



FOX CHASE CANCER CENTER
forward
Winter 2012

INSIDE
THE CANCER EXPERIENCE
Emotions, personal journeys, and what really matters

for•ward:

1. situated in the front
2. moving ahead
3. pertaining to the future

FOX CHASE
CANCER CENTER

HEARTS
plus
MINDS

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Fox Chase Cancer Center is one of the leading cancer research and treatment centers in the United States. Founded in 1904 as one of the first cancer hospitals in the nation, it holds the prestigious comprehensive cancer center designation from the National Cancer Institute—an honor that recognizes excellence in the full range of cancer science and medicine, as well as community outreach.

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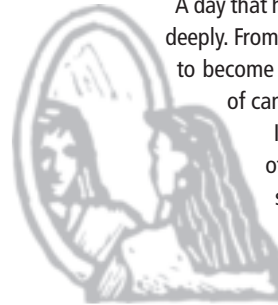
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A Lesson in Living

When I met Dara Barr, I felt relief. Her pink sweatshirt and easy smile projected an energetic, can-do air. She looked like what she was: a mother and teacher in her early 40s who was accustomed to marshaling unruly classrooms, soothing bruised feelings, and putting Band-Aids on boo-boos. She did not look sick.

But Dara is sick. I met her at Fox Chase when *Forward* photographed her for the story on page 6 about the emotional aspects of having cancer. As I chatted with her, following along on her familiar route from doctor's appointment to infusion room for chemo, I considered the phrase "treatable but not curable," which applies to Dara's advanced gynecologic cancer. The words weighed heavily in my mind. Dara is close to my age and has three young sons.

A day that had become routine for Dara rattled me deeply. From behind the barrier of a desk, it is easy to become removed from the individual realities of cancer.



I suspect my relief at Dara's appearance of good health stemmed from the same source as the impulse to look away from people who wear their illness more obviously, in gaunt faces, thinning hair, sallow skin. Facing the reality of their mortality, or of Dara's, would mean facing my own.

As someone fortunate enough to be living without cancer, I imagine that an invisible, indelible barrier divides me from those diagnosed with lung cancer, sarcoma, melanoma, advanced gynecologic cancer. Even after cancer's tendrils have reached out to threaten a beloved grandmother and two aunts, I imagine myself to be different.

People in Dara's shoes don't have a choice; they know there is no barrier. They know we are not different.

Contemplating a patient's situation inevitably raises the question, How would I react? My answer: Not well. Not as well as Dara, for example, who throws an annual party to celebrate her life with friends. Who no longer puts off the trip she wants to take, the yoga classes. Dara herself would disagree with my assessment. She is doing, she says, what most anyone would: The best she can.

They say courage is not being without fear, but being afraid and acting anyway. I may not yet have the courage to look fully, with clear eyes, at the uncertainty of my life in the face of diseases like cancer, with its seeming cruelty and wanton unfairness. But making the effort yields valuable lessons. The lesson I take from Dara is to live as well as I can in the time I have, however long that may be.

—Abbey J. Porter, Editor

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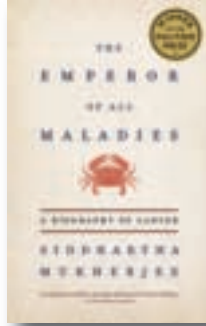
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Jenny Glusker has spent six decades pushing boundaries—as an early female chemist and as a researcher who unravels the processes behind how the body works.

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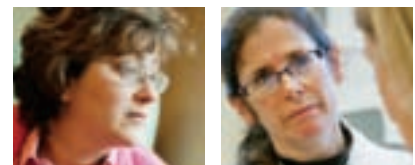
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ON THE COVER: Inside the Cancer Experience



This issue explores the interior terrain of experiences with cancer. In particular, dual feature stories look at the emotional aspects of cancer: from the perspective of the patient (*page 6*), and the clinician (*page 12*). For each, cancer can bring intense challenge and hardship, unexpected insight—and sometimes, transformation.

Stories on pages 6 and 12

A Friday Reminder

I look forward to Friday afternoons. Not because they signal the end of the work week, but because they're my favorite part. Around noon, I leave the office and head to our Women's Cancer Center, where I pull on a white jacket with my name stitched over the pocket, open the door to an exam room, and greet the first of the patients I'll see that day.

The four to six hours I spend in the clinic each Friday reset my mind as to what's important and put everything else—arguments over committee agendas, squabbles over office space—into perspective.

I take care of ovarian cancer patients. It is an extraordinary experience.

Life with ovarian cancer comes with many compromises, to put it mildly, and tremendous stress for women who have the disease, and those who love them. Most ovarian cancer patients live with the disease for years, some for more than a decade. Because the disease and its management become increasingly challenging over time, physician and patient become increasingly connected.

My patients are looking for help and earnest advice. I strive to be honest, compassionate, and hopeful when possible—to provide whatever they need, whether it's being a skilled physician, handing someone a tissue, acting as a cheerleader, or just listening. Even if the news I have on a given day isn't particularly good, I can still walk with a patient (or close behind) on her journey with cancer.

Many of my most inspirational patients have been those who knew their disease would not be eradicated. I am inspired by people who manage to put aside the fact that their disease will probably shorten their lives and focus on doing good for their families and communities. They are a testament to the power of hope and courage, the tenacity of the human spirit.

I still get cards from former patients—some of whom are alive and well 10 to 12 years after their diagnosis—and from



patients' spouses. One arrives each Christmas from Eddie, whose wife was diagnosed with uterine sarcoma shortly after giving birth to their son. When she died after a four-year struggle with the disease, Eddie took full-time responsibility for raising the boy. His most recent card included a photo of the now-15-year-old catching a black marlin, its dark scales gleaming in the sun.

I went into medicine to make a difference in people's lives, and I knew that as director of a cancer center with a strong research team, I could make a far greater difference than by myself. But while we have made exponential leaps in the past decade in understanding and treating this complex set of diseases, there are days when it feels, quite simply, like not enough. As long as mothers die of cancer before having a chance to raise their children, it will continue to feel that way.

I invite you to take a moment to consider the people who remind *you* of what's important. For me, it's the patients with whom I spend Friday afternoons, who seem to give me more than I can give them and who drive my resolve—and that of my Fox Chase colleagues—to prevail over cancer.

Wishing you a healthy year,

Michael V. Seiden
President and Chief Executive Officer

forward WINTER 2012

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See more of *Forward*, comment on stories, and read other readers' feedback at forward.foxchase.org.

I N B R I E F

Center Opens Doors for Public Talks

A new program brings community members to Fox Chase, not for treatment or testing but to learn about and discuss cancer and cancer experiences. "Cancer Conversations," a series of public talks and presentations, opened in 2011 with readings by two authors. A documentary filmmaker is slated for February.

In honor of the recent launch of the Women's Cancer Center, two former breast cancer patients kicked off the series. Kelly Corrigan read in November from her *New York Times* best-selling memoir *The Middle Place*, which details her experience as both cared-for and caregiver after her father is diagnosed with bladder cancer while she is in treatment.

"The quality of my interactions with people, since the day I got diagnosed, has been richer and realer and better in every way,"



Screening of the documentary film 'Not As I Pictured' is the latest in a series of events hosted by Fox Chase.

Corrigan told the Fox Chase audience.

In March, Susan Conley discussed her memoir *The Foremost Good Fortune*, which describes her experience with breast cancer while living in China.

On February 2, Pulitzer Prize-winning photographer John Kaplan will screen his documentary, "Not As I Pictured," which follows his diagnosis at 48 with

a rare form of lymphoma.

"We want to educate and support people who are affected by or interested in cancer," says vice president for communications Franklin Hoke. "This series brings members of the community to Fox Chase to engage with an enriching experience, regardless of whether they are facing an illness."

For information, visit www.foxchase.org/conversations.

Prevention Program Marks 20th Anniversary

In November, the Risk Assessment Program celebrated 20 years of providing personalized prevention education and early-detection services. One of the first efforts of its kind in the nation, the program was founded by medical oncologist Mary B. Daly, head of clinical genetics.

Formerly known as the Margaret Dyson Family Risk Assessment Program, the initiative—which originally served patients with a family history of breast and ovarian cancers—has expanded to include those at heightened risk for prostate, gastrointestinal, and lung cancers, as well as melanoma.

In honor of the milestone, several program participants were invited to make videos documenting their experiences. Fox Chase partnered with WHYY-FM, the region's NPR station, to produce the videos, which debuted at a celebration at the station's studios in Philadelphia.

"Knowledge is power," says participant Carlette Knox in her video. Knox was introduced to the program after being diagnosed with breast cancer while both her parents were also being treated for cancer. The program provided "the opportunity to explain the mystery of why this disease claimed the lives of so many in our family," she says. "It allowed me to make a more informed decision about...treatment options."

The event included a panel discussion featuring mental health expert Dan Gottlieb, host of WHYY's "Voices in the Family" program.

The Risk Assessment Program has helped more than 13,000 individuals map their families' cancer history, understand their genetic risk, and protect themselves through screening and other preventive measures.

More information is available online at www.foxchase.org/rapcelebration.

AMERICAN CANCER SOCIETY HONORS BIOLOGIST

Molecular biologist Erica A. Golemis received the American Cancer Society's Scientific Research Award, which recognizes accomplishments in basic or clinical cancer research, in October. Golemis has made transformative discoveries in the analysis of cancer signaling, with work spanning the investigation of basic cancer cell biology to the design of targeted therapies. Besides serving as deputy chief scientific officer, she co-leads the Keystone Program in Head and Neck Cancer and the developmental therapeutics research program.

COLLABORATION TO ENABLE GENETIC ANALYSIS

Fox Chase took a major step on its path to launching the Cancer Genome Institute, a program that will provide individualized genomic analysis and foster the development of personalized cancer care, when it established a collaboration with the biotechnology company Life Technologies in June. Beginning later this year, the institute will use leading-edge technology to compare the genetic profiles of individual patient tumors against a panel of 46 known cancer-related genes. Patients with advanced cancers can elect to be examined for those genetic abnormalities, with the potential of being matched to established and experimental therapies.

PHYSICIAN RECOGNIZED FOR OVARIAN CANCER RESEARCH

Gynecologic surgeon Robert Burger, director of the Women's Cancer Center, received the Rosalind Franklin Excellence in Ovarian Cancer Research Award from the Ovarian Cancer National Alliance in July. Burger emphasized the need to "extend progression-free survival and improve quality of life" for patients when he accepted the award at the group's annual conference in Washington, D.C. His research includes studies of molecularly targeted therapies and novel prevention strategies, as well as clinical trials of ovarian cancer treatments. The award, which recognizes devotion to medical research, honors British scientist Rosalind Elsie Franklin, who played a key role in the discovery of the structure of DNA. She died of ovarian cancer in 1958.



NEWSFLASH: Fox Chase will join Temple University Health System, according to an agreement signed in December. The Center will retain its identity and mission as a member of the system, which is part of the Philadelphia-based Temple University, a public education and research institution. Expected to finalize in July, the affiliation will allow Fox Chase to grow and enhance patient care. For more information, see www.foxchase.org.

A Portrait of Cancer

AUTHOR DISCUSSES PULITZER PRIZE-WINNING EPIC

*Perhaps no one knows cancer better than Siddhartha Mukherjee, author of *The Emperor of All Maladies: A Biography of Cancer*, which won the 2010 Pulitzer Prize for nonfiction. (A paperback edition was released in August.) Geared to a general audience, Mukherjee's 600-page epic traces cancer from its first written description more than 4,000 years ago to the promise that genome mapping holds for the future of cancer medicine. A physician and researcher at Columbia University, Mukherjee provides an engrossing history of the disease along with fascinating and not-always-flattering portrayals of the people—scientists, clinicians, activists, and patients—whose lives and careers it intertwines. Reading by turns like a novel, biography, and scientific text, *Emperor* provides an enlightening and ultimately hopeful depiction of the perplexing puzzle that is cancer.*

Why did you call your book a biography instead of a history?

If we look at the same entity over time, it's like developing a portrait of a character. In that sense, the fundamental creature cancer is extremely diverse. It turns out not to be one thing, but many things, and even those things keep changing. There's an evolutionary quality to cancer.

Some cancer physicians say they hate the disease. You seem to have a fascination, even a respect toward it.

From the standpoint of medicine or biology, you have to have some degree of awe for one of the most elemental families of diseases we've ever encountered. The fact that we are struggling to prevent and treat and cure some cancers is a testimony to how complex the biology of the disease is. As a scientist, you understand that if you corrupt the very processes that keep our cells alive and growing, you get cancer. So if you have any awe for normal cellular physiology, then you have a similar awe for cancer.

If you could rewrite history, what would you change in cancer treatment?

At a fundamental level, one thing I would change is the idea that one solution fits all and more is better. We now know that's not true. In fact, in many forms of cancer, specificity is more. It turns out that high-dose chemotherapy is relevant for certain cancers, but treating other cancers the same way is a mistake. Treating breast cancer is very different from treating ovarian cancer. We need to be sensitive to the differences.



DEBORAH FEINGOLD

The Mind of a Scientist

Researcher shares perspective with donors

How do you view the legacy of the so-called "War on Cancer" that began in the 1970s?

The good thing about the War on Cancer was that it took away some of the stigma around cancer. It created a kind of public platform on which we could become, as a nation, invested in the idea that we were going to cure cancer. That investment was important—not only the financial investment, but also the psychological one. But we've been sufficiently humbled by the hype around that campaign [which touted finding "a cure" within several years] that I don't think we'll go back to that idea or that kind of timeline.

Can you imagine a future without cancer?

Certainly we can change our habits, our environment, and reduce the risks of certain forms of cancer, but the idea that we could eliminate cancer completely from our society and our bodies is very unlikely. Many cancers are part of our genetic inheritance in the sense that the very genes that allow embryos to grow and our bodies to grow—if you distort them, you get cancer.

