



# SICKLE CELL DISEASE COALITION

## GUIDING PRINCIPLES

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*These Guiding Principles set forth the fundamental mission and structure of the Sickle Cell Disease Coalition, the qualifications for new members to join the Coalition, and the conditions for continued participation by existing Coalition members. Entities wishing to participate in the Coalition initially must demonstrate that they meet the criteria applicable to the relevant member category. Existing members are expected to continue to meet the criteria applicable to their member category and to conduct themselves in accordance with these Guiding Principles to continue their participation in the Coalition. These Guiding Principles shall be formally reviewed every five (5) years; however, the Sickle Cell Disease Coalition reserves the right to modify these guidelines at any time in its sole discretion.*

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## MISSION

### BACKGROUND:

Sickle cell disease (SCD) is an inherited, lifelong blood disorder that causes individuals to produce abnormal hemoglobin, leading their red blood cells to become rigid and sickle-shaped. This sickling results in the blockage of blood vessels and a constant shortage of oxygen-rich red blood cells, which causes a variety of clinical complications ranging in severity. Possible symptoms of SCD include severe pain, acute chest syndrome, stroke, organ damage, and even premature death.

Though classified as a rare disease, it is estimated that more than 100,000 Americans live with SCD<sup>1</sup> and that more than 3,000,000 Americans carry the genetic trait that leads to this blood disorder.<sup>2</sup> In the United States, SCD predominantly affects African Americans, LatinX Americans, and Hispanic Americans. Globally, it is estimated that at least 300,000 infants are born annually with SCD and more than 100,000,000 people carry this recessive genetic trait.<sup>3</sup> Sickle cell is prevalent within many malaria-endemic regions, such as parts of sub-Saharan Africa, India, the Middle East, the Mediterranean, Latin America, etc. Unfortunately, many regions that face the heaviest burden of SCD also struggle with limited resources and health care infrastructure.

Historically, treatment options and social support for individuals impacted by sickle cell have been sparse and subpar, predominantly due to racism and marginalization of people impacted by SCD. However, in recent decades, scientific advancement, community-based advocacy, and increased public and private investment in sickle cell has improved the quality of life and outcomes for individuals living with the disease. While the rise of resources and stakeholders interested in supporting the sickle cell community is a key sign of progress, this influx of support and interest also opens the door for uncoordinated and duplicative efforts. Additionally, though scientific and health-engaged entities are becoming more interested in sickle cell, other key stakeholders, such as the general public, remain largely unaware and/or misinformed about the disease.

In 2016, the American Society of Hematology (ASH) established the Sickle Cell Disease Coalition (“SCDC” or “Coalition”), an association of independent entities and organizations representing a variety of stakeholders that are united to collaborate, coordinate, and conquer SCD. The SCDC aims to support the sickle cell community through three key objectives:

- ***Broaden, amplify, and harmonize voices within the sickle cell community to spread sickle cell awareness, engage new stakeholders, and motivate community-centered change***
- ***Unite diverse stakeholders and interdisciplinary experts to lead initiatives that improve health outcomes and quality of life across the lifespan for individuals living with sickle cell worldwide***
- ***Promote evidence-based interventions and shared decision making related to sickle cell care within health care systems and society at-large***

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<sup>1</sup> “Data & Statistics on Sickle Cell Disease,” *Centers for Disease Control and Prevention (CDC)*, <https://www.cdc.gov/ncbddd/sicklecell/data.html>

<sup>2</sup> “Incidence of Sickle Cell Trait in the United States, 2010,” *Morbidity and Mortality Weekly Report*, <https://www.cdc.gov/mmwr/preview/mmwrhtml/mm6349a3.htm>

<sup>3</sup> “Sickle Cell Trait,” *American Society of Hematology (ASH)*, <https://www.hematology.org/education/patients/anemia/sickle-cell-trait>

The SCDC will serve as a platform to encourage stakeholders to regularly communicate and collaboratively develop and implement important projects and activities that will ultimately further the goals above.

