



# SICK CELLS

ANNUAL REPORT | 2021

[www.sickcells.org](http://www.sickcells.org)

# Table of Contents



ABOUT US	01
PROGRAMS	02
COVERAGE FOR SCD SUMMIT	10
COVID-19 COMMUNITY OUTREACH	12
COMMITTEES AND MEMBERSHIPS	15
REACH AND ENGAGEMENT	16
FINANCIAL RECAP	18
A LOOK AHEAD	21

## **Sick Cell**

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# About Us

## Mission

Sick Cells is a sickle cell disease (SCD) advocacy nonprofit founded on February 28, 2017. **Sick Cells' mission is to elevate the voices of the SCD community and their stories of resilience.** In highlighting the grave disparities this community faces, we hope to influence decision makers and propel change.

## Personnel

### 2021 Staff



Ashley Valentine  
President, Co-Founder



Abby Tainter  
Operations Manager



Maggie Jalowsky  
Director of Advocacy



Emma Andelson  
Program Manager

### Board Members



Ashley Valentine  
President, Co-Founder



Terri Booker, Esq.  
Vice-Chair



Max Matite  
Board Member



Adrienne Shapiro  
Board Member



Dorinda Lawrence-Sims  
Board Member



Dan Jabs  
Board Member

### Contractors



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Government Affairs  
Consultant



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Content Developer



Karla Sintigo  
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Michelle Wesley, JD  
Legal Consultant



Covington & Burling LLP  
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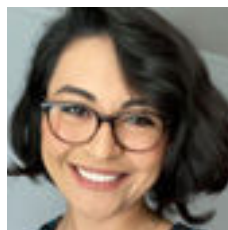


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Advisor

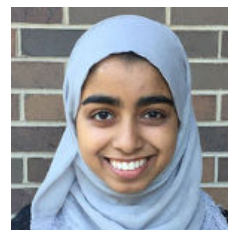
### Interns



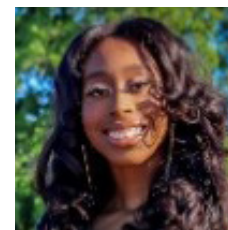
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Karla Sintigo  
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SCoViD, Medical Student at UIC



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Masters student at Emory  
University



Arielle Krahenbuhl  
Business Development Intern,  
Masters student at John Hopkins  
University

# Programs

## Faces of SCD Storytelling Program

### Introduction

**Sick Cells' Faces of SCD initiative** was the initial keystone program that inspired the formation of Sick Cells. This program captures the stories of patients and caregivers and serves as an educational resource for the SCD community and beyond. Sick Cells seeks to tell the untold stories within the community as well as expand awareness of the diversity of the SCD patient population to better represent the community as a whole.

### Program Successes









#### Social Media Metrics

Sick Cells engages our network through social media. We produced in-depth stories in audio format to engage more advocates and enable their stories to reach more people. Sick Cells has over 14,000 followers on social media with 5.5 million impressions engaging with the stories. Sick Cells introduced 20 new Faces last year. The new stories received over 150,000 website views.

#### Sick Cells Blogs

Sick Cells stands out by leading educational blogs dedicated to SCD, offering a unique and standalone resource in the SCD community. Through an extensive environmental scan of the SCD landscape and valuable feedback from advocates, it has become evident that the SCD community, including patients, caregivers, healthcare providers, and allies, greatly benefit from centralized patient journeys, updated information on new treatments, and engaging discussions on topics extending beyond health. Sick Cells recognizes these needs and aims to fulfill them by providing comprehensive education, fostering dialogue, and addressing a wide range of relevant subjects for the SCD community. In 2021, we interviewed **12 advocates and published 14 blogs**. We translated two blogs into **Spanish**.

#### The blog topics included the following:

 New Treatments	 Patient Journeys
 Impacts of Racism in Healthcare	 Caregiver Perspectives on SCD
 Effects of COVID-19 Pandemic on SCD	 Music Therapy & Pain Management
 Why Advocacy Is Important	 Aging with Sickle Cell

**Storytelling Series**

SCD stories were shared by way of themed story series. Organizing sickle cell stories and collaborating with partners expanded our stories' reach and educational impact. By organizing these stories and collaborating with partners, the reach and educational impact of these narratives were significantly expanded. The initiative to collect and share SCD stories not only amplified their visibility but also fostered a broader understanding of the disease, its challenges, and the experiences of those living with it.

