

THE JOHNS HOPKINS KIMMEL CANCER CENTER

KIMMEL IN THE COMMUNITY





Darlene Young

AFRICAN-AMERICAN WOMEN AND BREAST CANCER

Although their overall rate of developing breast cancer is lower than white women, African-American women tend to have worse breast cancer outcomes.

Kimmel Cancer Center breast cancer experts are currently studying novel treatments and improved early detection and risk assessment techniques specifically in African-American women. This includes studying genetics and other inherent differences in this group so we may better tailor prevention and treatment options.

As with all of our patients, our providers work with every African-American breast cancer survivor to ensure individualized treatment plans are created that account for tumor characteristics, patient preferences, potential comorbidities, lifestyle factors, age, family history and racial/ethnic differences.

Darlene's Story

The Caregiver's Cancer Journey

Darlene Young is a caregiver, always putting others first. Her consideration for others' well-being ahead of her own almost kept her from receiving lifesaving treatment for her breast cancer. Last year, when she felt a lump in her breast—so large that she awoke in the middle of the night thinking her TV remote control was on her chest—she waited two months before going to the doctor.

"I was thinking about my mom, who just had surgery," says Darlene. "I didn't want her to be alarmed."

When she finally went to the doctor, the diagnosis was breast cancer and a recommendation to go to the Kimmel Cancer Center.

"I have to admit: I was hesitant at first. My inclination was to stick with my community hospital," says Darlene. "Johns Hopkins is so big. I didn't think I would matter."

Despite her concerns, she decided to follow the doctor's advice, and after meeting with breast cancer expert **Roisin Connolly** and the nurses, she changed her mind.

"I felt the love and support of the people that work there," she says. "Everyone is so sweet and supportive. I come home from my treatments energized. My husband has to tell me to slow down."

Darlene has a type of breast cancer classified as estrogen receptor-negative and HER2-positive, referring to specific

characteristics that could influence the growth of the cancer and can be targeted with drug treatments. Dr. Connolly says it accounts for about 8 percent of all breast cancers. Standard treatment calls for surgery to remove the tumor, followed by a combination of antibody therapy to cut off the ability of the HER2 gene to support the growth of breast cancer cells and chemotherapy to directly kill any lingering cancer cells that escaped surgery. Dr. Connolly says a proportion of patients—about one-third—can have complete shrinkage of the cancer at the time of surgery with use of antibody therapy alone and may in the future be spared chemotherapy. This approach can minimize unpleasant side effects for patients, including nausea, hair loss, fatigue and increased risk of infection.

"The challenge is that we don't yet have a good way to differentiate the patients who could be treated with antibody therapy alone and those who need the addition of chemotherapy," she says.

Darlene is among the patients whose experience is helping Dr. Connolly and collaborators figure it out. Working with colleagues in nuclear medicine, Connolly is using Positron Emission Tomography (PET) scans as a biomarker to distinguish patients who will need antibody therapy and chemotherapy from those who can be treated only with antibody therapy.

"PET scans illustrate sugar uptake in cancer cells. If the PET scan still lights up brightly two weeks after starting antibody therapy, we know the cancer is active, and those patients should receive the combined antibody/chemotherapy treatment. They are very unlikely to get a complete response with antibody therapy alone," says Connolly. "If it does not light up, antibody therapy may be enough to keep the cancer in check, and those patients may in the future be spared the toxic effects of chemotherapy. Further research is still required to investigate this before it can become standard practice in the clinic to make treatment decisions, but it is extremely promising."

Darlene had a lumpectomy to surgically remove her tumor followed by radiation therapy. She initially received the antibody/ chemotherapy

combination, but struggling with side effects, she opted to stop chemotherapy after a few rounds of the treatment. Today, she receives only antibody therapy, and her breast cancer remains in check.

"We know many patients with this type of breast cancer will not need chemotherapy. We owe it to them to figure it out. PET scans may be the way," says Connolly.

At a recent meeting of the American Society of Clinical Oncology, she presented findings to breast cancer doctors from across the country on a multicenter clinical trial she is heading to evaluate PET as a biomarker to guide treatment for patients like Darlene, who received the HER2 antibody treatment—a quick 30-minute infusion—through August.



"WE KNOW MANY PATIENTS WITH THIS TYPE OF BREAST CANCER WILL NOT NEED CHEMOTHERAPY. WE OWE IT TO THEM TO FIGURE IT OUT."
- ROISIN CONNOLLY, M.B.B.CH.

Darlene says interacting with other patients and encouraging them through their journeys helped get her through her own.

"God gives me peace when I look after others," Young says. "Cancer is hard. I've had some tough days, and bringing comfort and encouragement to others helps me through this too."

Her joy and concern for others is magnetic, and it changed the dynamic of shared patient spaces.

"As I sat in the waiting room, I noticed that patients were looking at each other but not speaking to one another," she says. "If you are going through treatment, you have to go through it right. There are no sour faces when I am in that waiting room." Darlene has a way of putting patients at ease with a smile and words of encouragement.

She recalls a patient she met as they were both waiting to get CT scans. The woman looked distraught, but she did not speak English. Darlene couldn't speak words

of encouragement, but she provided the next best thing—a hug.