#### SCOPE:

In September 2020, the National Academies of Science, Engineering, and Medicine's (NASEM) published a report entitled, [\*Addressing Sickle Cell Disease: A Strategic Plan and Blueprint for Action\*](#).<sup>4</sup> This consensus study assembled an array of experts to: a.) assesses barriers to care experienced by Americans living with sickle cell and b.) identify strategies to improve outcomes and access to high-quality treatment for SCD throughout the United States (U.S). While the NASEM report on SCD focuses on the U.S., the Coalition is interested in addressing strategies outlined within the report domestically and internationally. As such, the SCDC has adopted a set of revised strategies based upon the report to advance a coordinated and global effort; these strategies are outlined below and modifications from the NASEM report are underlined and italicized:

- A. Establish a national system to collect and link data to characterize the burden of disease, outcomes, and the needs of those with sickle cell disease across the life span.
- B. Establish organized systems of care that ensure both clinical and nonclinical supportive services to all persons living with SCD.
- C. Strengthen the evidence base for interventions and disease management and implement widespread efforts to monitor the quality of SCD care.
- D. Increase the number of qualified health professionals providing SCD care.
- E. **Improve SCD awareness and strengthen advocacy efforts through targeted education and strategic partnerships among international regulatory bodies, national governments and domestic health care providers, advocacy groups and community-based organizations, professional associations, and other key stakeholders (e.g., health departments, funding agencies, industry, and media).**
- F. Address barriers to accessing current and pipeline therapies for SCD.
- G. Implement efforts to advance understanding of the full impact of sickle cell trait on individuals and society.
- H. Establish and fund a research agenda to inform effective programs and policies across the life span.

The Coalition shall align its activities with the recommended strategies listed above, focusing primarily on advancing **Strategy E**. Accordingly, SCDC subcommittees (see OPERATIONS section) shall develop specific initiatives that advance these strategies, largely through targeted stakeholder engagement, resource and information sharing, and priority setting. Please note, the SCDC's scope and objectives are subject to change with resources and the needs of the community.

## OPERATIONS

### ORGANIZATIONAL & MEETING STRUCTURE:

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<sup>4</sup> "Addressing Sickle Cell Disease: A Strategic Plan and Blueprint for Action," *National Academies of Sciences, Engineering, and Medicine (NASEM)*, <https://www.nap.edu/read/25632/chapter/1#iv>

The full Coalition meets virtually on a bimonthly basis to discuss timely and widely applicable sickle cell matters, SCDC operations, and current activities. These meetings are organized and led by ASH staff.

Similarly, the SCDC Steering Committee (see GOVERNANCE section) meets virtually on a quarterly basis to discuss SCDC strategy and any executive decisions related to the Coalition. These meeting are also organized and led by ASH staff.

The SCDC also regularly convenes five subcommittees to dive deeper into topical areas of importance to the sickle cell community, address recommendations outlined in the 2020 NASEM report on SCD, and foster closer collaboration among members. The Coalition’s subcommittees meet virtually on a bimonthly basis. Each subcommittee is led by two Co-Chairs (see GOVERNANCE section) with support from ASH staff. The current SCDC subcommittees include:

- *Access to Care Working Group*
- *Global Issues Working Group*
- *Research & Clinical Trials Working Group*
- *Blood Donor Diversity Task Force\**
- *Sickle Cell Trait (SCT) Task Force\**

\*Please note, as Task Forces address more niche issues, the SCDC chose to open participation in these subcommittees to vested organizations that are addressing related problems but may not already be members of the Coalition, nor find the SCDC’s other activities within their organization’s scope. As such, the SCDC has allowed organizations that are not formal Coalition members to participate in “Task Forces”, per the approval of the relevant Co-Chairs and ASH staff. However, SCDC subcommittees identified as “Working Groups” are limited to formal SCDC members (see MEMBERSHIP section). The continuation of subcommittees designations as “Working Groups” and “Task Forces” are reviewed every three (3) years along with subcommittee charters (see GOVERNANCE section).

