HOPE
PROJECT

Hispanic Outreach Promoting Equity Project:
Final Report

Sick Cells

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Funded by: Global Genes Health Equity Grant

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Foreword

The purpose of the Hispanic Outreach Promoting Equity (HOPE) project was to understand how race and ethnicity have impacted the experiences of Hispanic individuals with sickle cell disease (SCD). We hoped to learn more about the unique challenges they have faced and outline recommendations for addressing existing gaps in care for the Hispanic SCD community.

We are grateful to our subject matter experts (SMEs), Nilda Navedo and Maria Rivera, for providing their insights and expertise throughout this project. We thank them for their continuing commitment to advocating for SCD, and we would like to acknowledge their loved ones Vanessa Felix and Jazmine Rivera, whose memories we honor through this project.

We would also like to thank our reviewers, the SMEs and Dr. Titilope Fasipe, for their input on the final report of this project.

In addition, we thank our roundtable participants Servio Astacio, Carmen Navedo, Doris Polanco, and Stephanie Ramos for sharing their stories with us and helping us develop our understanding of the Hispanic SCD community. Thank you to Dr. Fasipe for providing the perspective of a provider for this community.

We are optimistic that through this project we will raise awareness about Hispanic individuals with SCD and help combat the race-based medicine that is prevalent in SCD care.

Ashley Valentine
Co-Founder and President
Sick Cells

Sick Cells is a nonprofit sickle cell patient advocacy organization founded in 2017. Sick Cells' mission is to elevate the voice of sickle cell disease (SCD) community and stories of resilience. By highlighting the grave disparities in the sickle cell community, Sick Cells aims to influence decision-makers and propel change.

Karla Sintigo
Research and Community Engagement Intern
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As of 2021, Karla is a 2nd year medical student at the University of Illinois College of Medicine at Chicago. Her mission is to serve the Hispanic community and all communities of color to promote equity in healthcare. As a future physician, she hopes to provide culturally competent care to all of her patients.

Executive Summary

Introduction: Sickle cell disease (SCD) is a hereditary blood disease that causes devastating complications for patients and their families. In the United States, the SCD population is primarily comprised of Black and African Americans and Hispanic Americans. According to the Centers for Disease Control and Prevention (CDC), in the United States, SCD affects about 100,000 Americans. SCD occurs in about 1 in every 365 Black or African American births, and in about 1 out of every 16,300 Hispanic Americans births.[1] The racial and ethnic makeup of the SCD population has led to poorer health outcomes and has contributed to a history of health disparities. This has resulted in a general misunderstanding of the disease, leading to barriers in access to care.[2] Although SCD disproportionately impacts Black and African American people in the United States, there are growing populations of Hispanic Americans living with SCD and individuals who identify as first-generation US citizens. [1]

Based on our own study and that of others, Sick Cells identified the need to conduct further research into the unique educational gaps for the Hispanic SCD community. To address these gaps, Sick Cells launched the Hispanic Outreach Promoting Equity (HOPE) project. The objectives of the HOPE project are as follows:

- **Objective 1:** Conduct a systematic environmental scan of the existing resources available in Spanish and/or specifically targeting the Hispanic population living with SCD.
- **Objective 2:** Host a roundtable discussion that will serve as a focus group, consisting of caregivers and individuals living with SCD from the Hispanic community. Release a summary report of key findings from the roundtable discussion and environmental scan that highlights key gaps in educational needs.
- **Objective 3:** Expand Sick Cells outreach to the Hispanic community and provide them with educational resources and a place to network with other SCD advocates with similar experiences.
- **Objective 4:** Create recommendations for educational tools. Feature a diverse representation of Hispanic people living with SCD and create Sick Cells tools in Spanish.

Environmental Scan: Sick Cells conducted an environmental scan of current educational resources for the Hispanic population living with SCD. The goals of the environmental scan were to: (1) define the terms “Hispanic” and “Latino” (2) understand what resources exist for the Hispanic community living with SCD; and (3) find Spanish-language resources related to SCD.

