The Bad News and the Good News About Cancer

I t’s an unfortunate fact: one in two men and one in three women will develop cancer in their lifetimes. So, this disease is likely to affect either you, a friend, or a family member. However, we can take heart that a whole community is here to help, not only with medical treatment, but also by supporting the emotional and social well-being of patients with cancer and their families. In this issue of Breakthroughs, you’ll meet a person who plays a key role in supportive care at Duke Cancer Institute (DCI) and learn how her mother’s battle with cancer inspired her career. In addition, you’ll read about a good friend of DCI—a partner in raising funds and awareness for breast cancer—who has been diagnosed with a metastatic recurrence of breast cancer herself. Because of research happening every day, she has hope. In this issue you’ll also meet a few of the physicians and scientists working to end metastases and, if necessary, make cancer a chronic disease we can live with, rather than die from. At Duke Cancer Institute, all of us are here fighting for you and for each other. Please join us.

Michael Kastan, MD, PhD Executive Director, Duke Cancer Institute

Therapy App Aims to Bust Stress

A cancer diagnosis can bring on feelings of anxiety, such as worry, fear, and sadness. For some, the feelings do not subside but worsen to affect daily life. When this happens a patient may develop post-traumatic stress disorder (PTSD), an anxiety disorder usually associated with traumatic events such as war or physical attacks. Duke University School of Nursing, with a pilot grant from Duke Institute for Health Innovation, is leading a study to measure the effectiveness of a therapy app they’ve developed to help patients, their caregivers, and survivors manage the post-traumatic stress of cancer. Associate Professor of Nursing Sophia Smith, PhD, a two-time cancer survivor herself, leads the study. The Cancer Distress Coach app uses guided imagery, meditation exercises, inspirational quotes, music, and photos to help patients and their caregivers learn about symptoms and available resources, understand their level of stress, build a network of support, and gain coping skills to manage stress in the moment. Researchers hope that eventually the app will be a standard component of cancer care. “Our vision is that, via the app, all survivors will have access to the supportive services that they need to help them manage the trauma associated with cancer, no matter where they are in the cancer trajectory—newly diagnosed, in treatment, or post-treatment survivorship,” Smith says. The app is an expansion and redesign of a predecessor that Smith and a team of nursing researchers developed in partnership with the National Center for PTSD and US Department of Veterans Affairs. They tested the app in 2015 and found the app reduced their anxiety and provided practical solutions to PTSD symptoms.

Two-time breast cancer survivor Betty Parker, who participated in the 2015 pilot study, said her breast cancer’s unexpected reoccurrence the day before her birthday sent her “into a depressed mode,” but an in-app relaxation exercise comforted her. “Her voice was so soothing,” says Parker. “On those days when the radiation was unbearable, it took me to another place.” Researchers are hoping that the new app—soon to be available on both iOS and Android devices—will also attract younger cancer patients, who they say are at even greater risk for PTSD following a cancer diagnosis.

By Julie Harbin

Oeffinger to Lead Survivorship and Onco-Primary Care

Kevin Charles Oeffinger, MD, has been named director of the Duke Cancer Supportive Care and Survivorship Center. (He will work closely with Cheyenne Corbett, MD, LMTF, administrative director.) Since 2014, Oeffinger has directed the Cancer Survivorship Center at the Memorial Sloan Kettering Cancer Center in New York City. Oeffinger has also been charged with establishing the Duke Center for Onco-Primary Care, a program of Duke Cancer Institute that will partner with Duke University Health System to unite cancer specialists and primary care clinicians. Look for more information about Oeffinger, survivorship, and onco-primary care in a future issue of Breakthroughs.
Cheyenne Corbett, administrative director of the Duke Cancer Supportive Care and Survivorship Center, was inspired to pursue a career in family therapy by her mother’s and family’s experiences with cancer.

Duke cancer patients are screened for physical, social, and emotional distress at every visit.

Nurses and patient navigators refer patients and their families to a vast array of services to address physical and emotional distress, as well as to remove practical barriers to care, such as concerns about transportation and finances.