**In 2021, we ran five campaigns including:**

- BraveHearts Therapeutic Horseback Riding
- My Black History Month
- Blood Donation Saves Lives
- Stories from the Hispanic Community (HOPE PROJECT)
- Sickle Cell Community Win



Terrance (Left) and Marqus (right)

## Mapillar with daughters Tully, Deej, and Hajar

WELTH THE FACES



It's important to have a lot of options because everyone is impacted differently. My middle child has never had a pain crisis, but she was seven when she had a stroke. Now, she's [had] about 10 surgeries and receives monthly blood transfusions. My youngest is asymptomatic and only takes Hydroxyurea. My oldest is the only one of the three who has pain crises.

- Mapillar, Virtual Interview



Shawn (left) and Dan (right)

## Ambassador Program

### Introduction

Sick Cells’ Ambassador Program is the foundation of high-performing advocacy and will collectively help drive our community’s advocacy missions forward. We help Ambassadors direct their skills to advance the interests of the wider SCD community. Likewise, the Ambassadors receive training and education to facilitate ongoing advocacy in their local communities.

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### The program’s success is due to several qualities that the group possesses:

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**Diversity.** Our Ambassadors represent 25 different states across the U.S and bring creativity and a broad range of ideas to the table from their local communities. Ambassadors also come from diverse stakeholder groups including people with sickle cell, people post-transplant, caregivers, family members, friends, medical providers, and people with sickle cell trait.



**Fresh Talent.** 50% of Ambassadors indicate advocacy experience of 5 years or less, which brings fresh perspectives and enthusiasm to the team.



**Motivation.** 80% of Ambassadors expressed interest in a mentorship opportunity, demonstrating their motivation to develop knowledge, skills, and abilities.

### Purpose of the Program

Sick Cells’ Ambassador Program is unique in educating and leveraging the skills of diverse advocates to advance the interests of the SCD community. The Ambassador Program also serves as a policy hub for the larger sickle cell community, including other SCD organizations. Sick Cells has a diverse network of patient advocates that we connect to current events and policy initiatives. This is achieved through monthly meetings called Priority Topic Meetings (PTMs), where we take a deep dive into identified topics, quick 30-minute Tea Chats that informally address current events, and our growing pool of toolkits and resources.

## Recruitment

Sick Cells' Ambassador Program gained 53 new Ambassadors in 2021, bringing the total enrollment to 104 Ambassadors. Our Ambassadors include representatives from 25 states and DC.

## Engagement

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### Priority Topic Meetings (PTMs)

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Sick Cells convenes Ambassadors monthly to brief them about a priority topic. Each topic is the focus of two monthly meetings; in the first month, Ambassadors hear from an expert in the field, and in the second month they practice using the advocacy tools developed.

#### In 2021, Sick Cells covered the following topics:

- Social Media & Marketing for Advocacy with guest speaker Patrick Baskin, Brand Director at Liweli.
- Leveraging Your SCD Story into Data: Part 1 & 2 with guest speaker CAPT David Wong, Office of Minority Health, HHS.
- Self-Care and Advocacy: Wellness Fundamentals with guest speaker Dr. Marjorie Dejoie-Brewer.
- SCD Caregiver Help Desk Launch with guest speaker Nichole Goble, Caregiver Action Network.
- Insurance Coverage: How to be a Patient Advocate with guest speaker Elizabeth Johnson, NAMAPA.
- Driving Sickle Cell Legislation in Your State: Part 1 & 2 with guest speakers Mary Brown, Sickle Cell Disease Foundation; Gina Glass, Dreamsickle Kids Foundation; and Tonya Prince, bluebird bio and Sickle Cell Association of Houston.
- How to Pitch to the Media with guest speaker Holli Holson, Lippe Taylor.

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### Tea Chats

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Virtual Tea Chats are hosted monthly to provide updates on current events and opportunities in the realm of policy and education for the SCD community. All Ambassadors can submit their updates prior to the call or jump in to share during the calls. The purpose of the call is to keep the Ambassadors informed and up-to-date on current events and accomplishments.

