



# SCDC Snapshot

September 2021

The Sickle Cell Disease Coalition (SCDC) is an alliance of diverse stakeholders from across the world uniting to conquer sickle cell disease (SCD). Since its establishment in 2016 by the American Society of Hematology (ASH), the SCDC has grown tremendously in its membership, operations, and impact. In celebration of the Coalition's fifth year, the SCDC is sharing some highlights of its past, present, and future through this 2021 SCDC Snapshot.

## SCDC Goals



Amplify voice of sickle cell stakeholder community



Promote awareness

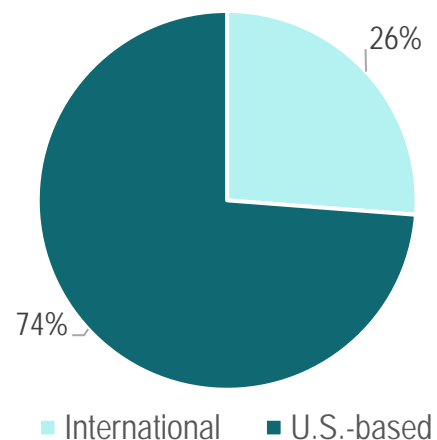
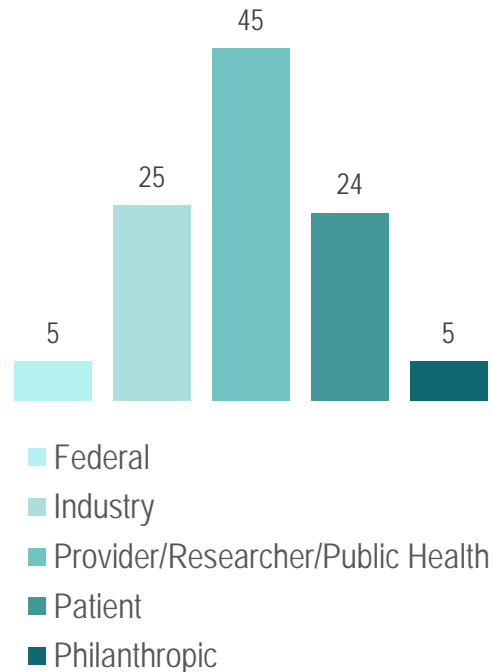


Improve outcomes for individuals with SCD

## SCDC Committees & Current Priorities

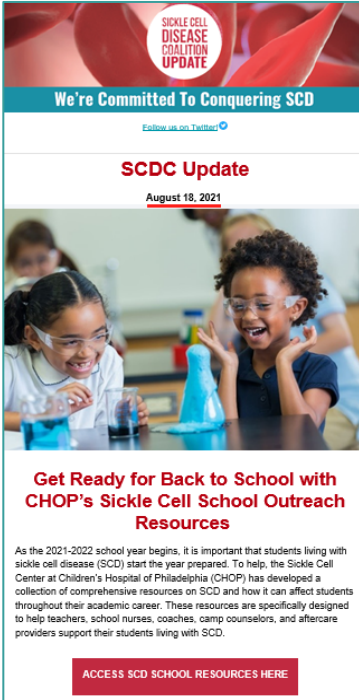
- **Access to Care (in the US) Working Group**
  - Developing mental health and social services initiative focused on supporting students with SCD in school and extracurricular settings
- **Blood Donor Diversity Task Force**
  - Identifying data needed to improve the surveillance of blood supplies and recruitment of diverse donors
  - Supporting partners' efforts to develop promotional materials for diverse blood donors
- **Global Issues Working Group**
  - Collating existing training and education resources on sickle cell care for health care providers in low-resource settings
- **Research & Clinical Trials Working Group**
  - Disseminating fact sheets and derivative products on newly available SCD therapies
- **Sickle Cell Trait (SCT) Task Force**
  - Promoting SCT awareness, screening, documentation, and high-quality genetic counseling