Is that why you write about making cancer a chronic, manageable condition, versus curing it?

I think that goal is probably the best we will be able to achieve for many forms of cancer, and even that is a major undertaking. Our understanding of cancer is still changing, and the capacity to convert many cancers into chronic diseases will be very important, but we're not there yet. 📍

Interview by Jacquelin Sufak

Fox Chase friends and supporters attending September's Laurel Society event got a glimpse into the complex world—and mind—of a scientist, thanks to immunologist Glenn F. Rall.

"The brain of a scientist is a mysterious place," said Rall at a dinner honoring Laurel Society members—donors who contribute \$1,000 or more to Fox Chase in a year. "It's worth a minute to talk about how scientists approach problems, what motivates us, and how we factor into the larger Fox Chase family."

Rall knows whereof he speaks: A Fox Chase researcher for 20 years, he is an active scientific and administrative leader.

"We see our role in performing research and treating patients as far more than a job," he said. "There is a personal connection we have to this place—that I have to this place—that is hard to describe, but deeply rooted. Our mission of prevailing over cancer is something

we live out each day we come to work."

A Laurel Society member himself, Rall acknowledged the importance of donor support: "You may not know it, but you are all scientists yourselves. Your support of Fox Chase is, in a sense, an investment in a grand experiment to outwit a dreaded disease."

The evening also featured the presentation of the first Laurel Society Award, which recognizes exceptional support of and service to Fox Chase, to Margaret Mauran Zuccotti. Diagnosed in 2006 with inflammatory breast cancer, Zuccotti has been active in supporting other patients and promoting the Center.



"The brain of a scientist is a mysterious place."

—Glenn F. Rall

Physicians Named 'Top Docs'

Fox Chase doctors rank among the region's best, according to *Philadelphia* magazine, which lists 31 Center physicians of varying specialties in its "Top Doctors" issue. Published in May 2011, the annual list highlights physicians who are peer-nominated, then screened by physician-led research teams based on criteria such as education and experience.

Two Fox Chase nurses also were featured in the issue's cover story, "What Nurses Wish You Knew." Joanne Hambleton, vice president for nursing and patient services, and Theresa Pody, clinical director of inpatient medical oncology,

served on a panel of 33 of the region's top nurses, convened by the magazine to answer questions ranging from "Does the nurse-to-patient ratio affect outcomes?" to "Should patients self-diagnose using Google?"

"It takes a lot to be there while someone suffers," Hambleton says in the article, reflecting on the unique characteristics of nursing. Pody adds: "We always feel we have to fix things. Sometimes you don't have to fix anything. You just have to be there."

For more information and a list of Fox Chase "top docs," visit www.foxchase.org/topdocs.

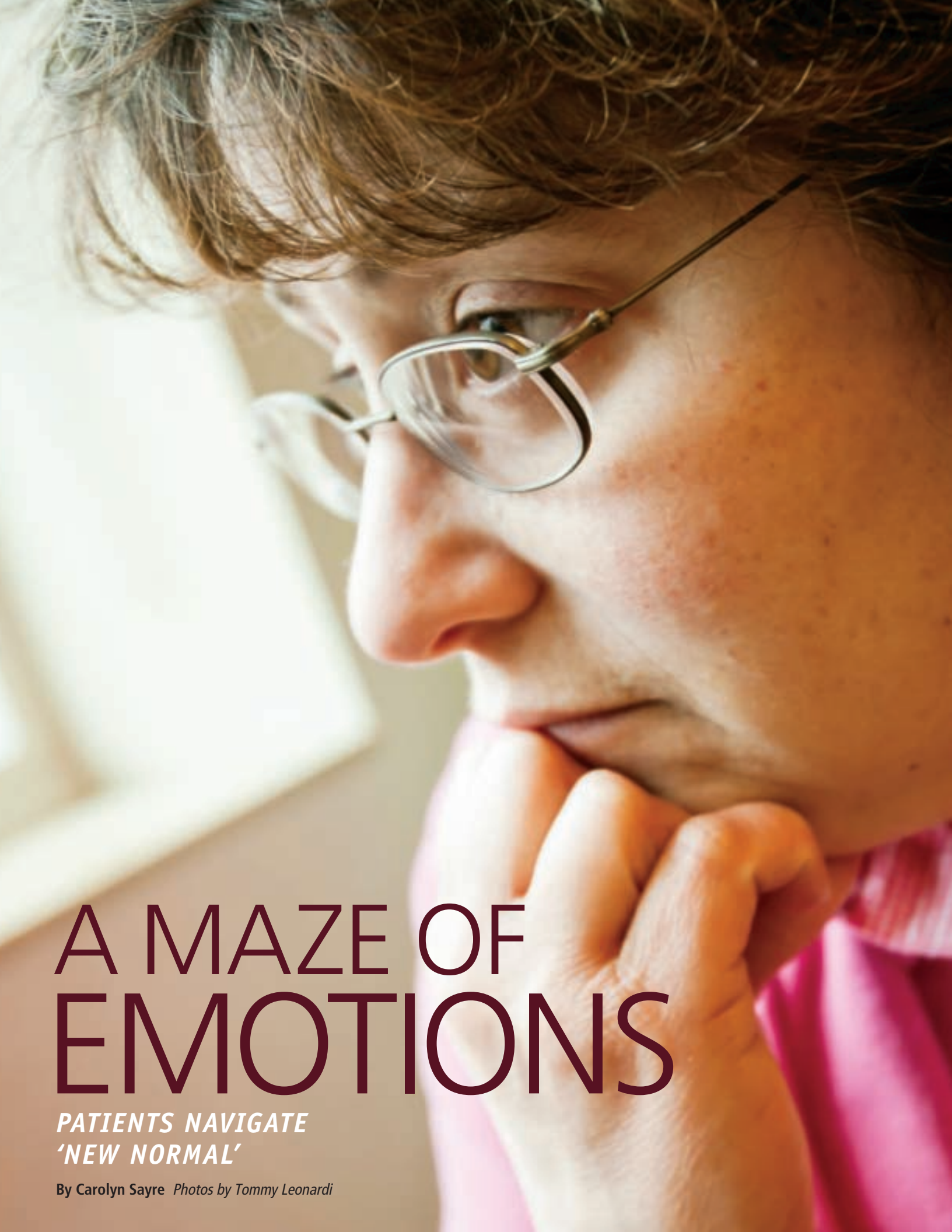
Fox Chase Receives Humanitarian Award

The Center received the Axios Award in July from the American Hellenic Educational Progressive Association's Fifth District Cancer Research Foundation. The honor recognizes those "whose humanitarian purposes and endeavors contribute to finding a cure for cancer, unselfishly and devoutly in the name of mankind."

The occasion marks the first time the

award has gone to an organization instead of an individual. Biologist Biao Luo, director of the Cancer Genome Institute, accepted the award on the Center's behalf at a gala in Edison, New Jersey.

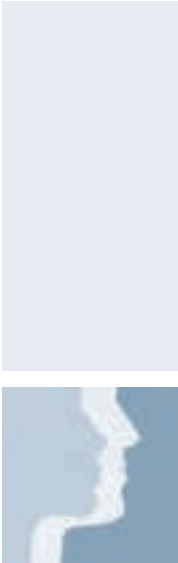
The Greek American association also awarded Jeff Boyd, senior vice president for molecular medicine, a \$10,000 grant for research on ovarian cancer.



A MAZE OF EMOTIONS

*PATIENTS NAVIGATE
'NEW NORMAL'*

By Carolyn Sayre *Photos by Tommy Leonardi*



When it comes to having cancer, Dara Barr says, there are two struggles every patient faces. The physical one is obvious: traveling back and forth to the hospital, undergoing sometimes-debilitating surgeries, and dealing with the effects of the disease—and the side effects of treatment. The emotional challenge is less visible: grappling with the host of feelings a diagnosis can stir up, finding a way to stay positive when your mind veers toward the worst-case scenario, and accepting the “new normal” cancer can bring.

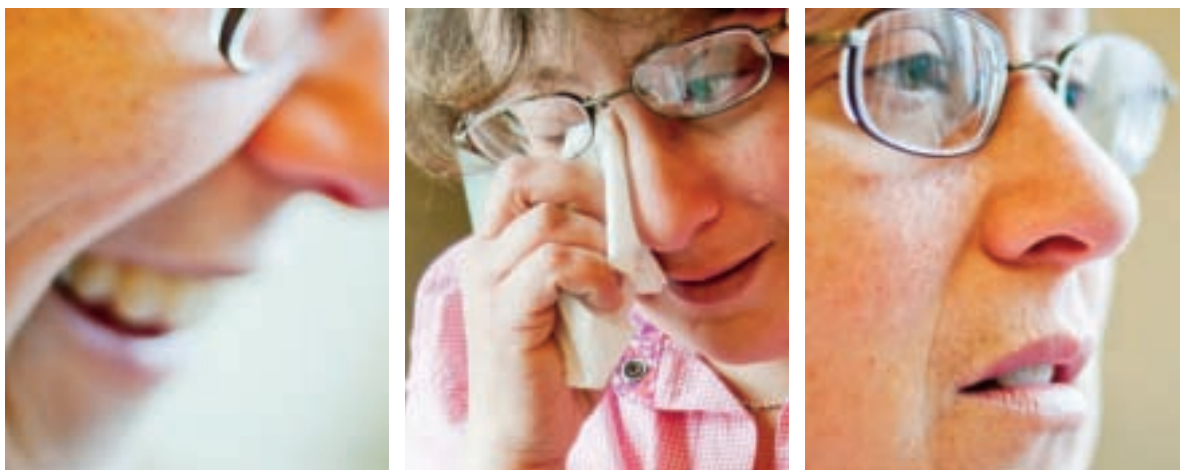
FOR BARR AND MANY other patients, the emotional experience of cancer can be as daunting as the physical one.

“Living with cancer is a rollercoaster ride—I have to be mentally prepared for anything,” says Barr, who was diagnosed with fallopian tube cancer in 2007 and has experienced two recurrences. “It can be just as challenging mentally as it is physically.”

Patients who, like Barr, are living with cancer may experience an array of competing emotions during their cancer journey, from sadness and fear to denial and anger, sometimes even clarity or acceptance. Many find themselves in

shock and disbelief when they are first diagnosed. During treatment, patients may find themselves overwhelmed by anxiety, fear, and depression. Others focus so much on the physical battle that they do not let their emotions surface until later. Feelings like anger and frustration may become most powerful during survivorship.

“It is a very emotional journey,” says scientist and psychologist Suzanne Miller, director of the psychosocial and behavioral medicine program at Fox Chase. “For most people, hearing the word ‘cancer’ is absolutely terrifying and comes wrapped with a lot of uncertainty and confusion.” ▷



“LIVING WITH CANCER IS A ROLLERCOASTER RIDE,”
SAYS PATIENT DARA BARR.

The Center is working to develop approaches to cancer care that treat patients based on their psychological profile as well as their physical one. Research by Miller, who studies patient responses to chronic illnesses like cancer, shows that most patients can be categorized either as “blunters”—who tend to downplay their condition and are less compliant with treatment—or “monitors,” who are hypervigilant about their health and prone to worry. Knowing how patients tend to react can help physicians tailor their discussions and treatments appropriately, Miller says.

“Patients benefit from us paying attention to them as a whole person,” says Luanne Chynoweth, director of the Center’s social work services department. “Knowing that someone cares about their thoughts can empower a patient to be hopeful and have a big impact on survivorship. ...Every patient is different and needs a different kind of attention.”

‘CANCER HAPPENS TO OTHER PEOPLE’

Lael Swank, a breast cancer patient who drove the two hours to Fox Chase in Philadelphia from her home in northeastern Pennsylvania for nearly a year—first for chemotherapy, then for radiation—says she has experienced every possible emotion since she first heard the word “cancer” applied to her in March 2010.

“I have felt it all,” says the mother of two. “I have been in denial—I was convinced they mixed up my pathology with someone else’s. I was afraid of dying and scared of what would happen to my children. I was anxious and woke up in the middle of the night with panic attacks. I was angry. I was frustrated.”

When patients are diagnosed, they often say they feel like they are dreaming or living someone else’s life. Daniel Wolfson, a kidney cancer survivor, couldn’t believe that it was happening to him. “Cancer happens to other people, not to me,” he remembers thinking. “I never smoked a cigarette or drank. I ran marathons. I was the guy who did everything right.” Wolfson was told he had six months to live by the doctor he consulted in New York City before he came to the Center for treatment. That was nine years ago. “Fox Chase surgeons saved my life,” he says.

Other patients turn their disbelief inward and blame themselves. Thoughts like “I shouldn’t have smoked,” “Why did I delay that screening for so long?” or “My life has been too stressful” are typical. “Self-blame and shame are highly common emotions,” Miller says. “People start wracking their brains, examining their memories of their lives to see what they did wrong.”

Many people also report feeling overwhelmed by the new information coming their way: lab reports, biopsy results,





DARA'S DAY

APPOINTMENTS AT FOX CHASE are part of the 'new normal' for patient Dara Barr, in treatment for recurrent gynecologic cancer. Accompanied by her friend Jill, Barr fills out forms (*top left*) before her check-up. Afterward, she's off (*above*) to the infusion room, where nurse Marge Bernesky (*top right*) prepares her for chemotherapy. Finger-knitting (*right*) helps pass the time; she wears a piece of her handiwork—in teal (*above middle*), for ovarian cancer awareness. Near the end of the hours-long visit, the effects of the day and the drugs begin to take their toll (*lower right*). Barr views a portrait of her family (*below*) taken on a brighter day, and shares a moment of comfort with her friend (*below left*). Stars tattooed on her arm, added post-diagnosis, represent each of her children and her husband.



different types of scans and treatments or surgical options. Barr says she didn't know where to start when she was first diagnosed. In cases like hers, a family member often steps in and helps with tasks such as doing research and scheduling appointments.

