



SICK CELLS

ANNUAL REPORT | 2019

WWW. **SICKCELLS** .ORG

A Note from Sick Cells' Founders

Faces of SCD Storytelling Program

Storytelling Interviews

Keyfindings and Next Steps

The Ambassador Program

Advocacy Events

Value Assessment

Awards Recognition

Red Cross Heroes Award

#letstalkaboutpain Storyathon

Marketing Outreach and Summary

Website

Social Media and Marketing

Financial Highlights

Growth from 2018 to 2019

Revenue and Expenses Tables

Donor and Corporate Advocacy Sponsorship

Other Grants

Partnership

Sickle Cell Disease Partnership

Other Patient Advocacy Partnership

Closing

A NOTE FROM SICK CELLS' FOUNDERS

Sick Cells' co-founders, siblings Marqus and Ashley Valentine, reflect on an incredible year and share their gratitude and excitement for what's around the corner.

Over the last decade, sickle cell has challenged our family and larger community. We've witnessed loss and unprecedented wins. We cried, protested, celebrated and joined together to reshape the future of SCD.

This year has been special. Sick Cells has grown tremendously and our community is getting the spotlight it deserves. We're grateful for our staff, volunteers, family and other rare disease advocates for their day-to-day support. Your time, generous donations and supportive messages do not ever go unnoticed.

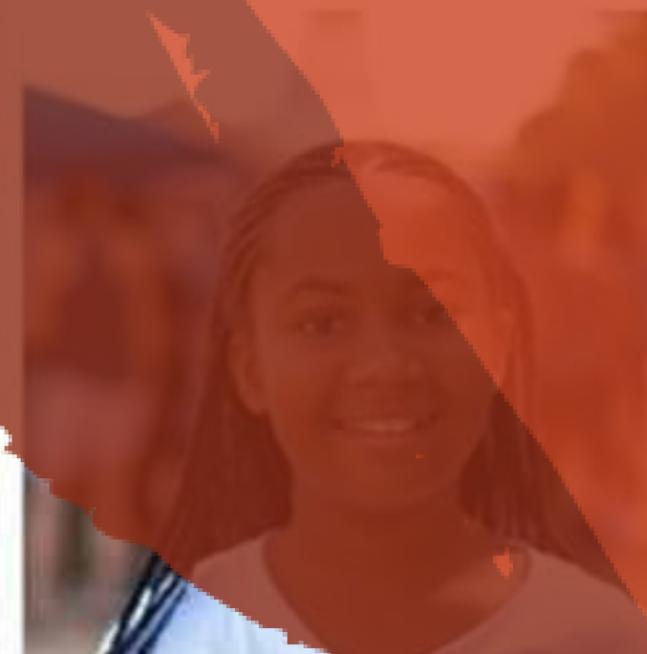
In 2020, a fresh decade, we'll continue to work to fulfill our mission to elevate the voices of those living with sickle cell. One important lesson we've learned throughout our Sick Cells journey: baby steps turn into miles. From 2009 to now, even our smallest actions have played a role in where our organization is today. Again, thank you. Cheers to a promising future!

– Marqus and Ashley Valentine, 2019





FACES OF SCD STORYTELLING PROGRAM



The *Faces of SCD Storytelling Program* is an initiative to eliminate stigma and other challenges faced by the SCD community. Sick Cells aims to help people understand this misunderstood disease by sharing stories of resilience and creating change through the voices of the SCD community – including the views of patients, family, and caregivers. Our stories are largely collected at local sickle cell walks, as we meet and have in-depth talks with participants in person. In highlighting the grave disparities this community faces, our continued goal is to influence decision-makers and propel change.

This year, the program began to come to fruition, as we started to see the success and produce the results that were intended and hoped when we established the program in 2017. After years of hard work to collect these stories, we began to see the power of patient narratives and the impact our storytelling efforts can have for the SCD community. Below we highlight our work to continue the collection of stories, and the start of translating those narratives into key research findings with actionable next steps to better inform clinical communities, reduce stigma, educate decision makers, and amplify the voices of the SCD community.

Thank you to each organization that welcomed us, our sponsors who funded this program, and volunteers, and a very special thank you to those who were willing to share their stories with us -- without you, none of this would be possible.



At each event, our team recruited SCD community members to share their stories in three different ways:

- Hosting an information table
- Walking around the event with recruiters
- Local community-based organizations (CBOs) encouraging people to share their story with Sick Cells



“I could see it’s definitely people living with a chronic health condition that need more help than they’re getting. They need coordinated care and there’s a lot of barriers in the healthcare system and with pain management and emergency rooms.”

- Mark, sickle cell advocate.