#### COMMUNICATIONS:

Between SCDC meetings, the Coalition amplifies sickle cell awareness and SCDC members’ activities to the larger community through a variety of communication platforms. To develop messaging, SCDC members share content with ASH staff who manage the Coalition’s communication platforms; these ASH staff members then create and disseminate related communications materials promoting the content shared by SCDC members.

The Coalition communicates with the general public through the SCDC website ([www.scdcoalition.org](http://www.scdcoalition.org)), Twitter (@ConquerSCD), and monthly *SCDC Update* e-newsletter. The Coalition communicates with its members internally through weekly SCDC Flash Friday emails that feature timely Coalition activities; sickle cell-related news, opportunities, and resources; and upcoming events; these emails are sent exclusively to SCDC members.

## GOVERNANCE

#### LEADERSHIP ROLES & RESPONSIBILITIES:

The SCDC is governed primarily by three types of leadership bodies: its Secretariat, Steering Committee, and subcommittee Co-Chairs. The roles and responsibilities for each of these governing entities are outlined below:

- **Secretariat** – The Coalition’s secretariat provides administrative, communications, meeting organization, legal, and project management support to ensure steadfast operations of the SCDC. A detailed outline of the SCDC’s secretariat’s responsibilities is listed below:
  - Administrative activities, including record keeping, calendar management, committee staffing, member onboarding, meeting documentation, conflicts of interest (COI) disclosure collection, and SCDC mailbox maintenance.
  - Communications activities, including managing the Coalition’s external information sharing platforms, like the SCDC’s website ([www.scdcoalition.org](http://www.scdcoalition.org)), the SCDC Twitter account (@ConquerSCD), and monthly *SCDC Update* e-newsletter, as well as the Coalition’s internal information sharing platforms, like the weekly SCDC Flash Friday emails and SCDC Symposia Calendar.
  - Legal activities, including procuring legal services for the Coalition on matters regarding its Guiding Principles, COI communications, and other legal matters that arise related to the SCDC.
  - Meeting activities, including preparing and facilitating all bimonthly SCDC-Wide meetings, quarterly Steering Committee meetings, and annual SCDC Summits, as well as supporting subcommittee co-chairs in planning and facilitating their bimonthly meetings.
  - Project management activities, including leading and coordinating the development and dissemination of any projects the SCDC and its subcommittee choose to pursue.

As founder and primary funder of the SCDC, ASH will serve as the Coalition’s secretariat. ASH staff will be assigned to complete the roles and responsibilities outlined above.

- **Steering Committee** – The Coalition’s Steering Committee oversees the Coalition’s strategy and membership decisions. A detailed outline of the SCDC’s Steering Committee’s responsibilities is listed below:
  - Leadership selection activities, including selecting subcommittee Co-Chairs to lead SCDC Working Groups and Task Forces.
  - Membership activities, including evaluating SCDC membership applications, identifying additional organizations that should join the SCDC, and ruling on any disputes among SCDC members or violations of the SCDC’s Guiding Principles.
  - Strategic activities, including prioritizing activities and competing interests within the Coalition, offering guidance and resource distribution to SCDC projects and subcommittee activities, and recommending ways for the SCDC to enhance and streamline operations.

The SCDC Steering Committee is comprised of three (3) organizations – ASH, Sickle Cell Disease Association of America (SCDAA), and Global Alliance of Sickle Cell Disease Organizations (GASCDO) – as well as the Co-Chairs of the Coalition’s five (5) subcommittees. ASH, SCDAA, and GASCDO serve as the three standing organizational members of the Steering Committee due to their roles as SCDC Secretariat, national convener of SCD community-based organizations (CBOs), and international convener of SCD CBOs, respectively.