"It really runs the gamut," Chynoweth says. "Some people have a way of just marching forward with things and don't tune into their feelings as much. Others are so overwhelmed that they almost come to a standstill."

THE KNOWN AND THE UNKNOWN

Chynoweth says it is crucial that patients get help coping with their emotions—in particular, feelings like fear, anxiety, and depression, which often come to the surface when patients are going through treatment or dealing with a relapse.

"I remember worrying about what chemo would be like," Barr says, before her first treatment. "I wondered how I would function, whether I would feel sick—and I dreaded

the thought of being bald. It was scary not knowing what to expect."

When her cancer recurred in 2009 after two years of remission, Barr was overwhelmed with a different kind of fear—the fear of dying. "I knew the drills at the hospitals, the tests and the meds," she says. "It wasn't the unknown that scared me anymore, but rather the fact that I knew my cancer was treatable but not curable—my doctor says five years is generous." She recalls pulling the blanket of her hospital bed over her head and sobbing. "I'm scared to be helpless and in pain. . . I don't want to be a victim in those final days as people watch over me."

For some, emotions come to the surface when treatment is over. Swank—whose tumor was successfully removed in May 2010—says her fears emerge when everything is quiet, when she isn't running to the hospital for chemo or talking on the phone with the doctor's office. Though her physician is optimistic about her progress, she sometimes wakes up in the middle of the night in a state of panic.

"In the beginning, people are so busy getting second opinions and deciding on treatments," Miller says. "For many, it is when the treatment is over and they have a minute to think that the feelings come flooding in."

Sometimes that overriding emotion is anger. "For many, there is a feeling of unfairness," Chynoweth says. "Maybe the person has already had a lot of hardships or they feel they are too young." Such was the case with Swank: As the one-year anniversary of her diagnosis approached, she says, she was "so mad" that she had lost a year of her life to cancer. "I am only 39 and my body has changed irreversibly," she says. "What did I do wrong to deserve this?"

Thankfully, Swank says, Fox Chase has the resources not only to treat her advanced cancer but also to help her deal with its psychological impact. In individual and group counseling sessions, social workers teach relaxation techniques and visualization exercises to help patients manage stress and anxiety. Social workers and psychiatrists also offer individual counseling for patients and their families. As Chynoweth explains it, "We act as a sounding board for people." Swank says her counselor—who happens to be Chynoweth—is like her angel. "Whenever I feel crazy or out of control, she is there to talk to me," she says.

Fox Chase's psychiatric staff also is equipped to evaluate and treat patients suffering from issues like depression, anxiety, sleep disturbances, and substance abuse. "There is a high comorbidity of certain types of cancer with psychiatric problems," explains Karen Mechanic, director of psychiatry, who treats patients with medication and a form of talk therapy known as cognitive behavioral therapy. "It is impor-

What Helps

When someone you know has cancer

DO

- Take your cues from the person with cancer. Respect her need to share—or for privacy.
- Respect her decisions about treatment, even if you disagree.
- Offer to help in concrete, specific ways.
- Be open with your feelings, such as by saying, "I'm not sure what to say, but I want you to know I care."
- Listen without feeling compelled to respond. Sometimes a caring listener is what the person needs most.

DON'T

- Offer advice the person hasn't asked for.
- Avoid talking about the illness—or talk about it constantly. The person might enjoy conversations that don't involve cancer.
- Comment on changes in the person's appearance, such as weight loss, which may make her self-conscious.
- Be afraid to hug or touch the person if doing so was part of your relationship before the illness.
- Say, "I can imagine how you must feel." In reality, you can't.

Source: the American Cancer Society. For more information, visit pubweb.fccc.edu/forward/acs.

“I HAVE TO BE MENTALLY PREPARED FOR ANYTHING.”

tant to manage these symptoms because they can become disabling and interfere with treatment.”

Support groups run by social workers and nurses and organized by cancer type are also available, along with programs such as Kids Night Out, a group designed to help the children of cancer patients process their experience.

Even after three surgeries and several rounds of chemo, Wolfson says the psychological aspect of his experience with cancer has been 85 percent of the battle. Throughout the long and difficult fight, Wolfson says: “I wouldn’t accept anything negative that the doctors were saying.” Instead, he did guided imagery meditation every day during his treatment. “I kept my running shoes at the end of my bed and kept saying over and over again, ‘I am going to run again.’”

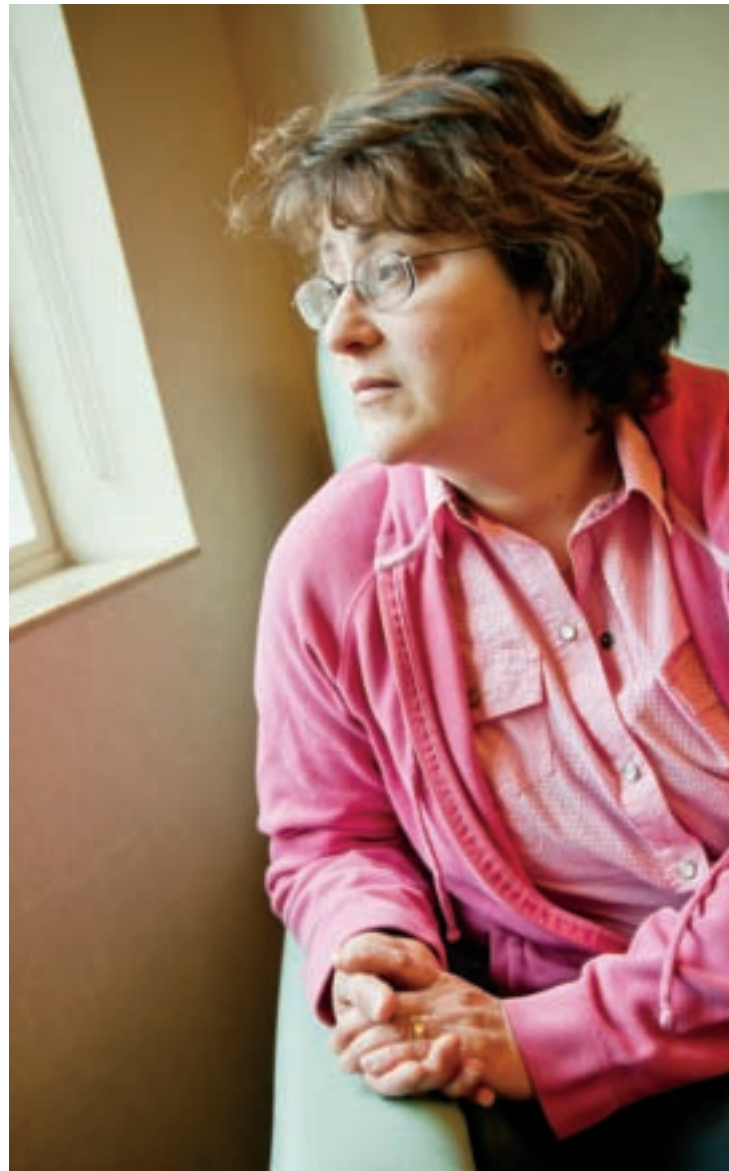
He kept his word. In May 2008, Wolfson completed the 10-mile Broad Street Run in Philadelphia, and he completed a half-marathon in September 2011. His cancer remains in remission.

AN ONGOING JOURNEY

As time passes, many patients experience a sense of contentment or clarity connected to their diagnosis. “It seems odd to talk about positive emotions,” Miller says. “But toward the end of the physical fight we see a lot of people who are able to reframe what has happened to them. They say they have learned something and want to give back.”

Barr is one of those people. She knows her time is limited, but her years of hardship have shifted her focus to helping others as best she can. “I am not the type to sit back and wait to see what happens,” she says. The mother of three boys spends her time volunteering, reaching out to other cancer patients, taking her kids to ice hockey practice, and going on weekly date nights with her husband. “I am very hopeful, but I am also realistic,” she says. “If I lose that, then that, to me, is denial.”

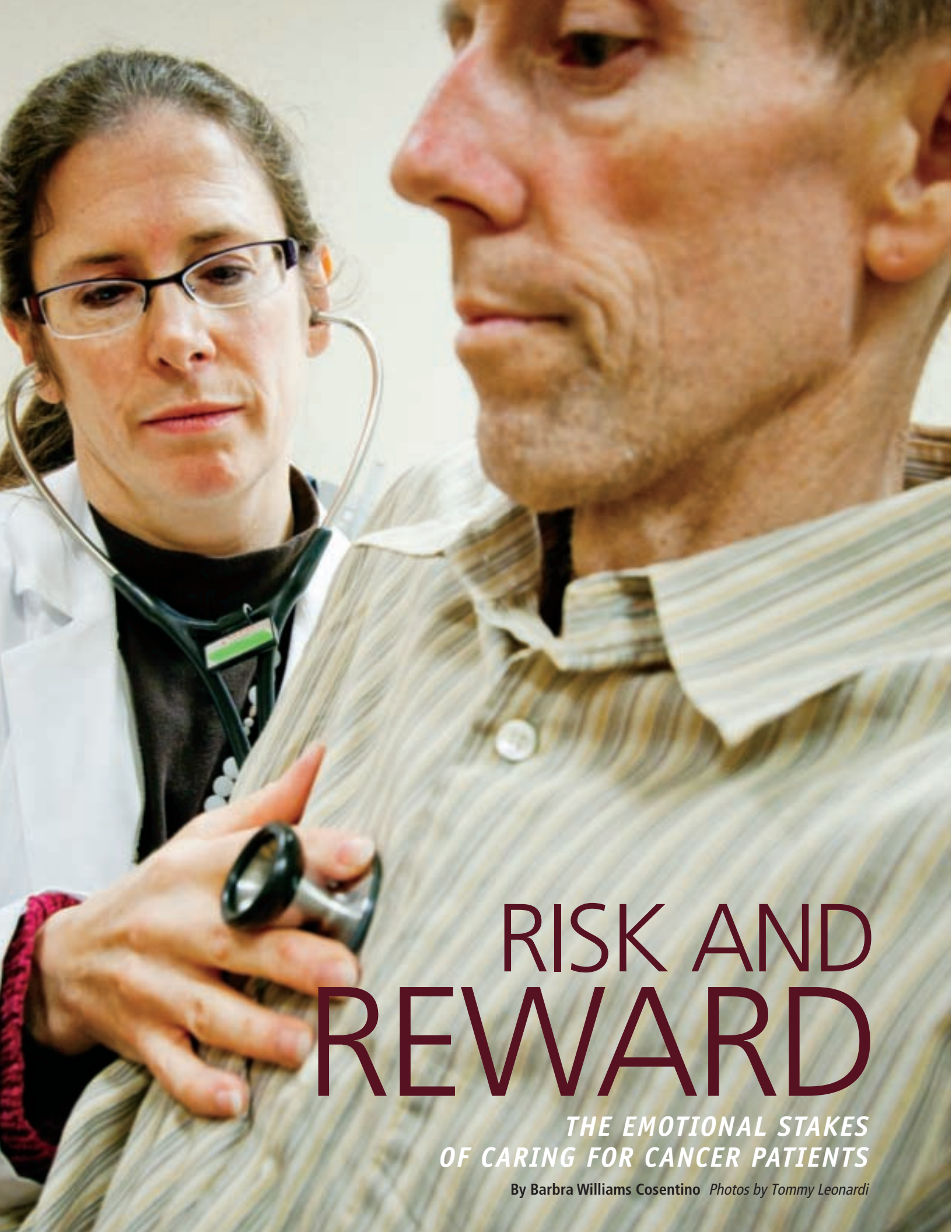
Physically, Barr has seen it all, from surgeries to chemotherapy, and now is enrolled in a clinical trial to which she has responded well. Emotionally, her journey is ongoing. She says that while she still feels anxious and over-



whelmed sometimes—such as at holidays, or when she goes for tests—she is mostly concerned for her family and how they will manage without her.

“Every day brings a new challenge,” she says. “Sure, I have sick-as-a-dog symptoms and side effects, but at this stage of the game it is the emotional experience that is the hardest—all I can think about is my family and how they will go on. It takes time to feel grounded and have a clear head, but I am confident that I am finding that peace. This is our journey, and we are going to deal with it as best we can.”

Carolyn Sayre is a freelance health writer whose work has been featured in The New York Times, Newsweek, TIME Magazine, Redbook, and Health.com, among others. She was previously a staff science reporter at TIME. She lives in Berkeley Heights, New Jersey.



RISK AND REWARD

*THE EMOTIONAL STAKES
OF CARING FOR CANCER PATIENTS*

By Barbra Williams Cosentino Photos by Tommy Leonardi



Delivering a diagnosis that no one wants to hear. Getting a positive response to a new therapy. Telling a patient her cancer has progressed—or that she is finally cancer-free. Perhaps no medical specialty encompasses as many dramatic highs and lows, sometimes in the course of a single day, as oncology.

While acknowledging that their jobs can be stressful and difficult, clinicians who treat cancer patients say their work also yields deep satisfaction. As longtime medical oncologist Mary B. Daly puts it, “I always feel both drained and enriched after a day in the clinic.” The challenge, experts say, is to find a balance between engaging emotionally with patients and maintaining the boundaries that help them practice effectively in the long term.

HIDDEN REWARDS

When people ask medical oncologist Crystal S. Denlinger about her occupation, she says, “they are always surprised to learn how much I love my job.”

Denlinger, who chose her career as a teen while her father was being treated for kidney cancer, says she considers it “a privilege” to care for oncology patients. “The relationships between physician and patient that develop during treatment are very special,” she explains. “I am intimately involved in my patients’ lives.” While she finds it “extremely satisfying” to cure many of her patients, she notes that she can still have a positive impact on those she cannot cure, “whether by improving their quality of life or extending their years on this Earth.”