Cheyenne Corbett knows firsthand how important it is for families to communicate openly about cancer. Ten years ago, Corbett’s mother, Nancy, was diagnosed with breast cancer for the second time and went through surgeries and chemotherapy.

“My mom was afraid that she would scare my little kids because she lost her hair. I explained to her that it is scarier if we don’t talk to them,” says Corbett, PhD, LMFT, administrative director of the Cancer Supportive Care and Survivorship Center at Duke Cancer Institute. Corbett talked to her kids and explained why their grandmother lost her hair.

“Within moments from these conversations, my kids went up to her, and she took off her turban. They touched her bald head, asked questions, and they were fine. For my mom, that was very therapeutic. We could talk about it and make it more manageable for all of us,” says Corbett, who also serves as director of the Duke Cancer Patient Support Program.
BY THE BOOTSTRAPS

The open dialogue that Corbett’s children had with their grandmother was very different from what Corbett experienced as a teenager, when her mother was diagnosed with breast cancer for the first time. “My parents tried to keep cancer in its place and away from the family’s every day. They attempted to control what they could in that situation—protecting our family from cancer, and making sure that my two brothers and I were happy,” says Corbett. “As children we were so protected from it that we were not connected to them through the process of dealing with cancer. They did not talk to us about cancer except once or two times to let us know that mommy was sick. We didn’t know how serious it was, what she was going through, and what should we be afraid of. We got through it with that old ‘be strong’ mentality. We pulled ourselves up by the bootstraps, took care of her, and continued through life going to school and playing sports.”

Corbett had planned to follow in her father’s footsteps and become a lawyer. In college, she began as a business major, but a few classes in psychology threw her in another direction. Corbett, who had not heard about family therapy before, read a paragraph about it in one of her textbooks. She immediately fell in love with the field and decided to switch majors. “I love connecting with people and learning about their strengths and how they face challenges and overcome them,” she says.

Corbett decided to focus on working with families with cancer because the disease had affected her immediate and extended family. Her mom’s sister, and niece all died of colon cancer. “Nobody talked to my parents about how to talk to their kids,” she says. But cancer affects the whole family. “Cancer did not just impact my mom’s body, it affected her relationship with her husband, how she viewed herself as a woman and as a parent,” Corbett says.

MANAGING PAIN VIA SKYPE

Patients with cancer experience significant pain and find it to be one of the most distressing symptoms of the disease. Tamara J. Somers, PhD, clinical psychologist and director of research for the Duke Cancer Patient Support Program, tests how mobile technology can help cancer patients manage their pain.

Patients who participate in this research project, which is funded by the American Cancer Society, receive training in pain coping skills via Skype. Somers compares their experiences to that of patients who get such training in person. Pilot findings from this project suggest that Skype-based behavioral pain intervention works as well as in-person intervention, and that patients find it more convenient than traveling to clinics.

“People are much more open to receive this intervention that we know can help them manage their pain, if they don’t have to travel to receive it on top of their oncology appointments,” says Somers. “The Skype-based participants seem to finish the intervention a lot more quickly, and they really enjoy sitting at home while getting the same treatment that they would have gotten in person.” Somers hopes that her findings will help lead to a more widespread use of mobile technology for cancer pain management, which will be highly beneficial to patients who live far from medical centers, experience cancer-related physical challenges, or face other practical barriers to care such as transportation issues.

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HOW YOU CAN HELP
You can support the 30th anniversary of the Duke Cancer Patient Support Program and make a difference for families facing cancer. To donate, use the enclosed envelope, or visit bit.ly/dcispring2017

Fifteen years ago, while completing her doctoral degree in family therapy, and with a master’s degree in family therapy specializing in medical family therapy in hand, Corbett discovered the Duke Cancer Patient Support Program.

Rachel Schanbacher had managed the program 30 years ago in honor of her daughter, Linda, who passed away of Hodgkin’s disease at age 18. “She received incredible medical care, but nobody helped Rachel and her daughter deal with the psycho-social impact of cancer on the family. Nobody helped Rachel and her husband deal with having an 18-year-old daughter with a life-threatening disease,” Corbett says. “Their story really resonated with me. I just knew I had to work here.”