## Toolkits

Information from the PTMs and discussions at Tea Chats are used to develop informational one-pagers and toolkits to further assist the Ambassadors in their advocacy efforts. In 2021, the Ambassador Program output the following toolkits:

- **Wellness Fundamentals**
- **Nutrition Fundamentals**
- **Local Advocacy: Individual Advocacy**
- **Local Advocacy: Systemic Advocacy**
- **How to Do "Data-Driven" Advocacy**
- **Journey Map of a SCD Caregiver**



## Ambassador Policy Forum & Virtual Hill Day

On March 23, 2021, Sick Cells hosted its second annual Policy Forum virtually. The workshop featured educational presentations, special guests, and dedicated work time to produce a toolkit of resources for Ambassadors and other sickle cell advocates to use in 2021 and beyond. The event had 68 unique attendees, including Ambassadors, Board Members, speakers, and sponsors. The next day, Ambassadors virtually attended a Hill Day, which resulted in 49 meetings with House Representatives and Senators.

The agenda for the Policy Forum was separated into two themes and included a ten-minute break for yoga, led by a Sick Cells' Ambassador, Dr. Marjoie Brewer-Dejoie.

### The workshop featured the following panelists:

#### Working with Your Home Clinic for Policy Change

- Yvonne Carroll, RN, JD Director, Patient Services - Hematology, St. Jude's Children's Research Hospital, St. Jude
- Elodie Ontala, Sick Cells Ambassador
- Regina Dorsey, Sick Cells Ambassador

#### Working with Your Legislator for Policy Change

- Dr. Mary Hulihan, Centers for Disease Control and Prevention (CDC) - SCDC Data Collection Program
- Kimberley Miller-Tolbert and Gloria Nunez, Senator Cory Booker's Office - Meeting with your Legislator

## Training

A function of the Ambassador Program is to offer personalized advocacy training for Ambassadors. In addition to the annual Policy Forum, two monthly meetings, and innovative educational toolkits, Sick Cells connects Ambassadors to multiple advocacy opportunities and provides training to prepare the Ambassadors to advocate effectively.

### In 2021, the Sick Cells team:

- Prepared both Ambassadors and non-Ambassadors to attend **state Medicaid Drug Utilization Review Board (DURB) meetings** and share testimonies about the need for treatment options, including 22 advocates who attended DURB and P & T committee meetings in Washington, D.C., Illinois, Texas, Washington, Minnesota, Pennsylvania, Nebraska, Wisconsin, and Maryland.
- Offered a **one-on-one skill-building workshop** focusing on clear communication and

storytelling in order to call attention to SCD and move legislators to action.

- Hosted a two-part training on **business development and fundraising** for nonprofit leaders.
- Advised a small group of Ambassadors on submitting a response to a **federal request for information**.
- Worked with Ambassadors to develop a plan for their **local advocacy activities**.
- Collaborated with Ambassadors to produce **educational toolkits** for their own programs

## Successes

- 95% of Ambassador Responses said Tea Chats and PTMs were well organized and had interesting topics, events, and opportunities.
- 90% of Ambassador responses said advocacy toolkits were helpful for their advocacy work.
- 80% of Ambassador responses said guest speakers were engaging and informative.
- 75% of Ambassador responses said they were likely to share toolkits with other advocates in their community.
- 70% of Ambassadors said toolkits were easy and convenient for them to access and utilize.



## Policy & Government Affairs

Sick Cells is committed to educating the SCD community on policy advocacy and incorporating the SCD voice into legislation. We partner with other sickle cell organizations and patient advocacy groups to advocate for policies that allow people with SCD to access the high-quality, specialized care we need.

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### 2021 Policy Priorities and Successes