"There is no language barrier with hugs," says Darlene. "That's a universal language."

A few weeks later, the patient's daughter stopped Darlene in the waiting room to thank her. She told Darlene that her mother was ready to give up, but the hug and encouragement she received that day gave her mother the strength to continue her battle.

"I'm energized by helping others. We all witness to one another," she says. "I tell them, if I can do this, you can do it too."

Darlene chose the Kimmel Cancer Center for its expertise in treating cancer, but her journey became much more than that.

"Johns Hopkins has been a blessing to me," she says. "The doctors and nurses have taken wonderful care of me, but there are so many others who have helped me too. Social workers have helped me navigate financial burdens, like the cost of driving back and forth for treatments. I'm so glad I picked this place."

As Darlene's radiant smile transforms the clinic area and patients seek her out to share updates in their own personal journeys, it is clear what truly inspires her.

"I made it about others because I love people," she says.

Her mission is to put real faces and human spirit to this often impersonal and harrowing journey of cancer diagnosis and treatment. Her smiling face can be seen in the Kimmel Cancer Center even on days when she does not have an appointment. She is there to celebrate with patients who finish treatment and to support those going through difficult times.

Darlene's is not the cancer experience most imagine. She is rewriting that script.

"The people keep me coming back," Darlene says. I want them to know they are strong. I'm happy when I see patients fighting back against cancer. I can inspire them, and they inspire me."

SMOKING CESSATION PROGRAM TARGETS BALTIMORE RESIDENTS



Brendell Freeman was a longtime smoker. The 63-year-old estimates she picked up the habit when she was just 13 years old. Over the years, she tried to quit several times but was unsuccessful. A flyer that came to her house at Latrobe Homes, the public housing development near The Johns Hopkins Hospital where she lives, inspired her to try again and led her to finally quit for good.



The flyer provided information about an innovative research study offered by the Johns Hopkins Center to Reduce Cancer Disparities (JHCRC) and funded by the Maryland Cigarette Restitution Fund. The seed for the program was sown in the late 1980s, when Johns Hopkins staff members started analyzing the health disparities of Baltimore residents based on ZIP codes. “Where people are born and raised is a pretty good indicator of how long they will live,” said **Dr. James Zabora**, director of education and outreach for JHCRC. He points out that the life expectancy for a resident of low-income neighborhoods along Madison/East End is 64, compared to 84 for residents of the higher-income neighborhood of Roland Park—even though the communities are only 5 miles apart.

In response to these striking differences, the hospital staff began offering free cancer screenings to low-income community residents. In 2010, the Kimmel Cancer Center formally established JHCRC with the goal of providing all Maryland communities equal access to cancer prevention and treatment services. The Baltimore City Household Smoking Cessation Project, from which Freeman and other Baltimore residents have benefited, is an example of the center’s work.

The smoking cessation project used a multipronged approach to help residents from communities across Baltimore to quit smoking. It consisted of three group education sessions, nicotine replacement therapy (lozenges, gum and tablets that provide low levels of nicotine while reducing the urge to smoke) and a four-week follow-up period of individualized phone counseling. Latrobe Homes, senior centers and other places provided space for the educational sessions to make participation convenient for residents. Those who successfully completed the program received a \$50 Target gift card.

“I try to win the trust of the people. I let them know I’m part of the community.”

- THERON SCOTT

Recruiting by building trust

To create an effective smoking cessation effort, Zabora and team knew they would need to gain the trust of prospective participants, many of whom, he notes, “live in the shadows” of Johns Hopkins and may be uncomfortable with health care systems in general. **Theron Scott**, senior research coordinator for the center, led the recruitment efforts and took a practical, nonthreatening approach to the job. “I try to win the trust of the people. I let them know I’m part of the community,” says Scott, an African-American and former two-packs-a-day smoker. More than 70 residents from Baltimore signed up, and 50 successfully completed the smoking cessation program (47 black, three white).

The timing couldn’t have been better for Freeman and other participants from Latrobe Homes. In July, the housing development instituted a no-smoking policy, and residents will no longer be permitted to smoke in their apartments. **Funmi Adekunle**, service coordinator for Latrobe Homes Office of Resident Services, says it made sense to work with Johns Hopkins on the study given the new no-smoking policy. It offered a way to support residents interested in quitting smoking, he says. “It’s a wonderful, collaborative relationship,” says Adekunle.

Zabora and Scott originally planned to work only with East Baltimore residents but later made the smoking cessation program available to all low-income neigh-

borhoods of Baltimore City. The program is designed to help all members of the household quit smoking, but Zabora said most participants so far have been single mothers with children or, like Freeman, older adults living alone.

The education piece

When Freeman entered the program, she was struggling with several health conditions, including chronic obstructive pulmonary disease (COPD), diabetes and poor circulation. She wasn’t aware of the connection between smoking and poor health. “When I learned how it damaged the body, that helped me a lot,” Freeman says.

