



# The *Ambassador Program* Information Packet

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## Sick Cells Ambassador Program Snapshot

*Sick Cells Ambassadors Program* is a volunteer network of individuals dedicated to changing the landscape of sickle cell disease and empowered to spread awareness through policy change. Sick Cells is shifting the social conversation around sickle cell disease and activating sickle cell advocates to engage in priorities for sickle cell disease. Our Ambassadors advocate for programs and policies that help advance research and drug development, improve access to care, and raise awareness about sickle cell disease (SCD).

## Getting Involved

Sick Cells invites you to volunteer to be a Sick Cells Ambassador!

To be an Ambassador, all you need is a passion for helping people with sickle cell disease and the willingness to make your voice heard. Ambassadors represent a variety of stakeholders, including patients, caregivers, who have experience in all different areas of advocacy. There are no educational or training requirements required to join. We encourage individuals of all professional and educational backgrounds to become an Ambassador.

The program provides Ambassadors with the following opportunities:

- Formal trainings on sickle cell disease priorities and advocacy efforts
- Networking within the SCD community
- Access to educational resources and materials related to advocacy
- Public policy updates to share with your networks

Ambassadors determine how much time they can commit to the program. If you cannot devote much time, Sick Cells still encourages you to join to learn about ongoing advocacy efforts across the SCD community. Ambassador membership does not depend on level of involvement with the program since your time commitment may change over time.

**If you are interested in joining the program, first complete the [Ambassador Program Interest Form](#).**

After you have submitted the form we will contact you with the next steps for becoming a Sick Cells Ambassador. During an introductory call, you will discuss your background and interests with a Sick Cells staff member. After, you will be invited to join an upcoming meeting (refer to the “Activities of Ambassador Program” section to learn more about these events).

## Ambassadors Program Framework

The Sick Cells *Ambassador Program* mission, vision, and strategic objectives are our guiding forces for the Ambassador Program.

### Mission

The mission of the *Ambassador Program* is to:

- **Activate members of the communities** to be advocates for partnerships, programs, and policies that help advance research and improve access to care;

- **Educate policy makers and other stakeholders** about the challenges and needs of the SCD community; and
- **Connect the sickle cell community** to coalitions and other organizations that impacts their health.

## Vision

Our vision is through the *Ambassador Program*, we can bridge information and best practices between sickle cell advocates and elevate their work. We envision that our Ambassadors will bring their unique perspective and ideas to activate other communities and build connections. These partnerships will help shape public policy and enable communities to be more engaged on current priorities for sickle cell disease. Through this work, we will spread awareness and encourage action in policy, advocacy, and healthcare.

## Strategic Objectives

These are the critical objectives of the *Ambassador Program*:

1. Build and Promote Advocacy within the Sickle Cell Community
2. Share and Translate Public Policy
3. Engage with Community Leaders and Other Stakeholders

## Activities of the Ambassador Program

There are a variety of activities Ambassadors can be involved with. While the community primarily functions virtually, Ambassadors are encouraged to connect and collaborate outside of Sick Cells-hosted platforms or events. Sick Cells-hosted activities are further described below.

### Ambassador Priority Topic Meetings (PTM)

The Ambassador Priority Topic Meeting (PTM) is a virtual call to discuss current priorities and advocacy initiatives. The Ambassador PTM will be hosted on the 3rd Thursday of every month (noon). While there may be numerous advocacy issues at any given time, each PTM will focus on only one issue at a time. In the chart below, we have identified several priority topics for the *Ambassador Program* in 2020. The monthly PTMs will help Ambassadors develop advocacy activities and plan concrete strategies for achieving goals.

### Upcoming 2020 Priority Topics

Time Periods	Priority Topic	Advocacy Activities
February and March	Value Assessments and ICER Evidence Report	“My Life with SCD” Survey, Share Your Story Campaign
April and May	COVID-19	Weekly bulletins, Patient Support
June and July	Ensuring Access and Coverage	DURB Board Meeting and State Map Resource

August and September	Policy and Legislation	Guide for Writing Letters to Elected Leaders and Social Media for Advocates
October and November	Cost and Economic Burden	Champion advocacy research initiatives, identify funding opportunities
December	Recap and 2021 Planning	Achievements and Future Outlook

During the monthly PTM, the Ambassadors will work through the following essential steps for each priority topic:

1. Develop advocacy initiatives
2. Assess the needs and identify barriers for advocacy
3. Map advocacy strategies and activities

After completion, Ambassadors will be ready to launch their advocacy initiatives within their local community. Each priority topic will be discussed over a two-month period.

Monthly PTM calls will include:

- An Expert Presenter. An expert will be invited to speak about the priority topic. Presenters will provide an overview of the priority topic and discuss the importance for patient advocacy.
- Brainstorming Session. After the expert presentation, Ambassadors will participate in a brainstorming session. During this discussion, advocates will identify barriers and map out strategies to achieve advocacy. Through this discussion they will determine what materials or resources are needed in order to support the work of future advocates. After the initial topic call, Ambassadors will use the next four weeks to develop these materials and resources.
- Report Back and Discussion: The second PTM of each priority topic will be used to report back to the group on their developments and advocacy resources.

### Ambassador Tea Chats

Ambassadors will have the opportunity to join informal monthly chats with other Ambassadors. During these Tea Chats, Ambassadors should grab a warm beverage and tune in to the virtual meeting platform. Each month Sick Cells Ambassadors or Sick Cells Staff will give updates about sickle cell advocacy activities in their communities. This is an opportunity to discuss local advocacy issues that may be impacting your community and convene to discuss solutions. The Tea Chat will keep Ambassadors informed and up-to-date on current events, in both federal and local communities, as well as identify priority topics that the program is interested in addressing in future PTMs.

### Ambassador Mentor Program

The Ambassador Mentor Program is part of the Ambassador Program’s onboarding process to promote partnership, networking, and co-learning within the Ambassador community. The Mentor Program will help new Ambassadors feel better prepared to engage with the community.

Upon joining the program, new Ambassadors are offered the option to have a peer mentor, who is a longstanding and involved Ambassador. The Mentor Program presents an opportunity for new Ambassadors to gain a peer mentor who will help to enhance involvement and knowledge of advocacy efforts. We hope that both mentors and mentees will share their professional and advocacy interests and connections with each other.

The mentor and mentee relationship should be reciprocal and bidirectional as both individuals can be helpful with networking, partnership development, and peer learning. Sick Cells staff will pair mentors and mentees based on stakeholder type and advocacy interests. Mentors and mentees work together to set a schedule and create mutual goals. The program is designed with limited staff involvement to allow each mentor/mentee pair to tailor the relationship to their own unique goals and schedules.

### **Ambassador Hub**

The Ambassador Hub is an internal location where toolkits, information, and resources are stored. This hub allows Ambassadors to stay informed of current events and access resources in their local communities and advocacy work. The Hub is also where Ambassadors can locate sign-on letters, Call to Actions, and ways to stay engaged. The Hub will launch in June 2020.

### **Ambassador Summit**

The annual Ambassador Summit brings together active Ambassadors to collaborate and build a stronger community. We hope to align this in-person meeting with the BIO Patient & Health Advocacy Summit in Washington, DC in October. More information about the summit will be provided in summer 2020.

### **Ambassador Code of Conduct**

The Ambassador Code of Conduct is a written collection of the rules, principles, values, and expectations that Sick Cells considers significant and believes are fundamental to the success of the Ambassador Program.