Based on the environmental scan, Sick Cells found that there is a need for more information about SCD specifically for the Hispanic community. While there were limited clinical resources available, there are fewer resources that provide additional information about living and managing SCD, available treatment and therapies, disease progression, advocacy tools, clinical trials, nonprofit organizations, and more.

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[1] Centers for Disease Control and Prevention. (2020, December 16). *Data and Statistics on Sickle Cell Disease*. https://www.cdc.gov/ncbddd/sicklecell/data.html

[2] Haywood, Carlton Jr et al. “Perceived discrimination in health care is associated with a greater burden of pain in sickle cell disease.” *Journal of pain and symptom management* vol. 48,5 (2014): 934-43. doi:10.1016/j.jpainsymman.2014.02.002

Additionally, there is a need for the healthcare community at large to learn about who is impacted by SCD. Misinformation leads to race-based medicine practices that not only harm the Black and African American SCD community, but also the Hispanic SCD population.

Other findings from the environmental scan show that there are opportunities for companies, nonprofits, hospitals, and any other vested stakeholder in the SCD space to expand their resources to this population, starting with access to materials in Spanish. Furthermore, there is room for general education about SCD within the broader Hispanic community, specifically with regards to sickle cell trait (SCT) and how SCD and SCT are passed down in families.

Roundtable Discussion: The roundtable participants included four SCD warriors, two SCD caregivers, and one SCD provider. Sick Cells staff participated as moderators for the discussion. We recruited participants through the Sick Cells' Ambassador Program, Sick Cells' network of individuals, and two subject matter experts (SMEs). The roundtable discussion (RTD) was conducted over two hours and the team completed four of the five themed discussions. All participants except the provider were compensated for their time.

Roundtable Discussion Materials: In preparation for the RTD we translated the agenda and discussion guide into Spanish and prepared a presentation to facilitate conversation from the RTD participants. The RTD was conducted in English and Spanish. Participants were encouraged to engage in whichever language they felt most comfortable.

The roundtable participants shared their knowledge and personal experiences as Hispanic individuals living with SCD or caring for someone with SCD. We discussed five overarching themes:

- Need for more Awareness
- Need for more Support
- Racial Bias in Healthcare
- Communication Barriers
- Mistrust of medical providers

Social Media Campaign: From October 1 - October 15, 2021, Sick Cells launched a social media campaign on Instagram to feature the stories of two SCD warriors and one SCD caregiver from the Hispanic community. The team published one HOPE Project blog in both English and Spanish and published a Spanish version of a previous blog about COVID-19 vaccines and SCD.

Limitations and Recommendations:

Limitations: The project was funded by the Global Genes Health Equity Grant. With $15,000 of funding, we were able to conduct a systematic review of the online resources available to individuals living with SCD from the Hispanic community. While our findings are telling and insightful, we were limited in the number of hours spent on the environmental scan, individuals we could interview, and hours to review content. We see this as an opportunity to continue this work and create more-detailed recommendations to improve the quality of care and support for the Hispanic SCD population.

Recommendations: Our findings from this project underscore the need for a focus on the Hispanic SCD population.

- *Education:* There is a need for more education about SCD in the Hispanic population, stakeholders across the healthcare spectrum, advocacy organizations, legislators, and the general public.
- *Language Resources:* To increase reach, insurance and pharmaceutical companies, state health departments, federal agencies, and large organizations should have language options on their websites for both clinical and non-clinical information related to SCD and SCT. This will allow individuals who speak languages other than English to feel included and engage with the provided content.
- *Representation*: To increase awareness about SCD in the Hispanic community, storytelling that features Hispanic caregivers and individuals living with SCD should be incorporated into existing work, campaigns, educational materials, and beyond.