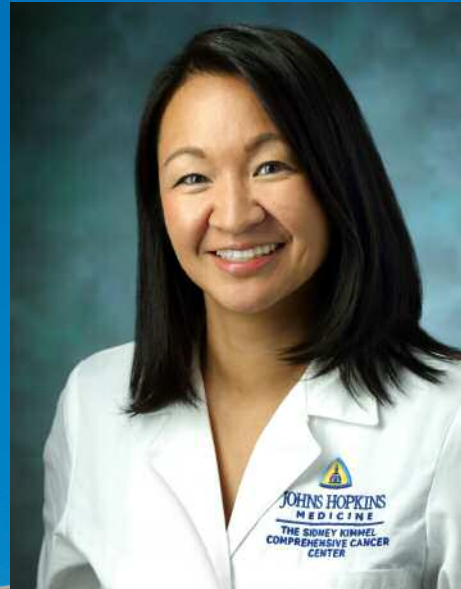
Understanding things that may trigger an urge to smoke, and how to manage them, was also very helpful to Freeman. Scott, one of two American Lung Association-certified smoking cessation facilitators who taught the classes, suggested finding a tangible replacement for triggers, such as stress, boredom, part of a routine or ritual, etc. “I tell them they have to find a new way,” Scott says.

Freeman took the lesson to heart. “I would be all right until something upset me,” she says. Now, she reaches for something other than a cigarette or simply waits 10 to 15 minutes until the urge to smoke passes.

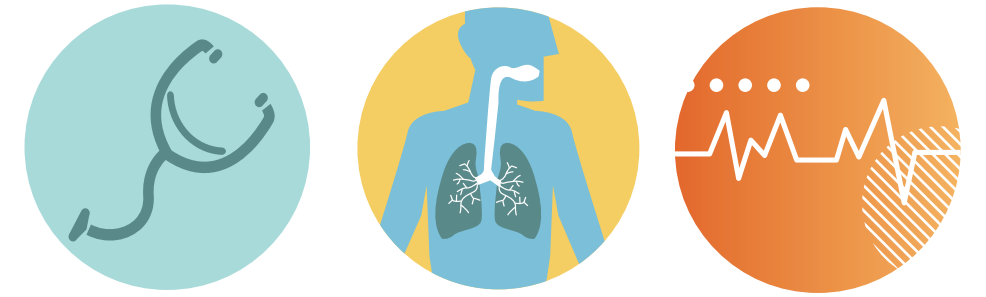
Freeman has been cigarette-free for six months, and her health has already improved. She no longer needs an inhaler to help her breathe. When she takes walks, she doesn’t have to stop every few blocks to catch her breath. “I don’t feel like I’m 16, but close to it,” she says with a chuckle.

HELP FOR LUNG CANCER PATIENTS

Lung cancer expert Joy Feliciano has a specific clinical interest in reducing barriers to treatment for minorities and the underserved. Among these groups, she says, many are diagnosed with the most advanced stages of lung cancer and resist treatment for economic reasons. Dr. Feliciano is committed to a new approach to personalized care—collaborating with colleagues at Johns Hopkins and other Maryland institutions to address ways to improve early detection of lung cancer, smoking cessation and to begin to address things like cost of transportation to appointments, drug affordability and other economic factors that deter many Marylanders from seeking and continuing treatment for lung cancer.



A 2011 LUNG CANCER STUDY OF 53,000 PATIENTS FOUND THAT SCREENING COULD BE EFFECTIVE IN REDUCING LUNG CANCER DEATHS BY FINDING CANCERS AT AN EARLIER STAGE, BUT **ONLY 4 PERCENT OF THE PEOPLE IN THE STUDY WERE NONWHITES.**



Through various research efforts and pilot projects, Dr. Feliciano and her colleagues are chipping away at the barriers to care that reduce the chances minority and underserved patients will survive their illness.

Feliciano practices out of the Kimmel Cancer Center at Johns Hopkins Bayview Medical Center, the hub of its thoracic cancer services, where about 90 percent of the patients seen have some type of lung cancer. In her practice, she worries that she too often sees a patient for the first time when he or she already has advanced lung cancer. About one-quarter of her patients are African-American or other minorities, and many of them have no insurance, receive Medicaid or are underinsured.

Her goal is to see patients sooner, before the cancer has spread. She cites a large 2011 lung cancer study of 53,000 patients that found screening could be effective in reducing lung cancer deaths by finding cancers at an earlier stage, but only 4 percent of the people in the study were nonwhites.

“To me, the question is how do you apply these results to the population we serve in Maryland, where 40 percent are African-American or other minorities,” she says.

She recognized that this dilemma started well before patients ever got to her. A lack of access to primary care physicians who can offer cancer screening and other preventive health care was contributing to the late stage at diagnosis. The patients she saw also had other medical issues, including heart disease and diabetes.

“These are patients who often do not have primary care physicians to whom they can bring their complaint or have a person who is monitoring them regularly,” Dr. Feliciano says. “They may not be evaluated early enough when they start to have symptoms.”

People who lack access to primary care also are unlikely to undergo screening for lung cancer, even if their risk for developing the disease is elevated—if they have a family history, they smoke or have been exposed to certain chemicals in the workplace.

“So many people have the false idea that screening is only if you have symptoms,” says Feliciano. “The point of screening is to get you when you don’t have symptoms so the cancer can be cured.”