It is perhaps no surprise that caring for cancer patients comes with certain challenges. A 2006 article in *Palliative and Supportive Care* that reviews research on the topic notes, “Cancer is a psychologically and physically threatening disease. Health care providers empathize with their patients’ losses and . . . may feel a personal sense of failure or futility.” The authors add that “working ‘on the edge’ between life and death poses daily psychosocial challenges and forces one to become acutely aware of the fragility of life.”

Margaret von Mehren, a medical oncologist who heads Fox Chase’s sarcoma program, says her work has given her a new perspective. “When I work with patients, it gives me insight into what’s really important,” she says. “As I watch them struggle to reorient their whole way of living to deal

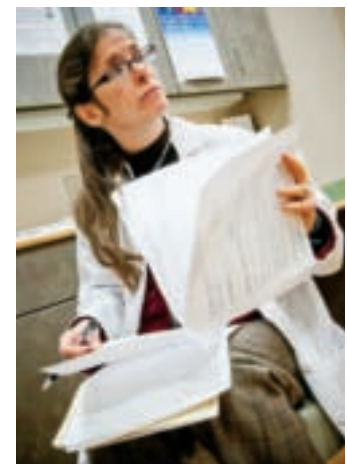
with their disease, it reminds me that there’s more to life than having your next success.”

THE COST OF CARING

The very aspects of clinicians’ work that can be most rewarding—such as relationships with patients and their loved ones—can also present the most challenges.

Von Mehren sees some patients over the course of many years. In some cases, their sarcomas are not curable. “There are always feelings of loss when someone you’ve been treating for years dies,” she says. “You’ve watched their children grow up and shared life experiences with them, and the ending feels profoundly sad.”

Medical oncologists aren’t the only ones to face such losses. Head and neck surgeon John A. “Drew” Ridge takes issue with the conventional wisdom that surgeons, who typically spend less time with patients than do their medical peers, are less emotionally engaged. “Surgeons are oncologists,” ▷



“WHEN I WORK WITH PATIENTS, IT GIVES ME INSIGHT INTO WHAT’S REALLY IMPORTANT.”

—Margaret von Mehren, medical oncologist

he says. “When we work with patients who have cancer, the stakes are high. Even when the prognosis is very good, to a patient a diagnosis of cancer is life-changing. Every interaction is potentially difficult for both patient and doctor.”

Research indicates that the emotional toll of clinical oncology can include feelings of powerlessness, failure, and guilt. Von Mehren is keenly disappointed when treatments don't work as well as she had hoped. “When I know that, theoretically, particular patients should do well but don't, I am frustrated by my inability to turn things around,” she says.

Self-doubt can compound such feelings. “Sometimes it's difficult not to beat yourself up or second-guess yourself,” says medical oncologist Elizabeth R. Plimack, who treats patients with kidney, bladder, prostate, and testicular cancers. “You can't be a good physician without revisiting the decisions you've made, but a negative outcome should not be viewed as a personal failure.”

Clinicians are sometimes particularly affected by certain patients. They might identify with a patient who is of similar age, for example, or a patient might trigger memories of

a lost loved one. Von Mehren, whose mother died at 61 of lung cancer, says she feels a particular pang when treating a middle-aged woman with the disease.

But research has found that embracing the emotional components of caring for cancer patients yields benefits for both patient and practitioner—including improved care and recovery, reduced anxiety for clinicians and patients, and lower rates of malpractice. A study published in *Psycho-Oncology* in 2005 found a “human connection” between physician and patient to be a “universal ingredient of effective cancer care communication.”

“You cannot separate yourself from the emotional aspects of taking care of someone,” says pain and palliative care physician Marcin Chwistek. “Emotions are what connect us to patients; clinicians just need to learn to recognize and manage them. As a clinician, understanding your emotions helps you take better care of the patient, but it also helps you take better care of yourself.”

Caring for oneself emotionally can help clinicians avoid the syndrome known as “burnout.” Psychologist and

RELATIONSHIPS WITH PATIENTS embody some of the most rewarding—and most difficult—aspects of the job for clinical oncologists. Clockwise from top left, Margaret von Mehren, who heads the Center's sarcoma program, assesses longtime patient Michael Estelle; a moment of gratitude and affection; Estelle and wife Danielle exchange smiles with von Mehren as they prepare to leave. [Editor's note: Michael Estelle died shortly after these photographs were taken.]



burnout expert Christine Maslach defined the condition as a feeling of emotional exhaustion; depersonalization, or detachment from one's work; and a reduced sense of personal effectiveness. Burnout has been linked to increased rates of medical errors and decreased patient satisfaction.

A survey published in *Journal of Oncology Practice* in 2005 found that more than 60 percent of American oncologists reported feelings of burnout, with the top three signs being frustration, emotional exhaustion, and lack of satisfaction with work. Other studies have identified burnout rates ranging from 30 to 50 percent among oncology clinicians.

A LARGER ROLE

Focusing on the many ways they serve patients beyond treating their disease—from educating to providing comfort and understanding—helps clinicians stay in touch with the contributions they make.

“After their diagnosis, some patients do online research and find articles that impart information in the most negative light, which can lead to a ‘doom and gloom’ attitude,” von Mehren says. “I find it emotionally and intellectually satisfying to help patients understand more about their disease, clear up misconceptions, and give them an honest picture of what will happen next.” Like many of her colleagues, she also takes satisfaction in knowing that her participation in research and clinical trials could help to develop more effective treatments in the future.

Communicating honestly with patients about their medical situations and treatment options can be important for both physician and patient, Chwistek says: “Discussions around healthcare decisions can be draining, but there is a real sense of being helpful when the conversations help patients to make decisions that are congruent with who they are.”

Veteran nurse Celeste Schiller, who has cared for hospitalized cancer patients for more than 20 years, says she focuses on her ability to make a difference however she can: “It is very gratifying when I can help my patients maintain hope that they can meet some of their goals, such as going home, in spite of their illness.”

Assisting patients in coming to terms with their situations can be deeply fulfilling, says surgeon Ridge. “One of my major rewards is helping people to find satisfying ways of living despite having had cancer,” he says, “and without being crushed by fear.”

HELPING THE HEALERS

Remaining alert to circumstances that might activate emotional reactions—such as encountering patients who bring up painful memories—can be the first step toward managing those reactions, says Luanne Chynoweth, director of social work services.

What Helps

Battling burnout among oncology staff

Research into decreasing stress and preventing burnout among oncology clinicians is in the early stages; however, preliminary investigations and anecdotal reports suggest potential strategies.

Communication skills are a common concern, particularly related to breaking ‘bad news,’ transitions in treatment, end-of-life care, and error disclosure. Controlled trials have documented improvement in communication skills following training courses. Changes are associated with positive shifts in attitudes toward patients’ psychosocial needs and patient-centered care.

Recognition and appreciation are recommended for staff retention. For instance, researchers have advocated retreats for oncology nurses at which participants share their experiences, acknowledge vulnerability and emotional responses, and provide mutual support.

Support groups and bereavement workshops can be helpful, but their effectiveness may depend on their structure and leaders.

Humor has been proposed as a strategy to assuage stress, miscommunication, and depression.

Stress-management workshops have demonstrated promise in pilot studies.

Other suggestions include providing mentoring for junior staff members, continuing education on self-care and well-being, and individual counseling for those at highest risk for burnout.

Source: “Caregiver Stress and Burnout in an Oncology Unit,” Palliative and Supportive Care, 2006.

“Social workers receive lots of training around self-awareness. We’re always looking at what can get triggered for us personally,” she says. “Having that awareness allows you to share and connect while also maintaining effective professional boundaries.”

In a March/April 2007 *Oncology Issues* article, Chynoweth and former colleague Joan Hermann describe a mindset of “detached engagement”: “A patient touches our heart and we respond with genuine feeling and concern. ... We remain emotionally engaged but able to guide the patient through the minefield of feelings and experiences that characterize a life-altering disease.”

Social workers strive to avoid conveying any personal pain they feel through such engagement, Chynoweth explains: “We do not want to telegraph emotional distress to our cancer patients, who then feel a need to ‘care for’ their professional caregiver.”

Striking a balance between emotional engagement and professional distance is no small task, however. “It is always challenging to set internal boundaries so that my patient’s emotional pain does not become my own,” Schiller says. “At a certain point, perhaps five or six years into practice, oncology nurses either grow in their ability to be deeply engaged with their patients without getting consumed by feelings of sadness or loss, or they leave the bedside.”

“I encourage younger nurses to focus on their ability to make a difference in the lives of patients,” she adds, “but to also develop the ability to leave work at work.”

Opening up to colleagues about emotionally difficult situations can bring relief. “Talking through a difficult situation can enable physicians to confront their own emotions ... reduce isolation and help build the network of support that is necessary for complex and demanding clinical work,” notes a 2001 article in *Journal of the American Medical Association*. But physicians may resist discussing the personal challenges they encounter.

Chwistek points out that traditional medical teaching held that emotions interfered with physicians’ work; doctors were taught to be objective and not let their feelings get in the way. “It has been deeply encoded in our brains to deal strictly with medical facts rather than to share the emotional challenges of our work with colleagues,” he explains.

To give physicians a forum in which to safely process their experiences, Fox Chase hosts the Schwartz Rounds, a bimonthly meeting designed for clinical staff to discuss challenging cases. Part of a national program based at Massachusetts General Hospital, the sessions aim to provide support to professional caregivers and improve their communication with each other and with patients.

“Being able to say what you’re thinking is therapeutic,” says Hossein Borghaei, chief of thoracic medical oncology, who shared a case at Schwartz Rounds involving a patient in her 30s who died of lung cancer, despite his efforts. “It’s good to get it off your chest.”

A PROFESSION AND A VOCATION

How oncology clinicians manage the psychological and emotional challenges inherent in their work may depend on the individual.

“Not everyone is cut out to do this work,” says Ridge. The bluntness of his words matches his affect; Ridge acknowledges a bedside manner more reserved than cuddly. But the gruffness belies an unyielding dedication to his patients—a commitment that extends far beyond the operating room. “If I cure them, I follow them for 10 years,” he explains. “If I don’t, I follow them until their treatments end—sometimes until they die.”

Ridge says he became an oncologist in part to “assume some of the weight” of cancer patients’ emotional and psychological burdens. After two decades, that interpersonal connection helps to keep him motivated. “You never hate cancer any less,” he reflects. “You never get tired of the struggle. ... But conquering the cancer is insufficient; you have to care about the patients.”

Ridge views his occupation as more than a job. “Being a cancer specialist is a chosen profession and a vocation,” he says. “Many are drawn by the satisfaction of helping people in their time of greatest need.”

But make no mistake, he adds: “The job is hard. You don’t stay at it long if you don’t find a way to deal with it.” ●

Barbra Williams Cosentino is a registered nurse, clinical social worker, psychotherapist, and freelance medical writer based in New York.

“I FIND IT EMOTIONALLY AND INTELLECTUALLY SATISFYING TO HELP PATIENTS UNDERSTAND MORE ABOUT THEIR DISEASE, CLEAR UP MISCONCEPTIONS, AND GIVE THEM AN HONEST PICTURE OF WHAT WILL HAPPEN NEXT.”



COMING OUT WITH OUTCOMES

By Ben Leach and Jacquelin Sufak

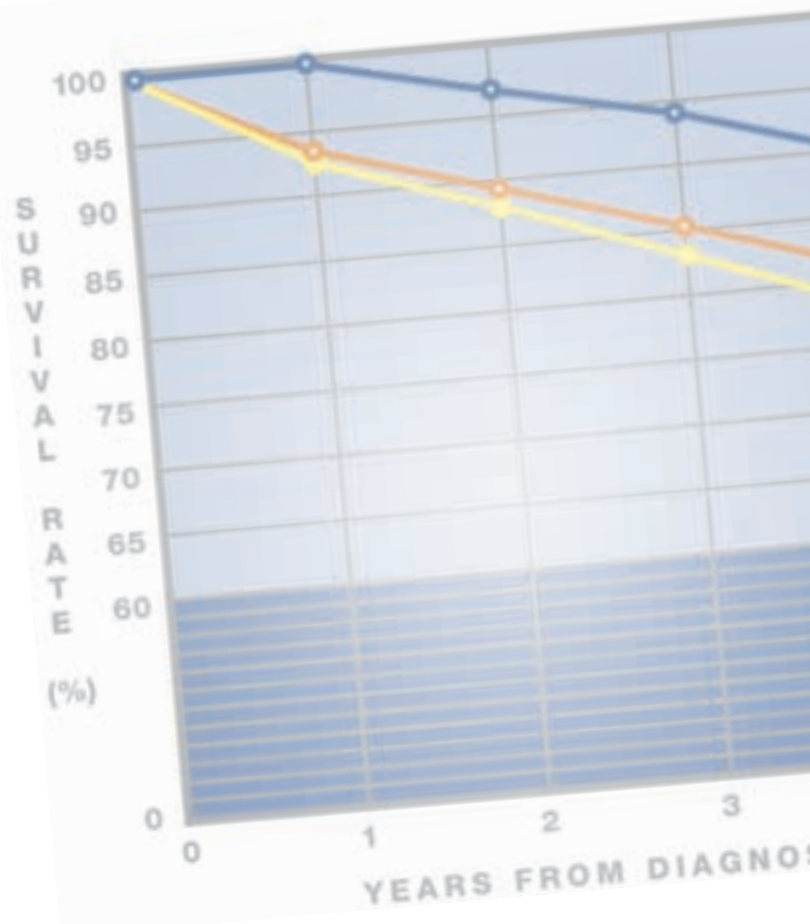
In an increasingly information-rich society, people have gotten used to finding out what they want to know with the click of a button. Figuring out the best place to go for cancer care, however, could stump the savviest Internet surfer, since hospitals have typically kept their track records for treatment success under wraps. Such information can make a life-and-death difference for patients, and Fox Chase is among those leading the charge for change.

