

Yale Cancer Center

centerpoint

MAGAZINE



Building a Life after Cancer
with Purpose

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On the Cover
Joshalyn Mills on location at her newly owned business.

Peter Baker **photographer**

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As Yale Cancer Center and the Smilow Cancer Network continue to plan our scientific and clinical programmatic priorities for the coming years, we have made significant investments in several programs since my arrival early in 2022.

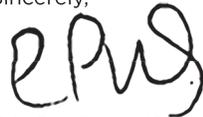
One such program is our Sickle Cell Program. Although Sickle Cell Disease is not a malignancy, it has long been part of the Cancer Center. As such, we are fully committed to reversing the many challenges that have been faced by the sickle cell community and recognize the need to develop better therapies and to attend to the day-to-day medical and psychosocial needs of these patients and their families. I am truly thrilled to announce Cecelia (Cece) Calhoun, MD, MPH, MBA, as the new Director of our Sickle Cell Program. Cece lives this mission daily through her clinical work and her research. Under her leadership, I know that our sickle cell program will thrive.

Investing in clinical cancer genetics is also an important need, and we recently welcomed Veda Giri, MD, as Chief of the Division of Clinical Cancer Genetics at Yale Cancer Center and the Smilow Cancer Network. Dr. Giri's own interests are in germline alterations in patients with prostate cancer and bringing genetic testing to underserved populations. As Division Chief, she will focus her attention on building our clinical genetics program to expand testing panels and access to genetic testing to patients and clinicians.

One of Yale's major priorities moving forward is the need to expand community outreach and engagement. Connecticut is faced with a major problem related to cancer care disparities; there is huge variation in socioeconomic status in our state leading to unequal cancer care and outcomes. We want to make sure everyone has access and care, like Joshalyn Mills, a survivor of triple-negative breast cancer that was offered a life-saving trial and shares her story in this issue of *Centerpoint Magazine*.

I am committed to using the strengths of Yale Cancer Center and the Smilow Cancer Network to reduce the significant inequities that exist in Connecticut. Providing outstanding care close to home is a first step in eradicating disparities, but alone it is insufficient. We are committed to reaching out to communities facing healthcare challenges and disparities and working together to find solutions and I look forward to sharing new initiatives in the coming months to partner with communities throughout Connecticut.

Sincerely,



Eric P. Winer, MD

Director, Yale Cancer Center

Physician-in-Chief, Smilow Cancer Network

Alfred Gilman Professor of Medicine and Pharmacology





Joshalyn Mills

Building a Life after



Emily Montemerlo writer **Peter Baker** photographer

To say that breast cancer was the last thing on Joshalyn Mills' mind at her final wedding dress fitting would not be entirely true; her great aunt passed from breast cancer and her mother is an ovarian and two-time breast cancer survivor, so her family history is often front of mind. However, she never expected to be diagnosed with breast cancer at the age of 33 and was shocked to learn she had an aggressive form known as triple-negative breast cancer (TNBC). When Joshalyn felt a lump during her dress fitting, she immediately scheduled an appointment with her gynecologist who sent her for a mammogram and biopsy. The biopsy was done two days before her wedding, and fortunately Joshalyn asked not to receive any results until after the celebration.

Triple-negative breast cancer accounts for 10-15% of breast cancer types and is considered aggressive because it grows quickly, is more likely to metastasize, and is more likely to recur after treatment than other types of breast cancer. The term 'triple-negative' comes from the fact that the cancer does not have estrogen or progesterone receptors, and does not make any or too much of the protein HER2. Since it lacks a specific protein to target with therapy, it is considered one of the more challenging cancers to treat, but recent progress has shifted that thinking.

Following her honeymoon, Joshalyn met with medical oncologist Andrea

40, women who are Black, or who have a BRCA1 mutation. For Joshalyn, who during the process learned that she carries the BRCA1 mutation, all three rang true. Dr. Silber suggested Joshalyn take part in a clinical trial looking at the concept of adding immunotherapy to chemotherapy prior to surgery. At the time of Joshalyn's diagnosis in 2017, chemotherapy before surgery was the standard of care for patients with early TNBC. The goal of combining the treatments was to eliminate any cancer present in the breast and lymph nodes at the time of surgery.

"Prior to this trial the standard of care being used in this setting had been around for over twenty years. There were no new options to offer patients," said Dr. Silber. "Over the last few years, that has changed, and patients like Joshalyn are a huge part of that change. The use of immunotherapy in the neoadjuvant setting is now the standard of care for these patients and the results have been life-changing for many."

Joshalyn had no hesitation in her decision to take part in the trial; if there was a chance it could save her life, she was going to take it. She was newly married, and together she and her husband have four children; there was no way she was going to leave a life she had only just begun. The decision to take part in the trial was easy, however the actual trial itself was not without difficulty. According to Joshalyn, she suffered from every possible side effect including her tongue

er Cancer with Purpose

Silber, MD, Professor of Clinical Medicine (Medical Oncology) at the Center for Breast Cancer at Smilow Cancer Hospital and Yale Cancer Center. Dr. Silber explained that TNBC tends to be more common in women younger than age

turning purple, full body rashes, and her finger and toenails falling off. Despite this, she saw results almost immediately.