Partnerships: To reach the broader Hispanic community, we suggest partnerships with organizations that focus on health and health literacy for the Hispanic population. We also suggest working with Congress and local legislators that focus on Hispanic issues to educate them about the importance of SCT testing, disease education, and the stories from various Hispanic communities about SCD.

1. Introduction

Sickle cell disease (SCD) is a hereditary blood disease that causes devastating complications for patients and their families. In the United States, the SCD population is primarily comprised of Black and African Americans and Hispanic Americans. According to the Centers for Disease Control and Prevention (CDC), in the United States, SCD affects about 100,000 Americans. SCD occurs among about 1 in every 365 Black or African American births, and in about 1 out of every 16,300 Hispanic Americans births.[3] The racial and ethnic makeup of the SCD population has led to poorer health outcomes and has contributed to a history of health disparities. This has resulted in a general misunderstanding of the disease, leading to barriers in access to care.[4]

1.1 Sickle Cell Disease in the Hispanic Community

Although SCD disproportionately impacts Black and African American people in the United States,[1] there are growing populations of Hispanic Americans living with SCD and individuals who identify as first-generation U.S. citizens. For example, in the Sick Cells Ambassadors program, 18 percent of Ambassadors self-report as an "immigrant group." Additionally, in collaboration with the SCD community, Sick Cells fielded a survey in 2020 about economic burden of SCD. Of the 452 completed responses, about three percent of respondents identified as Hispanic or Spanish, and three percent identified as "white" or "other."

1.2 Objectives of the HOPE Project

Sick Cells identified the need to conduct further research into the unique educational gaps for the Hispanic SCD community. The objectives of the Hispanic Outreach to Promote Equity (HOPE) project are as follows:

- **Objective 1:** Conduct a systematic environmental scan of the existing resources available in Spanish and/or specifically targeting the Hispanic population living with SCD.
- **Objective 2:** Host a roundtable discussion that will serve as a focus group, consisting of caregivers and individuals living with SCD from the Hispanic community. Release a summary report of key findings from the roundtable discussion and environmental scan that highlights key gaps in educational needs.
- **Objective 3:** Expand Sick Cells outreach to the Hispanic community and provide them with educational resources and a place to network with other SCD advocates with similar experiences.
- **Objective 4:** Create recommendations for educational tools. Feature a diverse representation of Hispanic people living with SCD and create Sick Cells tools in Spanish.

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[3] Centers for Disease Control and Prevention. (2020, December 16). *Data and Statistics on Sickle Cell Disease*. https://www.cdc.gov/ncbddd/sicklecell/data.html

[4] Haywood, Carlton Jr et al. "Perceived discrimination in health care is associated with a greater burden of pain in sickle cell disease." *Journal of pain and symptom management* vol. 48,5 (2014): 934-43. doi:10.1016/j.jpainsymman.2014.02.002

To achieve these objectives, Sick Cells worked with two subject matter experts (SMEs). We worked with one individual living with SCD (known as "sickle cell warriors" or "warriors") and one caregiver to an individual with SCD. We met with the SMEs every two weeks for three months to review the environmental scan findings, develop an appropriate discussion guide for the roundtable discussion, recruit individuals for the roundtable, and review all materials, including this final report.

2. Environmental Scan

Sick Cells conducted an environmental scan of current educational resources for the Hispanic population living with SCD. The goals of the environmental scan were to: (1) define the terms "Hispanic" and "Latino" (2) understand what resources exist for the Hispanic community living with SCD; and (3) find Spanish-language resources related to SCD.

To do so, we conducted a traditional internet search, as well as reviewed tools generated by federal and state agencies, the National Institutes of Health (NIH), and other national and local organizations. We also reviewed multiple social media platforms and conducted two in-depth interviews about the environmental scan results with our SMEs.

