



# SICK CELLS

ANNUAL REPORT | 2020

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# A NOTE FROM SICK CELLS' CO-FOUNDER

In 2019, Marqus and I concluded our annual end-of-year letter with the following:

“In 2020, a fresh decade, we’ll continue to work to fulfill our mission to elevate the voices of those living with sickle cell disease (SCD). 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.”

It’s hard to believe the start of this decade has already brought on so much unprecedented, unsettling and, at times, unbelievable change. Our community and country experienced so much loss – including the passing of my best friend and brother, Marqus – in addition to navigating a global pandemic that led to challenges that impacted families and individuals in different ways.

But through this year’s lessons, I’m reminded of what Marqus and I shared a year ago today: baby steps turn into miles. This year, our organization has made strides in our advocacy work, launched a new website, formalized our Ambassador Program, reshaped our Faces of SCD program, led campaigns, and even advocated for SCD on a national level at the White House. In the midst of all of this, we were also reminded of the importance of rest and slowing down when needed.

So even when the path forward feels like baby steps because we’re tired or mourning or planning or resting and reflecting, we know the baby steps are working toward miles in the grand scheme of things.

Thanks for all of your continued support. See you in 2021.

– Ashley Valentine, 2020

# IN MEMORY OF THE FIERCEST WARRIOR

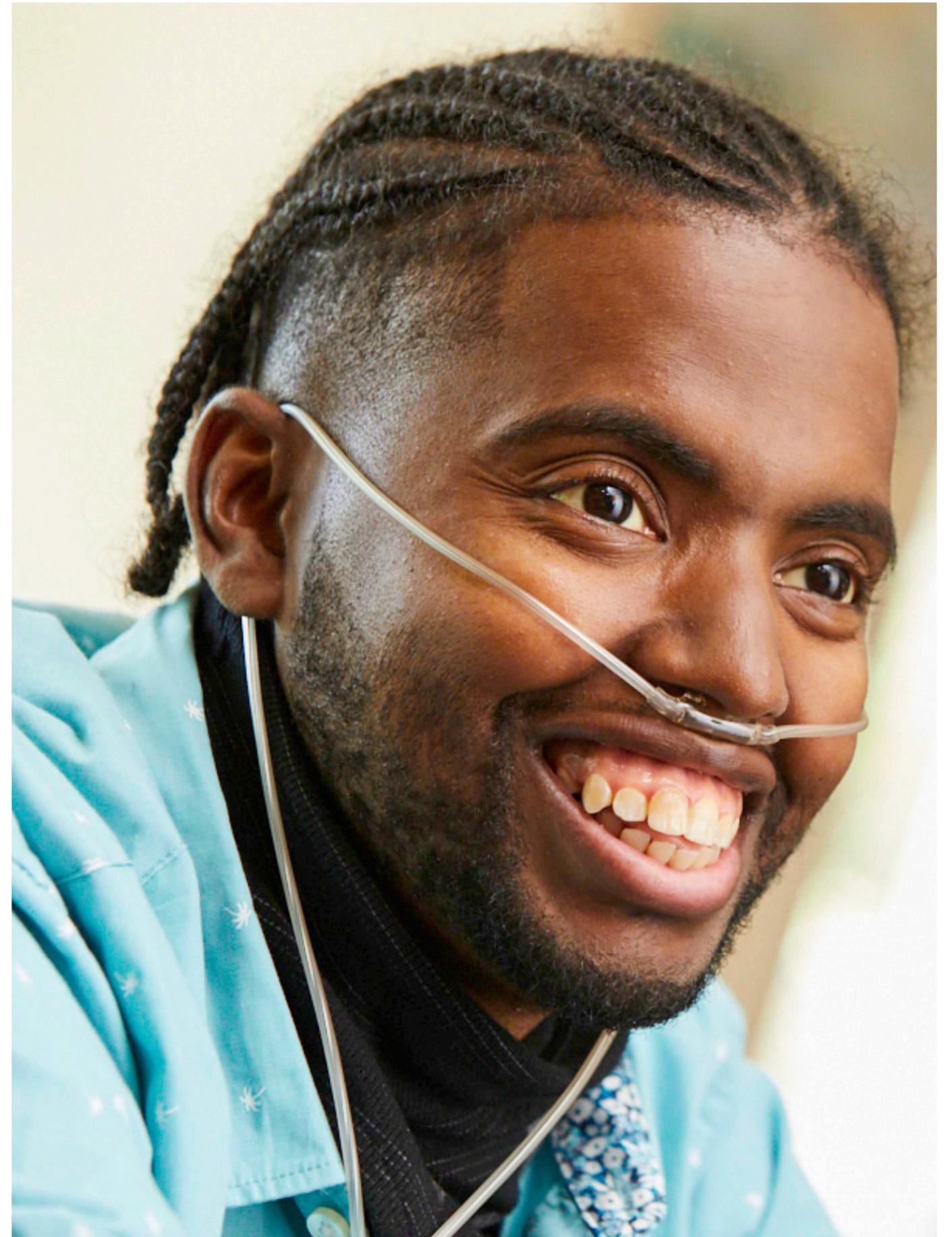
Marqus Valentine, our co-founder and the inspiration for Sick Cells, gained his warrior wings on June 22, 2020. After 36 years of enjoying Marqus' kind heart, hilarious jokes and selfless personality, words cannot express how incredibly sad this loss is for his family, friends, and the larger SCD community.

