



SICK CELLS

ANNUAL REPORT | 2022

www.sickcells.org

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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

2022 Staff



Ashley Valentine
President, Co-Founder



Abby Tainter
Operations Manager



Maggie Jalowsky
Director of Advocacy



Emma Andelson
Program Manager



Cory Lewis
Program Coordinator

Board Members



Ashley Valentine
President, Co-Founder



Terri Booker, Esq.
Vice-Chair



Max Matite
Board Member



Adrienne Shapiro
Board Member



Dorinda Lawrence-Sims
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Dan Jabs
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James Holloway, Esq.
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Karla Sintigo
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Edelman



Covington & Burling LLP



S-Square Statistical
Consulting Inc

Interns



Nichelle French
Policy & Research Intern,
Student at Coppin State
University

Programs

Faces of SCD Storytelling Program

Introduction

Our 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

Project Scovid

The goal of this storytelling was to reduce vaccine hesitancy and amplify trusted information for the SCD community. Through this storytelling effort, Sick Cells conducted **37 interviews** and published **15 audio and visual stories, five blogs with Spanish translations, and 101 educational graphics** on social media. Project SCoviD is an ongoing effort and will continue in 2023 in response to the pandemic through the stand-alone Project SCoviD effort.

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. The new stories received **over 150,000 website views**. Sick Cells has over 15,000 followers on social media, with 5.5 million impressions engaging with the stories.



Sick Cells Blogs

Sick Cells has one of the only stand-alone educational blogs about SCD. Based on an environmental scan of the SCD landscape and feedback from advocates, the SCD community - including patients, caregivers, health care providers, etc. - is in need of centralized patient journeys, education about new treatments, and discussion of topics beyond health. In 2022, we interviewed **22 advocates and published 11 blogs**. To date, we have published 31 blogs. We translated three blogs into **Spanish**.

The blog topics included the following:

	Centering the Patient Voice: A New Type of Advocacy for SCD		Aging with Sickle Cell
	Becoming a Hero: Diversifying Blood Donation		Chelation Stories (sponsored by Chiesi)
	It's Your Health Journey: Self-Advocating in the ER		Lessons from the Past: COVID-19 & the 1918 Flu
	Warriors with Pride: Voices of the LGBTQIA community		Una Luchadora de Principios: La Vida Durante Una Pandemia
	Access and Coverage		Vacunándose Para Proteger a Sus Seres Queridos
	Vivir mi Vida		

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.

- COVID-19 Vaccine Journeys** – Through Project SCoviD, we shared SCD warriors' testimonies about COVID-19 vaccination and how they navigate the pandemic. The goal of the stories was to reduce vaccine hesitancy and promote healthy living throughout the pandemic. Sick Cells conducted 37 interviews and published 15 audio and visual stories, five blogs with Spanish translations, and 101 educational graphics on social media.
- Warriors with Pride** – This Pride month, we looked to highlight the unique stories of LGBTQ+ members of the SCD community. A common theme identified from the series is that groups within the SCD community need to have their voices amplified. The campaign consisted of 16 published posts, 7,258 impressions, and 558 engagements. Sick Cells is the first SCD organization to publish dedicated stories about the LGBTQ+ warrior community and plan to continue to support this sub-population within the SCD population. To do so, we completed the following:
 - 5 Interviews
 - 18 Posts across Facebook, Twitter, Instagram, and LinkedIn
 - 1 blog

- **Remembrance Week** – Each week during the month of June, Sick Cells remembers SCD warriors that have passed away. Sick Cells Co-founder, Marqus Valentine, passed away June 22, 2020. This is a way to honor his legacy and continue to speak the names of other SCD warriors who impacted our lives and have now transitioned. This year we highlighted six winged warriors. The campaign consisted of 21 published posts and received 10,141 post impressions and 1,058 post engagements.
- **Feelin' the Love** – We celebrate the big and small ways we feel love across the sickle cell community. Powered by SCD warriors, we share stories touching on self-love, community love, and the power of love. The campaign included 36 published posts highlighting eight individuals and received 15,715 post impressions, 1,142 post engagements, and 121 web visits.
- **Hispanic Heritage Month** – Sickle cell disease occurs in about one out of every 16,300 Hispanic and Latino-American births. During this campaign from September 15 to October 15, we highlight stories from SCD Warriors who identify with the Hispanic/Latino community. There were 21 published posts, with six posts translated into Spanish, and received 6,996 post impressions and 605 total engagements.
- **Access & Coverage** – To contextualize our conversations related to the 2022 Coverage for SCD Summit, our Access & Coverage campaign highlighted stories from SCD Warriors, caregivers, and advocates about their experiences accessing quality care and needed therapies. There were a total of 28 published posts, 8,024 post impressions, and 474 total engagements.



