

# notes

FALL 2012

## New Research Yields Promising Smart-Bomb Against Breast Cancer

### Breast Program Offers Continuum of Care

**D**irector of the Duke Cancer Institute's Breast Program Kimberly Blackwell, MD, works hard every day for her patients – and for generations of future patients. As a physician and researcher, Blackwell has led many national clinical trials in search of new, more effective, and less toxic treatments for breast cancer.

Recently, she received national attention for her research on the development of a new treatment for HER-2-positive breast cancer, which represents 20 percent of all invasive breast cancers. The treatment – called the first smart-bomb for breast cancer -- links standard chemotherapy with a second agent that homes in on breast cancer cells to do a more effective job of killing those cells while sparing healthy cells. The clinical trial showed that the therapy extended survival time and significantly reduced side effects like nausea and hair loss.

“We've envisioned a world where cancer treatment would kill the cancer and not hurt the patient,” Blackwell, a medical oncologist, told the *New York Times*. “This therapy does that.”

This particular clinical trial has ended and the therapy, T-DM1, has not yet received approval by the Food & Drug Administration and is not yet available for patients. However, other clinical trials evaluating potential new therapies, and new patient care approaches and resources for various forms of breast cancer as well as other forms of cancer are available to patients at the Duke Cancer Institute.

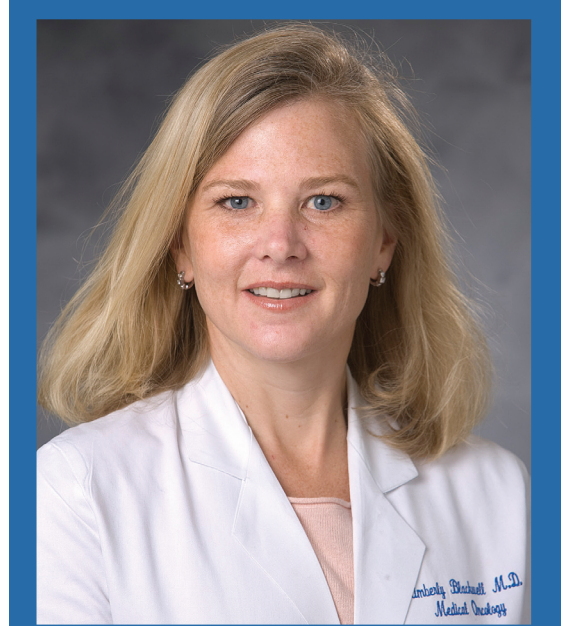
“We want our patients to have access to any

resources they need, and that includes clinical trials,” Blackwell said. “In 2011, more than 900 studies and 5,741 patients were enrolled in clinical trials at the Duke Cancer Institute.”

In addition to clinical trials, patients at the Duke Cancer Institute receive the most advanced imaging and diagnostic services, and medical and surgical care, as well as expertise in disease progression and recurrence, and supportive care for patients and their families. The Breast Program's multidisciplinary team provides expertise and services for all men and women. “Our team of experts treats only patients with breast cancer, so we understand the needs of all populations of patients and work to create individual treatment plans for each patient,” explained Dr. Blackwell.

The program has specially designed care strategies for younger women who may have fertility issues and other special needs, for older patients with complex medical conditions, and for women with inflammatory breast cancer (IBC is a rare but aggressive form of cancer). Neil Spector, MD, of the DCI is a nationally recognized expert in IBC. In addition, the DCI provides counseling in its Hereditary Cancer Clinic for families with a history of breast cancer, a program that medical oncologist Kelly Marcom, MD, leads.

A special Breast Cancer Survivorship Clinic, led by medical oncologist Jeff Peppercorn, MD, is devoted to addressing the special needs of the thousands of people who are living with a history of breast cancer.



Dr. Kimberly Blackwell, Director, Breast Oncology

A powerhouse of eleven surgical oncologists and reconstructive surgeons provide the most advanced surgical procedures, including oncoplastic surgery and the latest in microsurgical reconstructive operations.

“We have an outstanding team of specialists at our facilities in both Raleigh and Durham,” explains Blackwell. “Working together, our goal is to provide the most patient-centered, advanced and compassionate care to every patient that walks through our doors.”

For more information about the Duke Cancer Institute, including a complete list of services and specialists in the Breast Program, visit [dukecancerinstitute.org](http://dukecancerinstitute.org).

A full list of clinical trials available at the Duke Cancer Institute can be found online at [dukecancerinstitute.org](http://dukecancerinstitute.org). Click on the Patient Care section, and then the left-hand link to Clinical Trials. ♥

## Duke Cancer Institute Names New Deputy Director



Steven R. Patierno, PhD

**S**teven R. Patierno, PhD, has joined the Duke Cancer Institute as deputy director. Patierno now serves as the institute's senior administrator and scientific and operational leader across a broad spectrum of activities including cancer control, health equities and health disparities, global health, survivorship, informatics, and cancer policy.

Patierno most recently served as executive director of the George Washington Cancer Institute and as director of the Molecular and Cellular Oncology Program at George Washington University Medical Center.