"From August to December, I was in treatment, and by September my four centimeter tumor had shrunk almost

completely. I was shocked,” said Joshalyn. “Halfway through my treatment course I went from receiving treatment once a week to twice a week and that is when things became extremely difficult. Unrelated to the trial, I developed a blood clot in my lung and carotid artery. Thanks to the close surveillance I was under while on the trial, Dr. Silber is the one that first noticed the fatigue I was experiencing was not normal, and decided to investigate further; that is when they found the clot.”

During the moments when Joshalyn was feeling like she wanted to quit, and she shared there were several, she would remember the women that came before her to even make this trial possible. She remembers seeing her mother go through treatment and continuing to work with little side effects, but this was a different cancer and a different treatment regimen. She was not able to continue working and faced financial hardship as a result. Following her treatment, Joshalyn underwent surgery to remove any remaining tumor, but no tumor

was found. Her surrounding lymph nodes were also negative, meaning there was no invasive cancer present in the breast or lymph nodes; the trial had worked.

“Since I carry the BRCA1 mutation I decided to have a complete mastectomy and hysterectomy. Here I was, at the age of 34 with several body parts removed, no steady income, and all the plans I had for after my wedding put on hold. My advice is to take advantage of all the resources out there to help lessen the burden,” said Joshalyn. “And it may sound scary taking part in a clinical trial, but I would not be here today if it were not for the trial and the women before me that took part. I am proud to say that I am part of this story. If you have to face cancer, you might as well try and help others in the process.”

After her experience, Joshalyn officially quit her job and used cancer as the motivation she needed to start her own business. After all, she thought, ‘how hard could it be after fighting cancer?’ She had the opportunity to step back and think

about what she was truly passionate about, and is now living her best life after starting a clothing company which has since grown to include handbags, shoes, and other accessories.

Now, almost five years out from her diagnosis, Joshalyn commented, “I am determined not to let this experience stop me, but only propel me forward in every aspect of my life. It was challenging facing this cancer at such a young age, mentally, physically, and financially. I share my story so that young women know it is possible, and that they should get to know their bodies and speak up when something isn’t right.”

Joshalyn experiences no lingering side effects, except that her nails continue to fall off. She encourages other women to consider clinical trials and will often speak to those considering a trial that are unsure. She is able to have an open and honest discussion about her experience, and offer advice and support. 🔄



I cannot say enough about the altruism and generosity I have seen from patients that take part in trials, it is truly unbelievable. Joshalyn faced every obstacle head on and took charge of her health. Her participation in this trial likely saved not only her life, but future lives as well.”

—Andrea Silber, MD

A portrait of Veda N. Giri, MD, a woman with long dark hair, smiling warmly. She is wearing a light-colored, textured blazer over a patterned top. The background shows a modern building with large windows and a balcony railing.

Veda N. Giri, MD

A NEW CHIEF AND NEW PLANS FOR CLINICAL CANCER GENETICS

Steve Kemper writer Peter Baker photographer

The field of genetic testing for cancer is rapidly evolving. Veda N. Giri, MD, the new Chief of the Division of Clinical Cancer Genetics at Smilow Cancer Hospital and Yale Cancer Center is at the evolution's forefront. The field's dynamism excites her, and she has ambitious plans for a novel, comprehensive program at Yale.

"I'm a medical oncologist by training," Dr. Giri said, "and I've always had a deep interest in treating patients and in cancer risk assessment. Cancer genetics marries those two interests. Genetic testing has become central for informing us about better strategies for treating patients who carry specific genetic mutations, tailored cancer screening, and hereditary cancer assessment for patients and their families."

Dr. Giri joined Yale from Thomas Jefferson University, where she was director of Cancer Risk Assessment and Clinical Cancer Genetics since 2014. While the field of genetic testing has been grounded in assessing hereditary cancer risk, the field of precision medicine has skyrocketed the volumes of patients needing genetic testing to inform cancer treatment. "Patients and providers are increasingly interested in thinking about what genetic tests should be done to inform decisions about cancer treatment," said Dr. Giri. For example, multiple PARP inhibitors have been approved for use in the treatment of patients with a variety of cancers who carry mutations in DNA repair genes, such as BRCA1 or BRCA2, due to clinical responses. As such, patients may be referred for genetic testing to inform cancer treatment, but it still requires that patients understand hereditary cancer risk, which can be uncovered by genetic results.

