended a nerve-sparing radical prostatectomy, which he would perform using the robotic da Vinci® system,” said Mr. McCarthy, who was a fit and active 47-year-old at the time of his diagnosis. “As a trustee [and also a member of the board’s Executive Committee], I was committed to the health system, but before scheduling the surgery I did about 200 hours of research on prostate cancer and the various treatments.”

The surgery Dr. Kavoussi recommended was particularly appealing because of Mr. McCarthy’s busy schedule. A member of a big Roman Catholic family, he was raised to give back, and he is very involved at Southside Hospital in Bay Shore. He served on its board before Southside joined the North Shore-LIJ Health System. His work in real estate requires him to travel frequently, and many weeks he is out three or four evenings, fulfilling his philanthropic responsibilities.

“Dr. Kavoussi explained to me that with the da Vinci system, there would be only six small incisions, I should be up and about the next day and the overall recovery time would be fast,” he said. “That sounded like a good fit for me and my life.”

Lee Richstone, MD, chief of urology at North Shore University Hospital and vice chairman of urology for the North Shore-LIJ Health System, was ready to perform the surgery quickly. Mr. McCarthy said, “I called Dr. Kavoussi and asked him, ‘If you were having my surgery, who would perform it?’ He replied, ‘Dr. Richstone.’ That was all I needed to hear.”

The surgery went as smoothly as explained, and Mr. McCarthy spent only a day in the hospital. “The next morning, he looked great – like a pre-operative patient, not post-op,” Dr. Richstone said. He added that Mr. McCarthy has had a remarkable functional recovery. He is cancer free, feeling fine and going nonstop.

“I have long been a strong supporter of the health system,” Mr. McCarthy said. “As a trustee and a patient, I have gained a new perspective. I often hear Michael Dowling [North Shore LIJ’s president and CEO] talk about patient-centric care, ‘from the bed out.’ Having occupied a bed, and experienced the care and the caring, I know what that means. Now more than ever, the North Shore-LIJ Health System has my full faith, confidence and support.”

Help Make a Difference

Your gift to the North Shore-LIJ Cancer Institute can help us in the fight against cancer, which touches the lives of everyone. To give, visit NSLIJCancerCare.org. For more information on supporting the North Shore-LIJ Cancer Institute, contact Christina Bishop-Feeny at 516-465-2554 or cbishop@nshs.edu.
Cancer Survivors Day

Survivors Share a Special Bond

Amid music and memories, cancer survivors recently celebrated Cancer Survivors Day with family members and clinicians. The North Shore-LIJ Cancer Institute hosted events in Staten Island, Lake Success and Bay Shore.

Cancer survivors form a unique community. They are bound together by shared experiences: the uncertainty and fear of diagnosis, the travails of treatment, and finally, the hope and joy of life on the other side.

At Monter Cancer Center in Lake Success, Ed Sweeney shared his story of survival and support. With a family history of cancer, the Bayside resident described his journey that began with a colon cancer diagnosis and the treatments that helped him become cancer-free.

Under the guidance of Sharona Cohen, director of the Cancer Institute's Genetics Program, Mr. Sweeney underwent a blood test that revealed he has Lynch syndrome, an inherited disorder that increases the risk of many types of cancer – particularly colorectal cancer. Noting that many of his relatives also overcame the disease, he said, “We are a family of survivors. And me, I’m a survivor. The diagnosis was like a punch in the stomach.

But I’m here,” Mr. Sweeney now advocates for others to get the simple Lynch syndrome test because it could save their lives.

New York Times health journalist Jane Brody keynoted the Monter Center event. She was diagnosed with breast cancer and treated in 1999. “My immediate reaction was, ‘At least I don’t have a fatal disease,’” Ms. Brody said. “My knowledge of breast cancer and its cure rates told me that I had a very high chance of coming through this with flying colors.”

“It’S NOT ABOUT THE DIAGNOSIS”

Now 73, Ms. Brody urged her fellow cancer survivors to live each day to the fullest. “I can’t stress enough the importance of hope,” she said. “It’s not about the diagnosis, it’s about how you approach it. What really counts is what you do to make your life full.”

Summing up the spirit of the day, she concluded, “To me, breast cancer was a speed bump, not a road block. Stay positive.”

Bringing comprehensive care – including clinical trials – to community-based settings, rather than making patients and their loved ones travel long distances for care, is the North Shore-LIJ Cancer Institute’s mission, said Michael Dowling, the health system’s president and chief executive officer. Every year, the Cancer Institute treats about 16,000 new patients.
Expert disease-focused physicians
Our 200+ physicians in over 25 specialties are nationally and internationally distinguished for their expertise in cancer care and research.

Personalized care
We provide the highest level of compassionate, patient-centered care.

Multidisciplinary teams
Our multidisciplinary teams of specialists collaborate to develop personalized treatment plans, ensuring a coordinated approach to treating cancer.

State-of-the-art diagnostics
Patients receive the highest level of cancer diagnostics from state-of-the-art technology to subspecialized radiology and pathology expertise.

Dedicated childhood cancer and blood disorder center
Our specialized pediatric hematology and oncology team diagnoses and treats children with cancer and blood disorders at Cohen Children’s Medical Center.

Cutting-edge therapies
Our specialists actively conduct cancer research and stay abreast of the most recent advances to offer patients the very latest in cancer therapy.

Vast clinical trials program
Our clinical trials program has been conducting studies for over 30 years, offers patients access to over 125 active cancer clinical trials and receives support from the National Cancer Institute (NCI).

Bone marrow and stem cell transplant programs
Our adult and pediatric bone marrow and stem cell transplant programs are accredited by the Foundation for the Accreditation of Cellular Therapy (FACT).

Extensive network of support services
Patients receive support through our range of nutritional counseling, oncology social work, survivorship and support group programs.
From left: Michael Buchholtz, MD, and Richard Byrnes, MD, from the North Shore-LIJ Cancer Institute at Huntington.