2.1 Terminology and Vernacular

2.1.1 "Hispanic" vs. "Latino"

Sick Cells identified the need to define "Hispanic" and "Latino" for the purposes of this project. According to the Pew Research Center, there is no official definition of either term. The Census Bureau relies on self-reporting to count the number of Hispanic people in the United States. In 1976, the U.S. Congress passed a law mandating the collection of data on this specific population and described them as "Americans who identify themselves as being of Spanish-speaking background and trace their origin or descent from Mexico, Puerto Rico, Cuba, Central and South America, and other Spanish-speaking countries."[5]

While the Census Bureau tends to use the term "Hispanic," some people use "Hispanic" and "Latino" interchangeably, and some make a distinction between the two, claiming that Latinos are people who come from countries in Latin America regardless of what language they speak. The term "Hispanic" seems to be more tied to the Spanish language and Spanish speakers. For this project, we will thus focus on the Hispanic population living with SCD and use the definition of Spanish speakers.

2.1.2 Ethnicity and Race

It is helpful to note the difference between race and ethnicity in the context of the Hispanic community. The federal government defines "Hispanic" not as a race but as an ethnicity, encompassing people who come from many different backgrounds and could technically be of any race.[6] However, according to a

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[5] Lopez, Mark Hugo, et al. "Who Is Hispanic?" Pew Research Center, 23 Sept. 2021, https://pewrsr.ch/3nZsXP8.

[6] Bureau, U.S. Census. "About Hispanic Origin." *Census.gov*, 8 Oct. 2021, https://www.census.gov/topics/population/hispanic-origin/about.html.

survey of Hispanic Americans by the Pew Research Center, two-thirds of respondents say being Hispanic is also part of their racial background.[7]

Furthermore, people may also consider their country of origin or their family's country of origin as part of their ethnic/racial background. Specifying to this extent is relevant in the discussion of language because the population encompassed by the term "Hispanic" is incredibly diverse and thus, language and colloquialisms tend to vary by country or region.

2.1.3 The name "sickle cell disease" in Spanish

To understand how SCD is referred to in the Hispanic community, Sick Cells interviewed the SMEs and searched various social media platforms through hashtags. We learned that there are multiple terms for SCD in Spanish and that terminology differs depending on the region. Some populations have vernaculars and colloquialisms for "sickle cell disease." Subsequent conversations at the roundtable supported these findings. Table 1 highlights the identified terminology for sickle cell disease in Spanish.

Table 1: Terminology for "sickle cell disease" in Spanish

Term	**Comments**
Enfermedad de células falciformes o células falciformes	Term for SCD, seems to be the second most common term used on social media to refer to SCD in Spanish. This term is used on the Centers for Disease Control and Prevention (CDC) information and local government health department sites.
Anemia Falciforme	Most common term for SCD. The term is used in Brazil to refer to the disease and yields many posts written in Portuguese on social media. This term is also used on some local government websites.
Anemia drepanocítica	Less common term used for SCD; however, this term is used on the CDC information page and in various Facebook community groups
Drepanocitosis	Less common term for SCD
Enfermedad drepanocítica	Less common term for SCD
Mogote	Colloquial term used in regions of the Dominican Republic for SCD
Sicklemia	Fusion of "sickle" and "anemia." Less common term used for SCD

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[7] Parker, Kim, et al. "Hispanic Racial Identity: Multidimensional Issue for Latinos." *Pew Research Center's Social & Demographic Trends Project*, Pew Research Center, 18 Aug. 2020, https://www.pewresearch.org/social-trends/2015/06/11/chapter-7-the-many-dimensions-of-hispanic-racial-identity/.

2.1.4 Origins of Language

Sick Cells researched the origins of the term "falciforme." The word *falx* is a medical term meaning "a sickle-shaped part or structure"[8] and it is used as a prefix in medical terminology to describe anatomy (i.e., falx cerebri, falciform ligament). In this case, it describes a disease. In Latin, the term "falx" means "reaper" or "sickle." Both a reaper and a sickle are farm tools in the shape of a crescent moon. "Sickle cell disease" is derived from this term due to the shape of the red blood cells. In Spanish, the word *falx* is used as the prefix of the word "falciforme" which literally translates to "sickle shape."