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- Draft and Submit a letter to the Biden Administration
  - The **Letter to the Biden Administration** represented the community's unified requests for 2021 and 2022
  - There were 47 sign-ons from other Community Based Organizations (CBO)s and SCD nonprofits
- Request Appropriations for SCD Programs
  - This year's **appropriation requests** were \$25M for the CDC SCD Data Collection Program and \$15M for the **HRSA SCD Treatment Demonstration Program**
- Draft and Submit a letter to Congress for the 2020 NASEM Report
  - The **Congressional Hearing Request letter** outlines Sick Cells' request to Congress for annual hearings on the 2020 NASEM report, including its hosting committee and assigned witnesses
- SCD Caucus Formation
- Host a Policy Forum for Sick Cells Ambassadors
- Train and support advocates for Drug Utilization Review Board (DURB) Meetings
  - Trained and supported advocates for 8 Medicaid Meetings: IL, DC, FL, MN, WI and PA P&T/D&T Meetings; and TX and WA DURB Meetings
- Support community Sign-on letters for a unified front
  - NORD Project RDAC
  - SCTPN Support for SCD in NY State
  - EveryLife's Letter in support of the Speeding Therapy Access Today Act of 2021
  - Alliance for Aging Research
  - CMMI Letter of Support for CMMI
  - ASH Medicaid Demo Letter
  - ODTIC letter to Speaker Pelosi & Chairman Neal (W&M Committee)

# Dwayne

# MEET THE FACES



”

I had a sister with sickle cell. I had lost another sister with sickle cell. I didn't find out that I had the trait until I was a junior in high school. I did a report for this health class on sickle cell. And when I did the report, when it was over, the teacher looked at me and she said, 'Do you have the trait?' My entire life I never even thought to even wonder this! I had no idea!

- Dwayne, Illinois

# Coverage for SCD Summit



## Introduction

Sick Cells convenes sickle cell advocates for a Coverage for SCD Summit, which will be referred to as “the Summit” in this document. Payers and Providers are being greatly challenged to create effective programs and methods to deliver high-quality, patient-centric healthcare that improves outcomes while reducing healthcare spending. Manufacturers and researchers are working to generate valuable data and measure the value of new and emerging treatments.

The goal of the Summit is to improve the ability of patients to navigate treatment coverage by initiating patient-centered communication with key stakeholders. Attendees engage in a day of networking and dynamic panel presentations featuring knowledgeable leaders and executives who share their perspectives, valuable insights, and expertise on how to be best equipped for the rapidly evolving landscape of healthcare coverage for SCD care and treatment.

Attendees benefit from learning about best practices and strategies that have been deployed to address these challenges. Given the broad attendance from diverse stakeholder groups and other representatives, this event maximizes educational and networking opportunities and allows for future collaboration across the community.

The Summit underscores the importance of focusing on what matters most to the SCD community and identifies innovative ways to remove barriers to care and promote transparency to manage healthcare spending.

## Summit Success

The Coverage for SCD Summit provided a collaborative forum to discuss the changing landscape of healthcare coverage for SCD. This meeting brought together payers, providers, pharmaceutical manufacturers, patient groups, researchers, care teams, and policymakers to discuss ways to tackle the complexities of coverage and access to SCD treatments and care. We shared ideas on the latest strategies to measure value, improve patient outcomes, and better navigate healthcare costs. The Summit had 94 unique attendees, surpassing our goal of 50 participants. We publicized and promoted the event in various newsletters, on our social media accounts, through direct email marketing, and on our website. The following panels and panelists presented at the event.

### Welcoming and Opening Keynote

- Dr. Emily Riehm Meier - Co-Chair ASH, Keynote Speaker
- Terri Booker, Esq. - Sick Cells Board Member and Moderator

- Randall Curtis, PhD - Project Manager Hematology Utilization Group Study (HUGS)
- Maggie Jalowsky - Sick Cells, Moderator

### Panel 1: Emerging Approaches to Reduce Care Gaps

- Terri Newman, PharmD - Assistant Professor, University of Pittsburgh School of Pharmacy
- Maia Z. Laing, MBA - Vice President of Product, Optum
- Matt Powers - Managing Director HMA
- Ashley Valentine, MRes - Sick Cells, Moderator

### Panel 3: Determining the Value of Future Innovations for Sickle Cell Disease (Sponsored Session)

- Ravi Singh - bluebird bio
- Donna Christian-Christensen, MD; John Feore, and Samantha Holland - Institute for Gene Therapies/Vertex
- Nola Juste, MPH - Sick Cells Ambassador

### Panel 2: Generating Meaningful Data to Measure Value

- Kate Johnson, PhD - Postdoctoral Fellow, The Comparative Health Outcomes Policy, and Economics (CHOICE) Institute at University of Washington
- Morenike Ayo-Vaugh, MS - Former Senior Manager, Avalere Health



## Summit Outcomes

The learnings of the Summit shape the advocacy work of Sick Cells through the Ambassador Program. A **summary report** from the event highlighting learnings and panel discussions was published on our website. Best practices discussed at the Summit will be incorporated into our advocacy priorities for the upcoming year and will be shared with the Ambassador network through the Priority Topic Meetings (PTMs). Sick Cells works to improve the ability of SCD patients to navigate treatment coverage, and the Coverage for SCD Summit enhances our ability to continue this work.