- **Subcommittee Co-Chairs** – The subcommittee Co-Chairs lead the Coalition’s Working Groups and Task Forces and provide vital guidance with strategic planning, member engagement, and subcommittee initiatives. A detailed outline of the subcommittee Co-Chairs’ responsibilities are listed below:
  - *Meeting activities*, including developing the agenda, identifying relevant speakers and guests, and facilitating discussion for all meetings of their respective subcommittee.
  - *Membership activities*, including engaging with subcommittee members during and in between subcommittee meetings, recommending new organizations to engage in subcommittees, and mediating any conflict that arises within the subcommittees.
  - *Project management activities*, including contributing to the project’s development, recommending solutions to roadblocks that arise, and reviewing final products for quality assurance.
  - *Strategic activities*, including offering guidance on the SCDC-Wide policy and programs, maintaining the subcommittee charter and goals, and regularly meeting with ASH staff to check-in and collectively brainstorm.

Subcommittee Co-Chairs will serve for a term of two to three (2-3) years, ideally alternating with their Co-Chair partner. These term limits may be extended under extenuating circumstances with the approval of the Steering Committee.

All Steering Committee representatives and subcommittee Co-Chairs must complete and maintain an accurate conflict of interest (COI) form and disclosure slide to be eligible for their leadership position and to remain in good standing with the Coalition. ASH staff will initiate the COI process for all representatives in SCDC leadership positions; however, any updates or changes to a representative’s COI information beyond this initial disclosure must be reported to ASH staff and updated within the designated [COI reporting system](#) by the relevant representative. COI updates must be reported within four (4) weeks of taking effect.

#### NOMINATION & SELECTION PROCESS:

Vacancies in subcommittee Co-Chair positions will be filled through a formal and transparent selection process. These leadership vacancies open when a Co-Chair’s term limit expires, or if a Co-Chair must step down from their leadership role during their term. A new subcommittee Co-Chair will be selected and confirmed by a “selection committee” consisting of the standing Steering Committee members (i.e., ASH and SCDA) and the standing Co-Chair for that subcommittee; for example, if Co-Chair A and Co-Chair B lead a subcommittee, and Co-Chair A steps down from their leadership role, Co-Chair B would work with SCDC Steering Committee representatives for ASH and SCDA to select Co-Chair A’s replacement.

When a leadership seat becomes vacant, the SCDC will follow the following selection process to fill the seat:

1. ASH staff will announce the vacancy to the Coalition and share a nomination form through which SCDC members may nominate themselves or a colleague to fill the open subcommittee Co-Chair position. This nomination form will also solicit disclosure of any relevant COI information.
2. SCDC members will review and submit completed nomination forms to recommend new leaders for vacant leadership positions. The nomination form will be open for two (2) weeks.

3. Upon closing the nomination form, all submissions and recommended leaders for the vacant position will be summarized and shared with the SCDC for an open comment period. During this open comment period, SCDC members are encouraged to share any thoughts or concerns on the leadership nominees via email with ASH staff. The open comment period will occur for two (2) weeks.
4. After the open comment period, feedback received on nominees will be embedded into the overarching summary of nominees and shared with the appropriate selection committee for their review. Selection committees will have two (2) weeks to review nominees, discuss comments, and debate who would be best fit for the vacancy.
5. Selection committees will vote to choose new SCDC leaders to fill the vacancies.

Per the process outlined above, the full nomination and selection process takes approximately six (6) weeks. This process may be extended under extenuating circumstances with approval from the Steering Committee.

#### STRATEGIC PLANNING, DOCUMENTATION, & REVIEW CYCLE:

To ensure the Coalition is coordinated and advancing achievements for the sickle cell community in the short- and long-term, the SCDC has developed strategic documents to assess and plan its activities. The SCDC's strategic documents includes its Guiding Principles and subcommittee charters.

The SCDC Guiding Principles documents the overarching Coalition's mission, operations, membership, and bylaws. The SCDC Guiding Principles are reviewed and updated every five (5) years by ASH staff and approved by the Steering Committee. However, the Steering Committee reserves the right to modify the SCDC Guiding Principles at any time. Any changes made to the Guiding Principles will be shared with the full Coalition.

