



SICK CELLS

ANNUAL REPORT | 2018

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A NOTE FROM SICK CELLS' FOUNDERS

A SMALL FILM PROJECT

In 2008, Sick Cells started as a small film project to highlight the daily life of our family, the Valentines, as we navigated sickle cell disease (SCD). Today, we have grown to so much more.

A DOCUMENTARY

Marqus was born with sickle cell disease, a chronic blood disorder, and his condition has impacted our entire family. At the time, we wanted the public to see and understand how a person and their family lives with SCD day-to-day. In doing the Sick Cells documentary, our goal was to highlight the incredible lengths our family went to maintain our well-being. During the process, we realized a responsibility to share not just the Valentine's story, but that of the entire SCD Community.

A NONPROFIT

On February 28, 2017, Sick Cells proudly became a nonprofit. We saw the need to eliminate stigma associate with SCD to shape public policy and improve the quality of life for the SCD community. We are committed to diversifying the sickle cell voice to include all types and faces of SCD. Telling every type of sickle cell story is key to understanding this complex condition and the people that it touches.

After almost two years of working as a nonprofit, Sick Cells has grown legs and is ready to start running. We are incredibly grateful for all our volunteer staff and the achievements that we have accomplished to date. We look forward to the future for the SCD community and making this condition a household name.

– Marqus and Ashley Valentine, Co-Founders of Sick Cells.





FACES OF SCD STORYTELLING INITIATIVE

The role of sickle cell walks:

In 2018, Sick Cells attended three sickle cell walks to continue our “Faces of SCD” storytelling program. Faces of SCD is an initiative to address stigma and other challenges faced by 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 decisionmakers and propel change.

SCD WALKS AND INTERVIEWS

JUNE - SEPTEMBER 2018

During the months of June through September, Sick Cells traveled to Chicago, New York and Memphis and interviewed 44 SCD advocates about their experiences with SCD. Through the established event, motivated SCD advocates from the community convene in one location. We worked closely with community leaders to recruit these advocates and their interviews before we arrive at the event.

CHICAGO

Chicago Walk in Collaboration with the Sick Cell Disease Association of Illinois (SCDAI) - Sick Cells attend the Illinois Sick Cell Walk in June. The weather made it challenging to host a sickle cell event, with rain and high winds preventing people from attending. Regardless, the walk took place and the Sick Cells team was able to collect seven stories. While in Chicago, the team learned that the majority of the interviewees were unaware of clinical trials. We also found that many parents with children who have SCD were unaware of their sickle cell trait status. This finding aligns with IL state newborn screening policies, which did not include sickle cell trait or disease into screening until 1987. Finally, we met many parents of young children with SCD. They shared with us how they educated their school districts about their children’s condition. They were eager to learn about the national and local landscape of SCD. Sick Cells published the Chicago walk stories September through November.



“Well back then, you had to actually go into the library and read up on it. There was no internet back then. There was no hydroxyurea. The only thing that we could do was try to make her comfortable. The thing that made her comfortable was hot baths. Rubbing her stomach, rubbing her arm, wherever the crisis was happening. Tried to get her mind off of it, and tried to encourage her. She went to church. She was very, very active. We just tried to keep her in a positive attitude. That really, really worked. God really helped us with that.”

- Rod, daughter has SCD, hemoglobin SS



NEW YORK CITY

New York City Walk in Collaboration with Sick Cell Thalassaemia Patient Network (SCTPN) - The SCTPN welcomed Sick Cells to New York City in September. Sick Cells also partnered with Vita Coco®, who handed out coconut water to participants that shared their stories with Sick Cells and attended the event. On this hot day, the team interviewed more than 25 people. The NYC sickle cell population is unique. We interviewed many advocates and families from Haiti and various countries in Latin America. We also learned that the state of NY defunded sickle cell programs. The NYC community was encouraging advocates to attend a lobby day in January 2019 to request that the funding be re-instated. The team is publishing the stories in 2019.



MEMPHIS

Memphis Walk in Collaboration with Sick Cell Foundation of Tennessee

Sick Cells worked with the SCFT to attend their event. While in Memphis, the team spoke to **SCD warriors about mental health and the importance of support systems**. One interview, in particular, came from best friends who lived in the Carpenter House, a home donated by the Carpenter family for SCD warriors who were without housing due to their circumstances. The gentlemen were 25 years old, with one friend having SCD and the other friend registering to be his caregiver. They shed light on the impact of chosen family and the need for their supportive friendship. **Sick Cells collected 12 stories from Memphis, many of which are more than 40 minutes long.** The team is publishing the stories in 2019.

