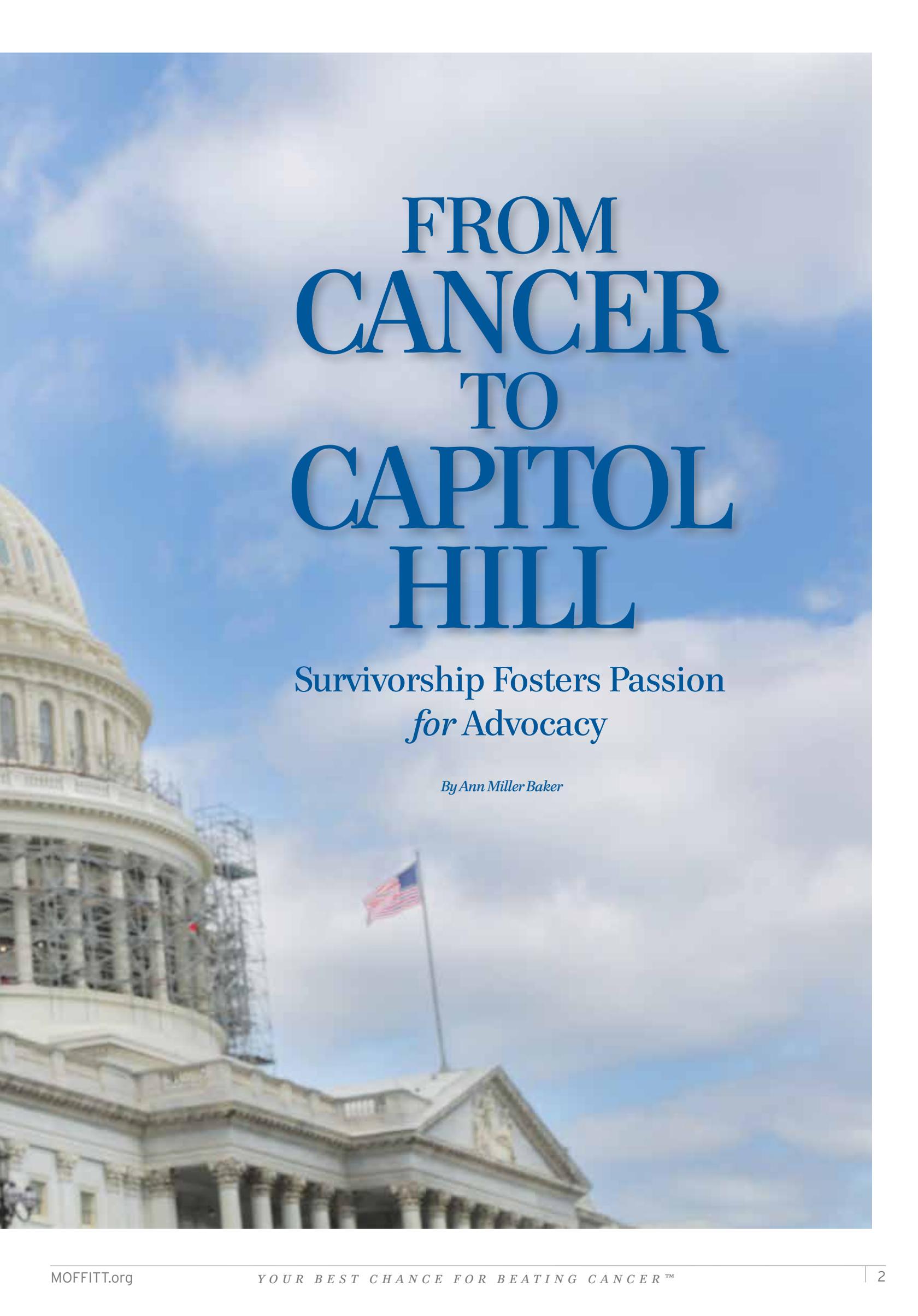




JACKIE SMITH
SURVIVOR + ADVOCATE

Photography: Jeremy Peplow



FROM CANCER TO CAPITOL HILL

Survivorship Fosters Passion
for Advocacy

By Ann Miller Baker

WHAT GOOD COULD EVER COME FROM A CANCER DIAGNOSIS?