John Donahue is meticulous by nature. After more than three decades working in research and development and regulatory affairs for the pharmaceutical industry, Donahue understands the importance of good hard data. So when he was diagnosed by his urologist with early-stage prostate cancer in 2006, he knew he needed more information.

Besides consulting with his doctor and industry colleagues, Donahue combed the Internet for information on treatment options. When he investigated Fox Chase, he learned that it was one of only two institutions in North America using a new radiation-therapy technology called Calypso that operates like a GPS for the body, locating and tracking prostate tumors and enabling more accurate delivery of radiation therapy.

“Doing the research was really helpful,” he says. “It certainly influenced my choices.”

Donahue opted to receive his care at Fox Chase because of the state-of-the-art treatments it offered, which he felt gave him the best chance of avoiding surgery. But at the time, he had no idea exactly how successful Fox Chase was at treating prostate cancer at its various stages—what percentage of patients survived for at least five years after diagnosis, for instance. In fact, anyone seeking that kind of information for most hospitals nationwide would have come up empty. Five years later, that is starting to change. ▶



BY COMPARISON

In 2011, the Center published data comparing survival rates for patients treated at Fox Chase to those treated at two types of community-hospital cancer programs.

- ▶ **Fox Chase**, as a National Cancer Institute-designated comprehensive cancer center, engages in both basic and clinical research, in addition to patient care, and meets peer-reviewed standards. It sees about 33,000 patients each year and provides a full range of diagnostic and treatment services.
- ▶ **Community-hospital comprehensive cancer programs** diagnose and/or treat 650 or more cases each year. They provide a full range of diagnostic and treatment services onsite or by referral and also conduct clinical research.
- ▶ **Community-hospital cancer programs** diagnose and/or treat between 100 and 649 cases each year. They provide a full range of diagnostic and treatment services, though patients often are referred elsewhere for part of their treatment.

Definitions: the National Cancer Data Base

In January 2011, Fox Chase became one of the first cancer centers in the United States, and the first hospital in the Philadelphia region, to make its clinical outcomes data publicly available, publishing the information online at www.foxchase.org/outcomes. The website charts survival rates for patients treated for four major cancers—breast, colorectal, lung, and prostate—and compares outcomes for people treated at Fox Chase to those treated at both large and small community-hospital cancer programs, using data provided by the National Cancer Data Base.

In nearly all stages of all four cancers, patients treated at Fox Chase survive longer. For Stage I colorectal cancer, for example, 83 percent of Fox Chase patients remained alive five years after diagnosis, compared to an average of 76 percent of patients treated at larger community-hospital cancer programs and 74 percent of those treated at smaller pro-

grams. The cancers for which the Center published data are among the most common in the United States and the most often-treated at Fox Chase. The Center determined that it treated too few qualifying patients to date to publish useful results for other cancers; however, it plans to publish additional data as it becomes available.

The publication of such information is not without controversy; healthcare providers debate whether such data should be made publicly available. Fox Chase president and CEO Michael V. Seiden says it's important to understand the data's limitations, including the fact that it cannot predict individual outcomes. However, he says publishing the information reflects Fox Chase's dedication to transparency and service to patients.

"We are committed to helping the public become more informed when making decisions about their health care," Seiden says. "We hope this data will enable patients to make the choices that are right for them."

THE (BUMPY) ROAD TO TRANSPARENCY

For Fox Chase, the publication of its outcomes data was sparked in part by a phone call from journalist Sharon Begley, then of *Newsweek*, in fall 2009. Begley was investigating the implications of receiving cancer treatment at a National Cancer Institute-designated comprehensive cancer center such as Fox Chase versus a community hospital, which typically lacks the same

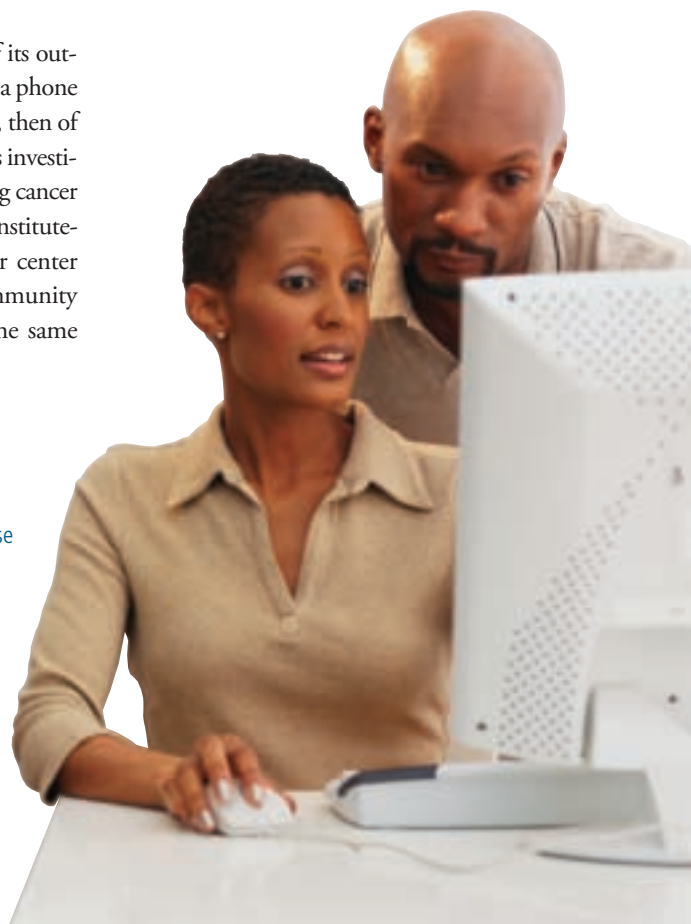
breadth of resources or volume of patients. The reporter was surprised to learn that comparison data was rarely available.

"In trying to find the oncologist or cancer center with the best track record on, say, stage IV bladder cancer, even the savviest patient quickly hits a wall," Begley wrote in her article, "What You Don't Know Might Kill You," published in October that year. "With few exceptions, cancer centers treat these 'outcomes' data like state secrets."

The article points to striking disparities in diagnosis and treatment among the nation's cancer-care facilities—in particular, between community hospitals and top cancer centers, but also among top centers themselves. About 85 percent of cancer patients are treated at community hospitals; however, her article suggests that while some cancers can be treated successfully in such settings, factors such as type and stage of disease can have serious consequences for survival rates. For example, Begley noted a five-year survival rate for Stage IV cervical cancer of 33 percent at the Cleve-

PEOPLE SEEKING CANCER CARE

can compare survival statistics of patients treated at Fox Chase to those treated at community hospitals nationwide at www.foxchase.org/outcomes.



land Clinic, a comprehensive cancer center, versus 16 percent nationally.

Fox Chase provided data for Begley's article, and the reporter's inquiry set off an exploration by Fox Chase leadership and clinical faculty into making the Center's clinical outcomes publicly available.

They had much to consider.

Third parties ranging from consumer magazines to Medicare rate healthcare providers on various performance measures, and although the reporting of clinical outcomes is expected to increase under the requirements of federal healthcare reform, such reporting is hotly debated among providers. Critics point out that patient populations and diagnostic criteria can differ from one institution to the next, preventing precise, "apples-to-apples" comparisons. For instance, there may be differences in patient populations—such as the age, general health, and socioeconomic status of those who seek treatment at major cancer centers instead of community hospitals—that are not accounted for in published data.

The handful of cancer centers that have released data also use different measures and comparison groups: While Fox Chase compares its results with those of community hospitals and provides data for each cancer stage, the Lurie Cancer Center at Northwestern Memorial Hospital in Chicago compares itself only to other teaching hospitals and does not separate its data by stages.

Fox Chase published its outcomes after lengthy consideration. "Ultimately, I think it's being responsible," Seiden says of the decision. "We have this data; shouldn't patients have access to it?"

QUESTIONS OF CONSISTENCY

John Birkmeyer, director of the University of Michigan's Center for Healthcare Outcomes and Policy, says the lack of uniform reporting might be misleading to patients who try to compare hospitals' published data.

"More and more cancer centers are going to be making their outcomes data public," Birkmeyer predicts. "But right now, each one is doing it independently. There's no model that currently exists that any of these cancer centers are required to follow." Given that hospitals could try to skew their data, he adds, even comparisons to established databases might be viewed with skepticism.

That concern arose more than 20 years ago in an early debate over outcomes. In 1989, the New York State Department of Health launched the first

In January 2011, Fox Chase became one of the first cancer centers in the United States, and the first hospital in the Philadelphia region, to make its clinical outcomes data publicly available.

statewide program to make outcomes statistics for cardiac surgery available to the public. Some members of the medical community protested that physicians might refer high-risk patients out of state, since their higher mortality rates could bring down the physicians' published survival rates. Conversely, some critics believed that physicians might be tempted to exaggerate patients' risk factors to give the impression that they performed well on serious cases.

Donald A. Berry, a biostatistician at the University of Texas MD Anderson Cancer Center in Houston, argues against the publication of outcomes data. In a March 2011 editorial in *The Cancer Letter* responding to the release of data by Fox Chase and other centers, Berry said he was proud of MD Anderson for not publishing its data, which would be difficult for patients to interpret. "Survival itself is a flawed measure of comparison, except in carefully controlled settings exemplified by randomized trials," he said, noting that such trials would not be practical for cancer patients.

CHANGES AHEAD


J. Robert Beck, chief medical officer and chief academic officer for Fox Chase, notes that while Fox Chase may be ahead of the curve in releasing its outcomes data, changes in healthcare policy may soon make the practice more common.

The Patient Protection and Affordable Care Act, signed into law in March 2010, calls for increased transparency and enhanced public reporting from hospitals—a requirement that could change reimbursement guidelines for hospitals. In the future, Beck predicts, "reimburse-

ment isn't necessarily going to be based on patient volume. It's going to be based on patient outcomes."

In the meantime, outcomes data remains one of many factors patients might consider when choosing a healthcare provider, says Fox Chase surgeon Robert Uzzo. When it comes to what patients care about, he says, the information constitutes an important piece of a larger puzzle that also includes factors such as physicians' interpersonal skills and accessibility.

Uzzo sees outcomes statistics as an important tool, nonetheless—and one that will continue to improve, since the Center plans to publish additional data. "We're going to have more and better data as time goes on," Uzzo notes. "This really is a starting point." 📍

 ON THE WEB
For outcomes charts
and more information, visit
www.foxchase.org/outcomes.



CRYSTALS AND CURIOSITY

*Chemist Honored for
Lifetime of Discovery*

By Carolyn Sayre

EVER SINCE Jenny Pickworth Glusker got her first chemistry set, she has been fascinated with how substances interact. Growing up in England during World War II, she spent a lot of time having “chemistry contests” with her friends.

“We would compete to see who could get the best colors and smells,” recalls the longtime Fox Chase chemist. “From a very early age, I was drawn to what chemists do—I wanted to figure out why materials react with each other in certain ways.”

Glusker has spent her nearly 60-year career doing just that, from studying and mapping the structure of molecules to unraveling how enzymes interact in the body. Her research helps to shed light on the processes that go astray when tumors develop so appropriate interventions can be developed.

“Chemistry is the key to understanding how the body works,” Glusker explains. “By learning about the ▶

*Chemist Jenny Glusker holds a cluster of crystals—
structures at the heart of her six-decade career as a researcher.*

science behind biological processes, we can better inform the design of therapies that treat diseases like cancer.”

In November, she received the prestigious John Scott Medal for her research. Named for a renowned Scottish chemist, the award has special meaning for Glusker, whose mother was Scottish. It also places her in the company of fellow recipients such as Marie Curie and Thomas Edison, who also made exceptional contributions to the “comfort, welfare and happiness of mankind.”

One of Glusker’s most notable scientific achievements dates to her graduate-student days in the early 1950s. While at England’s Oxford University, she contributed to the discovery of the chemical formula and structure of vitamin B12, a water-soluble vitamin found in foods such as liver that is essential for healthy nervous system function and blood formation. The finding constituted a milestone, unlocking the shape of the largest known molecule at the time and leading to a better understanding of how cells use energy to carry out chemical reactions.

Perhaps most importantly, the discovery also helped to eradicate pernicious anemia in the late 1960s. Caused by vitamin B12 deficiency, at the time the potentially fatal disease could be treated only by ingesting large amounts of raw liver. By identifying B12’s chemical formula, Glusker and her mentor Dorothy Hodgkin—who received the Nobel Prize for her efforts—enabled scientists to determine how bacteria manufactured the vitamin and how it could be synthesized in the laboratory.

“Chemistry is the key to understanding how the body works.”

The vitamin is now given by injection to treat pernicious anemia and other conditions.

It was at Oxford that the budding scientist met an American chemist named Donald Glusker, whom she married. In 1955, after finishing her graduate work, she moved to the United States with Donald and became one of the first women to be accepted into the California Institute of Technology’s prestigious doctoral program in chemistry.

The climate was challenging for female scientists. “There was a strange feeling about women in chemistry at that time,” she recalls. “Most potential employers thought that a woman who had a doctoral degree in chemistry should either work in a library or stop working as soon as she got married and had children.” Glusker had other plans.

After leaving Caltech, she accepted a position at the Institute for Cancer Research, which would become the scientific branch of Fox Chase, in the laboratory of Arthur Lindo Patterson. Patterson was a leading expert in X-ray crystallography—a method of using X-ray diffraction by crystals to determine the structure of molecules. For Glusker, it was a chance to continue the work she had begun as a student. After Patterson died in 1966, she became head of the crystallography lab. She has been con-

‘THE CENTRAL SCIENCE’

CHEMISTRY is the science of matter—especially its chemical reactions, but also its composition, structure, and properties. Chemistry is concerned with atoms and their interactions, particularly the properties of chemical bonds—the attraction between atoms through which they form molecules. It is sometimes called “the central science” because it connects physics with other natural sciences, such as geology and biology.