Her experience has been that people are receptive to screening information. Most have a family member who has had cancer, and many of them fear cancer. “They ask me, ‘Why have we heard about colonoscopy and mammograms, but not lung cancer screening?’” she says.

Even when screening is offered, it is often the wrong kind, she says. “To screen for lung cancer, doctors should order a low-dose screening CT scan, not a chest x-ray,” Feliciano explains. She recommends screening for people age 55 or older who have smoked a pack or more a day for 30 years or more and are a current or former smoker. Those with a family history of lung cancer and exposure to asbestos, radon or other known carcinogens should also consider screening.



Dina Lansey

Day to day, Feliciano sees the struggles many of her patients face. This experience inspired her interest to find ways to provide better care to minorities and those with low income. She decided to look beyond therapies to basic needs that were not being met because of financial and other barriers.

“Income, education, age, insurance status and race all factor into this, plus trust in us and support at home. It’s all of these things combined that create disparities in care,” she says. Case in point, she says, is the 35 percent rise in lung cancer death rates among those with less than a high school education.

“All of these things make it less likely that a person will receive stage-appropriate therapy,” says Feliciano. “It wasn’t that I didn’t have a good drug for their cancer. It was patients saying they could not come to see me because they couldn’t pay their electric bill or they didn’t have a ride to the hospital.”

Her goals are to diagnose patients earlier and to work with social workers, patient navigators and other members of the patient and family services team to make sure patients can complete treatment.

“Having appropriate resources, like social workers and counselors,

can make a huge impact for these patients, because it’s not just the cancer they’re dealing with. It’s many issues at home,” says Feliciano. “Lung cancer is really a disease that affects the whole family at many levels. There is a lot of room for improvement for resources to be directed to those who need them most.”

Another focus for Dr. Feliciano is the relative underrepresentation of African-Americans and other minorities in clinical trials of new—and possibly superior—treatments. She is working to identify more patients with lung cancer in Baltimore City and surrounding areas to make sure they are aware of clinical trials that may benefit them.

For this, she is collaborating with **Dina Lansey, M.S., R.N.**, who leads Kimmel Cancer Center efforts to increase minority participation in clinical trials. Lansey, assistant director for diversity and inclusion in clinical research, has successfully increased the number of minority patients treated in clinical trials through mandatory training and reporting for all clinical faculty and staff.

“I would get a patient with metastatic lung cancer who, without understanding the different types of lung cancer and treatments, wanted to give up, not even fight it,” says Feliciano. “There are things we can do for patients, but in their mind, all cancer is the same, and all treatment is the same. They don’t have hope. They believe it is over once you get it. They don’t want to get a biopsy because they fear surgery will make it worse. It’s so much information for patients, and if it doesn’t get explained in ways people can understand, that is a barrier to care. Sitting with patients, talking with them and having hard conversations is an equally important part of treatment.”

Lansey is putting this aspect of care for the underserved in a research framework. She matches minority and low-income patients to available clinical trials and uses a new database to track reasons patients decline to participate. On the patient side, she has developed several educational tools, including in-depth videos that explain clinical trials and provide patient testimonials. Feliciano is working with Lansey to identify lung cancer patients who are eligible for a clinical trial but didn’t enroll to identify socioeconomic and other demographic factors that may have impacted their decision. The data they collect will point to factors that predict for enrolling or not enrolling in clinical trials and guide the development of interventions when barriers to care are identified.

Working with Lansey, she is using the cancer registry to try to identify vulnerable patients who could easily fall through the cracks, linking the registry to the Kimmel Cancer Center’s outpatient database. This helps her follow up with inpatients to see if they return for outpatient appointments.

“Today, most cancer care is provided in the outpatient setting. This cross-referencing helps me see if there is discrepancy between who we diagnose with lung cancer and who

we actually treat. We have to help transition patients from inpatient to outpatient care and make sure they return for their treatments,” says Feliciano.

She is also working with her research colleagues to explore disparities in cancer survival at the genetic level. She is studying interesting genes—the instruction manual within every cell that tells that cell how to behave—that might be associated with cigarette consumption and lung cancer. She is looking to genetic clues to help explain why women, stage for stage, do better than men. Lung cancer in nonsmokers and genetic alterations that are prevalent among specific ethnicities are other areas being studied.



We have to help transition patients from inpatient to outpatient care and make sure they return for their treatments.

Feliciano and Lansey also recognize there are things beyond the clinic and the laboratory that, on the surface, appear to be unrelated to cancer treatment, such as transportation, yet may carry life-or-death significance for people struggling financially and facing a cancer diagnosis.

“After all, if patients can’t get a ride to a clinic or can’t afford parking fees, they can’t receive the treatment they need,” says Feliciano. She is working with Lansey to include her patients in a study to see if providing free transportation or parking has a positive impact on clinical trial participation. The program is currently available to patients who live in Baltimore City.

“The care can be very complicated. When patients are diagnosed with lung

cancer, we want to make sure that all of their other needs can be met. That includes access to transportation, helping them back and forth to appointments, and making sure they can get the medication from the pharmacy. These interventions that seem simple can impact whether patients complete their treatment,” says Feliciano.