Tabatha

MEET THE FACES



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It's so hard. I've always been working. In my mind, in my household, you don't work you don't eat. I've always found pride in being able to pay my bills on time. I've always found pride in being able to buy what I want because I've always had a job. Now that I get sicker as I get older the possibility that working may be out of my future is scary. It's something that I'm so used to doing, I'm independent, I do things for myself. When I have to rely on others or find a way to think outside the nine-to-five box it's a little scary.

- Tabatha, Tennessee

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. The programs' success is due to several qualities that the group possesses:

Program Successes

During 2022, the Sick Cells Ambassador Program **recruited 76 new Ambassadors across the Nation and engaged SCD advocates to advance the interests of the SCD community.** The program has grown to 180 ambassadors across 25 states. The majority of Ambassadors are sickle cell warriors, caregivers, and their family and friends. This year, we saw other stakeholders like providers, researchers, and payers join the program.

The Ambassadors participated in multiple events, activities, and projects, often being the first SCD advocates to do so. Over the course of the year, recruitment has grown 40%. Ambassadors have the chance to speak at outside opportunities through other organizations and partners.

Engagement

Priority Topic Meetings (PTMs)

Sick Cells virtually convenes Ambassadors monthly to brief them about a priority topic. PTM sessions are educational opportunities that cover topics such as ensuring access, coverage, policy, legislation and economic burden of SCD.

In 2022, Sick Cells covered the following topics:

- Priority Setting (Maggie Jalowsky, Sick Cells)
- Federal Legislation & Crafting Your Story (Leslie Brady, ASH)
- Part 1: A Historical Look (Emma Andelson, Sick Cells)
- Part 2: A Look at Federal Legislation on the Horizon: (ASH)
- Building a Community Health Worker Program (Jeanette Nu'Man, Karen Schaack, and Danina Battle, Sickle Cell Foundation of GA)
- Emergency Room Advocacy Part 1: Provider
- Insights and Resources (Dr. Jeffrey Glassberg, Mt. Sinai Hospital, NYC)
- Emergency Room Advocacy Part 2: Strategies for Patient Advocates (Dana Star Kiwacz, Sick Cells Ambassador and Founder of Inspired Life Design Studio)
- The Power of the Pen: Letter Writing Workshop (J Hoxi Jones)
- Measuring Value for Sickle Cell Disease (Maggie Jalowsky)
- Fundraising with Social Media (Emma Andelson)
- Year-End Review (Maggie Jalowsky, Sick Cells)

Tea Chats

Virtual Tea Chats were hosted monthly to provide updates on current events and opportunities in the realm of policy and education for the sickle cell disease 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 is used to develop informational one-pagers and toolkits to further assist the Ambassadors in their advocacy efforts. In 2022, the Ambassadors Program output the following toolkits:

- **FY23 Appropriations One-Pager**
- **Pitching to the Media: The Warrior Way**
- **State-Level Advocacy**
- **Advocacy in the ER**
- **How to build your own CHW Program**
- **Power of the Pen**

2022 Ambassador Policy Forum

The goal of the Policy Forum is to offer intensive advocacy training and Hill Day for Ambassadors. This two-day event provided an opportunity for Ambassadors to practice their advocacy skills and meet with their legislators to discuss the needs of the SCD community.

Those affected by SCD continue to be underserved and underrepresented in our healthcare system and legislation. We believe change must come from within. For many Ambassadors, this is the first time they were meeting with legislators and building a relationship. With much change on the horizon for SCD, equipping the Ambassadors with these tools is a critical need for advocacy.