STORYTELLING INTERVIEWS

This year, Sick Cells traveled to Detroit, Philadelphia and Houston and interviewed SCD advocates about their experiences with SCD. Through the established event, motivated SCD advocates from the community convened in one location. We worked closely with community leaders to recruit these advocates and their interviews at three events:

- In **Detroit, Michigan**, our team spent time with the SCDA Michigan Chapter and attended the Sickle Cell Matters Awareness Walk-a-Thon on September 14th.
- In **Philadelphia**, we attended the Walter E. Brandon Sickle Cell 5K hosted by the SCDA Philadelphia/Delaware Valley Chapter on September 28th.
- In **Houston**, Sick Cells completed its 2019 Faces of SCD tour with the Marc Thomas Sickle Cell Foundation at their 7th Annual Walk for Sickle Cell on October 19th.

During the interview, Sick Cells provides each interviewer with a standardized questionnaire to use as a conversation guide with the SCD respondent. This allows the interviewer to conduct a semi-formal interview. All respondents sign release forms and are informed of how their information will be used.

An important aspect of the Face of SCD Program includes our recruitment of trained volunteers for our story collection. All of the volunteers have been sourced from outside of the SCD community, which allows the general public to learn about this disease and build empathy for people living with SCD. As an interviewer, they actively learn about SCD and lived experiences that they would not hear about otherwise. This technique is an important grassroots strategy for building more sickle cell advocates in the general public and spreading awareness.

The Faces of SCD stories from those in Detroit, Philadelphia and Houston can be found on our website, in addition to our social media channels.

KEY FINDINGS AND NEXT STEPS

After years of capturing rich data through story collections, the next step is to translate these narratives into key themes and findings. Collecting findings and building themes will allow us to take actionable steps and better inform clinical communities and other stakeholder groups about the topics that are most prevalent to our community.

Our goals were to use thematic content analysis to achieve the following:

- Understand the respondent's relationship to SCD
- Highlight obstacles individuals have overcome related to SCD
- Understand societal constructs that impact the SCD community
- Capture human emotion that is highly relatable



These initial findings were shared at an educational seminar during the Sickle Cell Disease Association of America, Inc. (SCDAA) Annual National Convention on October 9-12, 2019. This convention was a major success and Sick Cells' work was well received by researchers, physicians, nurses, social workers, and individuals living with SCD or SCT in attendance.

These themes underscore how powerful storytelling is for our SCD community. In 2020, we look forward to continuing to build the *Faces of SCD Storytelling Program*, in addition to centering our advocacy goals to address the gaps identified in the key findings addressed above. The personal narratives collected through this program will serve as a powerful tool in future advocacy efforts. We look forward to continuing this important work to ensure the voices of the SCD community are amplified and heard.

The results showcase how effective storytelling can be to collect information on complex and abstract topics. Findings from our early analysis highlighted several important themes:

- **Need for robust data dissemination.** Many respondents were not aware of current clinical trials, legislative activities, or research occurring in SCD, and therefore miss critical opportunities to participate.
- **Need for sickle cell trait (SCT) awareness.** Many parents and caregivers shared stories about how they were unaware of their SCT status until they had a child with SCD. This highlights the importance for increased education about SCT and availability of testing.
- **Need for tools to advocate for local and federal legislation.** Advocates and community-based organizations discussed having limited knowledge about how to engage in policy and legislative advocacy. There is very limited information regarding best practices or strategies being shared across states or advocacy groups.
- **Challenges with stigma and discrimination within clinical settings.** An outward appearance of "being healthy" can present additional barriers to appropriate care and contribute to social stigmas surrounding the disease. Additionally, many respondents described experiences with general lack of awareness about the disease among nurses, hospitalists, and society at large. This means that healthy-looking patients suffering from pain crisis or other SCD-related complications may not be taken seriously or can experience discrimination.
- **Impact of SCD on caregivers and family members.** Family members have described the tremendous responsibility of caregiving, including the need to leave the workforce to provide care for their loved one, while facing the impact of lost wages and significant out-of-pocket expenses.



THE AMBASSADOR PROGRAM

This year was a big year of growth, as we kicked off a new advocacy program, the Sick Cells **Ambassador Program**.

Over the past few years working with other community groups, it has been evident that sickle cell advocates are active, however, they may have limited opportunities for knowledge sharing and learning across the community and advocacy groups. This is how the need for the program was identified, and the Ambassador Program was born.



The Sick Cells Ambassador Program is a volunteer network of individuals dedicated to changing the landscape of sickle cell disease and empowered to spread awareness through policy change.

The mission of the *Ambassador Program* is to unite, educate, and empower the SCD community through the following objectives:

- 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;
- Connect the sickle cell community to coalitions and other organizations that impacts their health.

Below highlights some of our early successes through program efforts.



ADVOCACY EVENTS

Rare Disease Week With the EveryLife Foundation

Sick Cells volunteers and staff joined over 500 rare disease advocates in Washington, D.C. for the EveryLife Foundation's annual Rare Disease Week on Capitol Hill. Each year, Rare Disease Week on Capitol Hill brings rare disease community members from across the country together to be educated on federal legislative issues, meet other advocates, and share their unique stories with legislators.

More than 40 sickle cell advocates joined this year from across the country to attend a week of events dedicated to empowering patients, families, and friends to become legislative advocates and learn lobbying techniques. While there, Sick Cells educated state legislators about legislation impacting the rare disease community, including the sickle cell community. As a result, the Rare Disease Caucus had six new members bringing the total membership of the caucus to 118 Representatives and 17 Senators.