Schanbacher wanted to hire Corbett, but she didn’t have a job for her. “I said, ‘Give me whatever you’ve got. I just want to be a part of this program,’” Corbett says. She started as a part-time volunteer coordinator and counselor. Within a couple of months, she became the program’s assistant director. When Schanbacher retired three years later, Corbett became director.

ASSESSING DISTRESS
Today, Corbett supervises a team of 45 clinicians, researchers, and trainees who listen to the challenges that patients and families describe and provide services like family therapy, child life services, psychology services, patient navigation, self-image services, pet therapy, oncology recreation therapy, adolescent and young adult oncology, tobacco cessation services, and sexual health and intimacy services. Their research focuses on the patient and the family’s experience with cancer and how they can better design programs that will improve that experience.

The team screens each patient for distress at every visit in the clinic. They use the National Comprehensive Cancer Network distress thermometer to assess distress caused by not only the patient’s physical condition, but also by practical issues like transportation and financial concerns, family challenges, and emotional and spiritual concerns. Nurses and patient navigators gather the data, educate patients on available resources at Duke and in the community, and make referrals to the services they need.

PUT ON A HAPPY FACE?
Psychosocial services help patients follow their oncologist’s recommendations better and motivate them to engage in treatments. “We want to know how our patients are doing and how their families are coping because this is an important part of our care,” Corbett says.

Corbett encourages patients to feel comfortable with sharing their concerns and feelings with their families and their medical teams. “We still struggle with a culture that expects us to be strong and put on a happy face, which is not necessarily a helpful approach. The reality is that we have good days and bad days, happy days and sad days, worries and joys. People should not go through something as stressful and life changing as cancer on their own,” she says. “We are here to help them.”

“I HAD HUGE CURLY REDDISH HAIR, AND WHEN IT STARTED TO COME OUT, IT WAS LIKE ‘OH MY GOD, I REALLY HAVE CANCER.’”

Belk Boutique volunteer Leslie Love

Leslie Love, 59, has been volunteering with the Duke Cancer Patient Support Program for more than 11 years now, assisting patients in the chemo room at the Morris Cancer Clinic. She never thought that she would flip to the other side. But in November 2014, she was diagnosed with breast cancer.

Losing her hair was traumatic for Love. “I had huge curly reddish hair, and when it started to come out, it was like ‘Oh my God, I really have cancer,’” she says. After her second chemo treatment, when she got home, she looked at her mom. “My mom said: ‘It’s time.’ I sat down between her knees like when I was a little girl. She started finger combing my hair, and it was coming out immediately,” Love says.

Love’s granddaughter, who was 10 at the time, asked her, “Are you going to be bald?” And I said: “Yes, I’m going to be for a minute, but it will come back.”

Along with Love’s oldest son, they all sat down in the kitchen to have a farewell ceremony. “We made a little beautiful altar on the kitchen table with water and white flowers, and we sat there in silence. It was a powerful experience of letting my hair go when all the generations of my family were beside me. We got through it, and not one tear was shed,” she says. Love started wearing a wig, but after a month she abandoned it. “I fell in love with my baldness,” she says.

“WE STILL STRUGGLE WITH A CULTURE THAT EXPECTS US TO BE STRONG AND PUT ON A HAPPY FACE, WHICH IS NOT NECESSARILY A HELPFUL APPROACH.”

Cheyenne Corbett

Her friends told her that she looked stunning and that they loved her style. “I wore big earrings and put on eye shadow, and it looked so natural. Now I don’t take hair that serious. It doesn’t define who I am. I shave it all the time,” Love says.

During her treatments at Duke, Love visited the Belk Boutique, which offers cancer patients gifts such as wigs, hats, scarves, skin care, and makeup. The boutique made her feel that she was not alone. “At the front of the store they kept a photo book of strong women who had gone through the process of losing their hair, and they were beautiful,” Love says. “I used to flip through the book and cry a little bit, but I got strength from looking at them.”