Genetic evaluation requires that patients receive information to make an informed decision for genetic testing. Since germline testing involves uncovering hereditary cancer risk, the first step, she

continues, is explaining basic heredity to patients: we inherit half of our DNA from each parent, and our genomes carry more than 25,000 genes. Genetic testing assesses genes of interest based on the cancer of concern and can also uncover additional cancer risks. For instance, a man with prostate cancer—one of Dr. Giri's interests—may show a mutation in the BRCA2 gene, which signals risk not only for aggressive prostate cancer, but for pancreatic cancer, male breast cancer, and melanoma. Cancer risks for females with BRCA2 mutations include pancreatic cancer, female breast cancer, ovarian cancer, and melanoma. Since this is hereditary cancer testing, children have a fifty percent chance of inheriting mutations, and the associated cancer risks. "There is a ripple effect in families, since the genetic mutation should be tested in all blood relatives and inform tailored cancer screening," said Dr. Giri.

One key reason for genetic testing, she adds, is to inform cancer screening and prevention. If that man with prostate cancer passes on a BRCA2 mutation to his son, Dr. Giri would recommend that the son start screening for prostate cancer at age 40 instead of age 50, which is the recommendation for average-risk individuals. She also would discuss screening for pancreatic cancer especially if there is a family history of pancreatic cancer, and an annual clinical breast exam starting at age 35 for male breast cancer screening. If the patient's daughter inherits the mutation, likewise, Dr. Giri would discuss screening for pancreatic cancer, and instead of an annual mammogram starting at age 40, Dr. Giri would discuss breast cancer screening starting at age 30 or younger based on family history of breast cancer with the addition of breast MRI. For females, the national guidelines also recommend risk-reducing surgery to remove the ovaries around ages 40-45 or after childbearing due to the higher risk

for ovarian cancer in females who carry BRCA2 mutations.

"The testing can be lifesaving, as far as identifying hereditary cancer syndromes. It really has a population-level impact."

Dr. Giri sees this intersection of genetic testing, clinical care, and population science as the future of cancer genetics. She has studied inequities in the availability of genetic testing for minority and underserved populations. To address the issue, she and her team developed projects to provide education on hereditary syndromes and the importance of genetic testing for individuals and their families.

One initiative recruited African American men and trained them as "peer genetic navigators" to educate individuals in their communities about prostate cancer and genetic testing. "The uptick of interest was remarkable," said Dr. Giri. When the rising volumes of patients in need of genetic testing led to a relative shortage of genetic counselors, Dr. Giri devised an inventive work-around: an educational video that patients with prostate cancer could watch to receive information about genetic testing. More than 70 percent of patients chose the video, and 94 percent of them proceeded to genetic testing. This was the first published patient-choice study of a pretest video in a male population regarding prostate cancer genetic testing.

"Thinking of novel strategies to deliver genetic information and access to genetic testing is very exciting to me," she said. "I plan to bring innovative models across cancer types so we can have an integrated effort to raise awareness across the diverse and underserved populations served by Yale, and ensure that standard-of-care genetics services are available across all clinical settings in the Smilow Cancer Network. That's one of my primary goals."

She also intends to leverage innovative genomic technologies to explore the genetic risk for cancer across diverse populations. These technologies can include expanded

multigene testing, large-scale genomic testing, exome sequencing, and RNA testing to help clarify genetic contribution to cancer. She notes that about 80 percent of the studies on genetic markers for the risk of cancer are based on Caucasian populations, creating a gap in the data for diverse populations. “Let’s investigate and see what genetic information we can find about cancer risk across diverse populations to ensure that genetic results are informative to cancer screening and treatment to each patient we see,” she said.

“There are multiple areas that deserve expanded and deeper innovative strategies regarding genetic evaluation, cancer screening, and precision medicine to serve our patients and communities,” she said. “From team-based approaches, we can make major strides to address gaps in genetics knowledge, explore family history, and expand access to genetic services. We can focus to engage with the community, reduce disparities and enhance equity regarding the benefit of genetic evaluation, and provide support for patients and their families.”

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—Veda Giri, MD



Cecelia Calhoun,
MD, MPH, MBA

LEADING THE CHARGE AGAINST SICKLE CELL DISEASE

As the new director of Smilow Cancer Hospital's Sickle Cell Program, Dr. Cecelia "Cece" Calhoun tackles a rare disease with an urgent need for change.

Kristin Rattini writer Peter Baker photographer

Patients with sickle cell disease are often called sickle cell warriors. These patients, who are primarily African American, struggle with debilitating pain and other physical hardships associated with the inherited blood disorder, but also societal inequities and disparities that can prevent them from receiving the care that they need.

As the new director of the Sickle Cell Program at Smilow Cancer Hospital, Cecelia "Cece" Calhoun, MD, MPH, MBA, strives to ease the suffering and burden of sickle cell warriors and advance their care options by building on the program's strong foundation and rallying the tremendous resources of Yale; but most importantly, the knowledge of the community.

"It shouldn't just be about our patients' resilience or fortitude," Dr. Calhoun said. "It should also be about how we, as providers

and a healthcare system, can be an example of how to support and care for patients from disadvantaged backgrounds and help them to live their absolute best lives.”

A DEVASTATING DISEASE

Approximately 100,000 Americans suffer from sickle cell disease, which is usually diagnosed at birth. Instead of being round, the red blood cells are shaped like sickles, which prevents proper blood circulation. These malformed cells cause tremendous pain, organ damage, anemia, joint degeneration, lower resistance to infections, and other health problems. The average life expectancy for patients with sickle cell disease is approximately 20 to 30 years shorter than for the general population.