The cost of medication can be another major obstacle for patients. Drugs for metastatic lung cancer can add up to \$150,000 or more a year, she says. Insurance coverage can significantly reduce that amount, but plans vary on how much they will pay for and how much patients must absorb. “Some

get their nausea medications because they had to use that money to pay another bill,” says Feliciano. “It’s these kinds of barriers that really impact what patients can get care in the first place.”

Many patients worry about the lost wages from missed work for medical appointments, the economic toll of side effects like nausea and pain and additional medication to mitigate those, and the cost of coping with the ravages of the disease on other parts of the body, then tack on the cost of getting to the appointment or parking. “There are so many costs that providers are unaware of and don’t take into account. We want

oral drugs cost \$8,000 to \$15,000 a month. Think about people with Medicare who reach their donut hole, and paying for one month’s supply means an out-of-pocket cost of \$900. Many people can’t afford this. If the copay is too high, patients won’t pick up the drug from the pharmacy, or they will ration it and take a half dose to make it last longer,” says Feliciano.

Many drug companies have programs to provide drugs to those who cannot afford them, and Johns Hopkins has a patient assistance program that helps patients access these services and identifies other support when necessary (see page 14).

“It was very frustrating seeing patients who would choose not to

better understand how financial burdens relate to getting care and outcomes,” Feliciano says.

She likes the team approach the Kimmel Cancer Center takes, involving nurses, social workers, navigators and other resources to assist patients.

“That’s what Johns Hopkins provides. This kind of directed collaboration and interest in helping improve cancer care for minorities and the underserved is not available everywhere,” she says. “We are mounting a great effort to identify barriers to care, and there is so much opportunity to implement the things we learn. Hopefully, we can expand this beyond our own patients to help patients at cancer centers across the country.”

As our nation's capital, Washington, D.C., is a tourist attraction, complete with trendy hotels and restaurants, upscale neighborhoods, and historical museums and monuments. Juxtaposed with newly gentrified neighborhoods with luxury condos and high-end restaurants are Wards 7 and 8, located east of the Anacostia River. Although only miles away, these neighborhoods are worlds apart.



A PARTNERSHIP THAT HEALS

WARDS 7 AND 8 ARE THE LOWEST socioeconomic areas of Washington, D.C. High unemployment and poor access to quality health care are among the daily struggles for many of its residents. Consider that Wards 7 and 8 have only three grocery stores servicing 148,000 residents, while the more affluent Ward 3 has nine grocery stores servicing 80,000 residents.

Elisabeth Tamasi, patient and family services manager for the National Capital Region at Sibley Memorial Hospital, is part of the Johns Hopkins team ensuring better health care for those who live in Wards 7 and 8.

Until 2015, United Medical Center was the only hospital located east of the Anacostia river. Since then, Sibley Memorial Hospital has worked in partnership with United Medical Center and Howard University to treat cancer patients for lung cancer, breast cancer, colon and other GI cancers, at the Sibley Oncology Clinic on the campus of United Medical Center.

Most of the patients treated are African-American, 60 or older, and qualify for Medicaid. Many of the patients have advanced cancers at the time of diagnosis and also suffer from other untreated health conditions, such as diabetes.

With a framework established, Tamasi and team set out

to define all of the barriers interfering with those living in Wards 7 and 8 to receiving the care that could lead to earlier cancer diagnosis and better cancer care.

Tamasi began using the National Comprehensive Cancer Network-developed distress thermometer to understand the issues getting in the way of care. The tool allows patients to score their level of distress on a scale of 0 to 10, 0 being no distress and 10 being extreme distress. The tool also includes a checklist of 39 practical, family, emotional, physical and spiritual/religious problems or concerns that patients can mark and also provides space to list problems and concerns not represented.

Using the tool, patients from Wards 7 and 8 were given a voice to begin communicating a variety of stressors. Housing concerns, child-care, insurance, sadness, family health issues, lack of food and fatigue were listed among the many barriers to care these patients faced. Transportation, followed by fear and worry, were the most common stressors marked.

"We can't care for patients if they can't get to us," says Tamasi. The first thing she did was fix the transportation problem. "This year alone, we've provided 300 round trips



for 19 patients through cab and, when necessary, medical transport," she says. About 65 percent of the patients are Medicaid recipients.

Surprisingly, the ability to pay was the easiest barrier for Tamasi and team to overcome. "We help patients apply for services they may be eligible for and get them help with the cost of medications." New contracts between Sibley and insurance companies were negotiated to make sure Medicaid and other coverage plans available to people living in Wards 7 and 8 were accepted at Sibley.

Sibley has a special needs fund that is used to provide charitable care not covered by other services. It also uses the fund to purchase grocery cards, prescription and over-the-counter medications, durable medical equipment and other essential items for patients from Wards 7 and 8.