# COVID-19 Community Outreach

## COVID-19 Community Hub

### Overview

In March 2021, Sick Cells launched the COVID-19 Community Hub. The goal of this collaboration was to reduce vaccine hesitancy in the SCD community, create resources for the CBOs and CHWs, and save lives. With funds from a GBT Accel Grant, we partnered with other SCD CBOs to collect data using an innovative solution by Dimagi, an “award-winning social enterprise supporting frontline health workers with innovative technology at scale.”

#### In order to do so, we:

- Disseminated trusted information to the SCD population and medical community about the impacts of COVID-19 on people with SCD and SCT.
- Built trust within the community about COVID-19 vaccines.
- Informed the SCD community about the

most-recent state health department vaccine guidelines.

- Understood barriers to accessing vaccines.

With funds from a GBT Accel Grant, we partnered with other SCD CBOs to collect data using an innovative solution by Dimagi, an “award-winning social enterprise supporting frontline health workers with innovative technology at scale.”



#### Made possible by:



### Results:

CHWs and volunteers made a total of 222 calls, engaging in conversations with 24 individuals, including 20 SCD warriors and 4 family members.

#### The data collected from these interactions revealed the following insights:

- Nine individuals were vaccinated, while 15 remained unvaccinated.
- Five respondents received either the Moderna or Pfizer/BioNTech vaccine, two received the

Johnson and Johnson vaccine, and two were uncertain about the specific vaccine they received.

- The primary reasons cited for not being vaccinated were concerns about side effects, concerns about misinformation, and concerns related to pre-existing conditions.

The main takeaway from the COVID-19 Community Hub is that there is a great need for more education to help the SCD community make informed decisions about the COVID-19 Vaccines. We found the most common causes of vaccine hesitancy in the SCD community were concerns about side effects and that more frequent and reliable information is required to address these concerns and reduce vaccine hesitancy.

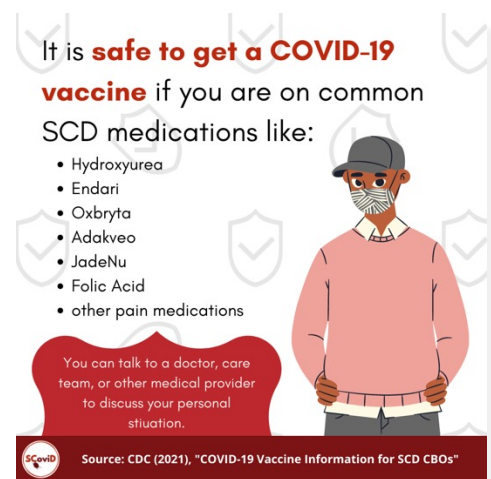
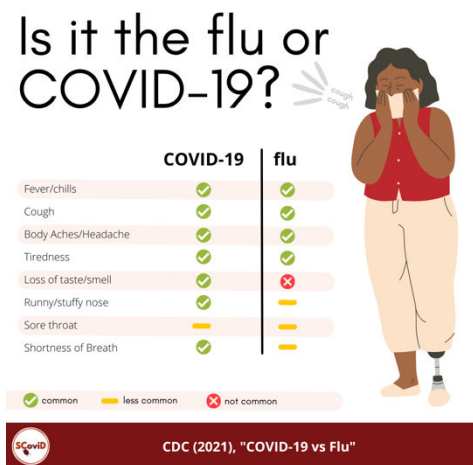
## Project SCoviD

### Overview

In addition to the initial Community Hub, Sick Cells continued our COVID-19 education through an innovative social media account Project SCoviD (@project\_scovid on Instagram and Sickle Cell Disease Community Education Project on Facebook). This portion of the project began on June 1, 2021.