When a severe pain crisis strikes, sickle cell patients often end up in the emergency room. Unfortunately, their rare condition is unlikely to be understood and their requests for opioid medicines, traditionally used to alleviate their suffering, are often misconstrued as drug-seeking behavior by suspicious providers. “Perhaps no other group of patients has suffered more from the impact of systemic racism in the United States than those with sickle cell anemia,” said Eric Winer, MD, Director, Yale Cancer Center and Physician-in-Chief, Smilow Cancer Network. “As a cancer center, we are fully committed to reversing the horrific challenges that have been faced by the sickle cell community.”

FINDING HER CALLING

It was Dr. Calhoun’s encounter with a patient with sickle cell disease during her medical school pediatric rotation that set her on the path toward her specialty. “It was the first time I saw a sickle cell patient who had had a stroke; she was only eight,” Dr. Calhoun recalled. “I told myself, ‘You see that something isn’t right here. You can help work on it.’”

While finishing her pediatric oncology fellowship, Dr. Calhoun also earned a Masters in Public Health, so that as a physician scientist she could make a difference for patients with sickle cell disease on a larger scale. “I have one-on-one interaction with patients, which is very meaningful and impactful,” she said. “I thought, ‘How do I scale that impact?’ In the world of academic medicine, you do that through research, where we can take things we discover and help and reach patients we never meet. That is an incredible opportunity for me, especially when trying to address a rare disease with an urgent need for change.”

In her research, Dr. Calhoun has focused on interventions to help pediatric sickle cell patients managing themselves and their care as they transition to adult care. “That transition time represents the convergence of multiple factors,” she said. “The more insidious complications of sickle cell disease are coming to fruition at that age, as there’s more wear and tear on the organs. There’s normal adolescent development, a growth and desire to be independent, learn the world, and explore, but also have space

to fail safely. There is a change in resources, such as housing and insurance. There is the transition of figuring out what you’re going to do next in life. And many patients with sickle cell disease live below the poverty line, so they have socioeconomic challenges that complicate their ability to care for themselves, which are exacerbated at a turning point like this transition time.”

AN EXCITING NEW CHAPTER

In her own transition to director of the Sickle Cell Program at Smilow Cancer Hospital, Dr. Calhoun is grateful to inherit a strong foundation to build on and take to the next level. “The hospital and our entire staff have made a huge investment,” she said. “Everyone connected to our program has such a deep commitment to our patients. How we deliver care—whether within the hospital or our outpatient clinic—has allowed us to create a space where patients are moving toward health and thriving, not just surviving.”

She is thrilled with the recent hire of fellow hematologist Layla Van Doren, MD, who will focus on staff training and development. “I can’t emphasize enough my enthusiasm around having someone with her level of intelligence and commitment who can bring her knowledge not only within our healthcare system to strengthen our trainees, but also share it with our patients and our community,” Dr. Calhoun said.

A top priority for Dr. Calhoun is strengthening community partnerships, especially with Michelle’s House which is the New Haven home for the Sickle Cell Disease Association of America’s Connecticut chapter, and through the Yale Center for Clinical Investigation’s Cultural Ambassadors.

“This is not just us teaching, but listening, learning, and understanding from people who lead, who live, and who have expertise,” Dr. Calhoun said. “Through this bidirectional knowledge exchange, we can look to them for accountability, for innovation, and new ideas. We can ask, ‘How is what we’re doing serving you? How can we make it better?’”

Those strengthened community ties can enhance patient trust and confidence, especially as the Sickle Cell Program develops new therapies and services and offers them in a trauma-informed way that honors these patients’ experiences and gives them access and opportunity for a better quality of life.

“We not only need to develop new and better therapies but must attend to the day-to-day medical and psychosocial needs of this group of patients and their families,” said Dr. Winer. “Cece lives this mission daily through her clinical work and her research, and under her leadership I am convinced that our sickle cell program will thrive—providing outstanding clinical care, researching critical questions, and playing a major role in altering the trajectory of the disease.”



HIV and Cancer: Meeting a Need

Jill Lacy, MD,
and Brinda Emu, MD

In the early 1980s and into the 1990s, HIV/AIDS and HIV-associated cancers emerged in epidemic numbers causing significant mortality among infected individuals. Scientists across disease areas joined forces to attack the problem. Specialists in infectious diseases and immunology worked with oncologists who treated cancers associated with advanced HIV infection (“AIDS-defining cancers”): lymphomas, Kaposi sarcoma, and cervical cancer. Collaborating researchers developed new drugs, antiretrovirals, targeting HIV (human immunodeficiency virus). Over the next two decades, breakthrough antiretroviral therapies were allowing people with HIV to manage their disease, a medical victory that continues. Cases of AIDS plummeted, as did the incidence of AIDS-related cancers and overall mortality among people with HIV. Many researchers and oncologists turned their attention elsewhere.