POLICY ENGAGEMENT

Our goal of educating the SCD community: The sickle cell community has historically been under represented in policy and legislation. Sick Cells is committed to educating the SCD community on policy advocacy and incorporating the SCD voice into legislation.

This section highlights Sick Cells' policy and legislation activities including participation in coalitions and legislation that has been passed with the help of Sick Cells.



– Kevin is a sickle cell advocate who attended Rare Disease Week for the first time in 2018.

SICKLE CELL TREATMENT ACT

WHAT HAPPENED, FIRST

Congress passed sickle cell disease legislation in 2018. House Bill HR2410, the *Sickle Cell Disease Treatment Act of 2017*, was co-sponsored by Representatives Burgess and Davis. It passed the House in February while Sick Cells and 44 other sickle cell advocates were in Washington, DC. In February, Senators Scott and Booker introduced the *Senate companion bill S.2465 the Sickle Cell Disease Treatment Act of 2018*.

WHAT WE DID

Throughout the bills’ journey through the House and Senate, Sick Cells recruited patient groups to sign onto letters of support and meet with their legislators to discuss the need for bill.

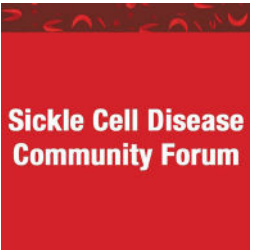
WHAT HAPPENED, NEXT

The Senate companion bill passed the Senate in October. It was, then, returned to the House for reconciliation due to language change.

WHAT WE DID

When this occurred, Sick Cells formed and led a task force to engender SCD patient and rare disease patient support. Sick Cells also worked closely with various stakeholders including Sen. Bookers’ and Scotts’ offices, and the Sickle Cell Disease Association America (SCDAA) to get the bill on the House voting calendar during the final weeks of lame duck in 2018.

THE RESULT THE BILL WAS SIGNED INTO LAW
DECEMBER 11, 2018



ILLINOIS FAIR CARE COALITION

WHAT HAPPENED

The IL Fair Care Coalition is a group of patient advocacy organizations that work in a coalition to ensure access to medication for Illinoisans with disabilities. The coalition is led by the US Pain Foundation and worked to pass House Bill 4146. The bill ensures that individuals receive prescription drug coverage by limiting mid-year drug formulary changes by insurers.

WHAT WE DID

With the help of Sick Cells participation, IL HB 4146 passed the IL House and Senate in 2018 and was signed into state law.



“ I’m not there [school] cause I have pain. It makes me lose where I’m at in school. [My friends] ask me what it is, and where did it come from. I explain the blood sickles, and it stops blood flow. It causes pain wherever it stops the blood flow. ”
- Javon, 15 years old, SCD hemoglobin SS

MEET THE FACES



“

Just fevers [and] it affect his hands and feet as well. When his hands and his feet swell. Each and every sickle cell patient is different. They go through different things, so some sickle cell patients may not experience other things but at least you know the history of your sickle cell patient, knowing the flare ups. You know the crisis that do occur most often. You know around the time of year.

- Reggie's Mother, April

”

MEET THE FACES

PART B ACCESS FOR SENIORS AND PHYSICIANS (ASP) COALITION

WHAT THEY DO

The ASP Coalition represents a broad cross-section of US health care providers and patient advocacy organizations. These entities are committed to advancing life-saving innovation in the US.

HOW WE'VE HELPED AND WHY

Over the course of the year, Sick Cells has signed onto three letters in regards to the Centers of Medicaid and Medicare Services' (CMS) proposed rules of Part B coverage for drugs and their pricing index. Sick Cells is active with this coalition because nearly 13 percent of the sickle cell population use Medicare as part of their benefits. Sick Cells has also recruited multiple other sickle cell disease organizations, including the SCDA, to participate with this coalition.



RARE DISEASE WEEK

Sick Cells became active in rare disease week during 2018.

WHO WE WORKED WITH

This year, we worked with the EveryLife Foundation (EveryLife) and the National Organization for Rare Disorders (NORD). EveryLife hosted Rare Disease Week on Capitol Hill in February.