2.2 Social Media Scan

Social media is a place where many individuals, including those in the SCD population, find community, information, and share updates about their lives.[9] Once we identified terminologies for SCD, the team followed various hashtags using the terms listed in Table 1. We looked through posts and comments pertaining to SCD on each social media platform and searched for organizations or nonprofit accounts using the identified terms. In the search, we looked for two types of content: *educational* (featuring facts about SCD, or advancements in treatment) and *advocacy and awareness* (posts bringing general attention to the SCD community, featuring stories and experiences of SCD warriors, or information about policy). The table below outlines the results from the social media search.

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[8] "Falx." Merriam-Webster.com Medical Dictionary, Merriam-Webster, https://www.merriam-webster.com/medical/falx. Accessed 22 Oct. 2021.

[9] Obar, Jonathan A. and Steven S. Wildman. "Social Media Definition and the Governance Challenge: An Introduction to the Special Issue." *Internal Communications & Organizational Behavior Journal* (2015) .

Table 2: Social Media Search

Social Media Site	Comments	Advocacy Orgs and Accounts
Twitter	Around 100 posts: - Various posts raising awareness for SCD in English & Spanish - Most content in English highlighted statistics on the incidence of SCD in the Hispanic population. - Most content in Spanish was from other countries, particularly in South America. There were many posts in Portuguese. - Basic educational content about SCD	- Sick Cells account has one post in Spanish. - Sickle Cell Association of Texas Marc Thomas Foundation has one post in Spanish. - Sickle Cell 101 en Español account provided the most educational material in Spanish. - Various Sickle Cell Warriors from other countries, but none of their accounts were strictly dedicated to posting about SCD
Instagram	- Very few posts under most terms except “Anemia falciforme,” which yielded over 17k posts. Most of these were from Brazil and in Portuguese - Posts featured basic educational material, awareness, advocacy, and some patient stories	- **@sicklecell101es** account again provided the most educational material in Spanish - **@yo_falciformia:** personal account of a Sickle Cell Warrior. She posts mostly about her experience with SCD. She is a Spanish speaker who lives outside of the U.S.
Facebook	- Found less educational material, more advocacy and awareness posts - Found the most community groups & organizations, both in the U.S. and internationally on Facebook (~100 community groups found under search for “anemia falciforme”)	- **Sickle Cell 101 en Español**: a page with educational materials - Multiple organizations in other countries found - **“Yo vivo, con anemia de células falciforme”**: page by a Sickle Cell Warrior telling her story - **Drepanodom:** an organization from the Dominican Republic - **Fundación Sicklemia:** a non-profit based in Colombia - **Anemia falciforme:** community page dedicated to SCD but consists mostly of Portuguese speakers
LinkedIn	Little to no materials in Spanish	- No organizations in the U.S. had any information in Spanish

2.3 Google Search

The team searched Google for educational materials, webpages, and advocacy materials in Spanish for the Hispanic SCD community. The Google search yielded over 900,000 results. We looked through the first 15 pages of results. We also searched health departments for all 50 states and the District of Columbia for information about SCD in Spanish. The team conducted the search using the terms previously listed in Table 1. Table 3 highlights our findings for government sites with information in Spanish for SCD.