During the Rare Disease Week, Ashley Valentine, Sick Cells co-founder and President, spoke on a panel at the legislative conference about how to mobilize communities to advocate for legislation. Her presentation was a powerful recollection of successful past advocacy efforts with a goal to inspire and motivate other rare disease advocates to get their voices heard by elected officials.

Sick Cells also hosted a Rare Disease Advocates Networking dinner for those representing SCD on Capitol Hill. From Nevada to New York, SCD patients and advocate groups came together to fellowship and discuss their roles in the community.

National Lobby Day with the SCDA

In April, Sick Cells joined 100 SCD advocates on Capitol Hill to advocate for funding for SCD in participation of the Sickle Cell Disease Association of America Inc (SCDAA) Lobby Day. The advocates educated Congress about several topics including the need to reauthorize the Newborn Screening Saves Lives Act and the importance of robust funding for the NIH and FDA.

Sickle Cell Disease Therapeutic Riding Day

Sick Cells also teamed up with the Sickle Cell Disease Association of Illinois (SCDAI) and BraveHearts for a first-ever sickle cell disease therapeutic horseback riding day in May 2019.

Reports show that there are many benefits of therapeutic riding for people with cognitive and physical disabilities, including contributing positively to the cognitive, physical, emotional and social well-being of individuals.



VALUE ASSESSMENT

Background

In August 2019, the Institute of Clinical and Economic Research (ICER) announced its plans to assess the comparative clinical effectiveness and value of new treatments for sickle cell disease. ICER conducts evidence-based reviews and economic evaluations of healthcare interventions such as drugs, devices, and diagnostic tests. ICER's reports assist patients, clinicians, payers, and other stakeholders to gain a fuller understanding of the potential benefits and harms of new healthcare innovations, as well as their long-term cost-effectiveness and budgetary impact.

