

Legislating Support Services for Persons with Sickle Cell Disease in Colorado

Challenge

Imagine hearing, “Too few people like you exist to warrant dedicated resources.” This was the reality for the [Colorado Sickle Cell Association](#) (CSCA), whose mission is to support, educate, advocate, and empower the sickle cell community. CSCA has relied solely on volunteers and small donations to create and maintain buddy programs with medical students; educate communities on what it means to live with sickle cell disease (SCD); and connect persons with SCD to community services, informal counseling, and each other. However, these programs have not been sustainable due to a lack of funding.

Approach

Representatives from the CSCA, sickle cell warriors, and physicians from the Colorado Sickle Cell Treatment and Research Center worked closely with two Colorado State Senators and two Colorado House Representative to put forth [Colorado Senate Bill 24-042](#), which will create the Arie P. Taylor Sickle Cell Disease Outreach Program. This bill sets aside state funds for outreach and support services for persons living with SCD and their families. The team used prevalence data from the [Colorado Sickle Cell Data Collection](#) program and personal stories in their testimony to Congress to show how the lives of hundreds of Colorado residents and their families would benefit from these services.

Impact

The bill was signed into law! In 2025, the Colorado Department of Public Health and Environment will award a community agency \$200,000 annually to implement an outreach program over the next 5 years. This program will provide essential resources and services to those who need them most, improving their access to care and their quality of life.



CSCA with Colorado State Senate Sponsors of SB 24-042

AT A GLANCE

Securing state funding to provide support for persons living with SCD can be challenging.

The Colorado Sickle Cell Association went to the Colorado Congress to educate the legislature on the impact of SCD on those living with the disease and their loved ones.

Data from the Colorado SCDC project and stories of those living with the disease were used to highlight the impact of SCD, which extends beyond those living with the disease.

“This important program will ... connect folks to supportive health care and community services and will help address long-standing health inequities that remain far too prevalent in marginalized communities across our state.”

- Colorado Senator Rhonda Fields

The CO-SCDC program, which provided some of the data used to educate the state legislature, is supported by a cooperative agreement from the Centers for Disease Control and Prevention’s Sickle Cell Data Collection Program (CDC-RFA-DD-23-0002). Please note that no funding from this cooperative agreement was used for lobbying purposes.



<https://www.coscdc.org/>