Table 3: Federal and Local Health Departments Information

Site	Available information
The National Institutes of Health (NIH)	Has comprehensive educational materials in Spanish with advice on many topics related to SCD including pregnancy, diet, etc.
The Centers for Disease Control and Prevention (CDC)	Has comprehensive educational materials in Spanish with advice on a wide range of topics related to SCD, including pregnancy, diet, etc.
State Health Departments	
Texas	Contained educational materials about SCD and SCT in Spanish. Additional resources linked back to the CDC website and the National Heart, Lung, and Blood Institute (NHLBI).
Illinois	Contained a one-page PDF with educational information in Spanish about SCD
Wisconsin	Featured a short pamphlet in Spanish with education about SCD and how it differs from SCT
Indiana	Contained a one-page PDF with education in Spanish about SCD
Utah	

2.3.2 Publicly Available Scholarly and Academic Literature

The team searched scholarly literature through Google Scholar, yielding around 13,000 results, of which we looked through the first 10 pages. In the search, we found articles about SCD and pregnancy (in Spanish) and scholarly articles about new treatments, epidemiology, and immunology related to SCD. Most of these articles were published in a Cuban scientific journal.

2.3.3 Non-Health Department Organizations

We found non-government organizations that had websites with information about SCD in Spanish. For the most part, these websites included education on SCD as well as recommendations for living with SCD. St. Jude's Children's Hospital, the Mayo Clinic, Cigna, and Blue Cross Blue Shield were among some of the websites found. The information is similar to other resources previously mentioned. Often, they provide a link back to the expanded resources that the NIH and CDC provide.

Some university systems such as the University of Illinois Health and UC San Diego have articles in Spanish with education on SCD as well. However, this information focuses on when a baby is born with SCD and describes SCT and how it compares to SCD. It does not focus on complications of SCD, treatments, new or emerging therapies, advocacy, or connecting individuals with community-based organizations.

Sickle Cell 101, a SCD advocacy organization based in California, has Spanish-language educational materials that discuss complications of SCD, which are also posted on their social media account.

2.3.4 Educational Guides

Sick Cells identified guides, listed below, that include robust information on SCD and were often linked as additional resources on other websites. These resources provide medical education about SCD, recommendations for caregivers, nutrition, complications and more.

- "Una Buena Vida con Anemia Falciforme" is an infographic created in 2012 by Centene Corp. It provides basic information along with recommendations on nutrition and immunizations.
- "Enfermedad de Células Falciformes: Guía de Recursos para Pacientes y Familias" is an undated booklet produced by the New England Pediatric Sickle Cell Consortium (NEPSCC) which can be found on their website This guide is very comprehensive and gives recommendations for caregivers, possible complications of SCD, tips for nutrition, and even addresses the emotional aspects of living with the disease. Additionally, their website also features multiple educational handouts for families and schools available in both English and Spanish.
- The website www.sicklecelldisease.net provides an educational repository and has multiple articles on different topics translated to Spanish for SCD patients.

2.4. Subject Matter Expert (SME) Interviews

We presented our environmental scan results to our SMEs for feedback. We conducted 60-minute interviews with each of them to discuss the findings and understand if our interpretations aligned with their lived experiences. One of our SMEs identifies as Hispanic American of Dominican descent, while our other SME identifies as Hispanic American of Mexican descent. The sections below summarize the interviews with the SMEs.

The SMEs confirmed that the terms listed in Table 1 and their usage were accurately described. Within their respective communities, they cited "anemia falciforme" as being the most-used term, followed by "anemia drepanocítica" or "drepanocitosis." One SME noted that the various names used in Spanish for SCD could pose a challenge when communicating information because not everyone knows the disease by the same name. It was also noted by one SME that, when posting information about SCD on social media, particularly when it comes to advocacy information, it may be easier to post the text in English, since social media sites such as Facebook can now translate posts into Spanish when necessary. They shared that there may be a benefit in this method in terms of outreach, particularly here in the U.S., where many individuals speak English and Spanish but may still want to see the information in both languages. This strategy would allow for the choice to translate the information as the person sees fit.