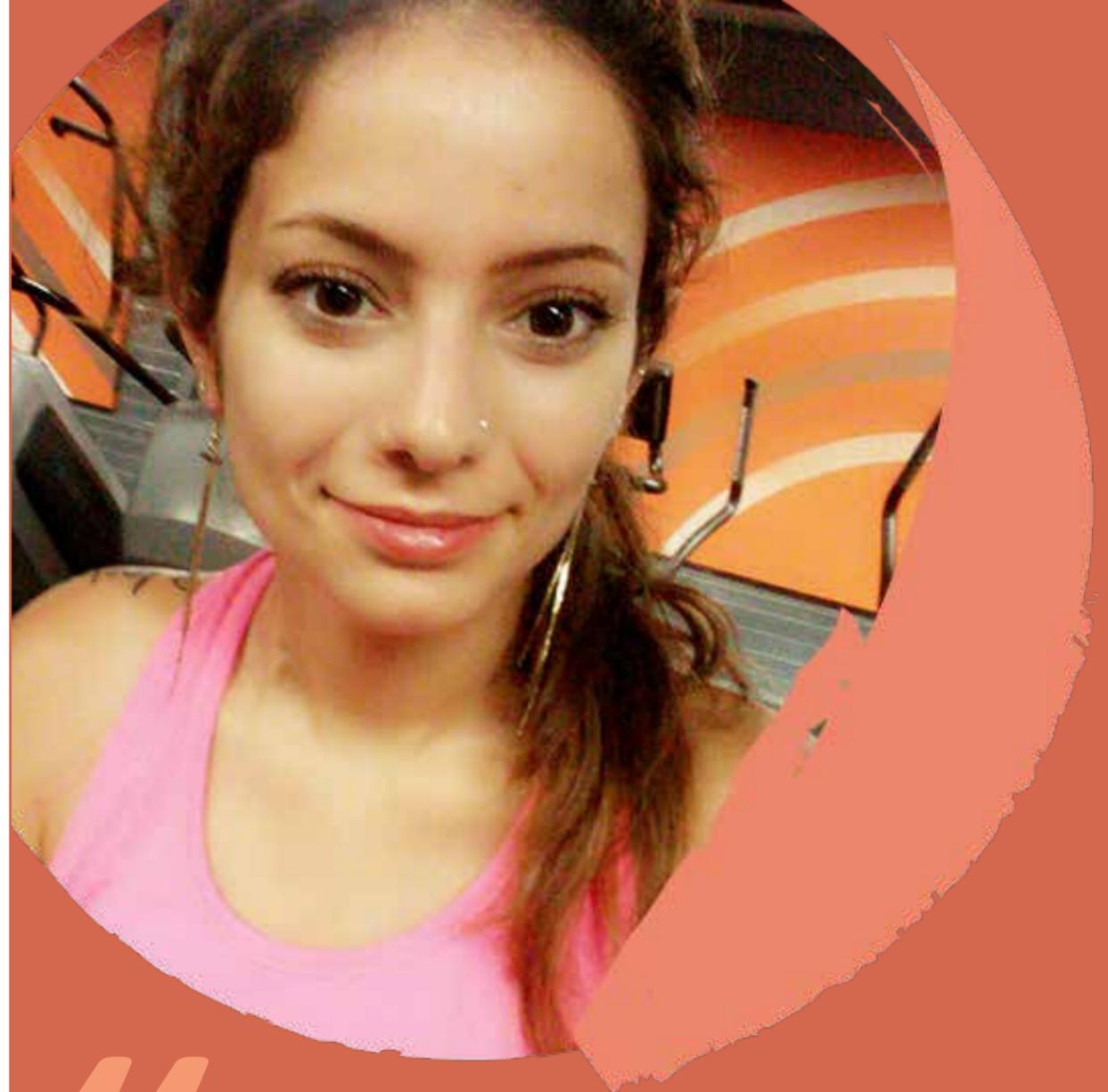


The Community Voice

At Sick Cells, we were focused on ensuring the voices of patients and advocates were included in the value discussion. Throughout each phase of the ICER review, Sick Cells lead community advocacy efforts. During the topic selection and scoping phase, Sick Cells knew it would be important for the community's voice to weigh in, and worked hard to strengthen community engagement during the initial open input period.

First, we raised awareness about value assessment and its importance related to access and coverage decisions by rallying community leaders. Secondly, we mobilized the community to become engaged by organizing a community task force and building an input form for community feedback. Due to these successful outreach efforts, public comments were submitted from 92 sickle cell patients and community stakeholders.

Additionally, Sick Cells led a large community sign-on letter and other organizational letters that were submitted to ICER. In December, Sick Cells hosted a month-long webinar series to educate the community on value assessments and drug pricing. Overall, Sick Cells is proud of our work to strengthen the community and mobilize individuals and other community-based organizations on this important topic.



“

I need much exercise because of the prosthesis in my hip and shoulder. I enjoy working out, but everyday isn't the same when you have sickle cell. I try to train three times a week, but I can't train if I'm in the hospital. Then, when I leave the hospital, I have to take time recovering. But I do enjoy working out and doing the exercises on my own. It makes me feel strong, like I can move forward and get better.

”

- Eda, 25 years old, SCD hemoglobin SS

MEET THE FACES



AWARDS AND RECOGNITION

Sick Cells was created with a goal of telling the world about sickle cell disease. Our organization was built on a hope for a brighter tomorrow for those living with and impacted by SCD. While we are motivated by the voices of the community to continue toward our mission each day, being recognized really puts fire under our feet to do, inspire and teach more.

This year our Sick Cells team was honored to receive several awards and recognition. We're making a difference and it's being heard, and we are both honored and humbled.

RED CROSS HEROES AWARD

Ashley and Marqus Valentine were awarded the Blood Services Hero award in Chicago at the Red Cross Heroes Breakfast. They were honored for their work in advocacy and storytelling in the sickle cell community on May 1, 2019. In April, The Valentines attended the Red Cross Heroes reception where they met the other heroes and the American Red Cross of Chicago & Northern Illinois staff.

#LETSTALKABOUTPAIN STORYATHON

In honor of Pain Awareness Month, U.S. Pain Foundation showcases video stories from people living in pain. Marqus Valentine, Sick Cells' co-founder, was selected to share his personal experiences about the day-to-day challenges of living with chronic pain. We are incredibly grateful to our supportive, passionate partners for bringing pain and sickle cell disease to the forefront of discussion, as recognition is the first step to creating awareness and change. Chronic pain is devastating, and Sick Cells was honored to take action, along with all the other brave individuals who shared their stories, in order to create more awareness.



2019 HEROES BREAKFAST



Ashley Valentine & Marqus Valentine

"Being honored at the Red Cross Heroes breakfast in May 2019 will forever be one of my proudest moments. I was so honored to be deemed a "hero" in the Chicagoland area alongside my sister, Ashley. From the beautiful venue to the people in attendance, everything was incredible.

While we were able to meet the other heroes at a reception in early April, it was even more powerful to see their videos and hear them talk about their personal stories live. I was just so overwhelmingly grateful to be honored alongside these incredible individuals."