At the boutique, Love met compassionate volunteers who introduced her to the self-image program and taught her how to put on eyebrows and make her eyes look good, even without eyelashes, and how to style beautiful head wraps. “It was a safe place for me, a place of refuge,” she says. Love has been cancer free for more than two years.

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LOCKS OF LOVE

A breast cancer survivor finds refuge in sharing her story with other patients.

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LOKS OF LOVE

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In October 2016, the Shingleton Society Luncheon honored Harry Rhoads and Stan and Melinda Epperson with the Shingleton Award, which recognizes the outstanding service and generosity of donors and volunteers committed to advancing the fight against cancer. Those who make a gift of $1,000 or more to DCI during a fiscal year receive membership in the Shingleton Society, which includes invitations to the annual luncheon and awards celebration. To learn more, visit dukecancerinstitute.org/benefits.


RISE WENT PINK! On October 28, 2016, in honor of breast cancer awareness month, all eight Rise donut stores in the Triangle donated 100 percent of sales of their pink sprinkles donut to DCI and delivered sweet treats to DCI staff. In addition, Rise CEO, Tom Ferguson, personally matched donations made that day. The Rise promotion raised more than $2,800.

MOVEMBER FUN. Every November, “MoDukes” band together to raise awareness of prostate cancer by growing their facial hair. In 2016, Durham’s Fullsteam Brewery capped off the month with a live auction. Up for bid: the rights to dictate shavedown styles. Shaves were donated by Durham’s Pedro Williams barbershop. The event raised more than $1,000 for the Movember Foundation USA to benefit DCI and others. Pictured: “MoDukes” members with friends.

GAIL PARKINS MEMORIAL OVARIAN CANCER WALK AND RUN. The September 2016 event raised more than $265,000 for research at DCI. For more information, visit www.ovarianawareness.org.

Shingleton Society Spring Luncheon
Wednesday, May 17, 2017
Noon – 2 PM
Sarah P. Duke Gardens, Kirby Horton Hall
420 Anderson Street, Durham, North Carolina

Please join us for a lunch and special presentation by Peter E. Fecci, MD, PhD
Director, Brain Tumor Immunotherapy Program
Assistant Professor, Neurosurgery

For more information, please contact Sara Wajda, 919-385-0039, dcidevelopment@duke.edu.

Supportive Care and Survivorship Day
for patients, caregivers, and survivors
Wednesday, June 7, 2017
10 AM – 3 PM
20 Medicine Circle
Duke Cancer Center

Free of charge
Hosted by the DCI Supportive Care and Survivorship Center

For more information: Kim Malugen, 919-681-1523
On an unseasonably warm February night, Pam Kohl tells a group of 20 of her most important friends that she has just been diagnosed with metastatic breast cancer.

Her friends are members of the organizing committee for the May 2017 annual Triangle Race for the Cure, the largest fundraiser of the year for the Triangle to the Coast Affiliate of the Susan G. Komen foundation, where Kohl works as executive director.

With remarkable composure, Kohl tells the group that her doctors are devising for her a “cocktail” of various medications that she hopes will give her good quality of life for years. “That cocktail will work, until it doesn’t,” she says. “And then I hope, because of our work and more research, there’ll be another cocktail to take its place. And then another. Together, we will find a way.”

**A DAILY BULLET**

Kohl first fought breast cancer seven years ago, before she began working at Komen. Duke doctors treated it with a lumpectomy and radiation. Then she took endocrine therapy for five years, to suppress the hormones that were feeding her cancer, which was estrogen-positive. “Just taking that daily bullet,” she says, with her deep-throated laugh.

“It used to be that every woman who had breast cancer had the exact same treatment. We didn’t know that breast cancer was really a lot of different cancers,” Kohl says. “Because of funding from Komen and others, doctors can provide personal treatment. I’m living proof that research matters.”

**A CURVE BALL**

She’s also proof that scientists have much more to understand. Testing of the genetic mutations in Kohl’s first tumor (oncotyping) had classified it as at very low risk for recurrence. And she was treated with the state-of-the-art protocol for her cancer type. So this new diagnosis is a curve ball, as Kohl says. “Because of funding from Komen and others, doctors can provide personal treatment. I’m living proof that research matters.”