“I am very impressed by Dr. Kastan's vision of the Duke Cancer Institute and the commitment by Duke to integrate all aspects of cancer care, research, education, and outreach into one entity,” says Patierno. “I am excited about this opportunity to help with this effort to bring together researchers, clinicians, community members, and policy makers to help fulfill the vision.”

An internationally recognized researcher, Patierno is a leading expert in cancer causation and carcinogenesis. His basic research laboratory has made major contributions to our understanding of the role of genetic damage in the balance of cell death and survival at the very earliest stages of cancer. He has also explored the mechanisms of development of cancer cell resistance to chemotherapy and the development of bio-therapeutics that control the metastatic spread of cancer. Currently he is engaged in studies on the genomics of cancer disparities, which he will continue in his own lab at Duke. Not content to limit his focus on basic science, over the past nine years Dr. Patierno extended his grant portfolio into cancer health services, survivorship, and community health research and is recognized nationally as leader in cancer health disparities and cancer control interventions in medically underserved communities including Patient Navigation. ♥





## New Breast Imaging Suite in Duke Cancer Center Offers Most Advanced Care

Duke Cancer Center Mammography and Imaging Suite

immediate access to the entire scope of care provided by the Duke Cancer Institute's Breast Oncology Program. These services include medical and surgical care, innovative clinical trials, supportive care for patients and their families, advanced plastic surgery techniques, and expertise in the entire spectrum of breast treatment. ▀

**D**uke Cancer Center is home to a new state-of-the-art Mammography and Breast Imaging Suite. This breast imaging center of excellence, designed for comfort and privacy, opened in spring 2012, offering patients the most advanced mammography and diagnostic imaging capabilities.

Breast ultrasounds, breast MRIs, screening mammograms, diagnostic mammograms, ultrasound guided breast biopsies, and stereotactic biopsies are offered at the new imaging suite. Saturday screening appointments are offered with same-day results and same-day biopsies are often available on week days. Fellowship-trained radiologists, specializing in breast imaging and care, offer these services using the most advanced technology available.

"We pride ourselves on providing the best care possible, and providing timely answers to minimize anxiety," says Jay A. Baker, MD, chief

radiologist of the Duke Division of Breast Imaging and an associate professor of radiology.

"A great deal of thought was put into this new breast imaging suite," says Marie Stone, chief technologist of the Breast Imaging and Outpatient Imaging Clinics. "The suite was designed based on patient feedback. We want our patients to have the very best experience possible; we listened to them as they shared their needs and wishes."

Mammography and breast imaging services are also offered at five other Duke Medicine locations throughout the Triangle. The Outpatient Imaging Center at Duke Medicine Plaza; Duke Raleigh Hospital; and Durham Regional Hospital all offer annual mammograms as well as diagnostic breast imaging. Locations at Duke Medical Plaza Patterson Place and Duke Health Center at Southpoint, both in Durham, also offer annual mammography services.

If needed, mammography patients have

### MAMMOGRAPHY FACTS AND GUIDELINES FROM NATIONAL CANCER INSTITUTE (NCI)

- A mammogram is an X-ray picture of the breast. Screening mammograms are used to check for breast cancer in women who have no signs or symptoms of the disease. Diagnostic mammograms are used to check for breast cancer after a lump or other sign or symptom of the disease has been found.
- Screening mammography can help reduce the number of deaths from breast cancer among women ages 40 to 70.
- NCI recommends that women age 40 or older have screening mammograms every 1 to 2 years.

## DCI Office Responds to Needs of Community, Patients and Physicians

**C**ancer is a medical condition that causes distress. When people aren't informed or don't have access to the right resources, their level of distress increases.

The Duke Cancer Institute (DCI) recently created the Office of Health Equity and Disparities to work in partnership with groups in the community to promote health equity in cancer care and remove disparities and barriers to providing the best care for all patients.

The office partners with many community groups including El Centro, Durham County Health Department, Wake County agencies, faith-based organizations, and grassroots organizations to educate and engage people in the community about the health care system and resources available to them. For example, the office recently began working with promotoras, Latino community health workers, and faith based organizations, to educate their community about the risks of cancer, the importance of being screened, and the resources available locally.

"Groups like this play a significant role in helping us reach the hardest to reach populations," says Nadine J. Barrett, PhD, MA, MS, the office's founding director. "We want to make sure every person who needs help and information has a place to turn – and we want to be that place."

The office operates as a center for information about resources. "For those needing screening services or in treatment, we offer assistance and advice about the best resources for an individual that can help them overcome barriers to receiving optimal healthcare," Barrett says. "Our office is committed to engaging and educating our community, helping our patients navigate

through their journey with cancer, and dispelling myths about health care."

The staff is also working steadily to remove any barriers that might keep a person from accessing and using cancer services at Duke. They work with community groups and individuals in the community to respond to misperceptions about clinical trials in particular. Some perceive these studies as experiments rather than opportunities for care provided by a new treatment.

Valarie Worthy, a patient navigator for the office, said that in spite of reassurances, myths still persist. "For example, some people may believe that undergoing surgery can cause cancer to spread," Worthy explains. "That's not true. Our job is to address those myths and

provide accurate information."

Barrett and her team also advise and work with physicians and providers at the Duke Cancer Institute to ensure that they are able to communicate effectively to their patients about their treatment, clinical trial opportunities, and resources available to them.