While mourning the loss of Marqus brings deep sadness, our memories of his life and the words he left behind are reminders of how special he truly was and how blessed we are that his presence was shared with us. Marqus touched the hearts of all of those who knew his radiant spirit. As co-founder of Sick Cells, he was dedicated to pushing forward our mission to elevate the voices of the sickle cell community. He was determined to improve the lives of future warriors and their families.



His involvement in the SCD community stretched beyond Sick Cells. Marqus was an advocate for blood donation, a recipient of the 2019 American Red Cross Blood Service Heroes award, a mentor for younger warriors, and a go-to source for advice. He was wise beyond his years and never hesitated to share his voice to help those around him.

Marqus' legacy is everlasting. He touched the lives of so many people who knew him both in real life and virtually. His triumphs, resilience, perseverance, positivity, and wholehearted devotion to uplifting others in every way he could will live on forever. Marqus' legacy will forever be a reminder of his triumphs, resilience, positive spirit, and complete dedication to uplifting others in every way he could.





# FACES OF SCD STORYTELLING PROGRAM



**Our Faces of SCD Storytelling** initiative was the keystone program that inspired the formation of Sick Cells and 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.

Due to the COVID-19 pandemic, our story collection in 2020 looked a little different, but we remained dedicated to sharing the experiences of SCD warriors and advocates. Our continued goal is to influence decision makers and inspire change by highlighting the grave disparities this community faces.

Sick Cells has collected more than 200 stories since the beginning of the program, and we continue 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 exciting future we see for this program.

## STORYTELLING ACCOMPLISHMENTS

This year, Sick Cells adjusted to the rapidly changing landscape shaped by the global COVID-19 pandemic and continued to tell stories. We conducted 24 interviews with adults living with sickle cell disease, caregivers, providers, and other advocates. The team expanded the storytelling format from in-person video interviews to an audio format and worked with advocates to tell stories. Their stories touched on the economic burden of their disease, the importance of public policy, and the day-to-day consequences of SCD on their lives.

**New Faces** Sick Cells introduced 25 new Faces this year. We produced in-depth stories in a new audio format to engage more advocates and enable their stories to reach more people. The new stories received over 100,000 website views. Sick Cells has over 12,500 followers on social media, with 5 million impressions engaging with the stories.

**Sick Cells Blogs** We launched an educational blog this year with topics based on feedback from the SCD community and our ambassadors. Our blogs featured interviews from 14 advocates, which produced 12 blog posts. Topics included the following:

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

**SCD Sticks Together** In response to the COVID-19 pandemic, Sick Cells published ten weekly bulletins to help advocates stay informed as our community adjusted to the public health crisis. The Weekly Bulletin was received by a mailing list of 1,200 people and featured tips from SCD advocates, wellness activities, the latest federal and local updates, and health alerts from the SCDA MARAC and the CDC.

**Value and Economic Burden of Disease** We worked with Partnership to Improve Patient Care (PIPC) to craft stories that highlight how SCD not only impacts the health of individuals and families but also has significant financial consequences. We published 4 standalone Sick Cells stories and produced 4 collaborative stories with PIPC.

**Music Therapy for Sickle Cell Disease** We partnered with Kids Rock Cancer and Seidman University Hospitals to produce stories about music therapy as a supplemental therapy. We highlighted stories from two music therapists and one SCD advocate over the course of 5 weeks. During that time, we published 3 songs, 2 blogs, and featured original content from the music therapy programs as tools for SCD advocates to explore this treatment option.