#### Project activities included:

- Sick Cells-run **Instagram** and **Facebook** pages
- Educational Infographics to support learning about COVID-19 and SCD
- Spanish translations for select materials to communicate with wider audiences
- Bi-weekly Instagram Live conversations with community leaders and experts, SCD warriors and caregivers, and more
- Community story collection to record and share experiences getting COVID-19, getting vaccinated, and more
- Informational posts that underwent a medical review by a physician at the University of Illinois - Chicago.
- Community focus group with 5 individuals representing various types of social media users from the SCD community. Topics explored included:
  - Relevance of information shared on Project SCoviD
  - Users' reliance on Project SCoviD as a reference
  - Users' preference of content type: Informational, Story-telling, Live Conversations, etc.
  - Opportunities for improvements for Project SCoviD accounts



#### Results:

According to the feedback received, participants expressed a strong preference for audio stories, COVID convos, and interview quotes. They found these content formats to be effective in humanizing the clinical information about COVID-19 and making it more relatable. When it came to information about SCD, participants preferred hearing from the community. However, for information on COVID-19, they relied on medical providers or trusted community leaders.

## Barbara

# MEET THE FACES



”

Both of my daughters have sickle cell traits. One daughter is healthy as a horse, and my youngest daughter has a lot of complications with pain. We found out she has fibromyalgia, but it acts just like sickle cell. Her pain is constant every day, but she could stop her pain with Advil. Whereas my pain, I would have to use the hard stuff, the codeine and the opioids to stop my pain.

- Barbara, Indiana



# Committees and Memberships

Organization	Type of Membership	Roles
Innovation and Value Initiative (IVI)	Paid members, Advisors	Ashley Valentine, Board of Directors Maggie Jalowsky, Patient Advisory Council
Patient-Centered Outcomes Research Institute (PCORI)	Advisors	Ashley Valentine, Advisory Panel on Healthcare Delivery and Disparities Research
USC Hematology Utilization Group Study (HUGS)	Advisors	Maggie Jalowsky, SCD Steering Committee
Everylife Foundation	Advisors	Maggie Jalowsky, Advisory Cmte Assessing Economic Benefits of Early Diagnosis in Rare Disease
National Organization for Rare Disorders (NORD)	Paid Members	Paid Members
Leavitt Partners SCD Alliance	Advisors	Part of Coalition
Sickle Cell Disease Association of America (SCDAA)	Paid Members	MOU Partnership
Value in the States Coalition (Led by Arthritis Foundation)	Members	Part of Coalition







Arielle (left) \_\_\_\_\_(center) and Emma (right)

# Reach and Engagement

## Social Media

In 2021, we ran both the primary Sick Cells accounts and the Project SCoviD social media accounts. We focused our efforts on curating captivating content through a combination of compelling text and visually appealing design. As part of our content strategy, we introduced audio stories through Project SCoviD, adding an engaging element to our posts. To optimize our reach, we diversified and tailored the content to suit each specific platform. We made it a priority to actively engage with our followers and subscribers by responding to comments, direct messages, and showing support for their own content. Notably, we significantly increased our level of activity on Twitter and LinkedIn compared to previous years, resulting in substantial growth of our professional audience on LinkedIn. We are proud of the progress we made in 2021 and are excited to continue expanding our online presence in the future.

The table below outlines our activity for the 2021 calendar year as compared to the 2020 calendar year.

Profile	Audience	Net Audience Growth	Posts	Impressions	Engagements	Engagement Rate (Per Impression)	Video Views
<b>Reporting Period</b> Jan 1, 2021 - Dec 31, 2021	14,035	1,324	1,350	694,189	30,711	4.4%	10,852
	8,044	-10	189	237,953	12,462	5.2%	5,025
	3,660	691	479	260,233	12,685	4.9%	4,648
	1,927	310	582	177,069	4,333	2.4%	809
	404	333	101	18,934	1,231	6.5%	370

This table highlights changes in our audiences; 2021 was a year of change for social media use following the first year of the COVID-19 pandemic.