The agenda for the Policy Forum (listed below) was separated into a keynote, three sessions, and included a ten-minute stretch break led by SCD Advocate Jonathan Nelson. The workshop featured the following panelists:

Keynote

- Adam Taliaferro, Esq., Bristol Myers Squibb
- Building Blocks for Advocacy at the State Level
- Dr. Titilope Fasipe, Texas Children’s Hospital
- Levell Strong, People’s Action
- Tracy Meeks, Vertex Pharmaceuticals
- Federal Priorities for SCD
- Emma Andelson, Sick Cells
- John Otsuki, SCDA
- Hill Day Prep & Mock Meetings
- Sick Cells Staff



Policy & Government Affairs

The sickle cell community has historically been underrepresented in policy and legislation. 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.

2022 Policy Work Accomplishments

Medicaid Drug Utilization Review Board (DURB) Meetings

- Recruited and prepared 6 advocates to attend DURB meetings in Georgia and Oklahoma.
- Informed advocates about DURB meetings in Texas and Minnesota.

#FundSickleCell Movement

- Led a grassroots effort to have advocates meet with their legislators
- More than 20 legislators were contacted
- Congress appropriated \$7.205M to SCD Programs for FY 2021
- Participation in external policy workgroups
- Leavitt Partners
 - To discuss (1) access to new therapies, (2) data, and (2) care delivery & access
 - EveryLife Foundation Community Congress
 - To discuss (2) access to care, (2) P&T/ DURB Advocacy

Sign on Letters

- HIV + Hepatitis Policy Institute and the Autoimmune Association
 - Signed by 51 patient groups, to HHS Secretary Xavier Becerra
 - Comments to the U.S. Department of Health and Human Services (HHS) on the Notice of Benefits and Payment Parameters (NBPP) for 2023 proposed rule
 - Read the letter here
- National Organization of Rare Disease's Project RDAC
 - Support for Assembly Bill 744: Rare Disease Advisory Council in Wisconsin
 - Signed by 13 organizations
 - Establishes a Rare Disease Advisory Council in the state
- Support for House Bill 458: Rare Disease Advisory Council
 - Signed by 18 organizations
 - Establishes a Rare Disease Advisory Council in the state

State Medicaid Programs

State Medicaid programs play a crucial role in providing healthcare coverage and access to millions of low-income individuals and families across the United States. These programs serve as a safety net, ensuring that vulnerable populations have access to essential healthcare services.

Sick Cells created recommendations for state medicaid programs including:

1. Perform outreach to community experts
2. Incorporate processes which facilitate meaningful stakeholder engagement
3. Create an alert system for meeting notifications and disease-specific agenda announcements.
4. Publish guidance to providing input
5. Offer additional opportunities for engagement and partnership
6. Promote transparency in decision making

Publications

- Advancing Stakeholder Engagement with Medicaid

Clifton

WEET THE FACES



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When it comes to school, it was always a challenge knowing that I would have doctors appointments, knowing that I would have days that I would miss. I always had to stay a step ahead of the game when it came to assignments, and I always had to talk to the teachers at the beginning of the year, throughout the year, to get them to understand my illness. And, it was challenging as a young kid, but the older I got, the more I was able to communicate with them, and let them know exactly what’s going on.

- Clifton, Michigan

Coverage for SCD Summit



2022
COVERAGE FOR SCD SUMMIT

SICK CELLS

Date: August 31st, 2022
Time: 12 - 4 PM EDT
Location: Virtual Meeting

Introduction

Sick Cells convenes sickle cell advocates for a **Coverage for SCD Summit**, which will be referred to as “the Summit” in this document.

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 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 event offers a 1-hour CME accredited course.

Summit Success

The Coverage for SCD Summit provided a collaborative forum to discuss the changing landscape of healthcare coverage for sickle cell disease (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.

The Summit had 105 unique attendees, surpassing our goal of 50 participants. We 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

- Introduction, Ashley Valentine, Co-Founder of Sick Cells
- Keynote” The Sickle Case: Rehumanizing Sickle Cell Care Together, Dr. Ahmar Zaidi

Session 1: Report Out from Sick Cells

- Emma Andelson, MPA

Session 2 (CME Credits, hosted by IMPACT Education): Improving Equity and Affordability of SCD therapies: Best Practice in Benefit Strategies and Payer Management

- The Patient Perspective: Francesca Valentine

Payer Perspective on SCD Treatment Outcomes and Coverage Policies

- Emily Tsio
- Dr. Terry Cothran

Session 3: Patient Journey Spotlight: What Does Access and Coverage Look Like for Patients?

