

Insights

Four Solutions for Sickle Cell Disease Support

Advice from a patient and mother



Precious and her son, Melvin

When Precious Lee was a year old, she began to experience severe pain in one of her arms. Her mother, Tammy, knew something was wrong—Precious had stopped eating and wasn't moving her arm at all—but the doctors at their local hospital didn't share her concern. "My mom brought me to the hospital multiple times, but they kept telling her that I had the cold or the flu," says Precious, who is now in her thirties. "They didn't know what was wrong with me, so they just kept sending me home."

Realizing her daughter needed urgent help, Tammy drove from their home in Illinois to a children's hospital in St. Louis, Missouri. Once there, Precious was diagnosed with sickle cell disease (SCD), an inherited blood cell disorder that inhibits blood flow, which deprives tissues of oxygen and can cause excruciating pain, stroke, and organ damage.

Now, over three decades later, Precious has spent her lifetime navigating the health system, first as a patient with SCD and then, after her son Melvin was born with SCD, as a mother. She has lived with the impact of SCD, witnessed significant advancements in care, and intimately knows

the barriers families still face.

Below, she describes those challenges and elaborates on opportunities for continued improvement.

Access to quality care

As a baby, Precious and her mother had to travel to St. Louis regularly because staff at their local hospital were not trained to manage the unique needs of SCD patients. Decades later not much has changed, and Precious continues to drive to St. Louis, now for her son's care as well as her own.

"I tried to get care at my local hospital again in my twenties, but it didn't end well," explains Precious. "I needed a blood transfusion, but they gave me the wrong blood type. After that, I thought, never again, and I've stayed with St. Louis ever since."

Precious's experience is not an isolated incident. While SCD affects approximately 100,000 Americans, making it one of the most common genetic disorders in the country, there is still a shortage of providers experienced in managing SCD care. This is especially true in rural and underserved areas.

Many people must travel hours—even crossing state lines—to receive the comprehensive care they need, often while simultaneously trying to balance employment and the needs of their family.

Now, telementoring is an opportunity to change this. By using telementoring to train and ultimately increase the number of clinicians knowledgeable about specialty disease care, like SCD, more patients can receive expert care that is up-to-date, timely and convenient. Telementoring has been a priority for the Sickle Cell Disease Treatment Demonstration Regional Collaborative Program ([SCDTRCP](#)), a national initiative funded and managed by the Health Resources and Services Administration (HRSA). Over the past 5 years, telementoring hubs for SCD have spread across the U.S., fostering [a rapidly growing national network for SCD training and knowledge-sharing](#).

The need for better support networks

"As a kid, I felt so alone with this disease," says Precious. "For a long time, I was embarrassed to tell people about it, because I was often sick and spent so much time in the hospital. One time, after I'd been out for a few weeks, a kid from school told me she wasn't allowed to play with me because her mother said I was contagious, and I just broke down."

"I didn't feel like anyone cared about people with sickle cell disease... like there was no support out there for us. It was just really sad, and I felt so lonely."

Feelings of isolation combined with a disease that causes significant pain put those with SCD at a higher risk of [depression and anxiety](#). Fortunately, an advent of community-based organizations, online patient support networks, and Facebook groups are creating a community of sickle cell disease warriors. Precious and her mother regularly attend conferences all over the country where they learn about the latest treatments and interventions, tell their story, and meet other people who share their experiences. After Precious's son was born, Precious and her mother started their own nonprofit, [A Precious Organization for Sickle Cell](#). The organization seeks to support those with SCD through community-based support, counseling, and financial assistance; and advocate for all those living with SCD.

"Between social media, the conventions and conferences, and our organization, I can just pick up the phone and talk to so many different people who know what I'm going through and who are doing things to improve our care," says Precious.

"It lets me know that there are a lot of people out there who understand and who are working to help us—and that is just refreshing. I didn't have these things as a kid."

While thankful for today's improved support networks, Precious still urges an increased focus on mental health for those living with SCD, citing her own mental health experience: "People with sickle cell disease can experience [post-traumatic stress disorder](#), and I've had severe anxiety. It takes a toll on your mental health as well as your physical health, so we need to make sure both are a priority."

Transition from adolescent to adult care

When Precious was 19, she found out she could no longer receive treatment at the children's hospital she had gone to her all her life.

"They told me I needed to start going to an adult hospital, and I was like, 'what?'," Precious recalls. "They kind of just kicked me out; I didn't get any information on an adult hematologist and I didn't know where to go."

For the next nine years, Precious tried to manage her disease without a hematologist or regular treatment. When she had a sickle cell pain crisis, she would go to the emergency room, receive a pain prescription, and then go home until she had her next crisis. It was a frightening and painful cycle—and one that is all too common for both adults and children living with SCD. Eventually, Precious began to have strokes, a severe and potentially deadly complication of SCD. It wasn't until her son was born with SCD that things finally changed:

"I brought Melvin to the same hospital I had gone to as a child, and they were wonderful," says Precious. "They asked what I was doing for my care and this time they properly transferred me to an adult hematologist. I then learned that my next stroke would have likely taken my life, and I now have blood exchanges every five weeks, so I won't have a stroke again. My son essentially was a lifesaver for me—if he hadn't been born, I would never have gone back to that hospital and been connected with better supports."

While Precious eventually transitioned to adult care, she spent nearly a decade living in pain, going through expensive and traumatic emergency room visits, and having her life put in danger. Her experience reflects an all too common trend for those living with SCD:

When young adults transition out of pediatric care, they face significantly worse health outcomes, including higher rates of emergency room visits and an increased number of deaths.

Many young people struggle to find a new provider or understand how to navigate the health system (e.g., manage appointment scheduling and understanding their insurance coverage), and their health and well-being pay the price. Importantly, there are many opportunities for hospitals to help improve transitions in care, including developing transition plans and checklists and partnering with community-based organizations. Two regional leaders on the SCD regional collaborative program share more about these strategies [here](#).

Celebrate successes *and* commit to continued improvements

While SCD was once considered a pediatric condition, advancements in care and treatment mean that more patients are living and thriving into adulthood. As someone who grew up amidst those improvements and is now raising a son with SCD, Precious can attest firsthand to the positive evolution of SCD care. And while she celebrates the changes that she's witnessed, she also knows there is still much work left to do.

"I type in #SickleCellWarrior on social media and I'm connected with all these wonderful people, but at the same time I see all these young people who have passed away and that scares me so much," Precious says quietly.

"I know we've come so far, but then I see this, and I think, 'what has happened?' There should be no one in their twenties or thirties dying from this disease. I know change is possible, but we still need to do more."

Ultimately, Precious's story offers both hope and a challenge: improvement *is* possible, but continuing that improvement requires renewed energy and innovation. This is why initiatives like the SCDTDRCP, national organizations like the Sickle Cell Disease Association of America, and community-based groups like Precious' organization are all vitally important—together, they are a comprehensive network of changemakers committed to improvement.