Audience Metrics	Totals
Total Audience	14,035
<b>Total Net Audience Growth</b>	<b>1,324</b>
Twitter Followers Gained	376
Facebook Pages Likes	270
Instagram Followers Gained	1,134
LinkedIn Followers Gained	335

## Newsletter

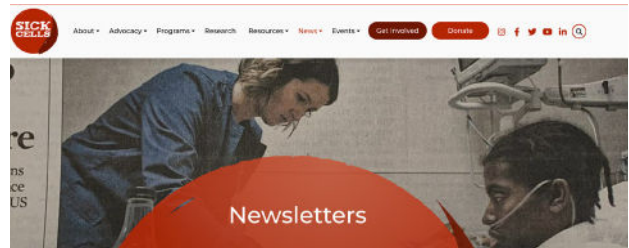
We are thrilled to share that we have reached a milestone of 1,614 subscribers for our monthly newsletters. It's an exciting achievement that reflects the growing interest and engagement from our audience.

In addition to our increasing subscriber base, we have introduced a brand new look for our newsletters starting this year. Our goal was to enhance the overall user experience and make the content more accessible and engaging.

### To achieve this, we have implemented the following changes:

- Simplified design: We have adopted a cleaner and more streamlined design for our newsletters. By simplifying the layout and visual elements, we aim to provide a seamless reading experience for our subscribers.
- Consolidated information: We understand the value of your time, so we have consolidated the information in our newsletters. This means that you can quickly find the content that matters most to you, without having to sift through excessive information.

- More visuals: To make our newsletters visually appealing and captivating, we have incorporated more visuals. These could include images, infographics, or other visual elements that enhance the overall presentation of our content.



## Website



Marqus (left) and Ashley (right)

# Financial Recap

## Revenue

Sponsorships	\$490,360.00
Grants	\$144,995.00
Donations	\$22,734.42
Other Income	\$144.67
<b>Total Revenue</b>	<b>\$658,234.09</b>

## Expenses

Program Expenses	\$319,383.73
Management and General	\$82,797.88
Fundraising	\$1,116.53
<b>Total Expenses</b>	<b>\$403,298.14</b>

## Sponsors



## Grants

### Rare Giving Event Sponsorship Grant - EveryLife Foundation

Everylife's Rare Giving Event Sponsorship Grant supports conferences and meetings that educate their audiences about the importance of public policy and advocacy to encourage the development of new therapies for rare disease patients. Sick Cells was awarded this grant in 2021 in support of our first ever Coverage for SCD Summit. This multi-stakeholder event brought together payers, providers, pharmaceutical manufacturers, patient advocacy groups, pharmacists, policymakers, and researchers to discuss ways to tackle the complexities of coverage and access to SCD treatments and care. Read more about this event in our final [report](#).

### STEP Program - Novartis

From this grant, Sick Cells partnered with the Caregiver Action Network (CAN) to strengthen their Caregiver Help Desk to serve the SCD community. Sick Cells and CAN worked with the SCD community, including caregivers, individuals with SCD, and medical professionals, to identify gaps in current resources available to caregivers, and provide training to the Help Desk staff so they can address the needs for the SCD community. The [Caregiver Help Desk](#) is a unique, free support center that provides support to caregivers via phone, email, or live chat. The output of this project serves as a roadmap of resources with educational tools and referrals to support SCD caregivers. This project was conducted through the support of Novartis' 2021 Solutions to Empower Patients (STEP) program. For more information, read more in our final [report](#).

### Rare Health Equity Grant - Global Genes

Sick Cells was awarded the Rare Health Equity Grant in support of our Hispanic Outreach to Promote Equity (HOPE) Project. Through this project, Sick Cells hosted a bi-lingual roundtable discussion with individuals from the Hispanic community who live with SCD or care for loved ones with SCD. The goal of the roundtable was to understand SCD within the Hispanic community, identify key educational gaps, and create targeted educational tools to fill those gaps. In addition to the roundtable, Sick Cells published a bi-lingual social media campaign for Hispanic Heritage Month. Our summary of findings from our project is available in either [English](#) or [Spanish](#).

### ACCEL Grant - Global Blood Therapeutics (GBT)

Global Blood Therapeutics (GBT) has awarded grants worth \$50,000 each to nine community-based, nonprofit groups and institutions across the U.S. to speed the development and use of sustainable, access-to-care programs. The Access to Excellent Care for Sickle Cell Patients Pilot Program (ACCEL) grant provides grant funding to support novel projects aimed at improving access to high-quality healthcare for sickle cell patients in the United States. Sick Cells was a recipient of this award to further efforts in heightening COVID-19 vaccine awareness among the SCD community nationally.