- Panel members: Rae Blaylark, founder and executive director of the Sickle Cell Foundation of Minnesota, Blaze Eppinger (advocate), Chifuan Powell (advocate)

Session 4: A Managed Care Approach for SCD

- John Stacil, RPh, National Account Director, Artia Solutions
- John Watkins, PharmD, MPH, BCPS-Pharmacy Manager, Premera Blue Cross
- Chanell Grismore, DrPH, MPH, MCHES, Director of Sickle Cell Center, Loma Linda University Medical Center



Research Collaboratives and Partnerships

Medicaid Research Project with Avalere Health

Background

In April 2022, Sick Cells collaborated with Avalere Health to conduct an environmental survey aimed at gathering insights from current or former Medicaid decision-makers. This initiative was undertaken to comprehensively scan the landscape and understand the existing treatment coverage policies and access barriers for the Medicaid population in relation to sickle cell disease (SCD).

Research Aim

The primary objective of this project was to enhance the understanding of SCD treatment coverage policies and identify access barriers specific to the Medicaid population. The gathered information was intended to shape Sick Cells' state advocacy plan and facilitate meaningful engagement with Medicaid decision-makers.

Results

The survey findings were further supplemented with an environmental scan, providing a comprehensive assessment of the current state of access to SCD therapies within Medicaid. The resulting report sheds light on the existing challenges and offers insights on potential avenues for improving access to these therapies.

The key findings derived from the research revolved around five central areas:

1. Prevalence of Utilization Management
2. Stakeholder and Content Agreement
3. Factors Influencing Decision Making
4. Role of Managed Care Organizations (MCOs)
5. Health Equity Initiatives

HR-QOL Survey, Disease Impacts, and Health Equity Survey Summary

Background

The Sick Cells team has collaborated with QC Medica and Vertex Pharmaceuticals to conduct a survey within the sickle cell community, focusing on the concerns related to quality of life and the impact of health on individuals living with sickle cell disease and experiencing recurrent vaso-occlusive (VOCs) crises. The findings of this survey were presented at the American Society of Hematology (ASH) conference in December 2022.

Research Aim

The aim of this survey was to gather insights into the frequency of VOCs requiring healthcare provider interaction, the self-management practices employed by patients at home, and the utilization of Hydroxyurea as a treatment strategy. The study aimed to provide a comprehensive understanding of the health-related challenges faced by individuals with sickle cell disease, with the ultimate goal of improving their overall quality of life and promoting equitable healthcare practices.

Results

A total of 142 participants with sickle cell disease took part in the survey. On average, these individuals experienced 6 VOCs per year, requiring interactions with healthcare providers. However, nearly 70% of the participants reported managing 4 or more VOCs at home within the past 12 months. Additionally, within the past month, 65% of the participants had used Hydroxyurea as a management strategy for their sickle cell disease.

More information about this study is available here. Click the button below to view more information on the ASH publication on the Health-Related Quality of Life, Disease Impacts, and Health Equity Survey.

Patient Preference Survey with Pfizer

Background

In early 2022, Pfizer worked with Sick Cells to develop an SCD Patient and Caregiver Preference Study to understand patient preference information, or what different features of sickle cell treatments matter to individuals with sickle cell disease (SCD) and their caregivers. 49 respondents completed the web-based survey fielded from February to April.

Research Aim

The primary aim of this research was to develop a community-based recruitment strategy that addresses the limitations of conventional research approaches in the context of sickle cell disease SCD. The strategy aimed to overcome barriers to participation and ensure a more diverse and representative sample of SCD patients, allowing for the collection of preference data that better reflects the perspectives and needs of the broader SCD community. By adopting this approach, the research aimed to enhance the validity and relevance of the findings, leading to more effective interventions and support for individuals living with SCD.