"The Duke Cancer Institute and the Office of Health Equities and Disparities have an opportunity to establish a better dialogue with members of our community. We know that when we understand and address community needs and the needs of the patient, we are better able to ensure that every patient receives the best care," says Barrett. "That's our goal." ▀

Kevin Seifert Photography



From left, Xiomara Manon Boyce, patient navigator; LaMisha De'lor Banks, patient navigator; Nadine J. Barrett, PhD, MA, MS, director; and Valarie Worthy, patient navigator.

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## Lung Screening Can Detect Early-Stage Lung Cancer

Low-dose CT screening is the most effective way to find very small abnormalities in the lungs, even before they can be seen on conventional X-rays.

At the Duke Cancer Institute's Lung Cancer Screening Clinic, individuals at high risk for developing lung cancer can participate in a lung cancer screening program that provides access to the most advanced diagnostic screening tool: low-dose spiral CT scans. In addition, smoking cessation evaluation and counseling are provided as well as follow-up treatment, if needed.

"Low-dose CT screening is a noninvasive medical test that can help physicians diagnose and treat lung cancer as early as possible," said Betty Tong, MD, MHS, an assistant professor in the Duke Division of Cardiovascular and Thoracic

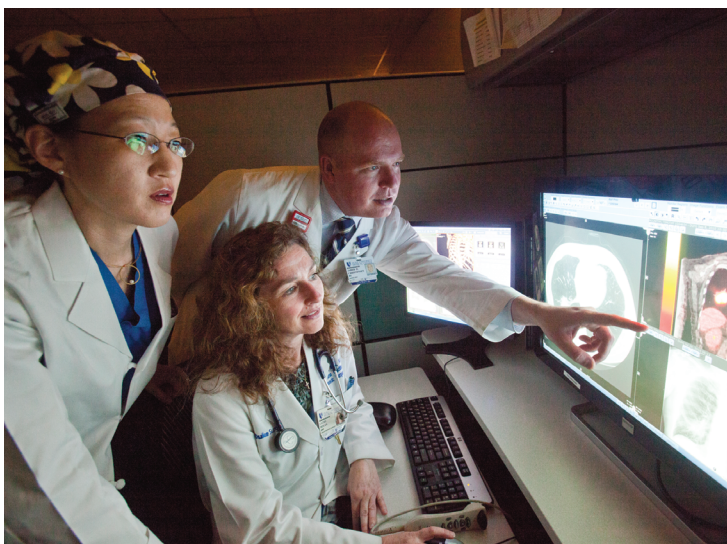
Surgery. "As with other forms of cancer, when lung cancer is diagnosed at an earlier stage, survival is greatest." Tong is co-director of the new screening program along with Dr. Jared Christensen and Dr. Jennifer Garst.

Results from the National Lung Screening Trial showed that among people at high risk for developing lung cancer, those screened with low-dose CT scans had a 20 percent reduction in lung cancer-related mortality compared to those who were screened with standard chest X-rays.

About one-fourth of patients who are screened may have a positive screen. (See sidebar to learn who should be screened for lung cancer). However, only about 4 percent of patients with a positive screen have lung cancer. For these patients, the screening study is the first step in the comprehensive care provided by the Duke Cancer Institute's team of lung cancer specialists.

To learn more about low-dose CT screening for lung cancer, call 888-ASK-DUKE. Appointments are available at both Duke Cancer Center and Duke Raleigh Cancer Center. ♥

Thoracic surgeon Betty Tong, MD, MHS (left), and radiologist Jared Christensen, MD, (right), co-directors of the Duke Lung Cancer Screening Program, examine a lung image along with Cathy Hogan, (center) a certified tobacco treatment specialist.



### WHO SHOULD BE SCREENED FOR LUNG CANCER?

Current guidelines recommend low-dose CT screening for patients who meet the following criteria:

Either

- Ages 55 to 74 years
- 30 pack-years\* or more smoking history
- Current smokers or individuals who quit less than 15 years ago

or

- Ages 50 or older
- 20 pack-years\* or more smoking history
- Have one additional risk factor for lung cancer:
  - Exposure to radon, asbestos, silica, or other carcinogen
  - Personal history of lymphoma or smoking-related malignancy (e.g., head and neck cancer, bladder cancer)
  - Family history of lung cancer

\*Pack-years, as defined by the National Cancer Institute, are calculated by multiplying the average number of packs of cigarettes smoked per day by the number of years an individual has smoked. The following are all equivalent to a 30 pack-year smoking history:

- 1 pack per day for 30 years
- ½ pack a day for 60 years
- 2 packs a day for 15 years

## Exercise: A Secret Weapon in the fight against cancer and its side-effects?

Lee W. Jones, Ph.D., is a man with a mission: He is investigating how exercise can benefit individuals with cancer. He wants patients to look at exercise as another weapon they have to fight and control cancer and its side-effects.

Jones, an associate professor in Radiation Oncology at the Duke Cancer Institute, is a crusader who believes that daily exercise is as necessary and essential as eating and sleeping.

He and his team have worked with numerous patients with many different types of cancer; they are documenting the benefits of defined exercise training among these groups.