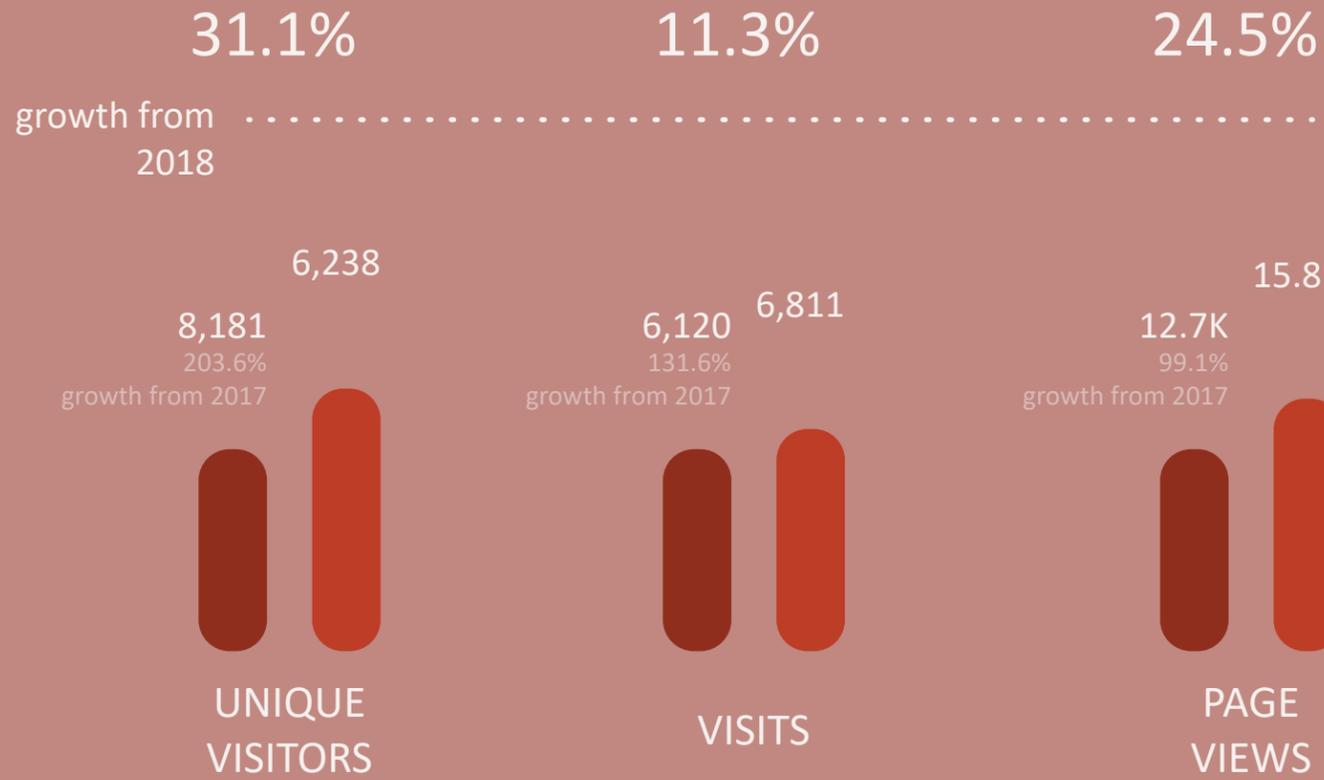
- Marqus Valentine

MARKETING OUTREACH AND SUMMARY

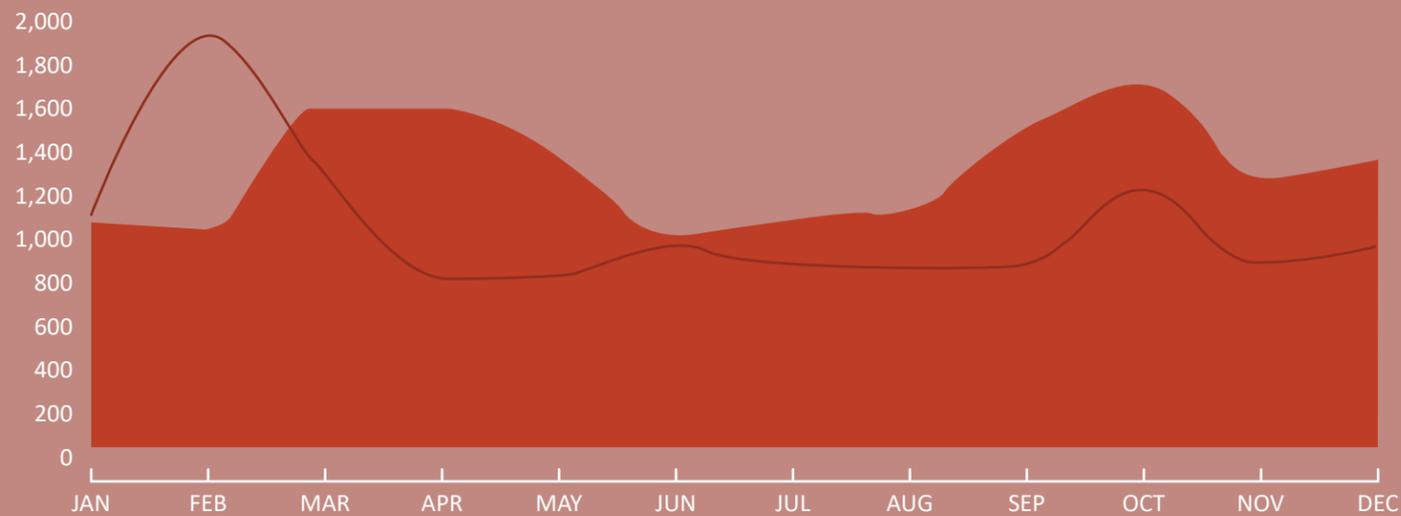


WEBSITE

2018 2019

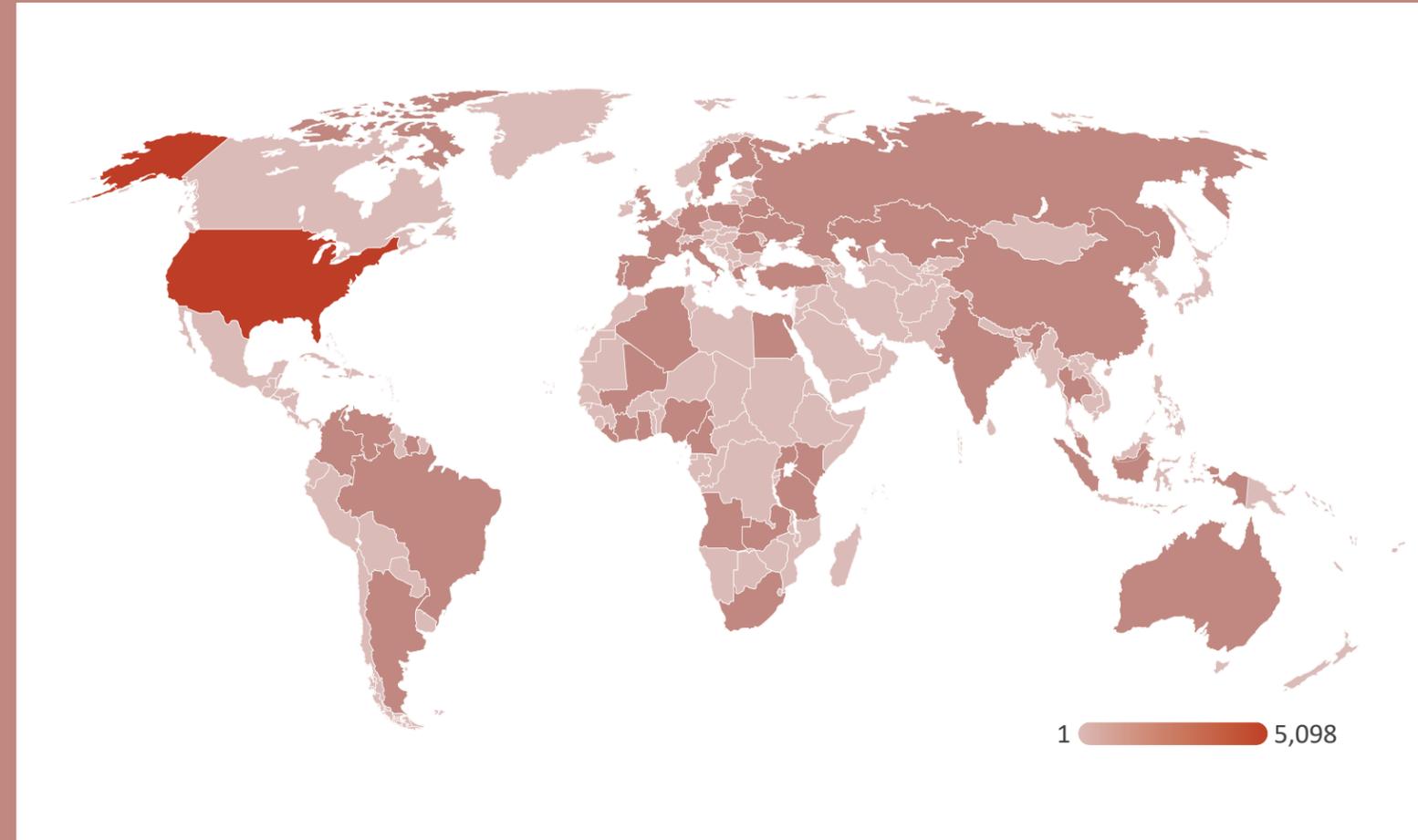


Page Views

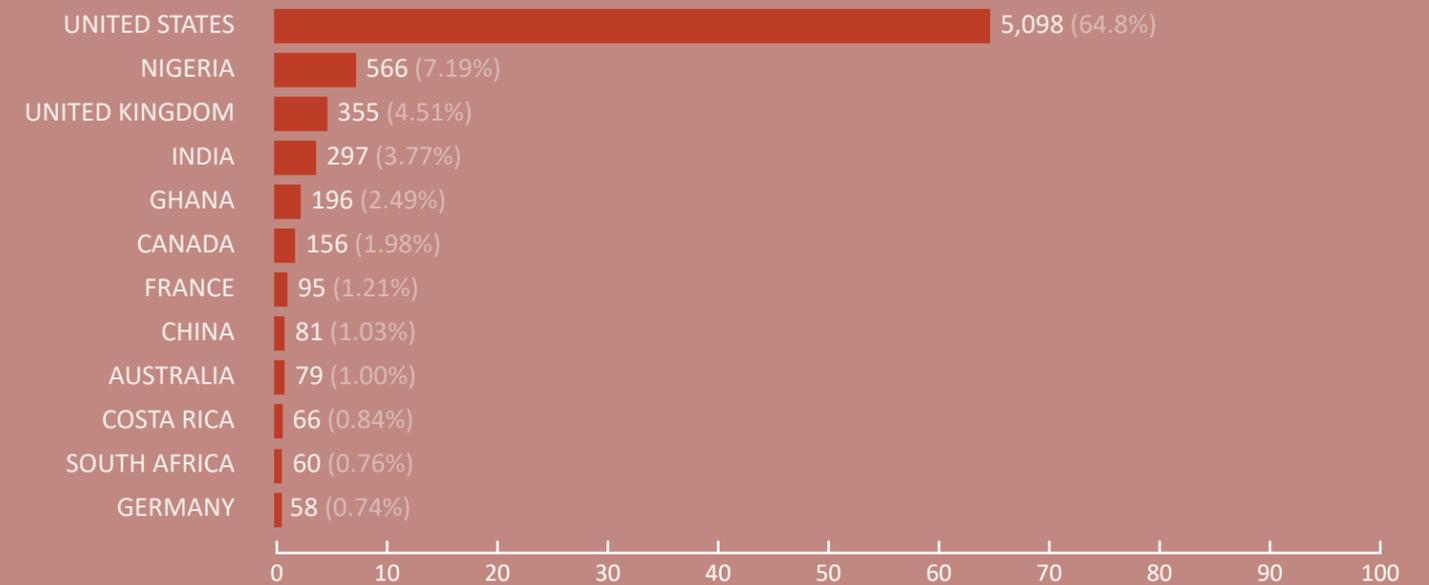


GEOGRAPHY

Tue, Jan 1 - Tue, Dec 31, 2019



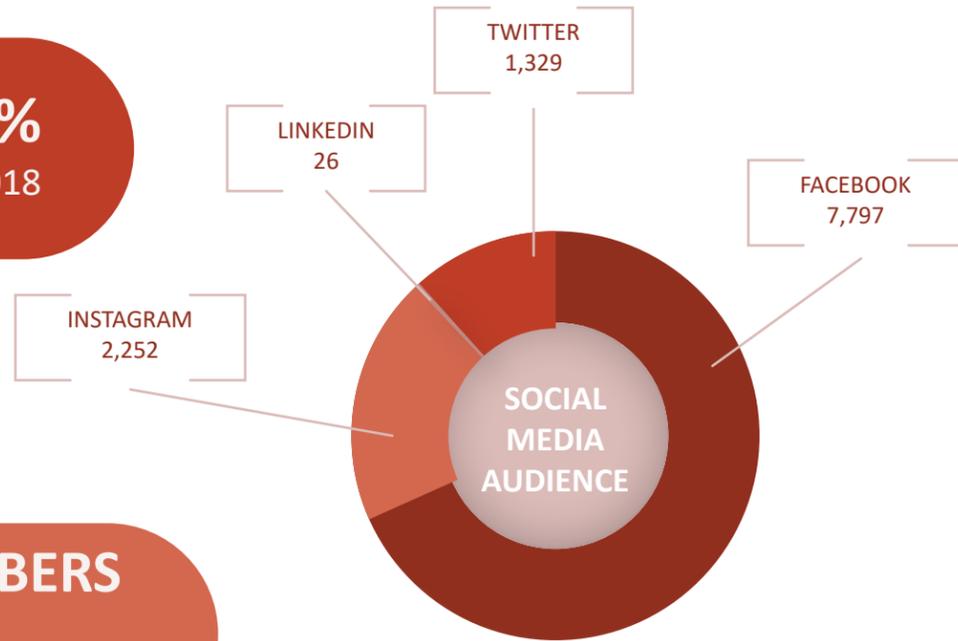
Visits Per Location



SOCIAL MEDIA & EMAIL MARKETING

Jan 1 - Dec 31, 2019

30.5%
growth from 2018



EMAIL SUBSCRIBERS
1,353
675 in 2018

CROSS NETWORK PROFILE



	NET AUDIENCE GROWTH	PUBLISHED POSTS	IMPRESSIONS	ENGAGEMENTS
	916	204	1,432,724	151,570
	450	165	133,068	8,341
	10	74	1,093	46
	186	276	113,866	2,334



“ I got a degree. I always wanted to be in media. I got my degree in digital media production and my associates degree in that. Did it in about three years. The reason it took three years was because again, still dealing with the sickle cell, I had skipped some semesters for pain management. I was in the hospital basically a whole month, one visit.