Overview

Sick Cells developed a community-based recruitment strategy. The Patient Preference Community Committee (PPCC) was formed as a new model of recruitment, enabling community experts to act as a bridge between researchers and patients. The PPCC was composed of five community-based organizations (CBOs) that utilize the expertise of community health workers (CHWs) and social workers. The inclusion of CHWs was a key requirement when partnering because of the rapport established between CHWs and the SCD community, and their understanding of the culturally-appropriate education. The trust in CHWs influences the acceptance of the community to participate in research and can enhance effective communication between members of the SCD community and researchers. All organizations had robust local communication networks, including other local partnerships with clinical centers and sickle cell treatment centers, and expressed interest in collaborative approaches to do research. During each training session, Sick Cells worked with the organizations to discuss any potential barriers to recruitment and developed materials that would help facilitate their outreach.

Results

The study found the three most important items to patients are reduced risk of organ damage, shortening the duration of pain crises, and reducing the risk of stroke. The three most important items to caregivers are reducing the level of pain during crises, reducing the frequency of pain crises of any severity, and reducing the frequency of pain crises of any severity (whether it is managed at home or at the emergency room). View the full summary [here](#).

Survey on Barriers and Facilitators to SCD Treatment with University of Pittsburgh

Background

The University of Pittsburgh School of Pharmacy is currently conducting research on the barriers and facilitators to the use of disease-modifying treatments (DMTs) in sickle cell disease (SCD). The Principal Investigator for this study is Terri Newman, PharmD.

Research Aims

The research aims to employ a mixed-method approach, utilizing both surveys and focus groups, to examine the factors that hinder or enable the utilization of DMTs in SCD. The survey will involve participation from healthcare providers, patients, and caregivers and will span a duration of six weeks, starting in March.

Overview

Sick Cells has provided iterative feedback on research focus and design (including choice of research questions and measurements), survey delivery, and inclusion criteria. Sick Cells will also lead the recruitment of patient, caregiver, and provider participants, manage incentive distribution, and assist with data analysis and summarization. The results of the study will be disseminated to the SCD community by Sick Cells. The survey recruitment will commence in March 2022 and will continue over the course of six weeks.

Results

A majority of individuals report having a good understanding of DMTs; however, many still believe they need more information about these treatments. Barriers to DMT use persist, even among individuals with relatively privileged socioeconomic backgrounds. Future research should aim to include a more diverse population to better comprehend the impact of socioeconomic factors, insurance status, and DMT use on treatment decisions and outcomes. Check out the summary on our website [here](#).

White Paper Series on Equity and Value Assessment with Innovation and Value Initiative (IVI)

This paper was co-created by IVI and Sick Cells in pursuit of a shared goal to advance racial and health equity in and through the practice of health technology assessments (HTA) in the U.S.

Background

It is Sick Cell’s position that value assessment for SCD therapies are critical, however value assessment methodologies must prioritize value to the patient and support health equity. Data and methods used for value assessment should adequately account for the diversity of patients and the urgent need to correct inequities in the healthcare system. The Innovation and Value Initiative (IVI) is led by nationally recognized scientists and health care experts that have pioneered new methods for measuring and rewarding value. Equity is a fundamental principle in IVI’s work.

Overview

A four-part white paper series, in partnership with IVI, will explore the intersection of equity and value assessment. Through sharing standing issues and problems, others can join our work and come together to find solutions to these challenges.

- Address impact of structural racism and existing inequities on current value assessment systems
- Consider methods and policies to help address system biases and inequities in future value assessments

Key themes emerging from this series will:

- Highlight challenges from Sick Cells experience with the 2019 ICER SCD review
- Discuss need for diverse patient and community engagement in value assessments

- Timeline: The series is expected to run through 2022.
- View the white paper at our website [here](#).

Mariza

MEET THE FACES



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Awareness is really big ,cause not a lot of people know about it. They sometimes say ,Oh, I have sickle cell’ and a lot of people don’t know how bad the disease is. [If] you look perfectly fine and you say you’re sick, they’ll think you’re not sick or that you’re lying ,cause you don’t look sick.

- Mariza, New York

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
EveryLife Foundation	Members	Community Congress Member
National Organization for Rare Disorders (NORD)	Paid Members	Paid Members
Leavitt Partners SCD Alliance	Advisors	Part of Coalition
American Society of Hematology (ASH) Sickle Cell Disease Coalition	Members	Part of Coalition
Sickle Cell Disease Association of America (SCDAA)	Partners	MOU Partnership
Value in the States Coalition (Led by Arthritis Foundation)	Members	Part of Coalition
Everylife Foundation	Members	Emma Andelson, workgroup member

Reach and Engagement







Social Media

We have implemented several strategies to enhance our social media content and engagement.