WHAT WE DID

Sick Cells worked with SCD volunteers to recruit and prepare more than 44 SCD patient advocates who came to Washington, DC and lobbied for rare disease and sickle cell disease legislation.

ONE RESULT

The EveryLife Foundation reported that this was the largest amount of SCD advocates to attend Rare Disease Week ever. For many SCD advocates, this was the first time they were made aware that SCD is considered a rare disease.

WHAT ELSE WE DID

On Rare Disease Day (February 28) Sick Cells attend a lobby day in IL hosted by NORD. While there, Sick Cells educated state legislators about funding gaps in IL for sickle cell patients. The team discussed with IL senators the prevalence of SCD in the state and the need for visibility at the state level.

ANOTHER RESULT

As a result of this work, Sick Cells' President and Co-Founder, Ashley Valentine, was nominated for the EveryLife Foundation's Rare Voice Award in patient advocacy at the State Level and Sick Cells became official NORD members.

NEWSLETTER

Goes out monthly

The Sick Cells newsletter is our most consistent form of communication with our constituents. The newsletter goes out monthly on the last working day. It has been active for more than two years.

The mailing list is growing

This past year, our mailing list grew significantly. Thanks to a Facebook advertising grant, Sick Cells was able to widen the newsletter audience and reach more readers.



MEDIA HIGHLIGHTS

Sick Cells has had multiple media engagements this year.

Co-Founders, Marqus and Ashley Valentine, actively use their voices to spread awareness about sickle cell disease and bring other voices into the advocacy space. This section highlights our main media appearances from 2018.

ABC 7 CHICAGO

ABC 7 Chicago — Co-founders Marqus and Ashley Valentine, in collaboration with the American Red Cross, appeared on a news segment in December. The news segment was to encourage participation in the Greater Chicago Blood drive. Marqus expressed his need for blood transfusions and discussed the importance of blood donation to the sickle cell community. Ashley spoke about Sick Cells and how sickle cell disease impacts the family.



NPR'S 1A

Marqus was a guest on NPR's 1A radio show in February. As a follow-up to the Kaiser Health News article, 1A did a story called, "Why You Don't Hear About Sickle Cell Anymore."

FOX 32 CHICAGO

Marqus Valentine, in collaboration with the Sickle Cell Disease Association of IL Executive Director, TaLana Hughes, appeared on a live segment in September for sickle cell awareness month. They spoke on air about the complications of sickle cell disease.

NATIONAL JOURNAL

Ashley and Marqus Valentine spoke with the National Journal, a political news outlet for Congress, about the importance of the sickle cell bill. The story explained how the House bill HR 2410 and the Senate companion bill S.2465 would improve the care for patients and families with sickle cell disease.

KAISER HEALTH NEWS

Marqus Valentine and his mother Francesca Valentine were featured in a Kaiser Health News feature story about sickle cell disease on December 26, 2017. The story gained national attention being picked up by outlets like the Washington Post and USA Today well into 2018.



PARTNERSHIP

The team's partnerships are growing: Sick Cells strives to maintain and foster partnerships, inside and outside of the sickle cell community.

During 2018, the team's partnerships grew to include many facets of the sickle cell experience. This section outlines our types of partnerships that Sick Cells established this year.

RARE DISEASE PARTNERSHIPS

Sickle cell disease is classified as a “rare disease” in the U.S. There are multiple rare disease nonprofits that focus on policy and legislation, drug development, and services for the rare disease community. A rare disease is a disease that affects 200,000 or less people in the United States. Sickle cell disease affects about 100,000 people.

Sick Cells actively increased SCD patient engagement in the rare disease space. This year, Sick Cells joined the National Organization for Rare Disorders (NORD) as a paid member. We are the first and only sickle cell disease organization to join NORD. Sick Cells is also part of the following organizations:

- GLOBAL GENES
- EVERYLIFE FOUNDATION
- INSPIRE



CHRONIC DISEASE AND MINORITY DISEASE PARTNERSHIPS

Sick Cells expanded partnerships to chronic disease and minority disease organizations. Complications from SCD cause many other compound conditions. To ensure that a robust patient voice is heard, Sick Cells recruited and participated in organizations that treat aspects of SCD including:

- US PAIN FOUNDATION
- BIO
- MINORITY HEALTH QUALITY FORUM
- NATIONAL HEALTH COUNCIL



“ All I wanted to do was dance. I couldn’t because I ached so much. I did my school work, I was a straight A student. I still just wanted to dance. But when it come to dancing, being a cheerleader, I wasn’t active as most girls. So now by being a grown woman, I got an opportunity to partner with someone to help me get a dance studio for the community. ”

- Laterrica, 34 years old with SCD, hemoglobin SS

MEET THE FACES



“My mama did not hold me back from enjoying my life. We never knew when I was going to leave. My mama was like I’m not going to stop you from playing basketball, I’m not gonna stop you from doing all of this. It gave me more to look forward to out of life.”

- Anthony, adult with SCD, hemoglobin SS

MEET THE FACES

SICKLE CELL DISEASE PARTNERSHIPS

Sick Cells worked with multiple sickle cell organizations throughout the year. We did so to capture the patient voices in different regions of the United States. When we attended walks, we worked with the local sickle cell organizations to recruit participants and highlight their local challenges and stories. Sick Cells worked with the Sickle Cell Disease Association of America in advocating for the federal sickle cell bill (S.2465 and HR. 2410) that was signed into law during 2018. Sick Cells partnered with the following sickle cell organizations in 2018:

- SCDAA
- SICKLE CELL DISEASE
- SICKLE CELL THALASSEMIA
- ASSOCIATION OF IL PATIENT NETWORK
- FOUNDATION FOR SICKLE CELL DISEASE OF TENNESSEE
- SICKLE CELL 101
- BOLD LIPS FOR SICKLE CELL
- THE SICKLE CELL FORUM
- THE MARTIN CENTER
- URIEL E. OWENS SCD SICKLE CELL DISEASE ASSOCIATION OF THE MIDWEST



FINANCIAL HIGHLIGHTS

Sick Cells saw growth from 2017 to 2018. The organization operated with volunteer staff and used funds for operations outside of donated services. This section shares financial highlights from 2018.

Below are the following highlights:

Year ending-December 31, 2017

Gross revenue was \$1,669.05 (formation) July through December 2017.

Year ending-December 31, 2018

Gross revenue was \$26,007.57; a 64% increase; continued growth to support vision and goals.

Year-end December 31, 2018

Revenues attributed to private donations, fundraising, loyal supporters, and contributors.



FINANCIAL SUMMARY

(COMBINED FINANCIAL SUMMARY FOR FISCAL YEARS 2017/2018)