**Blood Donations Save Sickle Cell Lives** We partnered with Versiti Blood Banks of the Midwest to tell the story of Sick Cells co-founder Marqus Valentine and the impacts of blood donation. We were featured in the Chicago Tribune and successfully hosted the largest blood drive in the area all year. We received 28 units of blood, saving 72 lives.

**Racism in Healthcare Campaign** This year, we saw the nation come together to fight against systemic racism that still plagues our country. Sick Cells captured the sentiment of the SCD community and country through social media campaigns aimed at raising awareness regarding disparities with funding, research, and viable treatment for SCD. We interviewed two SCD advocates, featured a blog, and generated a social media campaign. *Our health care disparity campaign content was shared or forwarded over 1,200 times and seen over 38,000 times.*



## FACES OF SCD NEXT STEPS

The Faces of SCD platform has become an effective tool for educating both the SCD and broader communities. It has also been a valuable source of qualitative research that can serve as the foundation for quantitative research and highlighting areas of increased advocacy going forward. In 2021, Sick Cells will continue to expand the platforms and reach of the Faces of SCD Storytelling program. We will achieve this through the following functions:



**Interviews** In light of the growth and change in our audience, we will expand the topics covered in our stories. In 2021 we will conduct 50 interviews from the perspective of caregivers, family members, and diverse populations within the SCD community. We will also strive to feature interviews in both Spanish and English.

**Blog** In 2021 we will publish 15 new blogs. Based on feedback from the community, we will focus the blogs on educational topics ranging from treatments, patient experience, and how current events impact people living with sickle cell disease.

**Podcast** Sick Cells has over three years of recorded qualitative interviews. Additionally, the team has worked with hundreds of SCD advocates across the nation. An innovative way to continue to tell stories and educate about patient journeys is by an educational podcast. In 2021, the team will release 12 podcast episodes featuring caregivers and interviews with 10–12 advocates.

**White Papers** Sick Cells will publish up to 6 white papers to underscore what we have learned through interviewing the patient population. These findings will help highlight areas of need from within the SCD community and also serve as a summary of the over 200 interviews the team has conducted over the years.



[SCD] affects my day-to-day life in pretty much every way. There's really not a minute that you don't feel off, like not your normal self. Being off is a steady state. So some days are good, pain is not too bad and I can do my normal day, whether it be work, or hobbies on the weekends. And then some days are not so great where energy is even lower than it normally is, and pain's higher than it normally is, and the day turns into a struggle.

- Carlyle, Hgb SS

# THE AMBASSADOR PROGRAM



Sick Cells formally launched the Ambassador Program this year to recruit and train members of the sickle cell community to engage with policy makers at all levels. This year, over 50 ambassadors from across 20 states and Washington D.C. joined the program. The program is a network of individual volunteers dedicated to changing the landscape of sickle cell disease through policy change.

The strategic objectives of the Ambassador Program are to:

- **Recruit diverse ambassadors from the SCD community to engage with federal and state legislators**
- **Educate ambassadors about key policy issues (including recently passed SCD legislation, clinical trial design and participation, and access to medicines through coverage and reimbursement)**
- **Equip ambassadors with tools for ongoing advocacy at local and federal levels**
- **Host ambassador forums**

Ambassadors focused on priority topics including value assessments of sickle cell drugs, ensuring access to and insurance coverage of SCD treatments, sharing SCD stories with legislators, and grassroots advocacy.

Highlighted next are some of our early successes of the program.



## ADVOCACY EFFORTS



### RARE DISEASE WEEK, hosted by the EveryLife Foundation

Recruited over 30 SCD advocates to attend and hosted an SCD ambassador forum.

### BIOTECHNOLOGY INNOVATION ORGANIZATION (BIO) PATIENT ADVOCACY SUMMIT

Sick Cells spoke at the summit and recruited SCD advocates to attend.

### DURB MEETINGS

Recruited and prepared 6 advocates to attend DURB meetings in Georgia and Oklahoma. Likewise, we informed advocates about DURB meetings in Texas and Minnesota.

### SICK CELLS | AVALERE HEALTH DIALOGUE

Sick Cells hosted a multi-stakeholder workshop to identify barriers to accessing quality care. The workshop included stakeholders such as payers, industry partners, regulators, public health officials, providers, nurses, and patients. Ambassadors worked with the team to drive the agenda and participated in the meeting.

### BUILD YOUR STORY WORKSHOP

Hosted a one-hour skill-building workshop focusing on clear communication and storytelling in order to call attention to SCD and move legislators to action.