Earlier this year, Jones and co-authors published findings in the *Journal of Clinical Oncology* that found that patients with brain cancer who exercised at the national recommended levels (150 minutes of moderate-intensity exercise per week) lived significantly longer than individuals not meeting these guidelines.

"This provides some initial evidence that we need to look at the effects of exercise interventions, not only to ease symptoms but also to impact progression and survival," said Jones, who was senior author of the study.

Although the study was not designed to test whether regular exercise actually causes longer survival among brain cancer patients, it established a strong correlation that could point to the advantage of exercise as another weapon in the fight against cancer.

In another study by Jones and his team published this spring, again in the *Journal of Clinical Oncology*, Jones studied women receiving care for breast cancer. All completed a carefully controlled

cardio-pulmonary exercise test on a stationary bike, which escalated until the patients reached maximum exertion. To their surprise, despite the breast cancer patients being several years out from the completion of treatment, their levels of exercise tolerance were very poor compared to women of the same age without a history of breast cancer.

"We know that exercise tolerance, which measures global cardiopulmonary function, is among one of the most important indicators of health and longevity in people who do not have cancer; however, relatively little research has been done assessing the clinical importance of these tests in patients with cancer," said Jones, who was lead author of the study. "Our work provides initial insights into the effects a cancer diagnosis and subsequent therapy may have on how the heart, lungs and rest of the body work together during exercise."

Exercise tolerance is an important predictor of the future risk of several different chronic diseases including cardiovascular disease, Jones said.

"This is important because women with breast cancer are at high risk for long-term cardiovascular disease after the completion of breast cancer treatment; it may also be an important predictor of cancer-specific survival among



Lee Jones, PhD, and patient Danny Robbins.

cancer patients," Jones said. "The beautiful thing about fitness, of course, is that we can improve it with exercise training. Although we currently do not know if improving fitness in cancer patients is associated with longer survival, our data provides initial evidence to pursue this question."

Indeed, the study examining exercise tolerance levels in breast cancer patients also included a small cohort of women with advanced cancer. Among these patients,

survival was significantly longer for women with higher cardiopulmonary function. Jones said the findings of this study indicate that exercise may be a good intervention for cancer patients both during and after therapy.

The Raleigh News and Observer newspaper reported this year that Jones' team has found that some kinds of tumors grow 30 percent to 50 percent slower in mice that exercise.

Exercise is one of those interventions that can fundamentally change people's lives, Jones said. "With the research we are accomplishing, I think we will be able to transform our bodies from a place where cancer likes to be to a place that is more hostile to cancer cells." ♥



# Looking Forward

Bride doesn't let diagnosis derail wedding, plans for future

2012 has not gone exactly as Maria Tyson expected.

As the year began, the bright, beautiful and accomplished North Carolina native was in love, and was looking forward to getting engaged and married. To work around her busy career as an academic advisor to student-athletes at N.C. State University, she and beau Kevin Crockett had already set the wedding date: September 8, 2012.

Then, on Valentine's Day, the unexpected happened. Concerned that "something didn't feel right," she went to her doctor in Raleigh, who immediately sent her for a CT scan and referred her to local specialists. Over the next six weeks, Maria had three biopsies, and on April 5, 2012, the diagnosis was official: the bride-to-be had mediastinal large B-cell lymphoma. Seeking a second opinion on treatment, Maria came to the Duke Cancer Institute on April 23 – just two days after Kevin's official proposal – to meet with oncologist Jon Gockerman, MD, and nurse practitioner Heather Brumbaugh. Four days later Maria began her first round of chemotherapy at the Duke Cancer Center in Durham.

## 'STICKING WITH THE PLAN'

Maria, Kevin and her parents discussed what to do about the wedding. Should they postpone? Should they change the scope of the wedding?

"Kevin and I were always on the same page that we still wanted to get married and didn't want to push the wedding back," says Maria. The couple decided to stick with the original plan for a large wedding at her parents' church in Nashville, N.C., with a reception in Rocky Mount.

"Being a wife is the one thing in life that I've always wanted to be. I have really good role models: my parents just celebrated their 40th anniversary, so that is something I've always aspired to. God brought Kevin and me together in His time. We both have been patient, and this is definitely our reward, because we are two peas in a pod!"

## DID SOMEONE SAY 'WEDDING?'

As Maria went through chemotherapy, she felt blessed that she didn't have tremendous side effects. "The biggest things were the hair loss and fatigue, but I was able to continue working fulltime and planning a wedding through it all."

One day at the Duke Cancer Center, Maria and her mother were browsing in the Belk Boutique. As they flipped through a "look book" filled with photos of fashionable women wearing stylish scarves and hats (Maria prefers these to wigs), they noticed a beautifully adorned headpiece and commented that they still needed to figure out what Maria would wear on her head for the wedding.



Grace Lukas with Maria Tyson and her mother Mildred Tyson

Grace Lukas, the bubbly boutique manager, overheard the word "wedding" and couldn't resist. Talking with Maria and Mildred, Grace mentioned that one of the Cancer Patient Support Program's volunteers might be able to design a custom headpiece and veil. A few days later, Maria was in touch with designers (and identical twins) Connie Bossen and Carolyn Warren – and the planning process for a one-of-a-kind wedding headpiece was underway.