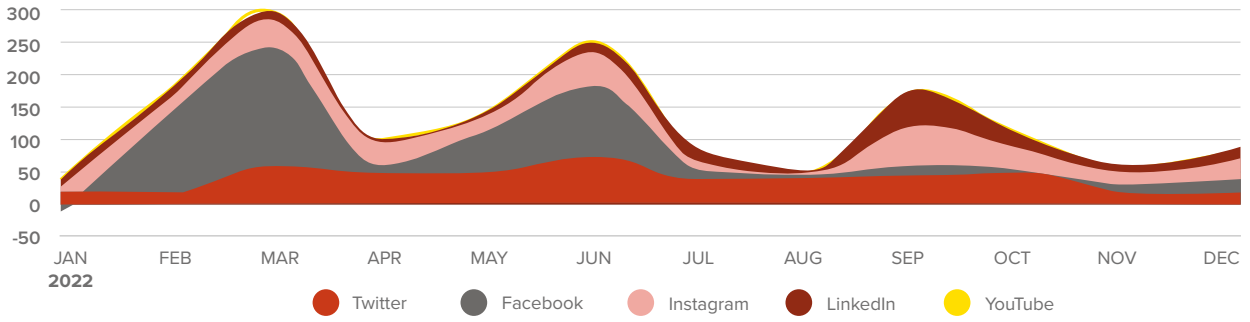
Here are the highlights from this year:

- Incorporating more videos: We have started including more videos in our social media content. Videos can be a powerful tool for storytelling and capturing the attention of our audience.
- Introducing new Faces of SCD Storytelling Campaigns: We have launched several exciting campaigns, including Feelin' the Love, Warriors with Pride, Remembrance Week, Hispanic Heritage Month, Coverage & Access, and our ongoing COVID-19 education initiatives. These campaigns allow us to connect with our audience on various important topics and promote awareness.
- Utilizing dynamic interfaces on Instagram stories: We have increased our direct engagement by utilizing interactive features on Instagram stories, such as polls, music, Q&As, and more. These features enable us to create a more interactive and immersive experience for our followers.
- Expanding our audience: We have continued to grow our audiences across all social media platforms. By reaching a wider audience, we can increase our impact and spread our message to more people.

These efforts demonstrate our dedication to connecting with our constituents, providing valuable content, and fostering engagement on social media.

Profile	Audience	Net Audience Growth	Posts	Impressions	Egements	Engagement Rate (Per Impression)	Video Views
Reporting Period Jan 1, 2021 - Dec 31, 2021	15,726	1,546	1,028	550,516	26,885	4.9%	21,036
	2,381	454	351	88,152	4,525	5.1%	849
	8,404	285	160	240,891	11,183	4.6%	11,172
	586	183	71	26,236	1,858	7.1%	1,563
	32	10	28	N/A	49	N/A	701
	3,997	338	368	140,817	8,340	5.9%	6,654
 Sickle Cell Disease Community Education Project	326	276	50	54,420	930	1.7%	97