The SCDC subcommittee charters document each subcommittees' mission, objectives, goals, membership, roles and responsibilities, and designation as a Working Group or Task Force. Subcommittee Co-Chairs will develop the initial charters for their respective subcommittees based on a template and guidance provided by ASH staff. Subcommittee charters and their embedded objectives, short-term goals, and long-term goals will be reviewed and updated at least every five (5) years. While subcommittee Co-Chairs are ultimately responsible for leading the charter's review and maintenance, SCDC subcommittee participants shall be included in the charter's review process and notified of any changes made to the documents.

## MEMBERSHIP:

#### MEMBERSHIP ELIGIBILITY:

The SCDC is comprised of organizations representing diverse stakeholders within the sickle cell community. The Coalition's membership largely includes public health, research, and provider organizations; patient groups; faith-based organizations; regulatory agencies; corporate organizations; philanthropic foundations and other entities with an interest in sickle cell. Definitions and specific membership eligibility requirements for each of these organization types is listed later in this section.

All organizations interested in applying to join the SCDC must meet the following minimum qualifications:

- a) Demonstrate that it is a legally established and recognized entity in good standing with its local, state, and/or national jurisdiction;
- b) Maintain an active website;
- c) Identify any past, current, and/or future initiatives or programming advanced by the organization related to sickle cell; and
- d) Explain how the organization intends to engage with the SCDC and its members around sickle cell.

More specific membership eligibility requirements for different types of stakeholder organizations are listed below:

- National / International Patient Advocacy Organizations – Organizations consisting of community members and advocates working at the national and/or international level to spread sickle cell awareness and support individuals living with sickle cell and their caregivers. National and international-level patient advocacy groups interested in joining the SCDC must:
  - a) Demonstrate active programming, classes, communications, or other initiatives to support and advocate for people living with sickle cell and their support systems;
  - b) Have at least one hematologist or other clinical expert in SCD on the organization’s board, advisory committee and/or medical/scientific board;
  - c) Demonstrate the national or global reach of the organization; and
  - d) Demonstrate that it is an established 501 c(3) non-profit corporation in good standing.
- Community-Based Patient Advocacy Organizations [U.S. Only] – Organizations consisting of community members and advocates working at the local, state, or regional level in the U.S. to support individuals living with sickle cell and their caregivers. To promote investment in existing CBOs and not infringe on the leadership of national / international patient advocacy groups, the SCDC shall not engage more than two (2) community-based organizations (CBO) from each of the following regions at a time: Pacific, West South Central, East South Central, East North Central, West North Central, Mountain, South Atlantic, Middle Atlantic, New England. U.S.-based CBOs interested in joining the SCDC must:
  - a) Demonstrate active programming, classes, communications, and other initiatives to support sickle cell warriors in their locality;
  - b) Have at least one hematologist or other clinical expert in SCD on their board;
  - c) Demonstrate that it is a registered member in good standing of SCDA, inc.’s national chapter; and
  - d) Demonstrate that it is an established 501c(3) non-profit corporation in good standing.
- Corporate Organizations – For-profit companies - such as those in the pharmaceutical, biotechnology, clinical research, and insurance industries - may become members of the SCDC if they meet the following criteria:
  - a) Have a SCD-related program, therapy, or device currently on the market or in an active phase 1, 2, or 3 trial;
  - b) Demonstrate that it is properly incorporated and in good standing in its state of incorporation;
  - c) Pay the applicable membership fees (see MEMBERSHIP FEES).

Representatives from corporate may not serve in a SCDC leadership, nor vote on SCDC matters. Corporate members should also note that the SCDC is not a platform for promotion of commercial products and services.