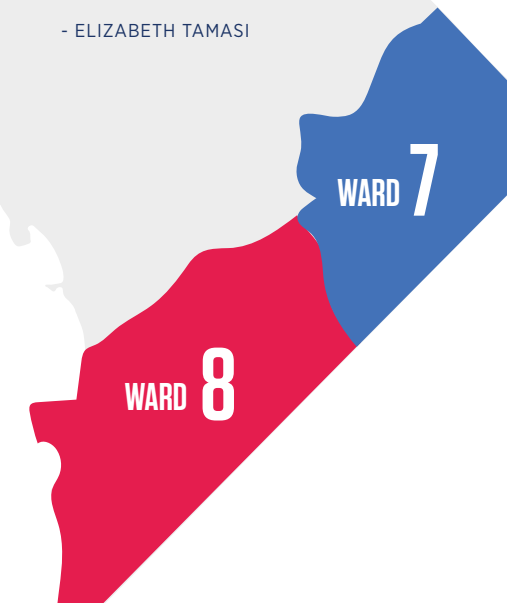
Tamasi's patient and family services team engage with patients from the onset. She assigns a patient navigator, social worker, and palliative care nurse practitioner (care aimed at addressing issues that cause discomfort for patients) for every patient. The patient navigators and social workers make sure patients understand their diagnoses and treatment plans, and work with them throughout their care to help manage barriers to getting the treatment they need. They also engaged other experts at Sibley to manage noncancer medical problems, such as diabetes.

"Improving access to care and reducing disparities requires identifying, understanding and addressing those barriers. This kind of support is key to the care," says Tamasi. "These patients have already been through so much and competing obligations often take precedence over their own health."

The success of this collaboration led to a new partnership, beginning this winter, with Ward 7-based Unity Healthcare, the largest network of community-based health centers in the District of Columbia. partnership is part of Sibley's expanding network of clinical services east of the Anacostia River and will be primarily aimed at improving care for gynecologic and prostate cancers.

"WE HELP PATIENTS APPLY FOR SERVICES THEY MAY BE ELIGIBLE FOR AND GET THEM HELP WITH THE COST OF MEDICATIONS."

- ELIZABETH TAMASI



A Measure of Success

One Ward 7 Patient's Story

William Pinkett has a fighting spirit. That soon became evident during hospital stays for lymphoma treatment, when he'd do 50 to 60 laps around the patient unit daily—far more than the recommended one or two—or while he pedaled a stationary bike that he convinced personnel to place in his hospital room. But when he first came to Sibley Memorial Hospital, he felt far more desperation than fight.

Pinkett, 52, was referred for treatment at Sibley through the Sibley Memorial Hospital/United Medical Center partnership that provides diagnostic care and treatment for underserved patients from the district's Wards 7 and 8.

Upon admission to Sibley, he was given an evidence-based tool known as a distress thermometer, which measures the user's level of distress based on responses to multiple questions on a range of issues, including housing, transportation, child care, insurance, family health issues and others. When Pinkett first took the test, he scored an 8 out of 10, signifying deep feelings of personal distress.

He says fear and anxiety—mainly over the return of lymphoma, with which he'd first been diagnosed 10 years earlier, and painful memories of his older brother, whom he'd recently lost to cancer—contributed to his high distress score. But soon after being admitted to Sibley, his feelings of distress plummeted, replaced by optimism.

He credits key staff members at Sibley for his turnaround. "I met the best doctor in the world," says Pinkett, referring to his oncologist, **Khaled El-Shami**. "When I met him, he said: 'I'll take care of you. There's nothing to worry about,'" he recalls.

Pinkett also speaks fondly of **Florence Odubayo**, a nurse practitioner at Sibley's oncology clinic. "She was a big part of saving my life," says Pinkett. She supported him in a variety of ways, even coordinating logistical details that ensured he had transportation to and from his house and Sibley throughout his treatment process.

His distress score is now zero. When completing his last distress thermometer, he wrote, "I want you to know that I love Sibley, and you saved my life."

TECHNOLOGY ENCOURAGES CANCER SURVIVORS TO EXERCISE

MAY REDUCE RISK OF CANCER RECURRENCE



“Alexa, did I get enough exercise today?”

That’s the question researcher **Ahmed Hassoon** is encouraging cancer survivors to ask. With support from the Maryland Cigarette Restitution Fund, he has designed and conducted a clinical trial that showed Amazon’s virtual voice assistant may help overweight cancer survivors increase their daily activity and ultimately reduce the chance of their cancer coming back.

Inspired by mounting evidence that being overweight increases the risk of cancer recurrence and his own research interest in artificial intelligence solutions to improving patient outcomes, Hassoon launched the Physical Activity by Technology Help, or PATH, study. The study compared three types of motivators—written material, text messages and voice assistance technology, like Alexa—to see which was the best motivational tool to support weight loss.

Hassoon says affordability, accessibility and personalization are key. “Activity and weight loss goals vary from one person to the next, but not everyone can pay for a coach,” he says. He believes technology may provide an easy and cost-effective way to provide personalized attention that meets each person’s needs.

The PATH study was primarily aimed at helping African-American cancer survivors and had 42 participants. Over four weeks, Hassoon and team evaluated two technological approaches and one low-tech option aimed at encouraging overweight and obese cancer survivors (defined as having a body mass index of 25 or above) to get in 10,000 steps each day. Participants were healthy enough to exercise but not currently physically active. They wore exercise sensors in wristbands or belt clips, known as accelerometers, that work in conjunction with a smartphone to monitor and capture physical activity.