Audience Growth

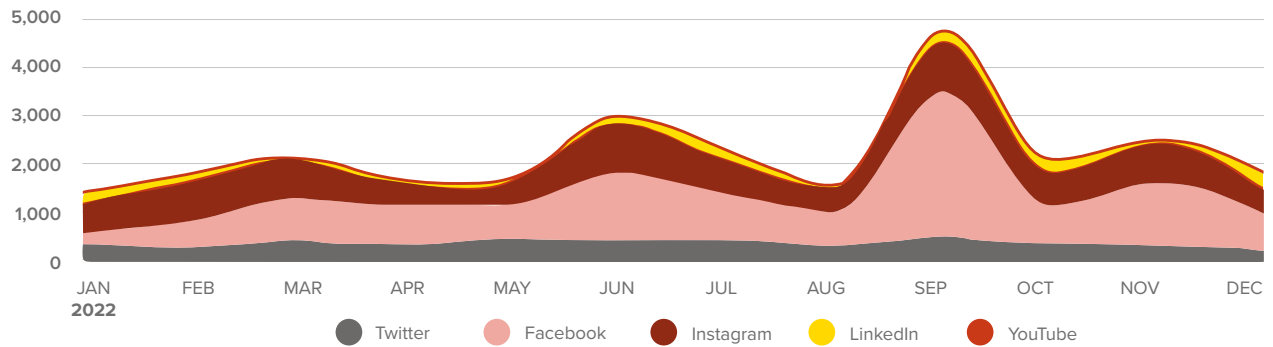


Audience Metrics

Totals

Total Audience	15,726
Total Net Audience Growth	1,546
Twitter Followers Gained	454
Facebook Pages Likes	561
Instagram Followers Gained	338
LinkedIn Followers Gained	183
YouTube Net Subscriber Growth	10

Engagement



Engagements Metrics

Totals

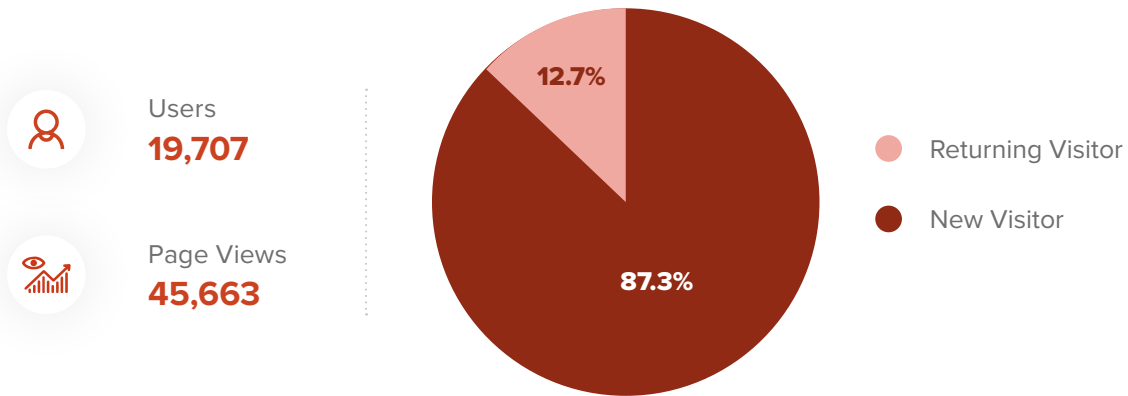
Total Engagements	26,885
Twitter Engagements	4,525
Facebook Engagements	12,113
Instagram Engagements	8,340
LinkedIn Engagements	1,858
YouTube Engagements	49

Newsletter

The Sick Cells newsletter releases once a month which is carefully curated from the Sick Cells team. The Sick Cells team reports the latest in treatment and policy news, spotlight SCD warriors, and gives

subscribers a “Minute with Marqus”. We currently have 1,724 subscribers for our monthly newsletters. View the newsletters archive and subscribe on our website [here](#).

Website



Financial Recap

Revenue	
Sponsorships	\$492,500.00
Grants	\$34,990.00
Donations	\$21,687.58
Other Income	\$34,470.00
Total Revenue	\$583,647.58

Expenses	
Program Expenses	\$421,958.07
Management and General	\$124,486.83
Fundraising	\$3,586.14
Total Expenses	\$550,031.04

Sponsors



Grants

PCORI Engagement Award

Sick Cells was selected for a funding award through the Eugene Washington PCORI Engagement Awards program, an initiative of the Patient-Centered Outcomes Research Institute (PCORI). This grant is intended to expand research to include more patients, caregivers, clinicians, and other healthcare stakeholders. The goal is to support projects that will build a community better able to participate in patient-centered outcomes research (PCOR)/comparative clinical effectiveness research (CER) and serve as channels to disseminate study results. With leadership from Sick Cells and collaboration with the University of Southern California (USC) Hematology Utilization Group Studies (HUGS) and The Comparative Health Outcomes, Policy, and Economics (CHOICE) Institute at University of Washington (UW) School of Pharmacy, this project will establish action items for research and value assessments to capture cost and other burdens that matter to SCD patients and caregivers. The funds will support the project titled **“Defining Value and Supporting Equity in SCD.”** This project started June 1, 2022 and will end on May 31, 2023.