## SCDC Membership = 100+ Organizations





## SCDC Accomplishments



**SICKLE CELL DISEASE COALITION UPDATE**

**We're Committed To Conquering SCD**

Follow us on Twitter

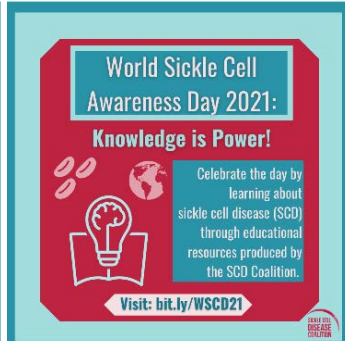
**SCDC Update**

August 18, 2021

**Get Ready for Back to School with CHOP's Sickle Cell School Outreach Resources**

As the 2021-2022 school year begins, it is important that students living with sickle cell disease (SCD) start the year prepared. To help, the Sickle Cell Center at Children's Hospital of Philadelphia (CHOP) has developed a collection of comprehensive resources on SCD and how it can affect students throughout their academic career. These resources are specifically designed to help teachers, school nurses, coaches, camp counselors, and aftercare providers support their students living with SCD.

**ACCESS SCD SCHOOL RESOURCES HERE**



**World Sickle Cell Awareness Day 2021:**

**Knowledge is Power!**

Celebrate the day by learning about sickle cell disease (SCD) through educational resources produced by the SCD Coalition.

Visit: [bit.ly/WSCD21](http://bit.ly/WSCD21)



**Sickle Cell Disease (SCD) Therapy Fact Sheets**

Fact sheets to help people living with SCD explore available therapies with their health care team, including:

- Crizanlizumab
- L-Glutamine
- Voxelotor

Visit [bit.ly/SCDfactsheets](http://bit.ly/SCDfactsheets)

## Looking Ahead: Aligning Efforts & Engaging Stakeholders

Over the next year, the Coalition will work to improve its service as a coordinating hub for the sickle cell community. The SCDC will focus on aligning members' efforts and engaging new stakeholders around the recommended strategies in the 2020 National Academies of Science, Engineering, and Medicine (NASEM) report, *Addressing Sickle Cell Disease: A Strategic Plan and Blueprint for Action*. These strategies are listed below, with a few SCDC additions/modifications\* to reflect global needs:

- **Strategy A:** Establish a national system to collect and link data to characterize the burden of disease, outcomes, and the needs of those with SCD across the life span.
- **Strategy B:** Establish organized systems of care that ensure both clinical and nonclinical supportive services to all persons living with SCD.
- **Strategy C:** Strengthen the evidence base for interventions and disease management and implement widespread efforts to monitor the quality of SCD care.
- **Strategy D:** Increase the number of qualified health professionals providing SCD care.
- **Strategy E\*:** Improve SCD awareness and strengthen advocacy efforts through targeted education and strategic partnerships among key stakeholders.
- **Strategy F:** Address barriers to accessing current and pipeline therapies for SCD.
- **Strategy G:** Implement efforts to advance understanding of the full impact of SCT on individuals and society.
- **Strategy H:** Establish and fund a research agenda to inform effective programs and policies across the life span.
- **Strategy I\*:** Establish and strengthen national newborn screening programs and care protocol for diagnosed babies.

To learn more about the Coalition and opportunities to collaborate, email [coordinator@scdcoalition.org](mailto:coordinator@scdcoalition.org).

- **Spreading Sickle Cell Awareness**
  - Website [www.scdcoalition.org](http://www.scdcoalition.org)
  - Twitter [@ConquerSCD](https://twitter.com/ConquerSCD)
  - Monthly E-Newsletter [SCDC Update](#)
  - World Sickle Cell Awareness Day Campaigns:
    - 2019: Access to Care in Sub-Saharan Africa
    - 2020: Blood Donations Needed for Sickle Cell Warriors
    - 2021: [Knowledge is Power](#)
- **Sharing Partners' Resources**
  - [SCD Community Resources Database](#)
  - [Global Resources Library](#)
  - [Blood Donations & SCD Resources](#)
  - [COVID-19 & SCD Resources](#)
- **Developing New Tools & Information**
  - [Plain Language Summaries of Sickle Cell Research Presented at Scientific Meetings](#)
  - [Repository of Global SCD Educational Tools](#)
  - [SCD Reading Lists](#)
  - [SCD Therapy Fact Sheets](#)
  - [Transition Toolkit](#)