## A SINGULAR – AND SURPRISE – HEADPIECE

Over the next few weeks, Maria, Connie and Carolyn spoke often, sharing ideas and meeting several times, including a fitting at the Belk Boutique where Maria wore her wedding dress along with the headpiece. Already stunning, the bride-to-be simply glowed.

"Connie and Carolyn have been amazing," Maria says appreciatively. "They have put in so much time to create something that is very meaningful to me."

The sisters relished the opportunity. "There aren't many options out there for women in Maria's situation. This is one of the most important days in your life, and you want to look gorgeous and glamorous, and also to feel really confident. For us to be able to help do that

for her has been extremely gratifying."

During the fittings, Kevin and Maria's father William chose not to see the headpiece so they could enjoy the surprise at the ceremony.

## CHEMOTHERAPY BEHIND HER

On August 9, Maria completed her last chemotherapy treatment, and was able to focus fully on the final wedding plans as September 8 approached. The wedding took place as planned without a hitch. After their honeymoon in Florida, Maria returned to Duke for a scan. She will come back periodically over the next few years to make sure the cancer has not returned.

## EXTRAORDINARY SUPPORT FROM FIANCÉ, FAMILY, FRIENDS – AND THE DUKE CANCER INSTITUTE

Having a strong support system is essential to making it through both cancer treatment and wedding planning, Maria says. On both accounts, she has had the best.

Kevin, a church musician, accompanied her to every treatment. Her parents, both retired, also came to appointments and helped her at home. Family and friends helped with wedding details.

"God has blessed me tremendously with great family, an amazing fiancé, and awesome friends



and co-workers,” Maria says. “I’m definitely Miss Independent, so having to rely on other people was a transition, but I was very thankful because I could delegate, and many people took it upon themselves to step forward and help.”

Support from faculty and staff at the Duke Cancer Institute has also been extraordinary, Maria notes. “One of the benefits of coming to a comprehensive cancer center is that you not only receive great medical care, but also additional support. Certainly having made the connection



Connie Bossen, (left) volunteer in the Belk Boutique, and her sister Carolyn Warren display some of the clothing in the boutique that they designed. They collaborate on selecting fabrics and specially designing headpieces for women with hair loss.

to be able to get a custom headpiece was absolutely amazing and unexpected! Plus, every time I go up to the fourth floor of the Cancer Center to get treatment, it’s hugs all around!”

Dr. Cheyenne Corbett, LMFT, director of the Duke Cancer Patient Support Program, says

Maria’s experience is a wonderful example of Duke’s commitment to support the whole person. “Caring for our patients goes beyond treating the disease. We want to support each person in whatever ways we can – in this case, by helping Maria feel even more comfortable and confident on her wedding day! The custom headpiece is beautifully crafted. Our team was honored to be a small part of helping make this day special for Maria and her family.”

#### ‘ATTITUDE IS HUGE’

Maria tells her N.C. State University students: “Being able to look forward gives you great focus and perspective. You can easily get caught up in the here and now, but the reality is, anything you can see is temporary.”

Dr. Gockerman has seen that positive attitude and courage throughout Maria’s treatment. “When a young woman is faced with a medical problem she did not create and she is uncertain as to how it will impact her future, then it takes great courage and fortitude to proceed with chemotherapy in this uncertain environment. Maria has had that courage and has proceeded ahead with her life.”

Brumbaugh, the nurse practitioner who has worked closely with Maria over the past few months, has also been impressed by her positivity. “Maria is a delight to work with. Despite her diagnosis she has continued to plan and look forward to her wedding, and I think that has helped her to get through her therapy.”

For Maria, the approach is a choice. “Nobody would make the choice to have to deal with cancer, but the attitude with which you choose to approach it is huge. God has been with me every step of the way, and brought me through, and surrounded me with amazing people.”

## THE HEADPIECE

Maria’s vintage-inspired headpiece plays off the ornamentation on her dress.

Designers Connie Bossen and Carolyn Warren created a gorgeous beaded cap with two veils: a traditional white tulle veil, and a beaded over-veil that matches the cap. The versatile design allowed Maria to wear the cap alone or with the beaded veil during the reception.

Connie and Carolyn enjoyed working together to make a singular piece for Maria’s special day. “It has been so gratifying for us to be able to use our talents and creativity to help Maria. She is such a beautiful person, inside and out,” Connie said.

*The sisters’ Niquelle Collection of “confidently chic headwear” is available at the Belk Boutique, conveniently located in the lobby of the Duke Cancer Center. The Boutique offers wigs, turbans, hats and scarves to patients experiencing hair loss as a result of their treatment. Patients can also receive consultations for post-surgical garments from the trained volunteers who staff the store.*



Maria Tyson’s wedding headpiece.



Maria Tyson with fiancé Kevin Crockett



## Advocate Works to Give Patients and Families a Voice

After undergoing her second lung transplant, Tiffany Christensen knew what she wanted to do with her life. Born with genetic lung disease, Christensen had been in and out of hospitals her entire life and knew the challenges patients faced.

"I wanted to use my own experience to help other patients," Christensen explained. She spent the next seven years speaking to and training patients and care providers about patient safety, patient advocacy, the patient experience and end of life care, and found time to author three books. In 2008, she was invited to join the Duke Medicine Patient Advocacy Council.