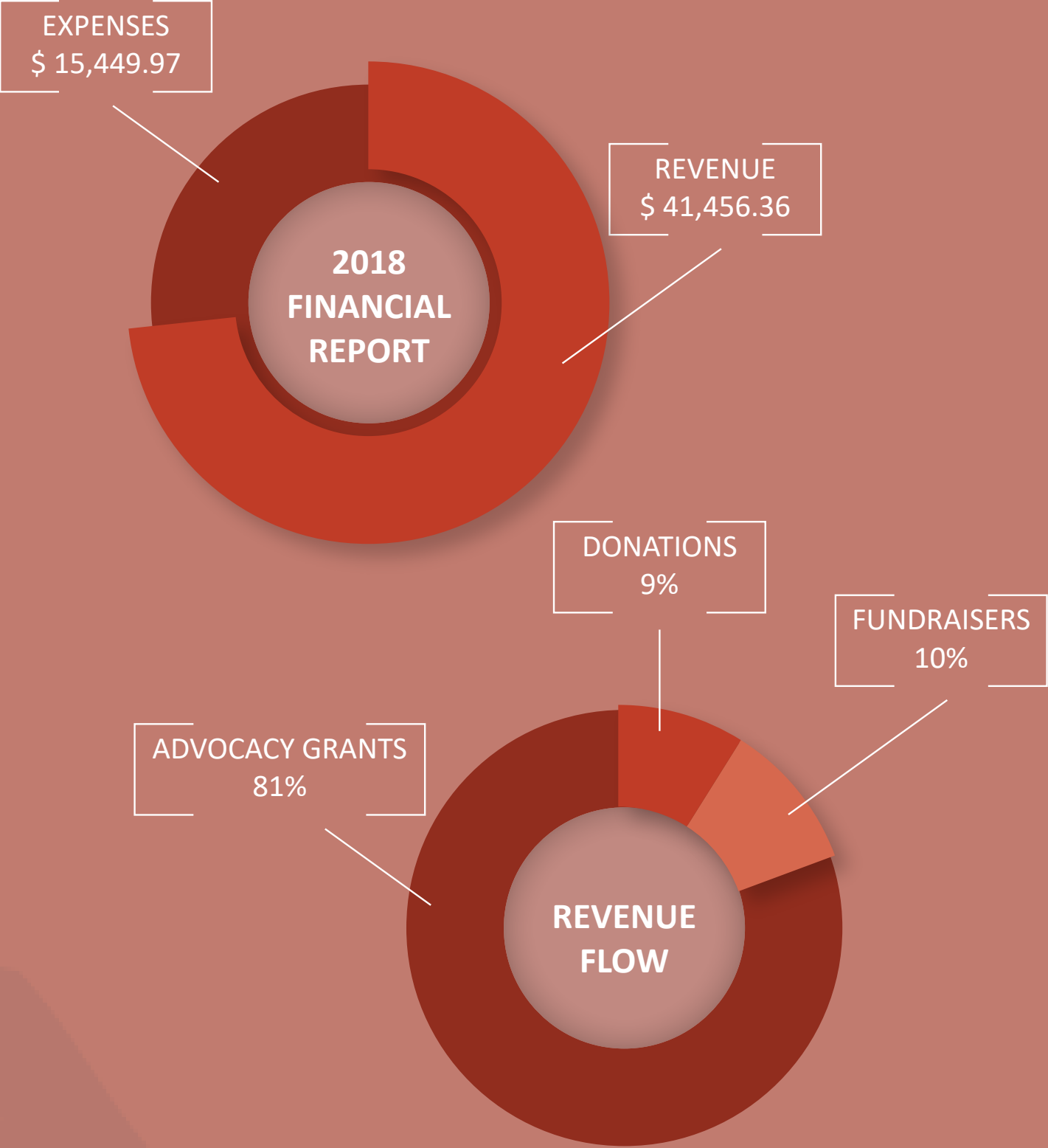
THE TABLES BELOW SUMMARIZE SICK CELLS ANNUAL FINANCIAL ACTIVITY

OPERATIONS RESULTS

	2017	2018
Revenues		
Investment Income	550.00	000.00
Fundraising/Donations	3,123.05	7,956.63
Advocacy Grants	000.00	33,500.00
Total Revenues	3,673.05	41,456.36
Expenses		
Administrative/General	1,000.00	1,500.00
Bank Fees	4.00	2.00
Program Services	000.00	9,481.79
Other	1,000.00	1,466.00
Total Expenses	2,004.00	15,449.79
Remaining Resources	1,669.05	26,006.57
Current Assets (2018)	26,006.57	
Current Liabilities (2018)	000.00	
Ending net liabilities/assets (2018)	26,006.57 (2018)	(Unrestricted)

REVENUE AND EXPENSES TABLES

THE TABLES BELOW SUMMARIZE SICK CELLS ANNUAL FINANCIAL ACTIVITY





“ 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. You look perfectly fine and you say you’re sick and they think you’re not sick or that you’re lying ‘cause you don’t look sick. ”

- Mariza, 22 year old, with SCD, hemoglobin SS

MEET THE FACES

DONORS AND CORPORATE ADVOCACY GRANTS

Our revenue was generated through the following avenues:

PRIVATE DONORS
FACEBOOK DONATIONS THROUGH NETWORK FOR GOOD
WIGGIN’ OUT ANNUAL FUNDRAISER
STONEWALL KICKBALL LEAGUE

Sick Cells received advocacy grants from the following companies:

BLUEBIRD BIO
NOVARTIS PHARMACEUTICALS
GLOBAL BLOOD THERAPEUTICS
PFIZER PHARMACEUTICALS



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 Adwords. We will continue this grant in 2019.

FACEBOOK ADVERTISING GRANT

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

CLOSING

We are committed to making an impact: As an organization, Sick Cells is committed to advocating on behalf of sickle cell disease patients, families and caregivers. This annual report is a testament to our standards of transparency and continuous strive for growth. We look forward to growing, sharing, and making an even larger impact within the SCD community in 2019