**SCARED AND HOPEFUL**

“I feel lucky because I work at Komen, and I know a lot. But I’m also unlucky in that way; I know enough to be scared,” Kohl says. “But I also know enough to be hopeful.”

She urges other women to get their annual mammograms and to advocate for themselves, as she did in requesting the PET scan. “I’m lucky that I live in the Triangle and I have Duke Raleigh, and I’ve got Duke Cancer Institute, and they work together,” Kohl says.

She has been at work throughout her journey to this diagnosis, including the day before her lymph node biopsy. She says her experience makes her feel closer to the women she serves at Komen every day. “I have sick leave. I have transportation. So many of the families that Komen works with on a day-to-day basis aren’t that lucky,” Kohl says. “My work is more important to me now than ever.”

“TOGETHER, WE WILL FIND A WAY.” – Pam Kohl

Here, Kohl gets a hug from Chantal Weedman, co-chair of the 2017 Susan G. Komen Triangle Race for the Cure.
Dorothy Sipkins, MD, PhD, became fascinated by leukemia during her medical training. She remembers studying a biopsy from an elderly patient who had just had chemotherapy and was in remission. “You couldn’t see any leukemic cells; the bone marrow looked clean,” Sipkins remembers. But she knew that because of the patient’s age, her cancer was highly likely to return. Before long, her bone marrow would likely be full of cancer cells. Where were these cells hiding?

“They’ve got programs of their own,” says Sipkins, who treats leukemia patients. “We are trying to understand their cellular program so we can be the puppet masters.”

Sipkins and another Duke researcher, Ann Marie Pendergast, PhD, are making progress in their quest to stop the spread of cancer, and turn it into a chronic disease rather than a deadly one. “Metastatic relapse—when cancer cells disseminate from their original site—is actually what kills most people who die from cancer,” Sipkins says.

THE CANCER SPY
Because metastases can happen so fast, Sipkins needs to spy on cancer cells in real time. To do that, in mice, she and colleagues label cancer cells with fluorescent dyes and use laser scanning confocal microscopy to peer down into the bone marrow.

Her research to understand leukemia and the bone marrow has led her to study breast cancer, which likes to spread to the bone. Many breast cancer patients may appear to be in remission, but as much as five years later, or more, they will have a recurrence that has already spread to the bone. Sipkins believes that happens because, early in the disease, breast cancer cells travel to the bone marrow and hide there. “We believe that breast cancer cells are actually shielded from therapies by the different cell types in the bone marrow and the factors that these cells secrete,” Sipkins says.

BLOCKING THE HIDING PLACES
With their detective work, the Sipkins lab has found that two different molecules help breast cancer cells enter the bone marrow and stay there. If the researchers block one of these molecules (CXCR4), they can force breast cancer cells from their hiding place in the bone marrow and back into the bloodstream, where they may be more vulnerable to treatments. In addition, if they also block a molecule called E-selectin, which acts like the key to a portal to let cancer cells into the bone marrow, they can prevent the cancer cells from going back inside.

Sipkins is working with Duke breast cancer physician Kelly Marcom, MD, to develop a trial of a drug that blocks both of these molecules, for metastatic breast cancer patients. They hope to get their trial approved by the end of 2017.

A CALLING CARD FOR METASTASIS
Another Duke researcher, Ann Marie Pendergast, PhD, has developed a “signature” that can be used to predict which lung cancer patients are at high risk for metastasis. She is also working with a lung cancer doctor to develop a clinical trial of a therapy to block signals that are required for lung cancer to spread.

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Dorothy Sipkins uses microscopy to watch breast cancer cells in real time as they spread to the bone marrow.

AT A GLANCE
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THE CANCER SPY
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A CALLING CARD FOR METASTASIS
Another Duke researcher, Ann Marie Pendergast, PhD, may have found a way to stay one step ahead of lung cancer. If anyone could do that, it’s Pendergast. She exudes energy. When she starts talking about her work, the technical terms come out rapid-fire—ABL1, ABL2, extravasation. What it all means, and the reason Pendergast is so excited, is that she may have found a way to predict when lung cancer will spread, then stop it.