Several years later in February 2012, Christensen joined the Duke Cancer Institute as an oncology patient advocate; she continues to serve on the Patient Advocacy Council.

"Tiffany is a huge asset to the Duke Cancer Institute - to our patients and staff," says Tracy Gosselin, PhD, RN, AOCN, associate chief nursing officer and assistant vice president for the Duke Cancer Institute "She creates opportunities for communication and problem solving that are critical to providing the best care for our patients."

"I have an intimate understanding of the patient experience, but I also have worked with physicians and staff and can see things that patients may not understand about the complexity of the healthcare system. I want to pull back the curtain and allow everyone to see

humanity on both sides," explains Christensen.

Information and communication are critical elements in great patient care, according to Christensen. She often acts as a liaison between patients and family members and the physicians and staff, facilitating conversations and exchanges of information.

She urges patients to complete the surveys they receive from Duke in the mail after an appointment. "That's how we know what needs to be improved. We can't fix what we don't know."

Her role includes working side by side with care providers. She offers training to help clinicians and staff recognize the challenges patients face and find appropriate ways to communicate effectively. She helps them learn how to determine what information is important to convey and how to convey the messages.

"Logistics can often be just as stressful as the actual treatment or care experience itself. It's important to understand that. Our patients and their families walk in the door to the Cancer Center often anxious and exhausted," says Christensen. "I know because I have been there."

Christensen and Gosselin are currently working to create the Duke Cancer Institute's Patient



(l to r) Tracy Gosselin, PhD, RN, AOCN; Margaret Skulnik; Tiffany Christensen; and Jennifer Loftis, RN, MSN, AOCNS, are co-chairs of the Patient Experience Council.

Experience Council, which will comprise patients and families as well as physicians and staff. The group will meet regularly to discuss a variety of topics including initiatives and programs. Individuals interested in participating on the committee should contact Christensen at [tiffany.christensen@dm.duke.edu](mailto:tiffany.christensen@dm.duke.edu).

"Our goal is to have our patients and families more involved and engaged," says Gosselin.

Christensen and Gosselin are also forming the Duke Cancer Institute's Patient and Family-Centered Care Committee. The group will take the information gathered from the Patient Experience Council and translate that information into action, implementing appropriate change into practice to enhance the experience for all patients.

"Every day my goal - and the goal of the Duke Cancer Institute - is to help our patients and their families recognize that they have a voice, that we care about what they have to say, and that they are understood," Christensen says. ▀

## Hope lives at The Preston Robert Tisch Brain Tumor Center at Duke *Brain Tumor Center Celebrates 75 Years of Discovery and Care*

Established in 1937 as one of the first brain tumor research and clinical programs in the United States, the Preston Robert Tisch Brain Tumor Center has advanced to become one of the leading pediatric and adult neuro-oncology programs in the world. Today, Duke is recognized as an international leader in comprehensive care that combines research breakthroughs, clinical trials and the newest therapies to patients with brain tumors.

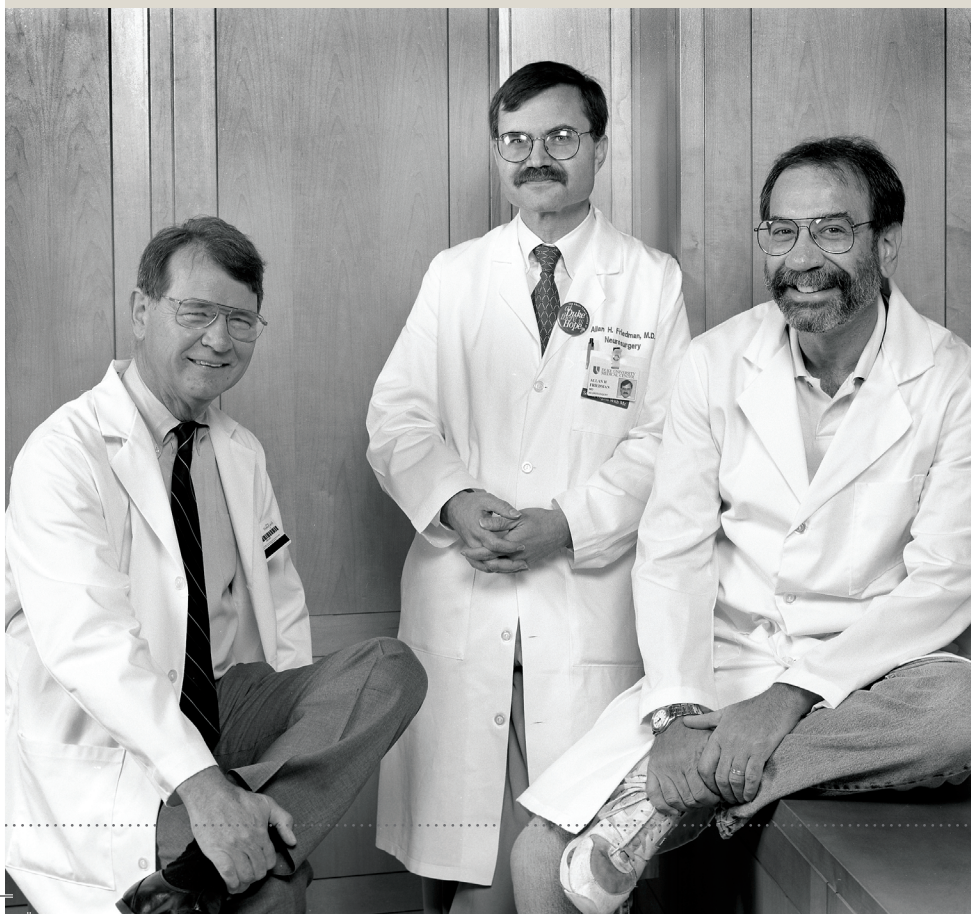
"We understand how overwhelming a brain tumor diagnosis can be, how it shifts life priorities, makes relationships more meaningful, time more precious. We show our commitment to our patients by accelerating progress in the race for a cure," says Henry Friedman, MD, deputy director of the Brain Tumor Center with Allan Friedman, MD. Darell Bigner, MD, PhD, serves as director of the center.