Spend awhile talking with Jackie Smith, and you begin to see what's possible.

Smith sees her future in research and advocacy, making life better for fellow cancer survivors through her participation in events like Vice President Joe Biden's recent Cancer Moonshot Summit and her work as co-chair of the District of Columbia Cancer Action Partnership Survivorship Committee.

She credits Moffitt Cancer Center with not only saving her life, but also shaping its trajectory.

She didn't always dream of making this her life's work. At first, she recalls, "I battled it." An undergraduate senior in child and family studies at Syracuse University, she noticed a lump in her bikini line that wouldn't go away. Repeated trips to a local health center all yielded the same advice: It's nothing to worry about. "And I believed it," she recalls, "because at 21, who wouldn't want to believe that you're healthy?"

Her family physician back home near Orlando sent her to a surgical oncologist with the reassurance that taking a lymph node biopsy was just a precaution. Days later when Smith returned for the pathology report, she could tell from the grave look on his face that the news would be bad.

IT WAS DEVASTATING — STAGE III (ADVANCED) MELANOMA.

"The first thing that went through my mind," she chuckles, "was I am not a fair-skinned, middle-aged Caucasian woman!" Smith had part of her risk assessment right. Melanoma is over 20 times more common in whites than blacks, according to the American Cancer Society. But surprisingly, it is one of the most common cancers in young adults (ages 20 to 39). The most sobering statistic: In 2002, when Smith was diagnosed, the five-year survival rate for stage III melanoma was 40 percent.

"All my friends were beginning their lives. It was pretty devastating to think about putting my life on hold, knowing I might never be able to resume it."

The glimmer of hope at that point, Smith says, was that further scans showed no signs of cancer elsewhere. And that led to choices. "I could either have a rather aggressive surgery and treatment," after which, the surgeon predicted, "you probably



Jackie Smith discusses cancer survivorship issues with Lara Hopkins, deputy chief of staff for Congresswoman Kathy Castor.

will never be able to accomplish any of those goals you have. Or we could just monitor it, since I was otherwise healthy. So we made the choice to just monitor it.

"I went back to my life and I really didn't think about cancer too much. I just moved forward."

Fast-forward to 2006. Smith was back at Syracuse starting a graduate program when "cancer reared its ugly face again," much like the movie "Groundhog Day." Another lump. More misguided reassurance from the local health center. Another surgeon doing another biopsy. Days before winter break, Smith got the pathology report: more melanoma cells. Her anxious mother, Barbara, flew up from Florida to offer support. "I'll never forget the look on her face when I picked her up from the airport — this fear and sadness," she recalls. "I think that hurt even more than knowing that I had to go through this journey."

There would be no avoiding surgery now. Lymph nodes near the groin would have to be removed along with any cancerous tissue, a procedure best handled by a specialist. But which one and where? Smith's search led to a New York specialist with a less drastic surgical approach. "He told me, 'If you were my daughter, I'd take you to Moffitt Cancer Center.'"



THE BEST HOPE, DR. SONDAK RECOMMENDED, MIGHT BE IN A NEW CLINICAL TRIAL.

“When we first saw Jackie,” Dr. Sondak recalls, “the only commercially available treatment was high-dose interferon, which routinely interfered with a patient’s ability to hold a job or, like Jackie, to go to graduate school.” However, researchers in Europe were studying a new modified version of the drug called pegylated interferon, administered once weekly (versus daily or three times a week for standard interferon) with potentially less debilitating side effects. “Moffitt was approached to participate in a U.S. clinical trial that would generate some of the specific blood level data needed for FDA approval. Jackie was probably the third or fourth patient in the country to be part of this trial.”