Fast forward 30 years. Patients with HIV are again at higher risk for certain

cancers and it is increasingly apparent that patients with HIV and cancer are also suffering worse outcomes. The reasons behind these developments are unknown and difficult to study, partly because people with HIV diagnosed with cancer are dispersed among disease-specific oncologists.

To address these issues, the Yale Section of Infectious Diseases and the Nathan Smith Clinic, Smilow Cancer Hospital, and Yale Cancer Center recently launched an HIV and Cancer Program and dedicated clinic, a novel approach for integrated care for people with HIV and cancer. Its founding co-directors are Brinda Emu, MD, Associate Professor of Medicine (Infectious Diseases), an infectious diseases specialist in viral immunology who has been caring for HIV patients for more than 20 years; and Jill Lacy, MD, Professor of Medicine (Medical Oncology), who began her career during the height of the AIDS crisis, caring for patients with AIDS-related cancers. This integrated approach to HIV and cancer care with a dedicated team of oncologists and HIV providers is the first of its kind.

"We're a natural team for this," said Dr. Emu. "The program comes from a history of caring for patients with HIV, and also seeing a real change in the types of cancers as well as an increasing number of cancers in our HIV clinics." The non-AIDS defining cancers include liver, lung, anal, melanoma, renal cell, and head and neck cancers, among others. Dr. Emu recognized the need to return to an interdisciplinary approach that addresses the unique challenges of treating patients with cancer who also have underlying immune dysfunction due to a chronic infection controlled by strong antiretroviral drugs.

"Most oncologists now see very few patients with HIV" said Dr. Lacy. "We no longer know the HIV drugs that well, and we wonder how the patients will tolerate cancer treatments. There's a lot of uncertainty about drug

interactions. So, there's a great need again for interdisciplinary attention. Bringing everyone together for clinical care, research, and tumor board discussions will be a vast improvement for these patients."

The same is true from the HIV side, adds Dr. Emu. HIV physicians see few patients with cancer and don't feel equipped to answer their questions about the interplay between an HIV diagnosis and cancer. "I think this partnership will improve care from both sides," said Dr. Emu.

She and Dr. Lacy also expect the new program to help remedy another issue: the stark lack of data about HIV and cancer. "Historically, a large percentage of Industry-sponsored cancer clinical trials have not included patients with HIV," said Dr. Emu. "Recent evaluation revealed that 90% of studies of immune checkpoint inhibitors have specifically excluded patients with HIV."

Dr. Lacy notes that the lack of data about how immune checkpoint inhibitors interact with antiretrovirals discourages some oncologists from prescribing these incredibly effective therapies to HIV patients. "I think that's where this clinic can be hugely impactful," she said. "Oncologists can have discussions with people like Brinda who really know the field, and we can feel comfortable with the treatment plan we come up with."

Dr. Emu notes that HIV physicians and patients are focused on maintaining immunological health and may be leery of cancer treatments that cause immunosuppression, such as radiation and chemotherapy, or drugs that intensify immunological response, like immune checkpoint inhibitors. Because the data is so thin, HIV patients sometimes make decisions based on fear rather than evidence, and oncologists may reduce dosages when a patient's T cell count drops.

Drs. Emu and Lacy have identified Smilow Cancer Hospital oncologists in every disease area to help build Yale's