Duke researchers and physicians work together to bring discoveries from the laboratories into the clinic to offer patients new options for treatments.

"In the last 75 years, the treatment of patients with brain tumors has improved dramatically. We have made great progress," says Bigner. "And each year, our team of researchers makes new discoveries and partners with Duke physicians to offer new and improved ways to treat patients with brain tumors. And we are seeing the results of our work as our patients live their lives and with a higher *quality* of life."

One Duke brain tumor researcher, Hai Yan, PhD, is using a \$1 million grant he received from Accelerate Brain Cancer Cure and the V Foundation last year to further his work in developing novel approaches to target gliomas, the most deadly form of brain cancer. "This grant provides me with an exceptional opportunity to conduct this study which could lead to a greater understanding of cancer metabolism. It may yield clues to targeting other cancers as well," said Dr. Yan. "These new discoveries and the areas of research give our patients hope." ▀

1999 photo of Darell Bigner, MD, PhD; Allan Friedman, MD; and Henry Friedman, MD (from left)





## Finding—and Sharing—Hope Against Cancer

Todd and Jennifer Sullivan never knew life together without cancer. Shortly before they were engaged, Todd was diagnosed with melanoma. With humor, close friends, and a deep commitment to each other and their families, they made the most of their brief time together. Todd died in November 2011.

“For all the heartache and disappointment the cancer caused, it also provided us a perspective that many are not fortunate to discover until later in life,” says Jennifer.



During his treatment, Jennifer and Todd spent weeks at Duke and thought of their care team as a second family.

“They knew our family, even our dogs, Molly and Gracie. Where we lost hope, Duke gave it back to us.”

As much as possible, Todd focused on the things he loved in life—music, cooking, traveling, and outdoor activities like bird hunting, fishing, and being in the mountains. Towards the end of his journey with

Todd and Jennifer Sullivan on the front porch with their dogs, Molly, left, and Gracie, right.

The Fayetteville couple, who met in Wilmington, N.C., came to the Duke Cancer Institute for Todd’s treatment. They credited the care they received from Doug Tyler, MD; Michael Morse, MD, MHS; Scott Shofer, MD, PhD; and Mark Onaitis, MD, with giving them six good years together.

“If you read the statistics on melanoma, we truly weren’t guaranteed those years,” says Jennifer. “I am thankful that the care Todd received at Duke extended his life.”

cancer, he began to think about what he could do to help others.

“We were sitting on our front porch at the very end of his life, and he said ‘You know what?’ Maybe we should do more for the cause.”

After Todd’s death, Jennifer began to enlist the support of family and friends to find a way to honor Todd’s memory and help others fighting cancer. She established an endowment in support of cancer research at the Duke Cancer Institute. In May 2012, just before what would have been Todd’s 38th birthday, Jennifer announced to a group of enthusiastic supporters in Fayetteville that the endowment was just \$6,000 short of the \$50,000 goal.

That night, she issued a challenge. She would match donations dollar for dollar. The guests would not hear of it. Six different families raised their hands to each donate \$1,000. That completed funding for the \$50,000 Todd M. Sullivan Endowment for cancer research.

“I have never seen an endowment come together this fast,” said David Mainella, deputy director of development at Duke Cancer Institute.

“This is what Todd wanted,” says Jennifer. The endowment will support research of melanoma and other forms of cancer. ♥

## Care at Duke Cancer Institute Inspires Gift to Cancer Fund

Growing up in Pakistan, Muhammad Khan knew much about the most storied universities in the United States—Harvard, Yale, and Duke. He earned his college degree in Pakistan, excelling in computer science, and landed a job in New York City, where he immigrated in 2002.

He later moved to Charleston, S.C., and became a businessman, opening several small businesses, including Uniform Land, a store that sells all varieties of professional uniforms. His business mantra has always been to give back to the communities that support him.

So when he opened Uniform Land in April 2012 at Northgate Mall in Durham, there was no question that he would support the medical mission at Duke, and pledged \$30,000 of unrestricted monies to the Duke Cancer Fund.

“The Duke Cancer Institute does a lot of great things, not only taking care of patients, but research as well,” said Khan, age 39.

Khan’s gift is somewhat non-traditional in that he had no prior ties to Duke, other than his deep admiration. His sister died in Pakistan of cancer in the late 1990s, when there wasn’t a single cancer hospital in the entire country.