Despite previous misgivings about clinical trials, Smith now considers herself fortunate to have qualified for this one. “I thought the trial was harsh enough. I can’t even imagine what other melanoma survivors experienced on the standard course of interferon.” Thanks to the courage of trial participants like her, others have a choice. Because of what researchers learned from that and other clinical trials, in 2011 the FDA approved pegylated interferon

as an alternative to the high-dose regimen.

Dr. Sondak says it’s important such trials include patients like Smith, who being African-American is an outlier from the stereotypical blue-eyed, light-skinned melanoma patient. “If we don’t do trials broadly representative of the people who’ll be receiving a drug once it’s FDA approved, we are setting up society for problems,” Dr. Sondak notes. “Drugs may be metabolized differently in different ethnic groups. For example, we’re seeing that people of Japanese heritage may experience more or different side effects than participants in clinical trials done with a largely Caucasian patient population. We need to test these agents in the people who are eventually going to need them.”

Moffitt is highly committed to encouraging and studying diversity in clinical trial participation. And Smith wound up sharing her experience in a breakout session of Vice President Biden’s Cancer Moonshot Summit at Howard University on June 28, 2016.

“I was surrounded by pharmaceutical executives, all focused on getting more representation in clinical trials. I think that, while there’s definitely a lack of representation of people of color, all people have these fears in general. They were very interested

OPEN TO HOPE AT MOFFITT

“I had never heard of Moffitt Cancer Center,” says Smith. “No clue what it was, where it was. When I looked it up, somehow I found Dr. Sondak’s email.”

Vernon Sondak, M.D., leads Moffitt’s Cutaneous Oncology Department and is a pioneering melanoma surgeon and clinical researcher.

Dr. Sondak answered Smith’s first email, and four more before her initial visit. “I’m surprised he hasn’t blocked my email,” she smiles. “He’s much more than just a doctor to me.”

From her first walk through Moffitt’s doors, Smith says she felt warmth and caring unlike the academic medical center that delivered her first diagnosis. And Dr. Sondak was honest while leaving the door open to hope.

“I remember my mother asked him, ‘Is my daughter going to die?’ He said, ‘I can’t tell you when your daughter will die. But I can tell you if she doesn’t have surgery, it’s more than likely that cancer will kill her.’ And I appreciated that. You don’t have to give someone false hope. But you can let people be hopeful.”

“I do have a dream that one day we will live in a world where if you receive a diagnosis of cancer, people don’t automatically wonder if you’ve made your final arrangements.”

to hear what I had to say and excited to know that I’m one of those people that benefited from a trial.”

Through surgery, clinical trial and subsequent radiation treatments, Smith says her Moffitt care team kept her focused on her future. “Everyone knew that I was in graduate school. So they kept saying, ‘We need to make sure you finish what you started.’”

Much like Smith herself, what she’d started has been changed by her cancer journey. “When I went into graduate school, I had no plans of focusing on any health-related issues. I had a criminal justice focus, in mandatory minimum sentencing laws,” she says. But the sociology dissertation she’ll be defending this November is “More Than Pink Ribbons: An Exploration into the Experience of Stage III Melanoma Survivors.” Smith’s new passion for survivorship research and advocacy is a product of relationships built while at Moffitt.

“To see journal articles dealing with health issues in my name, it’s kind of startling at times,” she says with a laugh. “I look in the mirror and I’m like, ‘Who are you?’” Perhaps, she says, a person with an important viewpoint to contribute. “There are all these people doing research, all these policymakers, but none of them really know what cancer survivors need. They haven’t experienced it. It makes my heart flutter a little knowing that I have somewhat of an ‘insider perspective’ on this field.”

While she currently shows no signs of disease, Smith recalls an acquaintance saying, “‘Cancer is the shadow that always follows you.’ And that makes me so angry! But it’s a very valid statement. Anytime there is something wrong, there’s always the chance that the cancer is back.