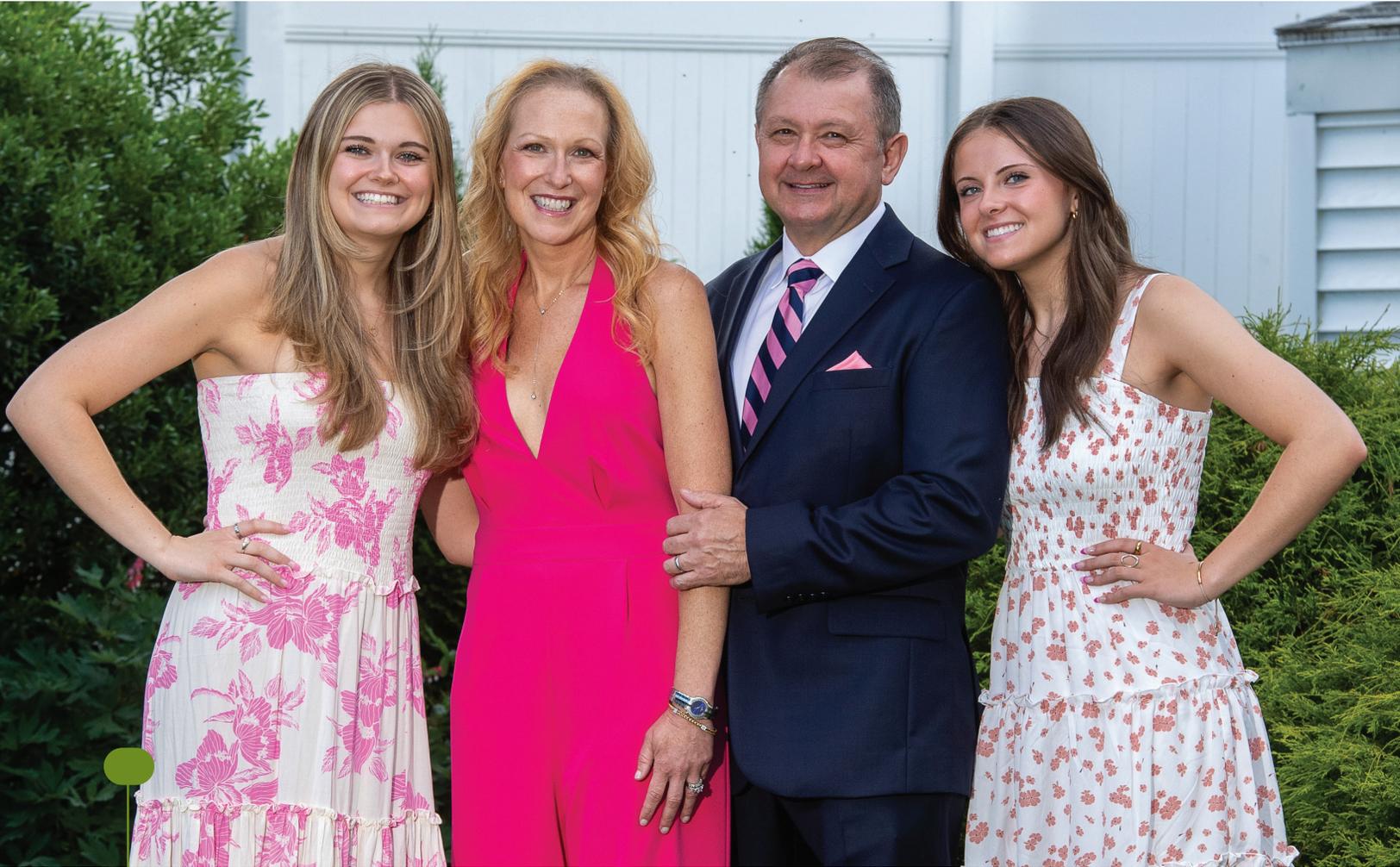


We're a natural team for this. The program comes from a history of caring for patients with HIV, and also seeing a real change in the types of cancers as well as an increasing number of cancers in our HIV clinics." —Brinda Emu, MD

expertise in HIV and cancer. Under the new program, when Dr. Emu or another HIV physician sees a patient with cancer, they will contact the patient's oncologist to talk through issues such as drug interactions and possible treatments. The program provides information, support, and guidance to HIV patients, physicians, and oncologists.

Drs. Emu and Lacy also are determined to start filling the data gap by enrolling HIV patients in clinical trials for cancer. There is already some evidence, she adds, that HIV alters cancer biology. Her lab has found that tumor microenvironments in non-small cell lung cancer and in head and neck cancer look different in patients with and without HIV. Does that difference influence a patient's prognosis? What are the implications for treatment? Such basic questions underscore the urgent need for this new program.

The clinic has been open for patient referral as of July 2022, and there has been great enthusiasm from patients and providers. By caring for patients in a comprehensive multidisciplinary way, including providing the necessary social support while engaging in cancer care, the team has already been able to identify important clinical and research questions relevant to the care of patients with HIV and cancer. By engaging a dedicated team of surgical, medical, and radiation oncologists, pathologists, and infectious diseases specialists, they are using team science and multidisciplinary care approaches to bringing improved cancer care to the community. 



A Labor of Love

After a recurrence of metastatic breast cancer in 2015, Sandy Cassanelli began to look for a charitable fund where she could channel her energy and emotion—and support. While researching online, she discovered the surprising statistics of how charities use their donations, and how so few dedicate 100% of their donations to their cause. According to CharityWatch.org, “The most highly efficient charities are able to spend 75% or more on programs,” leaving on average 25% of donations spent on general administration and expenses. Not one to sit on her hands, this disappointment quickly turned into inspiration, and Sandy launched her own fund that would directly support her oncologist and his breast cancer research.

At her next appointment with Eric P. Winer, MD, who was at the time was based at Dana-Farber Cancer Institute, Sandy posed the admittedly loaded question: “Can I do this for you—if I start a fund, can I contribute one hundred percent directly to your research?” From there, the Breast Friends Fund (BFF) was born. Its mission is to dedicate one hundred percent of every dollar raised to the metastatic breast cancer research led

The Cassanelli Family

by Dr. Winer, who is now Director of Yale Cancer Center and Physician-in-Chief of Smilow Cancer Network, and Sandy's oncologist for the last seven years.

Starting a fund like the BFF, Sandy says, "has been a gift given to her to be able to do something." She has met many fellow metastatic breast cancer (MBC) survivors who have become close friends—"her MBC sisters"—and she has lost many friends along the way as well. But establishing the fund and hosting events has created an outlet where she and her family can redirect their emotions and keep their minds busy, while also raising awareness of the disease.