Defining Value and Supporting Equity in SCD

A PCORI ENGAGEMENT AWARD PROJECT



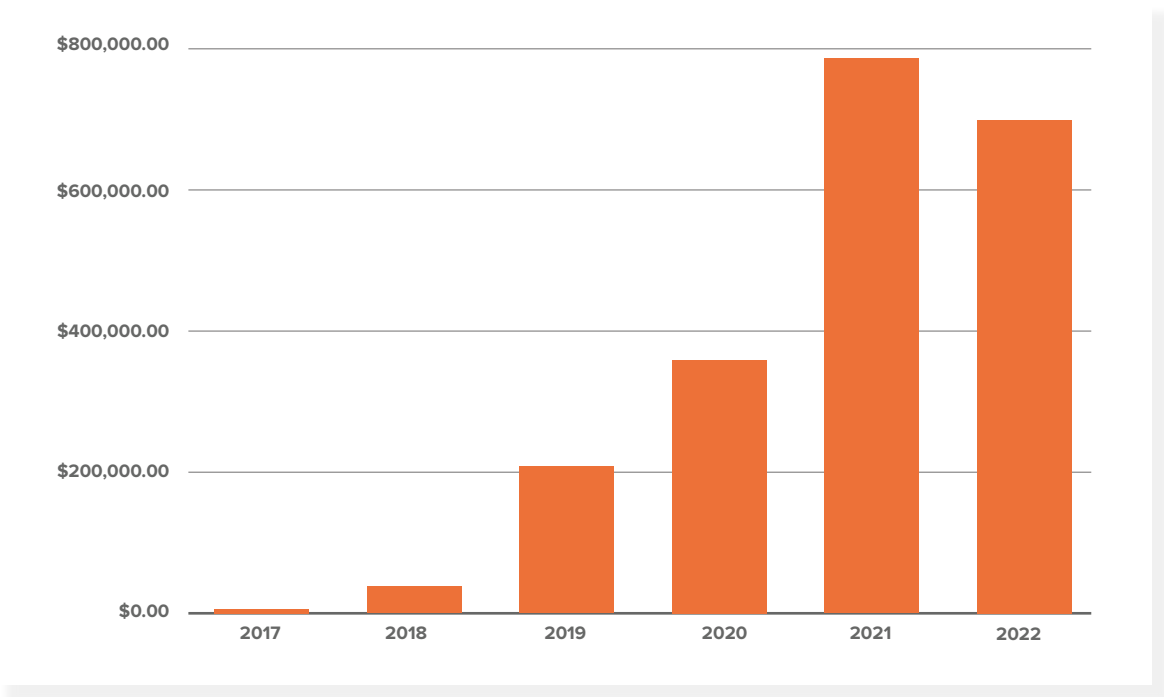
Edelman Community Investment Grant

The Edelman Community Investment Grant supports nonprofits up to \$2,500 in funding. The Edelman program has awarded over \$1,425,000 over the past 11 years to support 973 local organizations around the world with whom their employees volunteer. Sick Cells received a Community Investment Grant from Edelman in 2022. This grant was used to sponsor two campaigns within our Faces of SCD Storytelling Program.

PhRMA Foundation Advancing Value Assessment Grant

The PhRMA Foundation seeks to support research proposals that investigate challenges and potential solutions related to evaluating the delivery, safe use, effectiveness, and value (clinical, patient-centered, and economic) of medicines and other health care interventions. Funds are allocated to research that defines and measures value to ensure health care decisions are being guided by the best possible evidence. Sick Cells received an Advancing Value Assessment Grant from PhRMA Foundation in support of a peer-reviewed journal titled Community-Based Participatory Research Initiative for Sickle Cell Disease which is a publication looking at value assessment.

6 Year Look





Summary and Closing

Sick Cells would like to extend our heartfelt gratitude to everyone who has supported us throughout the year. Your unwavering encouragement, contributions, and dedication have played a significant role in our achievements. Together, we have accomplished great things, but our journey doesn't end here. As we reflect on the past year, we are inspired to reach even greater heights in the coming year. With your continued support, we are confident that we will achieve new milestones. We are excited for the opportunities and challenges that lie ahead, and we eagerly anticipate the remarkable things we will accomplish together. Thank you all for being part of our journey, and here's to an extraordinary year ahead!



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