The study participants were divided into three groups: Coachtext, MyCoach and a control group. The Coachtext group received remote coaching via personalized text messages directly to their cellphones. The MyCoach group used Alexa, a conversational, voice-controlled artificial intelligent personal assistant delivered via an Amazon Echo home “smart” speaker installed by the research team in the participants’ homes. The MyCoach algorithm draws on data from a number of sources, including the patient study file, physical activity wearable sensor, user’s calendar, geography/location data and more. It can perform a variety of functions, such as offering feedback to the user, assisting in formulating habits, providing reminders and alarms, and offering health tips. The control group received written materials about the benefits of physical activity and were simply



Ahmed Hassoon

advised to increase their physical activity to 10,000 steps per day.

Hassoon’s research goal was to identify the best tools for motivating long-lasting behavioral change.

“Many patients will get bored in a few months,” Hassoon says. “It’s adherence. We need to determine how we can engage patients long term.”

Hassoon found that PATH participants varied widely in their understanding of the importance of physical activity and their readiness to incorporate it into their daily lives. “Some patients didn’t know that physical exercise could reduce their risk of cancer recurrence,” he says. “Other patients are very motivated. They just need guidance.”

The Alexa-assisted MyCoach group, whose participants had an average age of 59 and had little or no

previous experience using voice-assisted devices, found themselves comfortably conversing with MyCoach.

“By the time we finished the trial, I probably had about 75 percent of the study participants pretty enthusiastic about using Alexa and 25 percent who were a little wary but willing to give it a try,” says **Yasmin Baig**, research coordinator for the study.

As voice-assisted and other emerging technologies become an increasingly integral part of people’s daily lives, Hassoon believes their application in translational research will also expand. “It’s a very cost-effective means of reaching out and delivering personalized advice and monitoring compared to conventional ways,” he says. “We think it saves tens of thousands of dollars without compromising the personal connection to patients.”

“BY THE TIME WE FINISHED THE TRIAL, I PROBABLY HAD ABOUT 75 PERCENT OF THE STUDY PARTICIPANTS PRETTY ENTHUSIASTIC ABOUT USING ALEXA AND 25 PERCENT WHO WERE A LITTLE WARY BUT WILLING TO GIVE IT A TRY.” - YASMIN BAIG

HELP FOR LOW-INCOME AND UNINSURED PATIENTS

A **DIAGNOSIS OF CANCER** is daunting enough, but for many low-income patients, who are uninsured or underinsured, learning the cost of treatment, including lifesaving drugs, can create a barrier to patients receiving treatment.

When the high cost of drugs is the barrier, **Lori Dowdy** often has a solution before patients come for their first appointment. Dowdy runs the Johns Hopkins Patient Assistance Program Medication Access Team and works with patients' doctors and social workers to get ahead of the problem.

"We take a proactive approach," she says. "Before the patient is made aware of the costs, we have already gotten the medicines approved and gone through the steps to have them ready for the patient."

to reduce the cost of medications for these families.

They primarily help patients with outpatient medications, but she and her team have also been successful on the inpatient side, acquiring drugs given by IV infusion.

"Too many patients are more concerned about the costs of care than getting well," she says. "It's an amazing opportunity for us to talk to patients who are worried about their families and how they are going to pay for medications, and to reassure them that it's all taken care of."

Beyond medications, patients without insurance, or enough insurance, worry about how they will pay hospital and doctors' bills. Kimmel Cancer Center Harry J.

care, particularly with advanced disease, involves chemotherapy and surgery. "Cure is still possible, but it requires more therapy," he says.

Research shows that where cancer patients get treated makes a difference, with academic centers of excellence, like the Kimmel Cancer Center, offering the best outcomes. With this in mind, Carducci worked with Jones to identify resources available to these patients. These include services offered by Johns Hopkins that are specifically directed at low-income and underserved patients, but also external resources social workers may explore to help patients.

She and her colleagues explore Medicaid, other medical assistance programs and opportunities to ob-

She and her team have helped more than 1,200 cancer patients obtain medications by working directly with the pharmaceutical companies that make the drugs, foundations and other grant providers to cover costs.

"If you're a patient who is already on a limited income, it's hard to fathom a \$10,000 pharmacy bill," says Dowdy. "Without this help, we know many patients would have to choose between purchasing their medications and buying groceries to feed their families. Many patients would go without their medications."

The high cost of drugs can also be a problem for middle-class families who have insurance, and Dowdy also works

Duffey Family Patient and Family Services Program social workers work with the clinical team to help patients who face financial or other challenges to accessing cancer care.

Genitourinary cancer expert **Michael Carducci** and colleagues recently had four young men present in the clinic with advanced testicular cancer. One patient had some insurance, but the others were uninsured.

Carducci, who oversees clinical research at the Kimmel Cancer Center, engaged the help of social worker **Marianne Jones**.

The prognosis is good for testicular cancer, says Carducci, but the

tain low-cost insurance through state exchanges. They may also connect patients with pharmacies that fill prescriptions for low-income patients at significantly reduced costs and often can assist with transportation to appointments.

Doing all they can to help patients in need can be a complex and laborious process for Dowdy, Jones, Carducci and others at the Kimmel Cancer Center, but it's one they embrace.

"We do our best to make sure patients have a safety net," says Jones.

While some of the young men still have more treatment ahead, currently they are all doing well, and Carducci is optimistic that their cancers can be cured.