The Breast Friends Fund is a huge undertaking and a labor of love for Sandy, and her family and friends. While Sandy does 90% of the work for its signature event, Taste the Cure, a food and wine fundraiser which features a silent auction, her daughters, Samantha, age 20, and Amanda, 16, manage much of the behind-the-scenes details while her husband, Craig, oversees the website. Sandy's friends help with event set-up and breakdown and gathering bottles of wine for the celebratory cork pull.

"I have a wonderfully great group of friends," says Sandy. "And my family, it's so special and meaningful to me that they are so supportive. Their love gives me the strength to keep going and keep fundraising."

So far this year, the fund has raised nearly \$200,000 with 72% coming from their signature event, while the rest has been generated from local fundraisers and golf tournaments held by businesses and friends. Seeing how far the Breast Friends Fund has come in six years, she encourages other survivors to consider starting their own fund. "Instead of waiting for new treatments and groundbreaking research to develop, I wanted to do something. We started small and every year, we developed momentum, doubling our donations, and creating awareness of metastatic breast cancer along the way."

Sandy understands her prognosis and is realistic about her future, but it has not slowed down her drive to contribute to critical research that will help other patients with MBC in the future and may possibly help her in the present.

"The work towards new cancer therapies has come very far, but we need more research. Being able to give directly so every dollar counts is so important. I'm so proud to be able to give every cent we generate directly to the work of Dr. Winer and his team."

Since Dr. Winer became Sandy's oncologist seven years ago at Dana-Farber and now at Smilow Cancer Hospital, they have formed a special connection that Sandy attributes to her continued positivity and relentless drive to raise attention and support.

"Dr. Winer is so much more than a doctor; he is part of our family, is invested in the lives of my children, and is someone

I consider a dear friend. Believing in someone like him who is compassionate, empathetic, smart—it makes me want to do more," she says.

And she does. Recently, Dr. Winer asked Sandy, a once avid runner who has never biked, if she would participate in the Closer to Free Ride, the annual bike ride in Connecticut where one hundred percent of all money raised by volunteers and riders goes to Smilow Cancer Hospital and Yale Cancer Center. Dr. Winer participated virtually, and asked Sandy if she would do the same. Without hesitation, she agreed.

"There is nothing I would not do for Dr. Winer and to support cancer research. Even though I am stage four, he always gives hope and I never feel like I am out of options. I trust him with my life, and he gives our family hope to find a cure in my lifetime." 🔄



Instead of waiting for new treatments and groundbreaking research to develop, I wanted to do something. We started small and every year, we developed momentum, doubling our donations, and creating awareness of metastatic breast cancer along the way."

—Sandy Cassanelli, Founder of the Breast Friends Fund



Medical-Legal Partnerships Bring Comfort, Relieve Stress

On a sunny Sunday morning, a 14-year-old boy accompanied his mother into a local hospital emergency department in Northwest Connecticut. The single mother, in her early 40s, had terminal cancer and was nearing the end of her life. Her only family member, her brother who lived out of state, was willing to care for her son, but without documentation in place, the hospital's social worker was mandated to call the state to take custody of the boy.

Fortunately, the mother mentioned that she had been working closely with a social worker at Smilow Cancer Hospital. Because of that, Attorney Rebecca Iannantuoni, legal supervisor at the Palliative Care Medical-Legal Partnership (MLP) at the Solomon Center for Health and Law Policy at Yale Law School, received a call at home that Sunday morning.

“These [Medical-Legal] partnerships improve access to housing and utilities, reduce stress, improve access for personal and family needs, and improve access to education and employment. We really see evidence of how these programs work as we support patients at Smilow Cancer Hospital.”

—Emily Rock, Medical-Legal Partnership Fellow

“I was able to talk to the social workers in both hospitals, the brother and the mom’s doctor at Smilow and pretty quickly worked out a standby guardian document,” said Ms. Iannantuoni, whose areas of expertise include elder law and planning for people with special needs. “The patient was transferred to Yale New Haven Hospital, where her regular providers were, with the plan to send her to stabilize her before sending her to hospice. I raced into the hospital that Sunday morning and the mom signed the standby guardian document. She was quite grateful. She was then transferred to hospice.”

The mother passed away with the peace of knowing her son was with her family. It’s just one example of how the Solomon Center Medical-Legal Partnerships allow medical providers and lawyers to work together to address patients’ legal needs, with the assistance of Yale Law School students.

“The Medical-Legal Partnership is a collaboration with Yale Law School and Yale New Haven Hospital, where lawyers and law students work together to help a number of patient populations,” said Emily Rock, Medical-Legal Partnership Fellow at the Solomon Center. “MLPs have grown over the last 10 to 20 years to over 400 across the country. Studies have shown these partnerships improve access to housing and utilities, reduce stress, improve access for personal and family needs, and improve access to education and employment. We really see evidence of how these programs work as we support patients at Smilow Cancer Hospital.”

Ms. Iannantuoni oversees a small team of Yale Law School students who work to address the legal needs of patients—often at the end-of-life. She works with Gena Lennon-Gomez, MSW, LCSW, a member of the Palliative Care Program at Smilow Cancer Hospital, who does a comprehensive social assessment of each new patient in need of assistance before making a referral to the Medical-Legal Partnership.

