It’s time to rewrite the story of sickle cell.

CURE SICKLE CELL INITIATIVE
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Executive Director

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Contact: curesickle.org
Cure Sickle Cell Initiative

Funded by the National Heart, Lung, and Blood Institute (NHLBI) and launched in September 2018

Vision
Accelerate the development of treatments aimed at a genetic-based cure for sickle cell disease.

Approach
Leverage resources and actively engage the sickle cell disease community of patients, family members, caregivers, advocates, and researchers to work together on a path to cures.

Contact: curesickle.org
Cure Sickle Cell Initiative: Leveraging Resources and Engaging a Community on the Path to a SCD Cure

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The Cure Sickle Cell Initiative is intended to fill in gaps that cannot be covered by traditional funding strategies.

NHLBI will continue to fund investigator-initiated applications focused on SCD.

Encourages collaboration among researchers, industry, non-profit organizations, and policy-making agencies who will play a role in curing the disease.

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Priority Activities: Overview

• **Voices** - Patient Representatives/Advocates serving on the Executive and Implementation Committees

• **Working with Federal Partners** led by HHS

• **Subcommittees** established to address:
  ✓ Patient Outreach/Engagement
  ✓ Communications/Social Media
  ✓ Assay Development
  ✓ Gene Editing/Gene Therapies
  ✓ Clinical Trial Design

• **MOUs** with ASH and CIRM to:
  ✓ Work together and coordinate resources and efforts to identify a curative therapy for individuals living with SCD

• **Data Strategy Consortium** established to enhance:
  ✓ Recruitment and outreach
  ✓ Data collection from a variety of sources
  ✓ Common data elements/harmonization
  ✓ Data management
  ✓ Data analysis
  ✓ Data sharing

Contact: cureSickle.org
Visit curesickle.org to learn more and sign up for updates

To subscribe to the NHLBI newsletter, visit https://www.nhlbi.nih.gov/health-topics/education-and-awareness/sickle-cell

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