- Public Health / Research Organizations – Organizations that are engaged in the science of protecting and improving the health of people living with SCD and their communities by promoting healthy lifestyles and informed decision making, researching symptom prevention and management, implementing quality improvement measures for care delivery, and/or detecting, preventing, and responding to social and environmental factors that worsen disease. When applying to join the SCDC, public health and research organizations must meet the general SCDC membership eligibility requirements and demonstrate the national or global reach of its efforts.
- Provider / Researcher Organizations – Organizations that represent a particular group of medical or research professionals or entities with an interest in improving outcomes for people living with SCD. When applying to join the SCDC, provider and researcher organizations must meet the general SCDC membership eligibility requirements and demonstrate the national or global reach of its efforts.
- Regulatory Agencies – National and international government agencies and departments may participate in the Coalition but may not participate in any discussions related to SCDC members’ advocacy efforts. If a regulatory agency is unable to officially join the Coalition because of restrictions at the agency, then it may be allowed to participate as an “ex-officio” member of the SCDC. When applying to join the SCDC, regulatory agencies must meet the general SCDC membership eligibility requirements and demonstrate the national or global reach of its efforts.
- Foundations -- Private foundation or grantmaking public charities with an interest in SCD, whose principal purpose is to provide grants to unrelated organizations, institutions, or individuals for scientific, educational, cultural, religious, or other charitable purposes. If a foundation is unable to officially join the Coalition because of internal rules, then it may be allowed to participate as an “ex-officio” member. When applying to join the SCDC, foundations must meet the general SCDC membership eligibility requirements.
- Faith Based Organizations – Organization whose values are based on faith and/or beliefs, which has a mission based on social values of the particular faith, and which most often draws its activists from a particular faith group to support the sickle cell community. Faith-based organizations seeking to participate in the SCDC should provide information on activities they are leading related to health education, promotion and interventions for individuals and families concerned with sickle cell. When applying to join the SCDC, faith-based organizations must meet the general SCDC membership eligibility requirements.
- Other Groups or Organizations Focused on SCD – Other groups and organizations working on sickle cell advocacy, research, clinical care, or education and training may seek participation in the Coalition by submitting an application outlining how they meet the general SCDC membership eligibility requirements and demonstrating in writing how their participation will further the mission of the SCDC; such groups’ participation shall be at the sole discretion of the Steering Committee.

The SCDC encourages organizations operating at the national and/or international level to serve as the representative for their respective constituencies, as to streamline and harmonize efforts; however, the Steering Committee may accept organizations represented under an existing SCDC member on a case-by-case basis.

Each SCDC member organization must identify at least one representative to participate in the coalition on behalf of the organization. SCDC member organizations may identify up to five representatives to serve on the SCDC at a single time.

Relatedly, the Coalition is currently not offering membership to individuals or individual institutions (i.e., individual universities, hospitals, health care systems, etc.). Individuals and organizations ineligible for membership on this basis are encouraged to stay abreast of Coalition news and activities by signing up for the monthly [SCDC Update e-newsletter](#) and following the SCDC on [Twitter \(@ConquerSCD\)](#).

#### APPLICATION PROCESS:

All organizations interested in joining the SCDC must complete and submit a written, online application located on the SCDC's website. SCDC membership applications will be reviewed by the Steering Committee on a semi-annual basis. This review aims to ensure that the organization meets the eligibility criteria defined for its member category in the above section and assess how the organization can advance the SCDC's mission. All membership decisions will ultimately be made by the Steering Committee, and thereafter communicated to the applying organization.

#### CORPORATE MEMBERSHIP FEES:

Beginning in 2023, all corporate organizations accepted as new members of the SCDC must pay an annual membership fee. The baseline membership fee for corporate organizations to participate in the SCDC is \$4000 each year. This membership fee grants a corporate organization two (2) representatives' access to, and participation in, SCDC meetings, activities, communications, networking opportunities, coordination efforts, and more. If a corporate organization would like more representatives to serve on the SCDC, the organization may pay an additional \$2,000 per one (1) additional representative up to \$10,000 annually for a total of five (5) organizational representatives to participate in the SCDC.

In conclusion, the tiered fee structure for corporate organizations to participate in the SCDC is as follows:

- \$4,000 annually = 2 participants
- \$6,000 annually = 3 participants
- \$8,000 annually = 4 participants
- \$10,000 annually = 5 participants

Corporate organizations that joined the SCDC prior to 2023 will have the \$4000 baseline membership fee waived for the first 12 months. However, if these returning corporate members would like to have more than two (2) participants in the SCDC within this 12-month period, they must begin paying the applicable tiered fee immediately (e.g., \$6,000 for 3 participants, \$8,000 for 4 participants, and \$10,000 for 5 participants). By July 1, 2024, all corporate organizations participating in the SCDC must pay an annual membership fee.

