



Cecelia Calhoun, MD, MPH, MBA

# LEADING THE CHARGE AGAINST SICKLE CELL DISEASE

As the new director of Smilow Cancer Hospital's Sickle Cell Program, Dr. Cecelia "Cece" Calhoun tackles a rare disease with an urgent need for change.

Kristin Rattini writer Peter Baker photographer

Patients with sickle cell disease are often called sickle cell warriors. These patients, who are primarily African American, struggle with debilitating pain and other physical hardships associated with the inherited blood disorder, but also societal inequities and disparities that can prevent them from receiving the care that they need.

As the new director of the Sickle Cell Program at Smilow Cancer Hospital, Cecelia "Cece" Calhoun, MD, MPH, MBA, strives to ease the suffering and burden of sickle cell warriors and advance their care options by building on the program's strong foundation and rallying the tremendous resources of Yale; but most importantly, the knowledge of the community.

"It shouldn't just be about our patients' resilience or fortitude," Dr. Calhoun said. "It should also be about how we, as providers

and a healthcare system, can be an example of how to support and care for patients from disadvantaged backgrounds and help them to live their absolute best lives."

## A DEVASTATING DISEASE

Approximately 100,000 Americans suffer from sickle cell disease, which is usually diagnosed at birth. Instead of being round, the red blood cells are shaped like sickles, which prevents proper blood circulation. These malformed cells cause tremendous pain, organ damage, anemia, joint degeneration, lower resistance to infections, and other health problems. The average life expectancy for patients with sickle cell disease is approximately 20 to 30 years shorter than for the general population.

When a severe pain crisis strikes, sickle cell patients often end up in the emergency room. Unfortunately, their rare condition is unlikely to be understood and their requests for opioid medicines, traditionally used to alleviate their suffering, are often misconstrued as drug-seeking behavior by suspicious providers. "Perhaps no other group of patients has suffered more from the impact of systemic racism in the United States than those with sickle cell anemia," said Eric Winer, MD, Director, Yale Cancer Center and Physician-in-Chief, Smilow Cancer Network. "As a cancer center, we are fully committed to reversing the horrific challenges that have been faced by the sickle cell community."

## FINDING HER CALLING

It was Dr. Calhoun's encounter with a patient with sickle cell disease during her medical school pediatric rotation that set her on the path toward her specialty. "It was the first time I saw a sickle cell patient who had had a stroke; she was only eight," Dr. Calhoun recalled. "I told myself, 'You see that something isn't right here. You can help work on it.'"

While finishing her pediatric oncology fellowship, Dr. Calhoun also earned a Masters in Public Health, so that as a physician scientist she could make a difference for patients with sickle cell disease on a larger scale. "I have one-on-one interaction with patients, which is very meaningful and impactful," she said. "I thought, 'How do I scale that impact?' In the world of academic medicine, you do that through research, where we can take things we discover and help and reach patients we never meet. That is an incredible opportunity for me, especially when trying to address a rare disease with an urgent need for change."

In her research, Dr. Calhoun has focused on interventions to help pediatric sickle cell patients managing themselves and their care as they transition to adult care. "That transition time represents the convergence of multiple factors," she said. "The more insidious complications of sickle cell disease are coming to fruition at that age, as there's more wear and tear on the organs. There's normal adolescent development, a growth and desire to be independent, learn the world, and explore, but also have space

to fail safely. There is a change in resources, such as housing and insurance. There is the transition of figuring out what you're going to do next in life. And many patients with sickle cell disease live below the poverty line, so they have socioeconomic challenges that complicate their ability to care for themselves, which are exacerbated at a turning point like this transition time."

## AN EXCITING NEW CHAPTER

In her own transition to director of the Sickle Cell Program at Smilow Cancer Hospital, Dr. Calhoun is grateful to inherit a strong foundation to build on and take to the next level. "The hospital and our entire staff have made a huge investment," she said. "Everyone connected to our program has such a deep commitment to our patients. How we deliver care—whether within the hospital or our outpatient clinic—has allowed us to create a space where patients are moving toward health and thriving, not just surviving."

She is thrilled with the recent hire of fellow hematologist Layla Van Doren, MD, who will focus on staff training and development. "I can't emphasize enough my enthusiasm around having someone with her level of intelligence and commitment who can bring her knowledge not only within our healthcare system to strengthen our trainees, but also share it with our patients and our community," Dr. Calhoun said.

A top priority for Dr. Calhoun is strengthening community partnerships, especially with Michelle's House which is the New Haven home for the Sickle Cell Disease Association of America's Connecticut chapter, and through the Yale Center for Clinical Investigation's Cultural Ambassadors.

"This is not just us teaching, but listening, learning, and understanding from people who lead, who live, and who have expertise," Dr. Calhoun said. "Through this bidirectional knowledge exchange, we can look to them for accountability, for innovation, and new ideas. We can ask, 'How is what we're doing serving you? How can we make it better?'"

Those strengthened community ties can enhance patient trust and confidence, especially as the Sickle Cell Program develops new therapies and services and offers them in a trauma-informed way that honors these patients' experiences and gives them access and opportunity for a better quality of life.

"We not only need to develop new and better therapies but must attend to the day-to-day medical and psychosocial needs of this group of patients and their families," said Dr. Winer. "Cece lives this mission daily through her clinical work and her research, and under her leadership I am convinced that our sickle cell program will thrive—providing outstanding clinical care, researching critical questions, and playing a major role in altering the trajectory of the disease." ☺