CRYSTAL CLEAR

X-RAY CRYSTALLOGRAPHY is a method of determining the arrangement of atoms within a crystal in which a beam of X-rays strikes the crystal and diffracts, or spreads in multiple directions. From the angles and intensities of the diffracted beams, a crystallographer can determine the positions of the atoms in the crystal, as well as their chemical bonds and other characteristics. Since a variety of organic and inorganic materials—including salts, metals, and minerals—can form crystals, X-ray crystallography has been fundamental to many scientific fields. It is the primary method for determining the structures of biological molecules including proteins and nucleic acids.

ducting critical research at the Center ever since.

Currently, Glusker focuses on determining the structures of anti-tumor agents, as well as chemical carcinogens such as those found in cigarette smoke. She also explores the structure of enzymes that control processes such as the growth of cells in the body. Such enzymes are often damaged or absent in patients with cancer, allowing for abnormal cell growth.

“All I have ever strived to do is gain a better understanding of what is going on around me and share that understanding with others,” Glusker reflects. “I can only hope that, through my work, I’ve done that.”

REMEMBERING BARUCH BLUMBERG

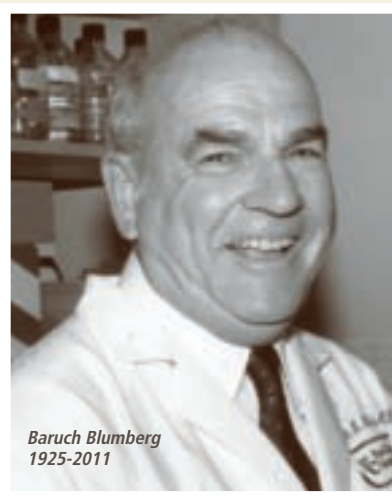
The scientific world lost a giant with the death of Baruch S. Blumberg in April 2011. Winner of the Nobel prize for his identification of the hepatitis B virus, "Barry," as he was known, remained engaged in his work and full of ideas for the next breakthrough until his death at 85. Fox Chase researcher W. Thomas London reflects on nearly a half-century of friendship and collaboration with a man for whom the world was a laboratory.

I met Barry Blumberg in July 1962 at the National Institutes of Health in Bethesda, Maryland. Having recently completed a fellowship in endocrinology at Memorial Sloan-Kettering Institute, I had enlisted in the U.S. Public Health Service and been assigned to the Epidemiology and Biometry Branch of the National Institute of Arthritis and Metabolic Diseases. Barry headed a section of the branch he'd created, Geographic Medicine and Disease. At just 36, he already had authored or co-authored about 50 papers.

Barry had chosen this hidden corner of the NIAMD because he thought it would allow him to pursue his own ideas and go where he pleased. He had begun what would become a lifelong practice of traveling, collecting blood samples wherever he went, and making observations about the people from whom they were drawn.

Scientifically, Barry was a throwback to the naturalists of the 19th century, like Charles Darwin and Alfred Russel Wallace. He was an acute observer of nature, and a collector. He was full of stories about his travels, which I found endlessly entertaining. He loved to tell one about a visit to Nigeria: After dinner, the guests would adjourn to the wall of the dining room to examine and discuss the insects and reptiles that had gathered there. Barry and I became colleagues and close friends and would remain so for the next 49 years.

Barry was interested in genetic polymorphisms in human blood—inherited variants of proteins or blood types that he believed were associated with disease. As a believer in natural selection, he thought



"He was a participator, not a spectator."

such variants must be important, or they would not have persisted.

In 1964, Timothy Talbot, the prescient director of the Institute for Cancer Research (which would become part of Fox Chase), recruited Barry to head a new division of clinical research, promising he could do what he wanted as long as his research had an impact on human disease. Barry accepted and began assembling a team. He asked me to join him, but I had never heard of the place and held out until 1966, when Barry finally convinced me the ICR was a scientific gem bound to gain national, even international, importance. His prediction would prove correct—and the ICR turned out to be a friendly, supportive institution to boot. I never regretted my decision.

Barry and I often walked at lunchtime in Lorimer Park near the institute and talked about what was new in the world, in science, and in our families. We each had four children that were close in age. He made life fun not only for my family and me but also for everyone in the division with picnics, hikes, and bicycle rides.



W. Thomas London

As he traveled, people he encountered began showing up in the lab: researchers from Finland, France, India, Thailand, and Israel became part of Barry's expanded family.

Barry had had relatively little training or experience in clinical medicine. He had faith, however, that his approach—identifying variants in blood, then finding out what they meant—was more informative than starting with a disease and trying to find its cause, as was then and is now the standard method. It was that approach that led him to identify the antigen on the surface of the hepatitis B virus. He later made a vaccine against the virus, which is the leading cause of liver cancer.

In 1976, Barry received the Nobel Prize in Medicine for his discovery. He shared his success with our entire group and took as many to the ceremony in Stockholm as was allowed—about 15, with spouses. The trip remains etched in my memory. It was like Cinderella going to the ball, complete with a handsome king, a beautiful queen (Barry's wife, Jean), and medieval venues. Barry loved it. He stayed up most of the night dancing.

I always knew Barry to be happy. He celebrated his life by living it to the fullest. He was a participator, not a spectator. He climbed mountains, kayaked, and traveled to the four corners of the Earth. As he hit succeeding milestone birthdays, my wife Linda and I would say Barry was the happiest 75-year-old we knew, the happiest

80-year-old we knew, and finally the happiest 85-year-old we knew.

I believe he died a contented man. His legacy of accomplishment has saved an enormous number of lives and prevented hundreds of millions of people from becoming ill with hepatitis B. And his enduring gift to me was his friendship of 50 years.

—W. Thomas London



PHOTOS: KARL SEIFERT

AN INTERVIEW WITH MICHAEL H. LEVY, DIRECTOR, PAIN AND PALLIATIVE CARE

'THE COMPLETION OF CANCER CARE'

Telling the Truth, Having Faith, and Finishing Business

MICHAEL LEVY was a medical student when he discovered his calling: caring for the gravely ill. He became a pioneer who helped to bring modern hospice and palliative care to the United States—and to cancer care. As head of pain and palliative care at Fox Chase—a program he founded 25 years ago—Levy strives to reduce the suffering of patients and their families and serve as a guide on their journeys with cancer.

As a palliative care physician, what kinds of services do you typically provide?

We treat pain and other physical symptoms and help the patient and family cope with any emotional or spiritual distress. We're involved at all levels of the cancer-care continuum, ▷

continued from page 23

from diagnosis to acute pain management to managing chronic post-surgical pain, as well as in dealing with end-of-life issues.

What are your goals in working with patients?

We try to get a sense of what's causing their symptoms so we can provide relief—and to find out what the patient's goals are. A patient might find that if they take enough medicine so their pain is a 2 out of 10, they're too sleepy to do what they want—but if we lower the dose so they're a 4, they can go play with their grandchildren. It's really about quality of life.

How is palliative care important specifically to oncology?

Palliative care is the completion of cancer care, not its antithesis. We palliate through-

out the disease continuum, and at some point there may be more palliation than anticancer treatment, but as clinicians we don't ever want to have to say to a patient,

'There's not anything more we can do for you.' We're going to do everything we can to maintain the quality of their life for as long as they live.



FAMILY MATTERS

The why of 'goodbye'

When it comes to providing end-of-life care, pain and palliative medicine physician Michael Levy strives to serve not only his patients, but also their family members or other loved ones.

"Unresolved grief is a major source of psychiatric illness," he says. "Getting your business finished with loved ones is really important."

Levy speaks from personal, as well as professional, experience. When his father became increasingly ill with Alzheimer's disease over the course of several years, he knew what he needed to do.

"As I saw it coming, I knew I had to resolve any issues that we had while we could still interact intellectually and emotionally," he says. "In the last few years, I went to visit him, I made him laugh, I took him food he liked." When his father died in January 2011, he says, "I felt very fortunate to know that I had finished my business with him, and that I knew he loved me and that I had made him proud."

At the end of his father's life, Levy says, he drew on the expertise of colleague Ira Byock, author of *The Four Things That Matter Most: A Book About Living*, to say goodbye. "I said to my father, knowing he probably wouldn't hear me or understand me, Ira's four things: 'Thank you, I love you, I'm sorry, and I forgive you.' And, you know, that kind of wraps it up.

"There's value in being able to do that," he adds, "and if, as a physician, you don't provide enough truth or information, you've deprived the patient and family of that opportunity."

How did you become interested in end-of-life care?

When I started out in the early Seventies, the dying were described as medicine's poor. They were the ones who needed the most but were getting the least; people were uncomfortable being with them. Once we learned, from programs like St. Christopher's Hospice in London, how to help terminally ill patients and their families cope with advanced illness, it was a matter of bringing that practice to the American healthcare system, and to oncology.

What did you find personally appealing about the work?

During my residency, I realized that I liked caring for people who were truly ill; I liked supporting them and their families. They were very appreciative, and I continue to feel privileged to care for them during a very intense period of their lives. This kind of care requires a

“Part of my goal is to make sure the patient and family are comfortable with what’s happening based on their cultural and spiritual beliefs.”

—Michael H. Levy
Director, Pain and Palliative Care



therapeutic presence that goes beyond medications.

Does religion or spirituality affect how you approach your work?

I think if you don't have some faith, it's hard to do this work. I look at my religion, and the main thing I get out of Judaism is that we have a deep responsibility—called *tikkun olam*—to make the world a better place. Part of my goal is to make sure the patient and family are comfortable with what's happening based on their cultural and spiritual beliefs.

What is your role when patients are in end-of-life situations?

When people know they are going to die and you come into that compressed part of their life, there's something I call "enforced intimacy": You learn more in the first couple hours than you would if you were dating someone for six months. They tell you all of their stories: of what hurts, and their families, and what issues they want to resolve, and you get swept into their life because to give them a good death you have to help them resolve these issues.

What is the most challenging part of your job?

We thought it would be caring for dying patients that would cause burnout in our field. But the real challenges come when you can't get a patient and family to a place you would like them to be—when there's a lot of unfinished business, when you don't think you've done enough or been as good as you can be.

What moments are the most satisfying?

It's rewarding to help people to understand their personal journeys and make choices to get the care they need. Once I had to explain to a 57-year-old woman that her disease had progressed and that she was too ill to try an experimental drug. I told her I'd like to refer her to our hospice program. She said, "You know, I'm really lucky." When I asked why, she said, "Most people don't know when they're going to die. I have some things I want to do, and I know that I should do them now."

Isn't it difficult to talk to patients about dying?

Sure. There can be a tremendous amount of denial. But the patient and family will

have more satisfaction if you are clear and you and they share the same expectations. False hopes can be disabling and prevent patients from finishing their end-of-life stuff.

Palliative care needs to be offered early enough to be effective. To not let people know they can have pain relief—that they can go to Disney World or whatever they want to do—is not being sincere and truthful. The cancer will be truthful, and the cancer shouldn't progress and make the patient and family feel their doctor lied.

Do you worry about taking away patients' hope?

We don't try to take away hope; we try to align it with realistic goals. Simply telling a patient what's happening and what you can do about it isn't negative. It's about saying, "You've come to me to help you get through this journey. I'm going to make sure you get the best care there is—to live as well as you can for as long as you do." It doesn't get any better than that. 🍎

Interview by Abbey J. Porter

ARTISTIC EXPRESSION can provide a unique means of understanding, communicating, and even healing from the experience of illness. *Forward* thanks the many contributors who generously shared their work for the debut of “Channels,” a forum intended to honor and showcase visual and written art inspired by experiences with cancer.

► **TO SEE ADDITIONAL SELECTIONS OR SUBMIT WORK** to be considered for future issues, visit *Forward* online at forward.foxchase.org.



CORPOREAL

BY BONNIE MACALLISTER, *Philadelphia, Pennsylvania*

A ‘cancer portrait,’ the painting depicts the artist’s husband, a four-year survivor of throat cancer. It was created using spray paint and oil on canvas.

Christmas Party

BY ARLENE BERNSTEIN, *The Villages, Florida*

*Do you recall the Christmas party at the home of friends?
You stand, dead center, living-room glimmering, shimmer of pulsating lights.
Your aluminum silver-gray cane gleams;
gray tweed coat (voluminous now);
slight fuzz of new white hair lighting your dark palette,
cancer-slim, incandescent.
We are leaving the party,
all goodbyes already uttered
but you linger—lungs, liver, brain, riddled, ruined.
Still the longing never dies; the longing keeps you riveted there,
unable to deliver the wishes throbbing behind your luminescent eyes.
Bent and mute, you prolong your visit.
The other guests (your friends)
perceive you simply, understandably, pitifully, slow, sickly slow.
They do not know what keeps you standing there
long minutes after they have shaken your cold hand,
embraced me with their knowing looks.
For they, with time at their command, impatient to return to
comfort, warmth, holiday glow, make merry as they may
but you—neither just staying nor simply moving at a pace
commensurate with your new and crippled state,
seem forever rooted
to the reddish-brilliant center medallion
of the Persian carpet
in the middle of
the burnished
hardwood
living-room floor—
rather, one by one, are tallying all that you will lose,
telling your rosary of grim adieux
as you have been doing these final months and weeks and days and minutes.
Dying happens thought by thought,
eked out in swift seconds’ slow summation.
This death-watch enervates, tolling away your life,
and I am depleted, trapped in your loss, bled of all patience, waiting impatiently
for you to accept your fate, yet fretting that I’ve missed your morphine dose.*

*Later, when I have helped maneuver your body into the car,
after I have driven us home in taut silence, after I have helped you negotiate
the car-door, the five cement steps to the house-door,
attempting gently to remove your coat, flinching as you flinch in pain at my touch,
searching your face, your burning eyes for what it is you want from me,
my pounding guilty ears and heart, your rasping, sad, accusing voice:
Why do we always have to rush?
Why are you always hurrying me away?
Why won’t you let me stay
Until I
say I am ready to go?*

Published previously in Schuylkill Valley Journal, Fall 2006.