### #FUNDSICKLECELL MOVEMENT

Through our Ambassadors Program, Sick Cells lead a grassroots movement to educate the community about federal appropriations for sickle cell legislation and activate SCD advocates to contact their legislators. Through this campaign, more than 20 legislators were contacted. Congress appropriated just over \$7 million for various sickle cell-related programs this year, which is the most that has ever been allocated.

## PRIORITY TOPIC MEETING (PTMs)

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

### 2020 PRIORITY TOPICS

VALUE ASSESSMENTS AND ICER EVIDENCE REPORT  
COVID-19  
ENSURING ACCESS AND COVERAGE  
POLICY AND LEGISLATION  
STORYTELLING FOR LEGISLATORS  
GRASSROOTS ADVOCACY

To date, the Ambassador PTMs have developed the following tools which are available on our website:

- State-Level Advocacy Guide
- Build Your 5-Minute Story toolkit
- How to Meet with Your Legislator
- SCD Fact Sheet
- Priorities for Improving Access to Care
- Guide for DURB Meetings



“

I've dealt with acute chest syndrome a lot. That is where basically you have a sickle cell crisis in your chest, in your lungs, and it affects your breathing. You have chest pain. It's very, very painful. So I've had that a lot, I've dealt with that a lot. I've dealt with breathing issues and bone damage, but I consider myself one of the healthier ones with sickle cell. There are a lot of people that deal with sickle cell that have a lot more challenges than I do. So I'm grateful to be able to travel, and go out, and do the different things that I do with my organization.

”

- Jew-El, Hgb SS



# ADVOCACY & EDUCATION

# INVITATION TO THE WHITE HOUSE

On September 14, 2020, Sick Cells co-founder and President, Ashley Valentine was invited to the White House for the first-ever roundtable focused on SCD. The event, hosted by Former First Lady Melania Trump, was entitled *Improving the Lives of Americans Living with Sickle Cell Disease*. Attendees included people with sickle cell and their families, medical providers, and officials from HHS, OMH, NHLBI, and White House. Attendees came together to mark Sickle Cell Awareness Month and discuss the challenges that our community continues to face.

We are optimistic that this meeting will bring a new level of awareness to sickle cell disease and will bring future action to advance the patient voice and highlight the issues impacting our community. By meeting with the Former First Lady, we hope we can continue to look to our country's leaders to commit to change that fosters greater inclusion and understanding.