### Vaccine Community Mobilization Grant - Chicagoland Vaccine Partnership

The purpose of the Vaccine Community Mobilization Grant is to support ongoing community mobilization efforts around the COVID-19 vaccine. This coalition works to ensure equitable access to COVID-19 vaccines, educate about vaccine safety, and mobilize community members to lead public health efforts. This grant funded the COVID-19 Community Hub.

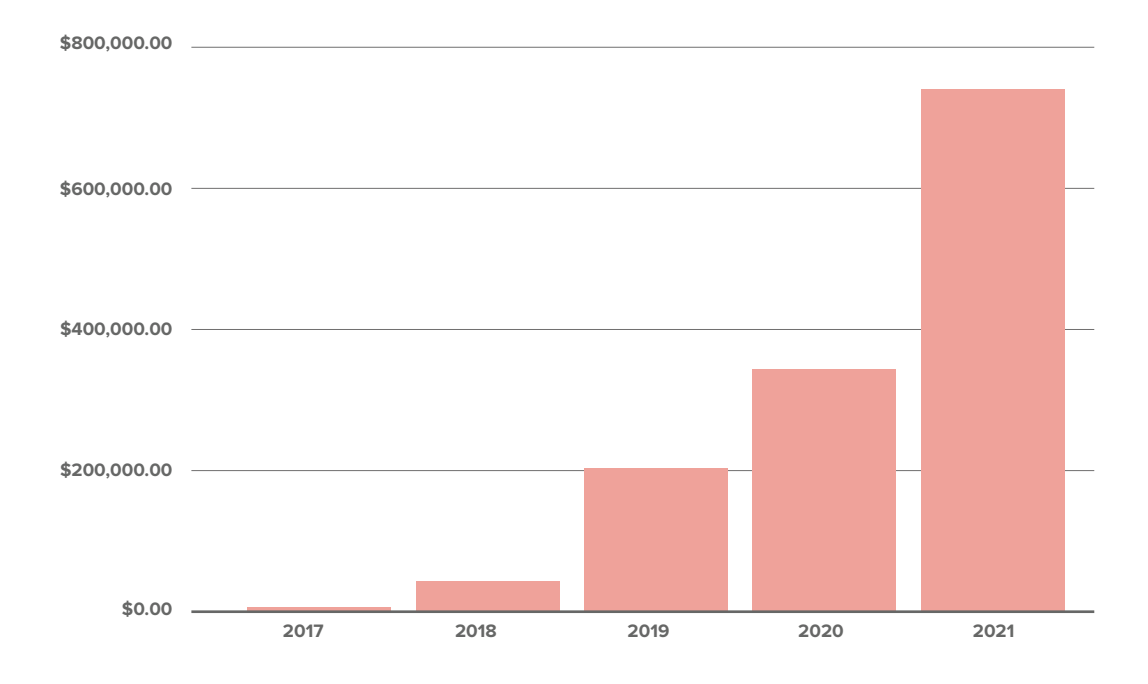
### BIOCares Grant - Biotechnology Innovation Organization (BIO)

The BIOCares grant assisted non-profit advocacy partners' efforts to rebuild, in light of the COVID-19 pandemic and economic fallout. This pooled grant program is funded by over a dozen BIO member companies, all of whom abide by BIO's Guiding Principles for Interaction with Patient Advocacy Organizations. Sick Cells was awarded the BIOCares Grant in support of our Faces of SCD Program and Ambassador Program.

### Biotechnology Innovation Organization (BIO) COVID-19 Communication Project Gift

The funds were allocated for the philanthropic purpose of enhancing public knowledge and understanding of COVID-19 and vaccines. The goal was to empower individuals to make informed decisions regarding vaccination. Sick Cells received support for the COVID-19 Community Hub, enabling us to contribute to this important mission.

### How We've Grown: 5-Year Graph



Cory



Crystal (right) and Family

## A Look Ahead

As we reflect on the achievements and milestones we've reached, we are filled with a sense of pride and excitement for what the future holds. We have accomplished great things this year, but we firmly believe that our best is yet to come. Looking ahead, we are eagerly anticipating the opportunities and challenges that await us in the coming year. With your continued support and enthusiasm, we are confident that we will reach new heights and make a significant impact in our field. Together, let's strive for greatness and continue to push the boundaries of what we can achieve.



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