Though at times fitting a corporate organization's "for-profit" definition, blood collectors will not owe a corporate membership fee to participate in the SCDC. Blood collectors are not subject to a SCDC corporate membership fee because of the donation-based nature of blood collection and urgent need to strengthen the blood supply for people living with sickle cell.

#### CONDUCT:

##### INTERNAL CONDUCT BY SCDC MEMBERS:

All SCDC members are expected to conduct themselves in a manner that fosters equitable inclusion and respect for all colleagues, races, cultures, disabilities, ages, and genders. Any disagreements and discussions should focus on positions and not individuals or specific organizations. Furthermore, all SCDC members must comply at all times with any and all applicable laws and regulations governing their conduct in their respective jurisdictions, as well as these Guiding Principles. Particular considerations relevant to each of the SCDC member categories are set forth under the “MEMBERSHIP” section.

SCDC members should conduct themselves in a manner consistent with the primary focus of the Coalition, which is the identification, coordination, and communication of innovative and ongoing efforts to conquer sickle cell. As such, all SCDC members are expected to support evidence-based initiatives and share evidence-based information when engaging with the Coalition. Relatedly, SCDC members are encouraged to use the Coalition as a platform to inform other participating groups and organizations about their ongoing sickle cell-related work and invite other participating groups to help develop, implement and fund those and other SCD-related projects. To this end, SCDC members are expected to notify the Coalition of any relevant initiatives, resources, requests for partnership, or other information they are leading and/or aware of by sending a written email to [coordinator@sdccoalition.org](mailto:coordinator@sdccoalition.org) and sharing verbal updates at the end of the SCDC meetings.

All SCDC members are expected to be active and engaged participants in the Coalition and its activities. As such, SCDC members are expected to attend at least three (3) SCDC-Wide meetings each year. Additionally, SCDC members are expected to assign at least one (1) organizational representative to serve in at least one (1) SCDC subcommittee (see “OPERATIONS” section for more information on the SCDC subcommittees). SCDC member representatives participating in an SCDC subcommittee are expected to attend at least three (3) of these SCDC subcommittee meetings. SCDC members are also encouraged to propose presentation or discussion topics for future SCDC meetings, volunteer to help with SCDC projects outside of meetings, and review and provide written feedback on drafted materials circulated for SCDC review.

However, members may *not* use the Coalition, its facilities, or their Coalition membership to (a) sell, market, promote, or solicit investment in their commercial products or services or to discuss any aspect of such sale, marketing or promotion of their commercial products or services, or (b) recruit research participants, without explicit approval from the Steering Committee. An organization that attempts to use the SCDC for commercial sales, corporate promotion, or product marketing purposes without prior approval from the Steering Committee will have their SCDC membership terminated.

#### EXTERNAL CONDUCT BY SCDC MEMBERS:

The Coalition has a number of external communication vehicles - including the SCDC website ([www.sdccoalition.org](http://www.sdccoalition.org)), SCDC Update (e-newsletter), and SCDC Twitter handle (@ConquerSCD) - to raise awareness about SCD, as well as provide updates about the Coalition and members’ activities.

When providing information for dissemination via the Coalition, SCDC members are expected to be honest, accurate, objective and complete. All content will be reviewed by ASH administrators and there is not a guarantee that all of the members' content will be published on the SCDC communication channels. As noted above, commercial marketing and research recruitment information will not be shared through the SCDC's communication outlets.

Any content provided via the Coalition's communications channels is purely for informational purposes and is not intended to provide medical advice or to substitute for consultation with a medical professional. The views, opinions, and other statements presented by an SCDC member via the Coalition's communication resources are solely those of the particular SCDC member, have not been reviewed, approved or endorsed by the Coalition [or by ASH], and do not necessarily represent the views, opinions or statements of the Coalition as a whole or any other Coalition member (unless otherwise specifically noted).

