

Patient hopes feedback inspires change

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Cheslie Johnson has been a Duke Health patient for more than 20 years. She was born with sickle cell anemia, a genetic red blood cell disorder that most commonly affects African Americans. Sickle cell anemia can cause strokes, high blood pressure and organ damage. For Johnson, the disease causes excruciating joint pain.

Normally, Johnson seeks care at [Duke's Sickle Cell Center](https://medicine.duke.edu/divisions/hematology/patient-care/duke-sickle-cell-center) (<https://medicine.duke.edu/divisions/hematology/patient-care/duke-sickle-cell-center>), where hematologists familiar with her condition provide care. She's had good experiences there and calls the center "one of the best in the country."

But sometimes she's in crisis and heads to the emergency room or an outpatient clinic. There, she has met clinicians not familiar with sickle cell anemia. And sometimes, they assume she has an ulterior motive.

"You're Black and you are saying you are in pain," Johnson said. "Some providers unfamiliar with sickle cell anemia think you are pretending to be in pain to get a prescription for opioids. This perception has been a barrier to receiving adequate treatment in a dignified and stress-free manner for my disease."

To provide feedback on the successes and challenges she's met along her patient journey, Johnson joined the [Duke University Health System Patient and Family Advisory Council](https://www.hsq.dukehealth.org/pfac-organization/) (<https://www.hsq.dukehealth.org/pfac-organization/>) or PFAC. The group's feedback is considered in Duke's quality improvement work.

"Our quality and safety work has a place carved out to include patients' voices," said **Shannon Haney**, the patient and family engagement coordinator at the [Duke Center for Healthcare Safety and Quality](https://www.hsq.dukehealth.org/) (<https://www.hsq.dukehealth.org/>). "There is a person behind each clinical encounter. Listening to their feedback allows us to become more patient-centered."

For Johnson, educating frontline providers about sickle cell anemia and how it can manifest differently for each person would be beneficial for those times when she cannot see her hematologist. She also believes providing implicit bias training, which Duke began mandating this year, will prevent the incorrect assumption that sickle cell patients are trying to gain access to prescription medication.

"The quality of care for patients like me – who are ill, misunderstood and underserved within the healthcare community – has become a new passion in my life," Johnson said. "My goal is to improve the patient experience."