THE SECOND DEATH OF EURYDICE

BY KEVIN CONVERY, Philadelphia, Pennsylvania

Created to honor a friend of the artist who died from bone cancer, the painting is based on the ancient Greek tale of Orpheus and Eurydice. After losing his lover, Eurydice, to the underworld, Orpheus is permitted to retrieve her—on the condition that he does not look back while traveling to the upper world. He fails the test and must accept his loss.

Published previously on the cover of Travels on the Night Sea, September 2011.

The Advent of Angels

BY GLENN MCLAUGHLIN, Pottstown, Pennsylvania

It was not a leap, just a calculation that I hoped would work when I asked the students, “Who in this room has cancer?” Not expecting any hands to rise one did and I noticed but moved on to “Who in this room has someone in their family that has cancer?” and four out of ten hands rose. It was a calculation to lead to conversation about why we do all these things so that when you are a father and your daughter makes you one of those four hands you know how to learn, investigate, write, ask, decide, to stand beside. After class, she stood beside me: clutching her books to her chest, pretty, long dark brown high school hair—straight, shimmering, luscious, reaching for the small of her back. “Leukemia” and “Three years ago” and “Cured.” is what I heard as I thought of her bald or left just with wisps on a bed with tubes in her arms. She was trying not to cry as she said, “Your daughter will be fine. I know she will. *I know she will.* Don’t worry, everything will be okay.” She left. I was speechless, frozen and convinced. You are never prepared for this—the advent of angels.

For Marcela.

Published previously in The Land I am Given, January 2011.

cancer in january

BY LYNN HOFFMAN, Philadelphia, Pennsylvania

*this malignant day is the testament of our permanent place
on a frozen earth—no shoots to beg, insist, demand
on sunlight, no leaf or tree to die.
today it’s cancer, swallow the stone.*

*it is a forever day as etched in ice as your families,
your loves, your best ideas, your many selves
the very cold is very proof.
the numbness is your promise of always-be.*

*what would you do if you knew
that sun would be higher in its course today
and then tomorrow and the next?*

*could you imagine the thaw?
what is it that lives through the death of ice?*

Genetic link to mesothelioma discovered *Mutation may underlie multiple cancer types*

Scientists at Fox Chase have discovered genetic changes that appear to increase the risk of developing cancers including mesothelioma, a deadly form associated with exposure to asbestos.

An aggressive cancer, mesothelioma usually attacks the lining of the chest and abdomen. Fox Chase researchers collaborating with scientists at the University of Hawaii found that, among two families with an unusually high incidence of mesothelioma, each member who developed the disease exhibited inherited mutations in a gene called BAP1.

The results, published in August in *Nature Genetics*, suggest that people who carry the mutations are at markedly increased risk of developing cancer if exposed to asbestos and therefore should undergo regular screening, says geneticist Joseph R. Testa.

"This is the first study that shows genetics can influence susceptibility to asbestos-related cancer," Testa says. "People exposed to asbestos and similar minerals, and those with a strong family history of mesothelioma, should be screened for BAP1 mutations—and, if the mutations are found, should undergo additional, regular screening to catch any cancer in its earliest stages."

The results suggest that people who carry the mutations are at markedly increased risk of developing cancer if exposed to asbestos.

The findings also may help explain why some people exposed to high levels of asbestos never develop cancer: They lack the BAP1 mutations.

Mesothelioma kills about 3,000 Americans each year, and new cases are on the rise in parts of the world including Europe, India, and China. It is one of the deadliest forms of cancer, with half of patients dying within a year of diagnosis.

Tumors are most often associated with job-related inhalation of asbestos dust and fiber or exposure to erionite, a naturally occurring mineral fiber similar to asbestos. The disease originates from the thin layer of cells lining the lungs and the walls of the chest and abdomen and progresses when the tumor cells invade the surrounding tissue.

Among the families studied, some people with the mutations also developed tumors of the eye known as uveal melanomas, as well as skin, breast, ovarian, pancreatic, and renal



cancers, suggesting the gene may underlie multiple cancer types.

The scientists also sequenced the gene in 26 individuals who developed mesothelioma but did not have a family history of the disease. Tumors from 22 percent of that group also carried BAP1 mutations. Two of the individuals were found to have inherited BAP1 mutations, and both had been diagnosed with uveal melanomas.

The research was funded by the National Cancer Institute, part of the National Institutes of Health.

Study Yields Clues to Gene Silencing

To prevent the development of cancer, the body relies on tools including the ability to "turn on" silenced genes that, once activated, can suppress tumors. Scientists have discovered a mechanism behind this ability that suggests the possibility of new therapies that would activate silenced genes when the body's normal process fails.

Researchers led by geneticist Alfonso Bellacosa investigated a process called methylation, in which a cell chemically "tags" specific genes to turn them off. The cell silences the genes by adding a chemical compound known as a methyl group to their DNA; without the methyl group, the genes remain active.

Scientists take great interest in methylation, Bellacosa explains, because it is a key

part of normal gene regulation—but when it goes awry and silences genes that normally suppress tumors, cancer results. Indeed, some cancer drugs work by demethylating, and thereby reactivating, silenced genes. But those drugs demethylate multiple genes, not just those involved with cancer, which causes side effects and other problems.

In a study published in June in the journal *Cell*, Bellacosa and his team present new clues to how demethylation works. The researchers discovered that a protein called thymine DNA glycosylase, or TDG—known to help repair DNA—is also responsible for removing methyl groups from DNA. The researchers found that in mice that lacked TDG activity, methylation was amiss—genes

that normally would be demethylated weren't and instead remained silenced.

"Since we now know there are proteins that actively affect demethylation, we can imagine a new type of cancer therapy that would demethylate only specific genes and not any others," Bellacosa says. "We would have a more precise, more targeted type of therapy."

Also exciting, he adds, is the discovery that cells use tools that normally repair DNA for a very different purpose: the reversal of gene silencing by demethylation. "We may be several years away from taking full advantage of this new knowledge," he says. "But we will get there."

The study was supported by grants from the National Institutes of Health.

Tool Helps Select Prostate Cancer Treatment

Prostate cancer patients often face tough questions about whether, when, and how to treat their disease—questions that can also be difficult for physicians. Thanks to Fox Chase researchers, making informed decisions just became easier.

Doctors often use a tool called a nomogram, which takes into account tumor stage and other factors, to determine a prognosis and guide treatment for men diagnosed with prostate cancer. A better prognosis might support a “watch and wait” approach, while a more serious prediction could argue for immediate treatment. Fox Chase researchers have developed a new nomogram that calculates the prognosis of patients who have undergone therapy and show signs of recurrence.

After a patient undergoes radiation therapy, doctors monitor the level of prostate-specific antigen in his blood, since an increase in PSA—known as “biochemical failure”—can signal the cancer’s return. Patients in biochemical failure often face difficult questions about next steps; some therapies that slow cancer’s growth also cause numerous side effects. “We haven’t really had much infor-

mation to guide us,” says radiation oncologist Mark Buyyounouski.

Buyyounouski collaborated with an international team to develop the tool using data from more than 2,130 patients in biochemical failure. They found that the sooner failure occurred following the end of radiation therapy, the more likely the patient was to develop metastases and to die of the disease. The researchers presented their findings in October at the annual meeting of the American Association for Radiation Oncology.

Doctors can enter information including a patient’s PSA level, tumor stage, and time before biochemical failure to estimate his five- and 10-year risk of death.

“It’s a very useful tool,” Buyyounouski says. “The decision to start a new treatment is often difficult, especially since patients rarely have symptoms when PSA levels return. If a patient knew he had a 50-percent risk of dying of prostate cancer in the next five years, that may make it easier to decide to pursue treatment.”

The researchers are creating an online version of the tool that will be freely available to the public, starting later this year, via the Fox Chase website at www.foxchase.org.

Database Aids Drug Development

Scientists at Fox Chase have cataloged the interactions between nearly 200 potential cancer drugs and hundreds of enzymes—proteins that catalyze chemical reactions—including many critical to the development of cancer and other diseases. The free, online library of results represents an important tool for accelerating the development of new, targeted cancer drugs.

The enzymes, called kinases, not only act as drivers for many forms of cancer but also help carry out an array of vital biological activities in the body. For those reasons, the candidate drugs, called kinase inhibitors, have the potential both to act as powerful anti-cancer agents and to interfere with normal processes, resulting in potentially serious side effects.

In a first-of-its-kind effort, cell biologist Jeffrey R. Peterson and his team used newly developed technology to catalog and cross-index the activity of 178 kinase inhibitors

against 300 kinases and published the results in the November issue of *Nature Biotechnology*. Researchers can freely access the data set online at Kir.fccc.edu to facilitate the development of drugs that block specific cancer-causing kinases without causing major side effects.

The study already has identified the first known inhibitors of some kinases that researchers believe are involved in cancer, suggesting the inhibitors could be chemically optimized to target those kinases and avoid any unrelated to cancer.

“These results have pushed the field closer to finding truly specific inhibitors of the processes that drive cancer,” Peterson says. “We now have a collection of kinase inhibitors that are well-characterized and understood. The next step is to use this information to identify specific, effective therapies that stop cancer in its tracks without affecting healthy processes.”

science SHORTS

STRESS, DEPRESSION LINKED TO TUMOR GROWTH

Supporting the notion that stress is bad for your health, Fox Chase researchers found that patients who reported feeling stressed had higher levels of vascular endothelial growth factor, or VEGF, a protein that can stimulate tumor growth. The researchers asked 37 patients newly diagnosed with head and neck cancer about their psychosocial functioning, then measured their levels of VEGF. More highly stressed or depressed patients expressed more VEGF in tumor tissue—and higher VEGF levels were, in turn, associated with shorter disease-free survival. The findings suggest that “your emotional state may be associated with biological processes that can impact tumor activity,” says behavioral researcher Carolyn Y. Fang.

ASPIRIN MAY CUT PROSTATE CANCER RECURRENCE

Aspirin improves outcomes in prostate cancer patients who have received radiation therapy, according to a study by Fox Chase researchers. Among more than 2,000 patients, those who took aspirin during or after radiation therapy were significantly less likely to see an increase in their prostate-specific antigen, or PSA level—a sign of recurrence—within 10 years. “It’s possible aspirin therapy is making the radiation more effective or preventing the cancer from spreading,” says radiation oncologist Mark Buyyounouski. Of the men who took aspirin, 31 percent experienced a recurrence, compared to 39 percent of those who didn’t.

PROTEIN PROVIDES CLUES TO DRUG RESISTANCE

A Fox Chase discovery could help to overcome a common problem in cancer treatment: resistance to anti-cancer drugs. Scientists have identified a protein known as Abcc10 that appears to play a key role in resistance to drugs used to treat breast, ovarian, lung, and other cancers. The protein works by pumping the drugs out of cells. The findings may help to develop inhibitors of the protein’s activity, perhaps countering drug resistance and extending the effectiveness of treatments. “This protein may be a clinically relevant target, but we need to do more studies to find out for sure,” notes molecular biophysicist Elizabeth A. Hopper-Borge.

A man with dark hair and light eyes, wearing a dark pinstriped suit jacket over a blue button-down shirt and a blue tie, is looking upwards and to the left with a thoughtful expression. He is positioned in front of large, colorful stained glass windows with geometric patterns in shades of yellow, orange, red, and blue. The lighting is warm and dramatic, highlighting his face and the texture of his clothing.

A BLESSING. IN DISGUISE

Rare diagnosis leads patient to 'wonder drug'

By Sarah Sweatt Orsborn

RYAN CORBI'S EXPERIENCE

with a rare type of leukemia involves what some might see as a series of fortunate coincidences. Corbi, who holds a master's degree in theology, sees the experience as a series of blessings.

In November 2004, Corbi—then a senior at Villanova University—consulted his family doctor for treatment of a bacterial infection. The infection seemed to clear up, and he never went back for the follow-up blood work his doctor had recommended. The following spring, when he began experiencing similar symptoms, he went to the university's student health center—where, as it happened, his doctor had recently begun practicing.

Corbi recalls, "The first thing she said was, 'You never came back to see me. Roll up your sleeve; we're taking blood.'"

The test results set off alarm bells: His white blood cell counts were elevated, suggesting leukemia. The next day, not wasting any time, Corbi's father Tom hand-delivered his son's medical records to Fox Chase, where Corbi's mother had had a precancerous mass removed the previous fall.

At the Center, hematologist Mitchell Smith happened to pass by and overhear Corbi's father talking about his son's case. He offered to take a look at Corbi's records and, upon reviewing them, immediately suggested that the young man come to Fox Chase for further testing. As luck would have it, Smith had an opening in his schedule that very week.

"I was seeing a doctor less than five days after my blood results came back," Corbi notes.

Tests revealed chronic myeloid leukemia, or CML, a potentially deadly disease in which the patient's bone marrow manufactures too many white blood cells. Relatively rare at Corbi's age, it usually strikes the middle-aged and elderly. The condition is linked

to the Philadelphia chromosome, a genetic abnormality discovered at Fox Chase in 1959. (See sidebar below.) The discovery led to the development of drugs that block the anomaly's effect—including imatinib (marketed as Gleevec®), which Corbi now takes daily. It was approved just a few years before his diagnosis.