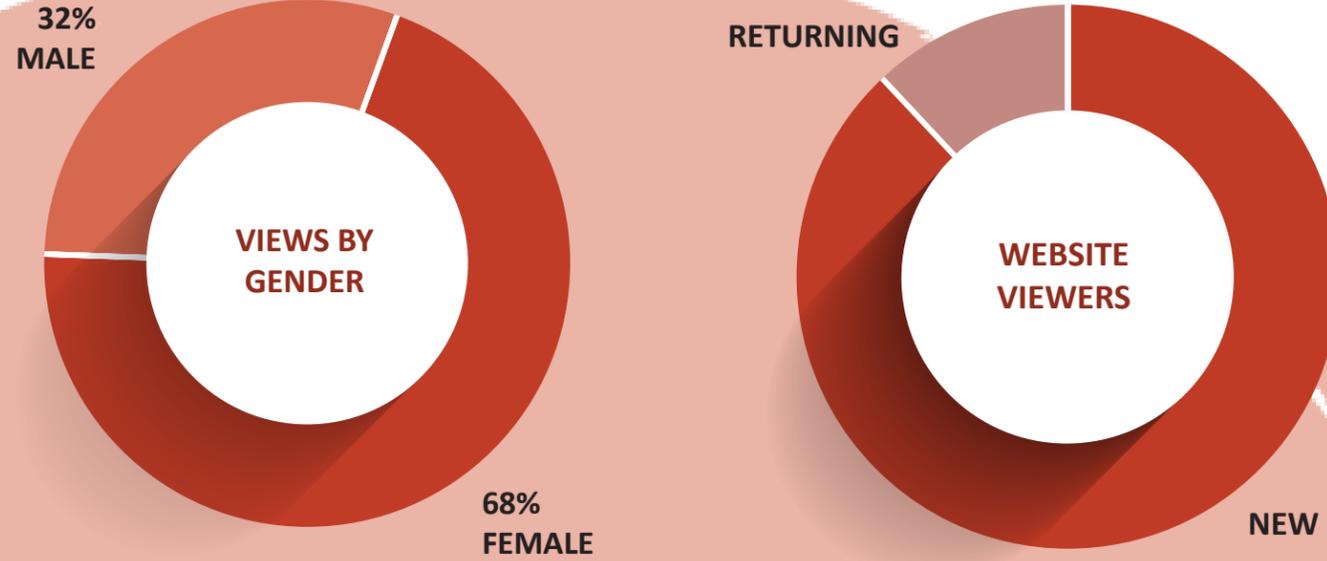
# MARKETING OUTREACH AND SUMMARY

**Team  
Sick Cells  
#FacesOfSCD**

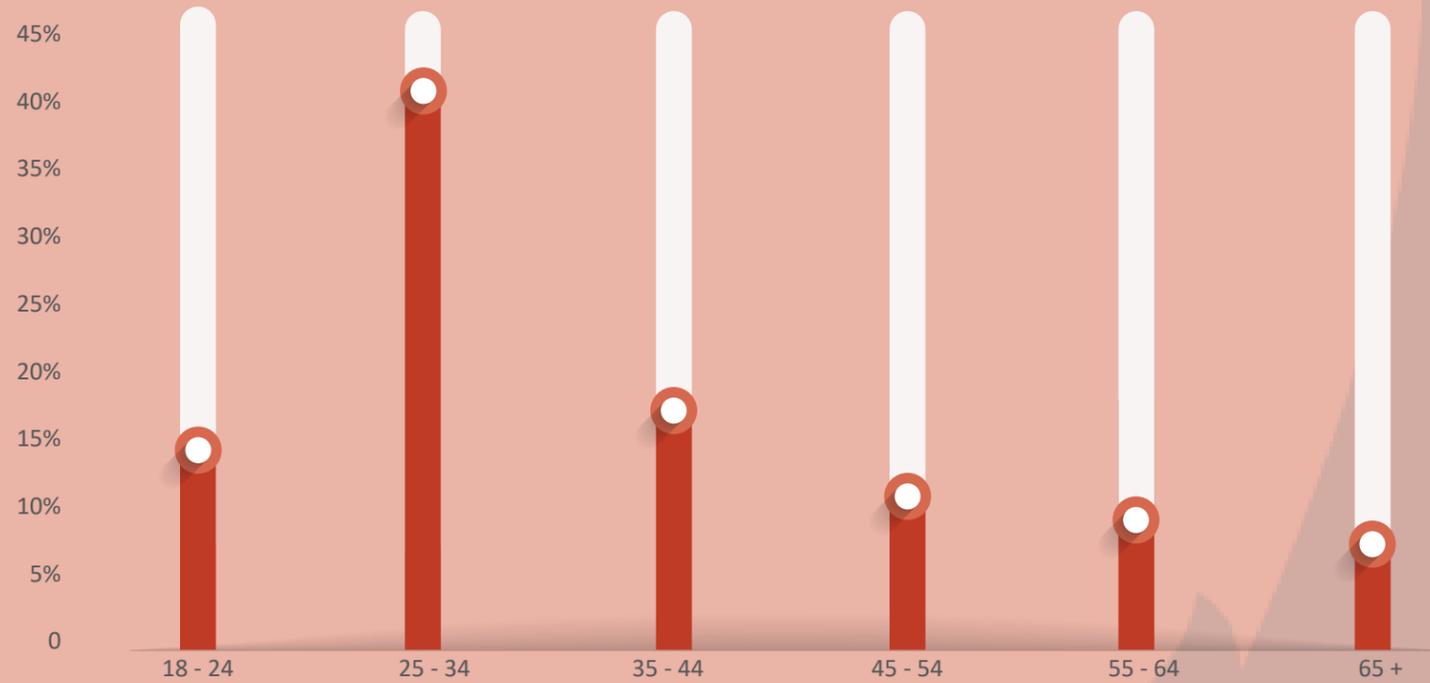
# WEBSITE

This year, Sick Cells launched a new website with a dedicated advocacy map, which resulted in total website views increasing from 16,000 to a combined 39,890 views and 33,620 unique views for both our old and new websites.