“The doctors there were not very educated on cancer treatment,” he said. “But the physicians at the Duke Cancer Institute are. If researchers at Duke can cure this disease, the whole world will benefit.”

Pakistan now has a cancer hospital—the Shaukat Khanum Memorial Cancer Hospital and



Muhammad Khan

Research Center in Lahore, thanks to donations from a famous Pakistani cricket player.

“A lot of folks donate to communities back home, which I do, too,” Khan said. “But I also want to do as much as I can in the communities where I do business. In my religion, which is Islam, if you do something good in this life you will get an everlasting benefit in the next world.” ♥

## thanks

The Duke Cancer Institute wishes to thank renowned North Carolina artist Bob Timberlake for his donation of artwork in support of our fundraising efforts in the fight against cancer. Mr. Timberlake has been a member of the Board of Overseers since 1994.





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# ask the expert

The Duke Cancer Patient Support Program offers psychosocial care and support including marriage and family therapy, support groups, self-image resources, volunteer companionship and peer support to patients of the Duke Cancer Institute and their families at no cost. **Cheyenne Corbett, PhD, LMFT, is director of the program.** Pictured left to right with Corbett (center) are Tracy Berger, MS, LMFT; Ben Weast, MA, LPC, NCC, CT; Patrick Plumeri, MS, LMFT; and Geoffrey Vaughn, MA, LMFT, ATR, all medical family therapists in the program. For patients with cancer, medical treatment focuses on their disease and their physical body. But cancer doesn't just affect their physical bodies: It affects the emotional, social/relational, psychological, practical, and spiritual aspects of their lives, as well.



## What are psychosocial oncology services?

**DR. CORBETT:** Psychosocial oncology services address the challenges that patients and families with serious illnesses often face. As recently as 30 years ago, there were few psychosocial oncology programs, and many people felt there was no one to support them throughout their cancer experience.

Our program was established in 1987 by Rachel Schanberg, MEd, NCC. Rachel's daughter, Linda, was a teenager getting ready to head off to college when she was first diagnosed with cancer. The Schanberg family saw the need for psychosocial interventions and services, and worked to establish the program here at Duke in Linda's memory. Through the years, we've seen an increase in the prevalence of psychosocial support programs. These programs are now vital parts of cancer care.

## Why are psychosocial oncology services important?

**DR. CORBETT:** At the Duke Cancer Institute, we care for the whole person and the entire family, because cancer touches the lives of each member of the family system. Research shows that psychosocial oncology interventions and services can help decrease distress; improve quality of life; and increase behaviors that promote better health. More importantly, we know these services help our patients and their families because that's what they tell us. When we listen, we can hear how people want to be cared for through their experience with cancer.

Psychosocial issues may arise for patients and families during their experience with cancer, or there may have been challenges prior to the diagnosis that are exacerbated by the cancer and its treatment. This distress, when not addressed,

can lead to increasing challenges, and may interfere with the patient's overall health and psychosocial wellbeing.

To help the patients and families we serve, we need to be able to identify distress and connect people to our psychosocial programs and services.

## What are the most common issues that patients with cancer face?

**DR. CORBETT:** Research tells us that approximately 40 percent of patients with cancer have significant distress. That means that the disease and treatment are getting in the way of them living their lives as they want or expect. At Duke, our therapists work with patients and their families to address many kinds of stressors and concerns, including marital conflict, end of life issues, self- and body-image; and issues related to parenting with cancer.

Often, when patients think of therapy, they may worry that someone may think there is "something wrong with them." But patients with cancer have a very significant health issue they are facing: To have distress is normal.

At the Duke Cancer Institute, we have a large psychosocial oncology team, with a subgroup forming the distress management team. We screen for all types of distress in our patients, including emotional, relational, practical, spiritual, and physical. Patients fill out a survey in clinic, so that their physicians and care teams can follow up with them to help identify any concerns, and connect them with the appropriate psychosocial provider. By having a formal way to screen for distress, we communicate to our patients and families that we recognize the multiple ways that cancer can impact them, and that we are here to help.

## Do physicians support patients seeking support or therapy?

**DR. CORBETT:** Absolutely. Our medical family therapists are trained to work in partnership with the medical team, the patient, and the family. Many of the physicians and nurses refer patients directly to our program for assistance in managing the distress they are experiencing. Everyone wants what is best for the patient. We have found that psychosocial oncology services and medical family therapy are beneficial on many levels. These services address the emotional and relational needs of our patients and their loved ones, and can also help with the clinical treatment of cancer, including compliance with treatments and enhanced quality of life.

## What if a patient doesn't feel they need therapy?

**DR. CORBETT:** Psychosocial oncology services are now recognized as so important that accreditation standards and policies are being put in place to ensure that support programs are available throughout the country for patients if and when they need them. We know that not everyone may need psychosocial oncology services; however, we hope that just knowing this kind of support is available can be a comfort to those we serve here at Duke, and that they, our patients and/or their family members, will access it, as needed. ♡

To find out more about the many services available to support our patients, contact the **Duke Cancer Patient Support Program at the Duke Cancer Institute.**

## CONTACT INFORMATION:

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