

Sickle cell disease (SCD)

SCD is a genetic blood disorder that produces abnormal red blood cells which cause ongoing damage to blood vessels and organs.¹ It is a lifelong illness that places physical and emotional burdens on patients and their families as they manage issues with work, school, and family.

Through the STEP ProgramTM, five organizations received a total of nearly USD 250,000 for their proposals to improve the lives of people living with the disease. Proposals were evaluated by an external review committee comprised of experts in the fields of advocacy, psychosocial support and multicultural health, as well as an SCD practitioner and patient.

Funded programs include:

<u>All One Blood's</u> video series - Revealing powerful stories of those living with SCD to encourage self-advocacy.

The Children's Research Institute's INSERTT (ImproviNg SicklE TRansition Through Telemedicine) - A study evaluating telemedicine on improving health outcomes for SCD patients as they transition to adult care.

<u>Sickle Cell 101's</u> FACTSS (FAcilitating Communication BeTween PatientS and ProviderS) - A digital toolkit with customized communication strategies to empower patients to take control of their care.

<u>The Georgia Health Policy Center</u> at Georgia State University's educational videos - Educate patients and caregivers about the benefits and potential complications of therapeutic blood transfusions.

<u>The Sickle Cell Foundation of Georgia, Inc.'s</u> interactive workshops - Providing adolescents with tools to successfully transition from pediatric to adult care.

References

1. Roseff S. Sickle cell disease: a review. Immunohematology: Journal of Blood Group Serology and Education. 2009;25(2):67-74. https://www.ncbi.nlm.nih.gov/pubmed/19927623. Accessed September 12, 2019.

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- 4. https://ghpc.gsu.edu/
- https://sicklecellga.org/
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