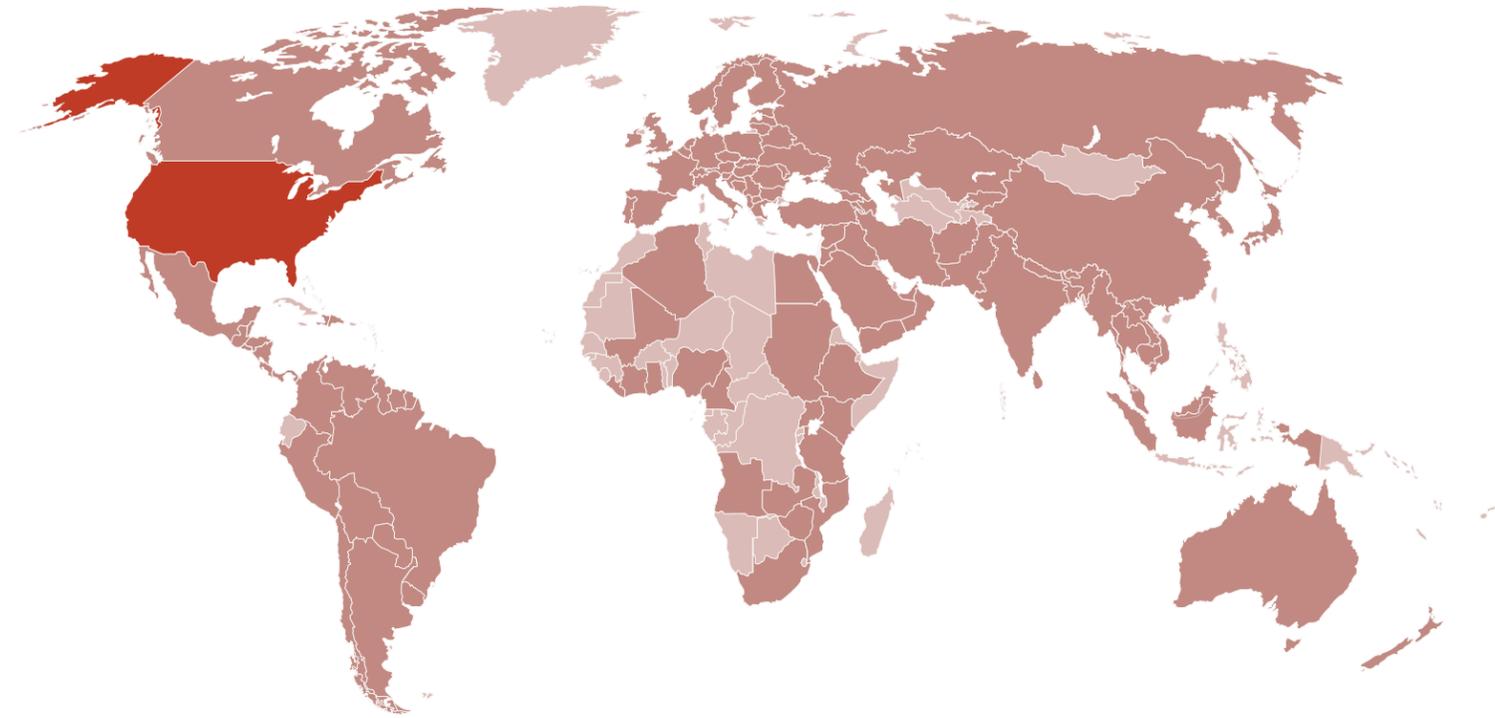
## NEW WEBSITE USERS



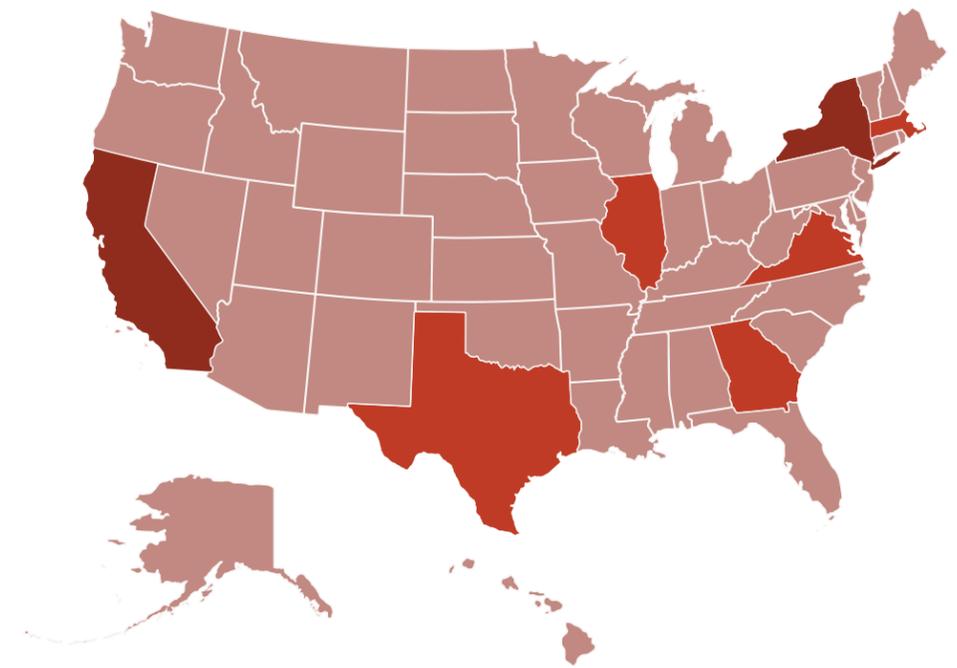
## USER'S AGE



## AUDIENCE LOCATION



1 7,138



2 1,271



MEET THE FACES

“ I try to stay hydrated. That’s very hard for me, because I don’t like water, but my doctor told me I can drink Gatorade, and get rest if I feel tired, and not to overdo it most of all, and taking my medicine. I just started like three months ago. I was not really wanting to, but since lately I’ve been getting more sick more often, my hematologist told me, ‘Let’s just start it, regardless of the side effects.’ Every medicine has its side effects, I guess.”

- Gabriela Torres, Hgb SC

## SOCIAL MEDIA

We greatly expanded our social media presence this year and organized several successful campaigns throughout the year. This created much greater engagement with and an increase in views of our website content. Social media was the number one acquisition source, with 21,330 views of the website by 3,645 total users.

ICER – Share Your Story	Sickle Cell Awareness Month
Covid-19 Bulletin	Promoting our newly launched website
Systemic Racism in Health Care	Fund Sickle Cell campaign
Ambassador Program Recruitment	Giving Tuesday
Faces of SCD Stories	Complementary Therapies

## EMAIL MARKETING

### NEWSLETTER SUBSCRIBERS

1,633

1,353 in 2019

### COVID-19 BULLETIN SUBSCRIBERS

1,472



## SOCIAL MEDIA BY THE NUMBERS

	13,001	1,647	938	1,011,349	55,918
	AUDIENCE	AUDIENCE GROWTH	PUBLISHED POSTS	IMPRESSIONS	ENGAGEMENTS
	8,347	601	225	639,501	37,871
	2,970	718	333	202,659	12,225
	72	46	71	3,483	267
	1,612	282	309	165,706	5,555

2020 TOTALS



# FINANCIAL HIGHLIGHTS

# REVENUE AND EXPENSES TABLES

## REVENUE

### Sponsorships & Grants

Corporate Sponsorship	\$5,500.00
