

Insights

Creating Better Advocates for Sickle Cell Disease Care



Quality improvement in public health means working through every sector and influence that affects how people live. At the highest level, this includes the rules and laws where people live.

This is what happened in Missouri as part of the Sickle Cell Disease Treatment and Demonstration Program ([SCDTDP](#)). As teams were working towards creating better care for individuals with this disease, they realized the potential in working with the state government to make impactful change. Estimates show that 1,793 people in Missouri are living with SCD, including 600 children near St. Louis. While the majority of people with SCD live in or near the major metropolitan areas, where care is available, there is still a number of patients who reside often hundreds of miles from the nearest SCD care provider.

“The large area and paucity of providers creates a burden for patients with SCD and likely leads to an increased financial burden for patients, families, healthcare facilities and local and state governments,” said Taniya Varughese, MSOT, OTR/L, coordinator of Occupational Therapy

Support at Washington University in Saint Louis, and a member of the Heartland Region (Missouri, Nebraska, Iowa, Kansas) of the SCDTDP.

In the Heartland region, there is a lack of providers trained to treat individuals with SCD—only one adult hematologist in the St. Louis metropolitan area—and many primary care physicians do not feel comfortable managing patients with this disease. For providers who are treating SCD patients, there is a lack of communication and coordination between providers, especially as pediatric patients transition to adult healthcare.

“The rate of morbidity and mortality drastically increases for SCD patients during their adolescent-young adult years, and we believe that the lack of transitional programming and provider-to-provider communication is a contributing factor,” says Varughese.

This is something that has been apparent through the SCDTDP. In many states, there are pockets where SCD is somewhat common, but overall the disease is rare. This means that many doctors have not encountered it before and likely have not received much training for treatments. In some states, people with SCD travel hours to reach the nearest expert provider.

In addition to the challenges faced by patients with SCD and their families, there is a high cost for burden of care to the state as well. According to Missouri Medicaid Data, SCD related emergency department visits cost upwards of \$138 million a year.

“There needs to be greater intervention to improve the quality of life for individuals with SCD and reduce the high financial burden of care,” says Sabrina Selk, ScD, NICHD’s project director for its Sickle Cell Disease Treatment Demonstration Program.

Raising Awareness

Improvement for care comes from every level, and that includes local government. The Heartland network recently approached the Missouri state legislation as part of Advocacy Day, an event that invites organizations and activists to engage state lawmakers in a drive to promote policy action. Members from the network, parents and patients met with 42 legislators during Advocacy Day. Most readily admitted that they had very little knowledge about SCD or the challenges faced by this population, and many legislatures were alarmed at the high financial burden imposed on individuals with SCD, their families, and the state for frequent emergency room visits and hospitalizations. The efforts were so effective that some advocates were invited to address the Mental Health Policy Committee.

“Our goal during Advocacy Day was to engage our legislators in conversation about SCD, bring awareness to the barriers to care individuals with SCD face, and garner their support for the bill,” says Varughese. “I think we definitely achieved that and I hope it encourages others to do the same in their state.”

Adds Selk, “Despite their great need, overall, there is a lack of support and advocacy for patients with SCD who are dealing with multiple barriers to healthful living. This type of change requires a great deal of coordination. Advancing government action can ensure that people with SCD get the support they need.”