ENCOURAGING COLLEGE AND HIGH SCHOOL STUDENTS TO CARE FOR THE UNDERSERVED

CUPID

CUPID (Cancer in the Under-Privileged Indigent or Disadvantaged) is a unique, laboratory-based summer fellowship program that exposes medical students to the problem of health disparities to promote interest in caring for underserved cancer patients. Kimmel Cancer Center experts mentor students throughout the seven-week program which includes laboratory-based research; a lecture series covering a variety of cancer research and treatment topics; clinician shadowing in medical, surgical and radiation oncology clinics; and a visit to the National Cancer Institute to meet researchers addressing health care disparities on a national level.

Six students from medical schools studying in Georgia, Washington, D.C., New York and Puerto Rico participated in this year's program and presented their research projects at a certificate ceremony hosted by Kimmel Cancer Center CUPID program directors **Fred Bunz** and **Sushant Kachhap**, who also mentored students.

Projects included novel research studies of combined immune and epigenetic therapies for advanced breast cancer, prostate cancer, gastrointestinal cancer, DNA repair and responses to radiation treatment.



Students who completed the 2018 CUPID program, from left, Alexander Tejada and Shannon Anderson, both from Howard University School of Medicine; Sofia Valbuena-Castor, City of New York School of Medicine; Soheemi Pagan-Leon, Ponce Health Sciences University; Alyse Ragauskas, Mercer University School of Medicine; and Ernie Diaz-Rivera, San Juan Bautista School of Medicine.

MERIT Health Leadership Academy

MERIT Health Leadership Academy is a program that provides longitudinal support and opportunities to Baltimore City students interested in health careers. Its mission is to eliminate health care disparities by transforming underrepresented high school students into health care leaders. MERIT was started by two Johns Hopkins medical students in 2011.

From 10th through 12th grades, MERIT Scholars receive intensive college and career mentoring; academic enrichment classes during the school year; internships in hospitals, clinics and research laboratories over the summer; and academic classes every Saturday during the school year. These experiences expose the scholars to health and science careers while equipping them with the skills and support to obtain them. Through partnerships with the Johns Hopkins University schools of medicine and nursing, MERIT has been able to grow to serve over 200 scholars this year.

"MERIT has an admirable goal and does a really good job of executing it," says **Ian Waters**, a graduate student conducting breast cancer research in the Kimmel Cancer Center and a MERIT mentor. "They find and support students from under-

served communities who are also passionate about serving underserved communities."

Shatera, one of the scholars Waters mentored throughout high school, recently graduated and is now on an honors scholarship at UNC Chapel Hill. Shatera plans to pursue a career in public health research focused on health disparities. Waters also hosts students in the laboratory over the summer to introduce them to cancer research.

"A lot of these kids are motivated and incredible students, but they don't know a lot of people who are involved in science and health care," says Waters. "The students are the driving force, but MERIT provides them with tools they need." Each summer, MERIT scholars are recognized at the Johns Hopkins C.A.R.E.S. (Career Academic and Research Experience for Students) Summer Symposium.

"A LOT OF THESE KIDS ARE **MOTIVATED AND INCREDIBLE STUDENTS**, BUT THEY DON'T KNOW A LOT OF PEOPLE WHO ARE INVOLVED IN SCIENCE AND HEALTH CARE."

- IAN WATERS

KIMMEL PART OF FIRST LARGE-SCALE STUDY OF AFRICAN-AMERICAN MEN WITH PROSTATE CANCER

THE KIMMEL CANCER CENTER is part of a \$26.5 million effort to conduct the first large-scale, multi-institutional study on African-American men with prostate cancer to better understand why they are at higher risk for developing more aggressive forms of the disease and why they are more likely to die from it.

The RESPOND study, for Research on Prostate Cancer in Men of African Ancestry: Defining the Roles of Genetics, Tumor Markers, and Social Stress, is funded by the National Cancer Institute, the National Institute on Minority Health and Health Disparities, and the Prostate Cancer Foundation.

“African-American men have been disproportionately affected by prostate cancer, and this study brings together researchers from across the country to figure out why, enabling the threat of prostate cancer to be reduced for all men,” said **William Nelson**, prostate cancer expert and Kimmel Cancer Center Director.

RESPOND will focus on both biological and social factors that may influence the development of prostate cancer in this group. Social stressors, such as discrimination, socioeconomic status, education, early life events and where men live, will be assessed via an online survey. Studies have shown that stress affects health, but little is known about whether stress has an impact on the development of aggressive prostate cancer.

“The overarching goal is to determine which factors contribute to poor outcomes among African-American men with prostate cancer so that we can begin to improve survival and decrease racial disparities in this disease,” says pathologist and prostate cancer expert **Tamara Lotan**, who will help perform centralized review of prostate tumor samples, noting changes related to adverse prognosis that should be studied more closely.

The study, which is expected to begin in fall 2018 and last for five years, is the first in any racial group to fully integrate genetic alterations with gene expression data, social determinants of health and markers of tumor aggression, she says.

Researchers hope to recruit 10,000 African-American men nationwide to participate in the study.



African-American men interested in participating in the study can learn more at: <http://respondstudy.org/>



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