Corporate Advisory Council	\$75,000.00
Ambassador Program	\$97,500.00
Avalere Partnership Dialogue	\$140,000.00
<b>Total Sponsorships &amp; Grants</b>	<b>\$318,000.00</b>

### Donations

General Public Donations	\$5,719.20
Event Fundraising	\$824.00
Web Donations	\$17,484.69
Speaking Engagements	\$500.00
<b>Total Donations</b>	<b>\$24,527.89</b>

**Total Revenue \$342,527.89**

## EXPENDITURES

Advertising, Marketing & Website Development	\$39,206.12
Bank Charges & Fees	\$213.00
Contractors	\$139,383.61
Registration Fees	\$50.00
Legal & Professional Services	\$8,875.00
Meals & Entertainment	\$505.12
Office Charges	\$299.99
Office Supplies & Software	\$3,522.97
Payroll and Taxes	\$68,349.40
Reimbursable Expenses	\$4,988.70
Other Taxes and Licenses	\$26.00
Advocacy Travel	\$2,903.37

**Total Expenditures \$268,323.28**

# DONOR AND CORPORATE SPONSORSHIPS

Sick Cells generated revenue through the following avenues:

### INDIVIDUAL DONORS

Total: \$24,527.89

### PRIVATE WEB DONORS

### FACEBOOK DONATIONS THROUGH NETWORK FOR GOOD

### EVENT FUND-RAISING

### SPEAKING ENGAGEMENTS



### SPONSORSHIPS & CORPORATE DONORS

Total: \$318,000.00

### BLUEBIRD BIO

### NOVARTIS

### GLOBAL BLOOD THERAPEUTICS

### BIOTECHNOLOGY INNOVATION ORGANIZATION

### PHARMACEUTICAL RESEARCH AND MANUFACTURERS OF AMERICA

### CRISPR PHARMACEUTICALS

### VERTEX PHARMACEUTICALS

### SANOFI GENZYME

### PFIZER

### TERUMO BLOOD & CELL TECHNOLOGIES

## OTHER GRANTS

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

**GOOGLE NONPROFIT GRANT** Sick Cells receives unlimited e-mail addresses, a web domain, unlimited G-Suite services, and \$10,000 a month in Google Awards. We will continue this grant in 2021.