Pendergast has worked for years to understand a group of enzymes called ABL kinases. In normal cells, their function is to signal cells to move and invade. Normally these invasion promoters are turned on only when needed. Pendergast’s latest work has shown that some of these enzymes—ABL1 and ABL2—are plentiful and highly active during several

BY ANGELA SPIVEY
steps in lung cancer metastasis.

That means that by testing lung cancer patients for levels of these enzymes (and some of the proteins that they turn on) she may be able to predict which patients will have a metastasis. Pendergast is applying for a patent for this “signature.”

A NEW THERAPY?

Even more exciting, in mice, if Pendergast inhibits ABL1 and ABL2 with a drug, or removes them using genetic engineering, she can stop a crucial step in metastasis (extravasation—when cancer cells exit the bloodstream and push their way inside an organ). “The animals that have these kinases deleted from lung cancer cells survive for a long, long time, while the ones that do not are dying of metastasis,” she says.

In March 2014, doctors at Cape Fear Valley Hospital, near Schneider’s home, used a non-invasive “Cyberknife” procedure to remove the cancer in her brain. Less than a year later, she began having weakness in her left arm and leg. That’s when she was referred to Duke neurosurgeon Peter Fecci, MD, PhD. Fecci suspected that Schneider’s weakness was caused by tissue damage (necrosis) from the Cyberknife treatment. He scheduled her for a procedure to destroy the damaged tissue, called laser interstitial thermal therapy (LITT). Offered at Duke and a handful of other centers nationwide, LITT uses targeted doses of high heat to treat brain cancer or necrosis, guided by MRI.

Facci is seeing more and more patients like Schneider. Since he joined Duke as a faculty member two and a half years ago, he has seen his overall surgical volume double, and the number of brain metastasis patients he treats has increased fivefold or sixfold.

As recently as ten years ago, patients with brain metastasis were rarely even offered surgical treatment. “It was essentially viewed as a death sentence,” Fecci says. But as treatments have improved, these patients have options. “Some of my patients from when I first arrived at Duke two and a half years ago are still doing well,” Fecci says. “A decade ago, that type of survival was just a dream.”

Facci saw a need for better-coordinated care for these patients. So he started the Duke Brain Metastasis Program, which involves doctors from neurosurgery, medical oncology,
In 1995, Macey Colvin and her husband Michael Colvin, MD, left their friends behind in Baltimore and moved to Durham for his new position as director of Duke Comprehensive Cancer Center (now Duke Cancer Institute).

Macey Colvin immersed herself at the cancer center, volunteering with patients every Tuesday. She also joined a small group of friends raising funds for the Duke cancer effort. They called themselves the Shingleton Society, after former cancer center director William Shingleton, MD. “Bill Shingleton and his wife Jane and everyone at Duke embraced us as family,” Colvin says. The Shingleton Society includes donors who give $1,000 or more annually to Duke Cancer Institute.

Michael Colvin led the cancer center until 2002 and was a champion of its progress until he passed away in 2013. Even as DCI has grown into a national leader that treats more than 51,000 patients a year, the Shingleton Society still feels like a group of friends, Macey Colvin says.

“The Shingleton Society is a way that even an English teacher like me can take part in finding a cure for this terrible disease. Donations are what took the cancer center to the next level. If we all gave one dollar, just imagine what we could do.”

JOIN THE FIGHT
To learn about how to get involved or to join the Shingleton Society, please contact Sara Wajda at 919-385-0039 or sara.wajda@duke.edu.

JOE C. HOBBS

Peter Fecci, MD, PhD, is an assistant professor of neurosurgery and director of the Brain Tumor Immunotherapy Program and the Brain Metastasis Program.
LOOKING UP

The atrium in DUKE CANCER CENTER, Duke’s flagship cancer facility, which turned five years old in 2017. In 2012, when the facility first opened, Duke Cancer Institute treated 6,000 new patients. Last year, the number of new patients had grown to 10,000.