- Jabril, 24 years old, SCD hemoglobin SS

”

MEET THE FACES



FINANCIAL HIGHLIGHTS

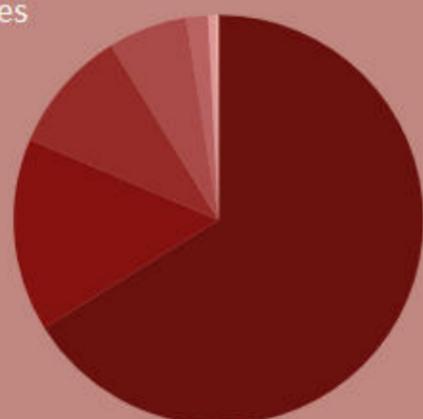
GROWTH FROM 2018 TO 2019



REVENUE AND EXPENSES

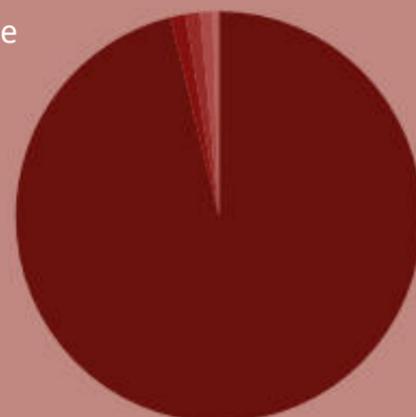
FINANCIAL SUMMARY

Expenditures



- Programs
- Administrative
- Advocacy Travel
- Advertising & Marketing
- Events
- Overhead
- Charitable Contributions
- Memberships

Revenue



- Program Sponsorships and Grants
- Web Donations
- Event Fundraising
- Speaking Engagements
- General Public Donations

TOTAL REVENUE	202,796.53
TOTAL EXPENDITURES	133,644.62
NET REVENUE	69,151.91

DONOR AND CORPORATE ADVOCACY SPONSORSHIPS

Sick Cells receives Donations through the following sources:

- Private web donors
- Facebook donations through Network for Good
- Wiggin' Out annual fundraiser

Sick Cells received corporate sponsorships from the following entities for the Faces of SCD Storytelling and Ambassador Programs:

- Bluebird Bio
- Novartis
- Global Blood Therapeutics (GBT)
- Biotechnology Innovation Organization (BIO)
- Pharmaceutical Research and Manufacturers of America (PhRMA)
- Vertex Pharmaceuticals
- CRISPR Therapeutics
- Sanofi Genzyme



Volunteers and staff at Sick Cells' annual Wiggin' Out for Sickle Cell Fundraiser in Washington, DC

OTHER GRANTS

Sick Cells received multiple grants for services this year. We were awarded the following corporate grants:

Google Nonprofit Grant

Sick Cells receives unlimited email addresses, a web domain, unlimited G-Suite services, and \$10,000 a month in Google Awards. We will continue this grant in 2020.

Facebook Advertising Grant

Sick Cells received \$500 in Facebook advertising grants. The team used these funds to boost subscribers for the newsletter.

PARTNERSHIPS

Sick Cells strives to maintain and foster partnerships, inside and outside of the sickle cell community. During 2019, the team's partnerships grew to include many facets of the sickle cell experience.



SICKLE CELL DISEASE PARTNERSHIPS

Sick Cells worked with multiple sickle cell organizations throughout the year as part of our various advocacy events and efforts. Together we can continue to improve patient care and outcomes for individuals with sickle cell disease and reduce the burden that SCD imposes on individuals, their families, and the healthcare system. Sick Cells partnered with the following sickle cell organizations in 2019:

Sickle Cell Disease Association of America (SCDAA)

SCDAA Philadelphia/Delaware Valley Chapter

SCDAA Michigan Chapter

Sickle Cell Disease Association of Illinois (SCDAI)

Association of IL Patient Network

Foundation for Sickle Cell Disease of Tennessee

Uriel E. Owens Sickle Cell Disease Association Of The Midwest

The Sickle Cell Forum

The Maryland Sickle Cell Disease Association

Queens Sickle Cell Advocacy Network Inc. (QSCAN)

The Martin Center

Sickle Cell 101

Cayenne Wellness

Axis Advocacy

Marc Thomas Sickle Cell Foundation

Sickle Cell Thalassemia Patients Network (SCTPN)



OTHER PATIENT ADVOCACY PARTNERSHIPS

Sick Cells is focused on forging partnerships among diverse healthcare and patient advocacy organizations who have shared missions. Several of our partners are focused on ensuring the voice of the patients and patient organizations are an integral part of healthcare. These partnerships enable us to create a collaborative environment and facilitate shared learning. Sick Cells worked with or participated in partnerships with the following organizations in 2020:

Global Genes

Global Healthy Living Foundation

Everylife Foundation

US Pain Foundation

Biotechnology Innovation Organization (BIO)

National Minority Quality Forum

Parent Project Muscular Dystrophy

Asthma and Allergy Foundation of America

Coalition For Headache And Migraine Patients (CHAMP)

National Health Council

National Multiple Sclerosis Society

Cystic Fibrosis Research, Inc.

Partnership to Improve Patient Care (PIPC)



CLOSING

As we closed the books on 2019, we looked forward to an even more productive and eventful 2020, as our advocacy programs continue to grow, and their results are made widely available as part of our efforts to improve patient care and outcomes for people with sickle cell disease

This was a very productive year for Sick Cells, marked by steady progress and notable achievements showcased in this report, and we are confident that we will continue to show all of our stakeholders the importance of our work and be a part of the exciting transformation ahead for our sickle cell disease community.

WWW. **SICKCELLS** .ORG