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

**CANVA PRO FOR NONPROFITS** Sick Cells receives Canva Pro, a \$120 service, for free through Canva's nonprofit program. The team uses this service to create high-impact social media graphics and marketing materials.

**SPROUT TECHNOLOGY GIVING PROGRAM** Sick Cells receives free access to the social media management solution application from Sprout Social. The team uses this service to organize, schedule and track our social media posts and engagement.

**SLACK FOR NONPROFITS** Sick Cells receives Slack's advanced plan, a \$150 service, for free through Slack's nonprofit program. The team uses this service to stay connected, organize conversations and projects, and share documents as we work virtually.

# PARTNERSHIPS

Sick Cells values partnerships as a way to grow awareness and educate about SCD. Through partnerships, we are able to inform the SCD population of resources and best practices from both outside of and within the SCD space.



## PARTNERSHIP ACCOMPLISHMENTS

**AVALERE HEALTH | SICK CELLS DIALOGUE** In a historic move, Sick Cells partnered with Avalere Health to host a multi-stakeholder dialogue about barriers to accessing care for people living with SCD. Patients, payers, government officials, health care providers, and industry partners discussed challenges and explored potential solutions, helping to pave the way for better outcomes for the SCD community.

**VERSITI BLOOD BANKS: REMEMBERING MARQUS VALENTINE BLOOD DRIVE** On June 22, 2020, Sick Cells and the Valentine family lost Co-founder and Sick Cells' inspiration, Marqus Valentine. In honor of his work to encourage blood donation, his family and Sick Cells partnered with Versiti Blood Banks to host a blood drive. In one day, the event received 26 whole-blood donations and 1 double red cell donation. This was the largest blood donation that Versiti Illinois has had since the pandemic started in March. The blood went to Marqus's home hospital, Edward Hospital in Illinois.

**MILKEN INSTITUTE: FASTERCURES** FasterCures is hosting a series of workshops on specific issues that impact patient access. Sick Cells is participating in programming and workshops to incorporate issues that impact the SCD community. The project brings all stakeholders to the table to address challenges related to the emerging landscape of gene and cell therapy and to elevate patients' voices in securing access to therapies.

**NOVA SOUTHEASTERN UNIVERSITY** In October, Sick Cells partnered with Nova Southeastern University's Medical School to lead a continuing education course about the pathology of SCD and the impact SCD has on patients' lives. The lecture was hosted by the school's Underserved Medicine Club. We have been invited to lead two sessions in 2021.



## SCD NONPROFITS PARTNERS

THE SICKLE CELL COMMUNITY CONSORTIUM  
SICKLE CELL DISEASE ASSOCIATION OF AMERICA, INC. (SCDAA)  
SICKLE CELL 101

## NON-SCD NONPROFITS PARTNERS

AMERICAN SOCIETY FOR HEMATOLOGY	FOUNDATION
NATIONAL MINORITY QUALITY FORUM (NMQF)	KIDS ROCK CANCER
ASTHMA AND ALLERGY FOUNDATION OF AMERICA	NATIONAL HEALTH COUNCIL
COALITION FOR HEADACHE AND MIGRAINE PATIENTS (CHAMP)	NATIONAL MULTIPLE SCLEROSIS SOCIETY
CYSTIC FIBROSIS RESEARCH, INC.	NATIONAL ORGANIZATION FOR RARE DISORDERS
EVERYLIFE FOUNDATION	PARENT PROJECT MUSCULAR DYSTROPHY
GLOBAL GENES	PARTNERSHIP TO IMPROVE PATIENT CARE (PIPC)
GLOBAL HEALTHY LIVING	

## CORPORATE ADVISORY COUNCIL

This year, Sick Cells began building strategic partnerships with businesses and corporations that share our vision of eliminating health care disparities and improving the lives of the sickle cell community. We developed the Sick Cells Corporate Advisory Council (CAC) to inform companies about health and policy disparities and the landscape, not only for people living with sickle cell and advocates, but for under-served populations overall.

The CAC was developed with the hope that together, Sick Cells and important stakeholders can work toward solutions.



## SUMMARY & CLOSING

As we closed the books on an unprecedented year, we looked forward to the new opportunities that 2021 will hold. As our advocacy programs continue to grow, we hope to continue making changes 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.

Thank you to each organization that welcomed us, our sponsors who funded our programs, our 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.

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