“Within that assessment, we’re understanding the family composition, their needs, their financial picture, and what’s worrying them—what’s causing that existential distress,” Ms. Lennon-Gomez said. The Palliative Care Team often sees a need for estate planning and custody arrangements for children. “When you’re diagnosed with a serious and life-threatening illness, you may need help executing those documents, and if it’s not in your budget—oftentimes, these are people who are already suffering some kind of financial loss—we try to help patients and families.”

She and other social workers determine patient needs, and share the information with Ms. Iannantuoni, who works with the Yale Law School students to provide the legal assistance. “I let the students do as much as they’re initially comfortable with and I review and supervise documents and their execution, so they’re never on their own,” Ms. Iannantuoni said. “It’s exciting to watch these future lawyers who are anxious about having those initial conversations with a patient start to learn how to have them. I’ve had more than one say, ‘this is the best experience of their

law school career.”

Housing and employment are two big areas where the Medical-Legal Partnership assists, Ms. Rock commented. She recalled an incident where they helped a woman receiving cancer care get housing assistance after she fell behind on her rent. She cited another case where the team helped a woman who took family and medical leave for cancer treatment only to be fired.

“In this instance, we were able to write a strongly worded letter to the employer and cite case law explaining why you cannot fire someone due to their medical treatment—and she was able to get her job back.”

The Medical-Legal Partnership team is often able to intervene earlier than most lawyers get involved, long before an issue becomes a lawsuit or legal action that could be lengthy and full of conflict. Ms. Iannantuoni and Ms. Lennon-Gomez agree the best part of their work is the ability to relieve patients of their existential distress. “You’re taking a person in an extreme point of crisis and distress and giving them some peace, it is quite a remarkable experience,” Ms. Iannantuoni said.

“You get a real sense of gratitude and honor to be part of someone’s life,” Ms. Lennon-Gomez added. “We always celebrate birth, but death is a critical part of life and if there’s any way we can help you through the process and relieve stress, that’s meaningful. We think that provides personal comfort.” ☺



meet the physician

Ian E. Krop, MD, PhD

Associate Cancer Center Director, Clinical Research Director, Clinical Trials Office
Chief Clinical Research Officer, Yale Cancer Center and Smilow Cancer Hospital

You recently joined Yale Cancer Center and Smilow Cancer Hospital to lead our clinical research initiatives. What are your priorities for the coming year?

This is an exciting time for clinical cancer research at Yale. Yale-led trials have recently led to the FDA approval of multiple highly effective targeted therapies for patients with cancer. There are also many promising new therapies developed in Yale Cancer Center laboratories and elsewhere that are currently being evaluated in clinical trials here. However, like most cancer centers, our research staff are stretched thin and are working very hard to keep up with the volume of patients who wish to participate in studies. My priority is to grow our clinical trial infrastructure and staffing so that all patients have access to the innovative new cancer therapies being evaluated in our clinical trials. We also know that not all patients can come to New Haven for their care and thus we have developed research teams in all Smilow Cancer Network sites so that patients throughout the Connecticut and Southern New England area have access to the latest and most promising clinical trials.

How do you plan to incorporate patient perspectives in the overall planning for clinical research?

This is a very important question as our patients have a unique and vital perspective to offer not only on the types of therapies that will have the most impact on people

with cancer, but also in the actual manner we conduct our clinical trials. To get this valuable input, we are fortunate to have many patient advocates, typically people who have been impacted by cancer themselves, working directly with our cancer researchers. These advocates are intimately involved in the initial development and ongoing management of virtually all the clinical trials developed here at Yale Cancer Center.

Many of our clinical trials also collect information on symptoms and quality of life directly from our patients on clinical trials rather than just from their physicians. We have found that this type of data, called Patient-Reported Outcomes, most accurately reflects the experience of patients on trials, both good and bad. We can then use this feedback to develop the therapies that optimally benefits patients.

Clinical trials have changed the landscape of treatment for women with breast cancer. How do you discuss options for clinical trials with your patients?

It is certainly no exaggeration to say that treatments for patients with breast cancer have improved dramatically in the past few decades and these improvements were possible because patients volunteered to participate in the clinical trials of these new therapies.

When discussing clinical trials with patients, I explain that the technologies used in developing new therapies for cancer have become substantially more sophisticated and our understanding of breast cancer is now much more detailed than it used to be. Because of these advances, the new drugs in our trials are typically targeted to specific vulnerabilities of a patient's cancer and thus have a much higher chance of being beneficial than clinical trials in the past. However, no trial is right for everyone, and it is important that we explain to a potential participant the possible risks and benefits of the trial, as well as the standard therapies available to the patient. In this way, patients can make an informed decision whether the trial is right for them at that particular point in their cancer journey.

Thank you to our riders, volunteers, and supporters for making the 2022 Closer to Free Ride a success!
SAVE THE DATE: SEPTEMBER 9, 2023