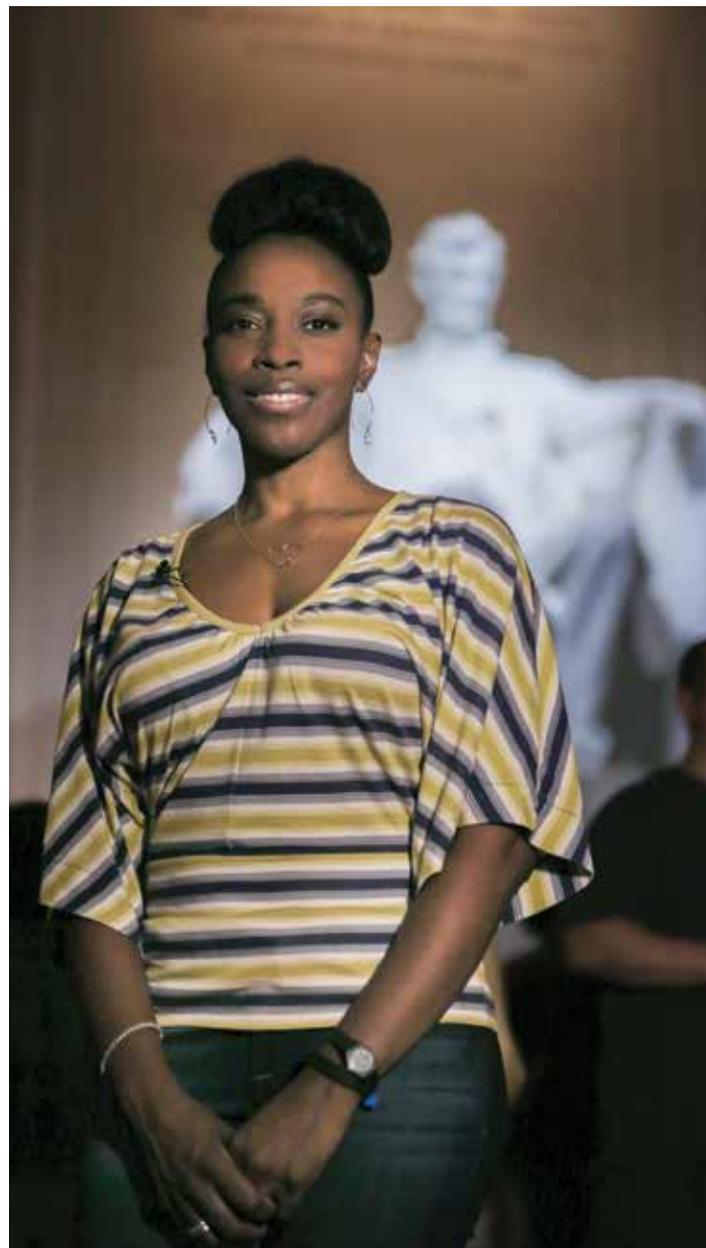
“You can plan for life, and then life actually begins to happen. That’s one of the things I’ve learned through this journey. If you wake up today, it can still get better.”

Like Moffitt Cancer Center on this 30th anniversary, Smith has high hopes for the future.

“Thirty years from now, I hope that I’ll have a family. I would hope I’ve played a strong part in shaping the ways we handle cancer survivorship. I’ll be honest; I would like to have had some sort of position at Moffitt because it’s been such a critical part of my life.

“If there were no Moffitt, I don’t know that I’d be here today. Because of you, I am here!”

For now, “here” is Washington, D.C. Visiting the Martin Luther King Jr. Memorial just blocks from where a quarter of a million people gathered in August 1963 to hear King’s immortal “I Have a Dream” speech, Smith shares her own courageous new dream.



“I do have a dream that one day we will live in a world where if you receive a diagnosis of cancer, people don’t automatically wonder if you’ve made your final arrangements. That we will begin to know that it’s not a terminal disease anymore. It really is something that’s chronic and that we can manage, or that we even have a cure for.”

That’s a dream both Smith and Moffitt Cancer Center vow to help make a reality. 🎧