No SCDC member or group of members may: (a) distribute nonpublic information about another Coalition member relating to that member's SCDC-related activities without the permission of the other member; (b) use the Coalition name, logo, materials, and activities without the prior express written permission of the SCDC Steering Committee; (c) use its participation in the SCDC for grant, fundraising or other revenue-generating purposes without the prior express written permission of the SCDC Steering Committee; or (d) lobby Congress, state legislatures or other government officials, or engage in public advocacy in the Coalition's name.

The Coalition will publicly identify the names and logos of SCDC members on the SCDC website and in SCDC media materials, as appropriate, unless the member requests that its name and/or logo not be used.

#### REPORTING CONDUCT ISSUES:

The SCDC is committed to creating a safe, inclusive, and professional atmosphere. All SCDC members will conduct themselves in a collegial and respectful manner, free from any form of discrimination, harassment, or retaliation. Inappropriate conduct, including but not limited to harassment; threatening physical or verbal actions; or disorderly or disruptive conduct, will not be tolerated. If you or anyone you know is being treated inappropriately, feels unsafe, and/or witnesses any unacceptable behavior, please contact [coordinator@sdccoalition.org](mailto:coordinator@sdccoalition.org) as soon as possible. SCDC leadership will do its best to respond in a timely manner and determine the appropriate next steps.

#### ADVOCACY:

Recognizing that the SCDC is an international alliance, and each member may have its own policies and priorities with respect to governmental advocacy: (a) no Coalition member may undertake or engage in advocacy before any federal, state or local government or government agency in the name of the Coalition; and (b) the Coalition shall not undertake or engage in such advocacy before any such government or government agency.

Although the Coalition will not directly advance legislative or regulatory recommendations, it may serve as a forum for discussion of issues related to such purposes. However, each SCDC member organization has the discretion to opt out of any such discussion. In addition, members of the Coalition, individually or

collectively, may engage in such advocacy before federal, state or local governments or government agencies, provided that they do not do so in the name of the Coalition.

No Federal agency representatives will participate in Coalition discussions related to advocacy.

## RESEARCH:

The SCDC engages with many stakeholders and entities interested in conducting, supporting, or otherwise advancing research related to sickle cell. The SCDC primarily supports sickle cell research by disseminating research publications and evidence-based results from studies conducted by SCDC member organizations and other vetted entities. This research is disseminated through the Coalition's communications channels (see OPERATIONS).

In compliance with the SCDC's policy around internal conduct (see CONDUCT), the Coalition shall not directly support recruitment for research studies. If the SCDC is approached for research recruitment assistance, the SCDC may inform individual SCDC members of the request and direct researchers to these applicable SCDC member organizations for further assistance.

## FUNDING:

Membership in the SCDC is free, except for for-profit corporations (see MEMBERSHIP). Administrative and programmatic costs for the SCDC are supported by the SCDC's secretariat (ASH), as well as revenue generated from corporate membership fees. New SCDC initiatives may also be introduced to further fundraise for special SCDC activities.

The Coalition expects to provide a platform for SCDC members to inform other organizations of their SCD-related projects and to partner with other members on projects of shared interest. Despite participation by multiple SCDC members, these projects will not be considered SCDC-led initiatives unless otherwise stated.

If an SCDC member would like to formally develop, fund, or collaborate on a project with the SCDC, a project proposal must be presented to the Steering Committee for approval as Coalition projects. Relatedly, the Steering Committee may recommend such projects for funding by other Coalition members.

## VIOLATIONS OF GUIDING PRINCIPLES:

A SCDC member will be notified of the violation and asked to cease the violating conduct and/or to remedy it. Failure to cease the violating conduct or engaging in other conduct violating the Guiding Principles of the SCDC may subject the violating member to sanctions, up to and including revocation of its right to participate in the SCDC. Sanctions for violating members will ultimately be determined by the Steering Committee.