Corbi says he has experienced neither symptoms of CML nor side effects from its treatment. "Twenty-five years ago, it would have been a bone marrow transplant or death," he says. "Now they have this wonder drug that is no more inconvenient than taking a vitamin. ... I haven't really had to deal with being sick from this disease a day in my life."

Seven years after his diagnosis, Corbi says his CML remains in remission. Recently married and looking forward to starting a family, he is "planning in terms of the next 25 years instead of the next one or two."

Whether the events surrounding his diagnosis and treatment are viewed as

I HAVEN'T REALLY
HAD TO DEAL WITH
BEING SICK FROM
THIS DISEASE A
DAY IN MY LIFE.

coincidence or blessing, Corbi says his life has been changed by the experience. For starters, he says, learning he had CML nudged him toward a career in theology, a field in which he hopes to teach.

"It galvanized me and shifted not just my personal faith and development but also how that relates to other people," he says. "I want to share my experience with others and help to educate them." 🗣️

Targeting cancer: a revolution in treatment

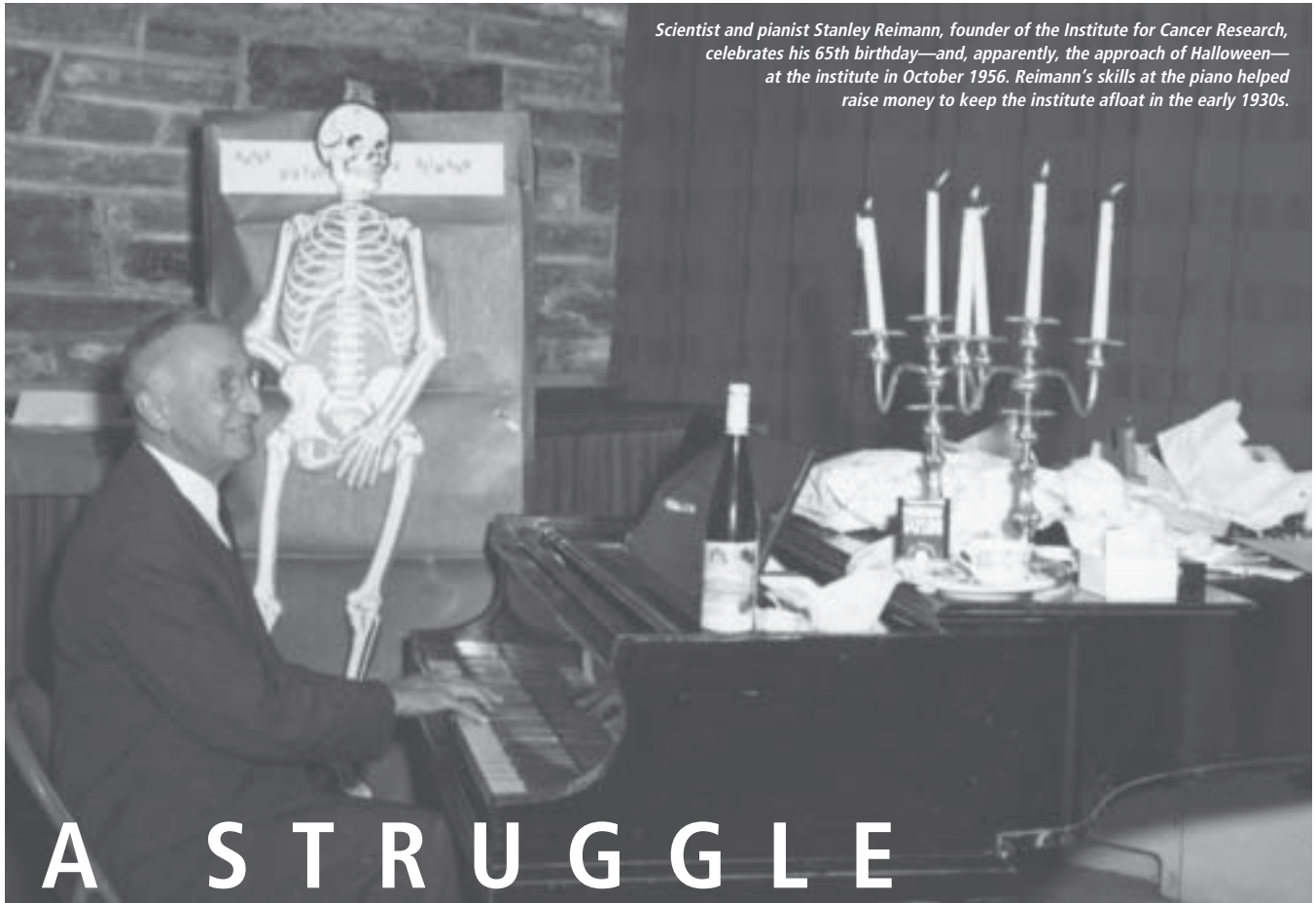
Not quite 50 years before twenty-something Ryan Corbi began treatment for chronic myeloid leukemia, or CML, another young man made a discovery under a Fox Chase microscope that would revolutionize cancer research and treatment.

Fox Chase graduate student David A. Hungerford was examining blood cells from CML patients when he noticed a small imperfection on a particular chromosome. Later research revealed that this abnormality—now known as the Philadelphia chromosome—results when two chromosomes swap material, creating a cancer-causing gene.

The discovery, made in collaboration with University of Pennsylvania pathologist Peter C. Nowell, provided the first evidence that cancer has a genetic cause. Because it stemmed from the investigation of chromosomes, which were little understood at the time, the finding encouraged scientists to focus on the fundamental molecules that make up cells—including RNA, DNA, and proteins—to shed light on cancer.

Hungerford's discovery spurred investigators to develop therapies that target specific cancer-causing genes. Besides imatinib (known by the brand name Gleevec®), which transformed the treatment of CML, targeted treatments include trastuzumab (Herceptin®), approved for the treatment of some breast cancers and gastric or gastroesophageal cancers; and bevacizumab (Avastin®), which treats the brain tumor glioblastoma and non-small-cell lung cancers, metastatic colorectal cancer, and metastatic kidney cancer.

In a recent Fox Chase study, bevacizumab also showed promise for the treatment of advanced ovarian cancer. For more information, visit pubweb.fccc.edu/forward/2010; see page 8.



Scientist and pianist Stanley Reimann, founder of the Institute for Cancer Research, celebrates his 65th birthday—and, apparently, the approach of Halloween—at the institute in October 1956. Reimann's skills at the piano helped raise money to keep the institute afloat in the early 1930s.

A STRUGGLE FOR FUNDING

Stanley Reimann was just one man, but in September 1930 he faced the daunting task of sustaining a fledgling research institute dedicated to unraveling the causes of cancer.

As the country descended into the grip of the Great Depression, the Lankenau Hospital Research Institute—later to become the research enterprise of Fox Chase Cancer Center—was coming into trouble of its own. Funds from the estate of benefactor Rodman Wanamaker, who had died in 1928, had run dry, and fundraising efforts by Reimann, the institute's founding director, had so far met with frustration.

"I spend a good bit of my time trying to wheedle, coax and threaten some of the funds of plutocrats into our coffers for research," he wrote to one colleague. The letter is one of hundreds Reimann sent—many now yellowed with age—that are archived in Fox Chase's Talbot Research Library.

A pathologist, Reimann was convinced that exploring normal cell growth would shed light on tumor development. It was a novel, even unpopular idea at the time, but with Reimann as its

HOW ONE MAN SAVED A RESEARCH INSTITUTE

By Maddy Weber

advocate, the institution had quickly gained esteem in the international scientific community since its founding in 1927.

Now, however, the hospital's trustees—not scientists themselves—doubted the enterprise, given its shaky finances. They gave Reimann an ultimatum: prove the

institute's worth or it would have to close.

No stranger to a challenge, Reimann got to work. Per the board's request to "obtain an independent opinion of the highest order" as to the institute's merit, he invited authorities in cancer research from across North America to visit Philadelphia. After touring the institute's stately ivy-covered building, each provided a glowing report attesting to the significance of the research and the abilities of Reimann and his staff.

"Surgery, radium and X-rays are of no service in a considerable portion of the cases of cancer," wrote professor A.B. Macallum of Montreal's McGill University, referring to the protocols of the day. "Can we conscientiously refuse to explore for other methods of treatment?"

Reimann's efforts paid off. The trustees voted unanimously to keep the institute open and even came forward with personal contributions, including a \$10,000 gift from businessman Irénée du Pont. But even du Pont's gift made up only a third of the annual budget.

Reimann forged ahead, writing letters by the dozens seeking support from bankers, philanthropists, and other people of wealth and influence throughout the region. His correspondence reflected his near-desperation. "We have a building and equipment costing a half million dollars. The building is half empty," reads one letter from 1931. "Any funds which we obtain can be put directly into salaries and expendable supplies."

His efforts to fill the institute's coffers didn't end at the typewriter. He plied his hand at another set of keys as well: A skilled pianist, he raised more than \$5,000 by playing a series of recitals.

Reimann's dogged efforts, combined with the board's support, added up. By late 1931, the institute had procured enough funding to cover its day-to-day operations.

Change was on the horizon when it came to the institute's financial stability: The next few years would see the formation of the organization's first women's auxiliary, a powerful force for fundraising and public outreach, and within a decade the National Institutes of Health would be established, ushering in an era of federal grant funding for science. But for a critical period, one man's determination kept alive a commitment to cancer research—and to the institution that would help form the future of Fox Chase. 📍

"I spend a good bit of my time trying to wheedle, coax and threaten some of the funds of plutocrats into our coffers."



Stanley Reimann in 1935 with some of his many letters.

PHOTOS: FOX CHASE ARCHIVES

A LITTLE HELP FROM ITS FRIENDS

Neighbors chip in to keep hospital on its feet

More than a century ago, employees and friends of the American Oncologic Hospital—later to become the clinical arm of Fox Chase—marshaled the same “pull yourself up by your bootstraps” ethic that would drive Stanley Reimann to carry the Institute for Cancer Research through its challenging early years.

Chartered in 1904, the hospital was among the first in the country devoted solely to cancer.

“Let us remember that of the 106 cases treated, nearly all, according to medical science, would have died in the space of three years, save for such treatment as they have received within our walls,” wrote hospital president George Stuart Jr. in 1905 in the institution's first annual report.

But patient volumes were outgrowing the aging Victorian house in West Philadelphia where the hospital operated, and it was spending three times what it made. Stuart and his staff reached out to the community for help, and area residents—many of whom had been treated at the hospital or who had friends or relatives who had been—rallied to the hospital's aid. Early annual reports, which meticulously cataloged each gift, reveal their willingness to give what they could. A sampling:

- MISS HOOD, 1 bottle chili sauce, parsnips and onions, 1 jar tomatoes, 1 bottle ketchup, 1 jar pickles.
- MR. WOOD, 3 pairs of scissors.
- REV. HERMAN L. DUHRING, \$5 for Xmas cheer and \$5 for New Year's cheer.
- MR. JAMES STEPHANY, 1 bunch of bananas.
- BADGER, WILLIAM, 1 gal. crab meat.
- FULWEILER, MRS., 1 bath robe.
- JOHNSTON, MRS. H. L., rubber sheeting, 2 bed-pans, urinal, feeding cup, 2 syringes, feeding tube, rubber sheet.
- PASSMORE, MISS HARRIET, 15½ bottles grape-juice.
- YOUNG, MR. J. P., 2 bottles whiskey.
- DENNY, JOS. J., ends of ham.



The donations were small but their collective impact significant. Community contributions made up more than half of the hospital's first-year deficit.

“Neighborly sympathy has lent its ministries of good-will in substantial tokens of clothing and delicacies,” noted Stuart in the 1905 report. Thanks in part to the community's support, he and his staff could focus on their primary goal: treating cancer patients.

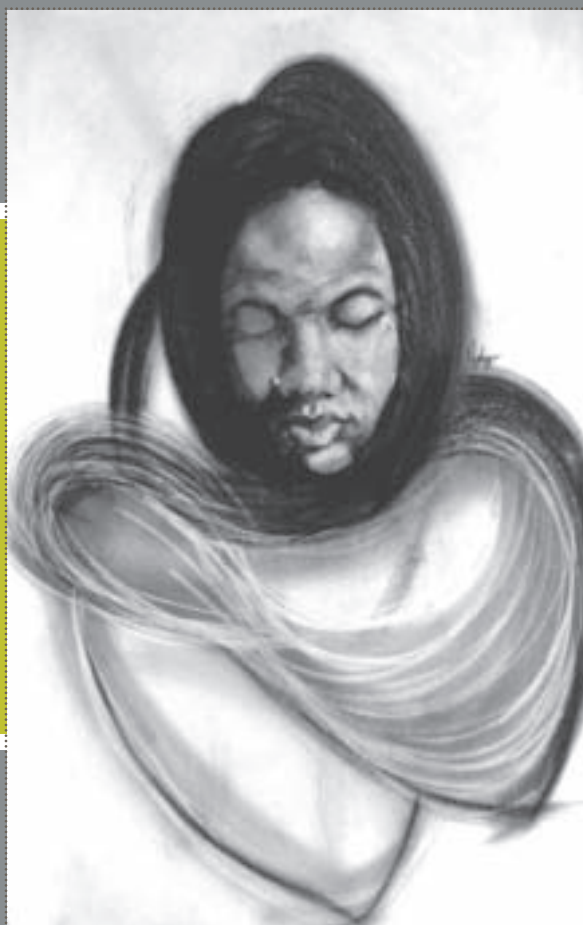
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'SOUL SURVIVOR,'
a charcoal-and-graphite
drawing, is among the
artwork submitted to
'Channels,' a new *Forward*
department featuring visual
and written expressions of
experiences with cancer.
See page 26 for more selections.



'SOUL SURVIVOR' represents "the sensation of survival through all odds as a feminine impulse," as described by artist Donald Stephens of Willingboro, New Jersey.



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