

# Sickle cell advocate petitions for standardized care

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Credit: National Institutes of Health

When Atlanta resident Blaze Eppinger has a sickle cell pain crisis bad enough to need emergency room care, he sometimes has to wait hours for treatment.

That's despite 2014 guidelines from the National Institutes of Health that state medical personnel should "rapidly initiate analgesic therapy within

30 minutes of triage or within 60 minutes of registration."

Sickle cell gets its name from the way some of a victim's red blood cells are shaped like crescent moons, or sickles, instead of being round. The rigid, sticky sickle [cells](#) become stuck in [small blood vessels](#), slowing or blocking blood flow and oxygen, and causing pain in the chest, joints and bones.

These pain episodes can sometimes be so severe the sufferer has to go to the [emergency room](#) for a blood transplant and pain medications.

But, Eppinger said, "As far as adult care, you go into the emergency room, and you wait hours and hours on end. The NIH guideline, that's not a reality for people living with sickle cell. Somehow, once you turn into an adult, you just turn into this junkie who just shows up for the pain meds. It's crazy."

Eppinger, whose job is advocacy and transition assistance at the Sickle Cell Foundation of Georgia, has started a petition to change that.

The Change.org petition seeks consistency in treatment that follows the NIH guides.

Marketing consultant Alexis Lott said she's had the same experience Eppinger described. Although both say [care](#) for pediatric sickle cell patients is excellent, "once I transitioned at 18 years old, everything changed," Lott said.

"One of the first things that happens if you go into the emergency room as (an adult) sickle cell patient is, are you a drug addict? Are you here for the medication? Are you here to, you know, basically get high?" said Lott, who splits her time between Atlanta and Columbus. "That sort of thing is what you get from the not necessarily nurses, but the doctors."

"That's everywhere," Eppinger added. "Advocacy is a big part of what I do here at the Sickle Cell Foundation of Georgia, so I have a lot of friends across the United States who have [sickle cell](#), and it's everywhere. You know, it's a stigma that they go through."

Eppinger's petition reads, in part: "What I hope to achieve with this petition is one word, [protocol](#). ... Sadly the consensus from the Sickle cell community does not reflect the data NIH published. Doctors are hesitant to administer certain medications, triage can take hours, and bedside manner can leave patients feeling unheard. I ask with these signatures that we receive consistency. Someone in pain should not dread the treatment they may receive when visiting the local ER room. You would like to feel a sense of relief when visiting the hospital, as you know your [pain](#) will soon be alleviated. This is a real problem, If you don't believe us, believe the National Institutes of Health."

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