2.4.1. Educational Materials for the Hispanic community living with SCD

According to our SMEs, they find 3 common misconceptions within the Hispanic community about SCD:

1. Given that the most common name in Spanish for SCD is “anemia falciforme,” **people in the community often mistake the disease for iron deficiency anemia** and think it can be cured or helped with iron supplements.
2. Participants expressed **having been doubted as having SCD due to not being Black** (this misconception was also discussed in the context of healthcare settings).
3. **People in the community do not fully understand the genetics** of the disease and how it is passed down to an individual.

Based on these observations, we asked the SMEs what educational materials they would like to see for the Hispanic SCD community. They shared the following items:

- Both SMEs spoke about how in their families, their parents or grandparents did not know what about SCT or what it means to carry it in their families. They also recounted stories and experiences of discrimination from the medical community and denial of SCT testing because of their skin color and ethnicity.
- Thus, the SMEs suggested that a focus on educating about SCT, the genetics of SCD, and its prevalence in non-Black communities of color could create the opportunity for more individuals to be tested for SCT, which could lead to increased awareness about the disease.
- Both SMEs shared that they believe the lack of knowledge about SCD has led to misconceptions about the disease. There is a general lack of understanding in the community about what SCD is and how it affects the health and lives of those living with it.
- The SMEs also suggested that there is a need for Spanish-language information on current research about the disease such as new treatments and drug development. Although there is information readily available on these topics, it is not found in Spanish.

2.4.2 Impact of Racism while living with SCD or caring for a sickle cell warrior

The impact of racism and the harm it has caused in the Black community and in the SCD community is well documented. Conversely, there is limited documentation of the impacts of racism on the Hispanic SCD community. We asked our SMEs how their race and ethnicity have impacted their experiences living with SCD.

Our SMEs expressed the difficulty that patients from the Hispanic community have in being seen by healthcare providers. They noted that because they do not look like the person providers and healthcare professionals expect to see when they think of SCD, they are treated with doubt and hesitation.

One SME stated about her daughter that, “For the past 25 and a half years that [Jazmine] had to be admitted to the hospital or go to the ER, [floor medical staff] would pass the room and say, ‘Oh, you’re not the patient we are looking for,’ just by looking at her face…Everybody assumes that sickle cell does not exist for the Hispanic community.”

The second SME recounted, “My cousin and I were the only ones in the family born with SCD. My cousin passed away when she was 20, and I was 18 at the time. I started advocating when she passed away, and it is still the same conversation [present day]. It is still me listening to people say, ‘Oh, I didn’t know that sickle cell runs in Hispanics.’ We are in a time when cultures are united. There’s different people connecting from different backgrounds. So, it is about knowing the gene.”

2.4.3 Desired Outcomes of the HOPE Project

Finally, we asked the SMEs what they hoped to see as outcomes from the HOPE Project and for future work in this area. They commented that, based on their experiences, they would like to see the following from this project:

- Testimonials and visuals showing that SCD affects people from many different backgrounds and not just African Americans and Black Americans
- Information in Spanish that adequately translates the medical terms in a way that can be understood
- Spanish language educational materials for parents to help them understand lab results, medical diagnosis, complications, and to help them navigate the medical information on SCD
- Targeted education for the Hispanic community truly to understand what SCD is
- Focused efforts to combat the misconceptions and misinformation through storytelling and education

Based on the experiences of the SMEs and our environmental scan, it is clear that there is a need for more research and documentation of the unique disparities faced by the Hispanic SCD community. There is also a need for increased awareness within the medical community and global healthcare community about the genetics of SCD and which populations are likely to be impacted by the disease.

2.5 Environmental Scan Discussion

Through our research, we were able to find information in Spanish that gives a basic explanation of what the disease is and how it differs from sickle cell trait. However, there are fewer resources that provide information about living with and managing SCD, available treatment and therapies, disease progression, advocacy tools, clinical trials, nonprofit organizations, and more. These resources are useful for patients and their families to empower themselves and take an active part in their healthcare.

This is an opportunity for companies, nonprofits, hospitals, health departments, and any other vested stakeholder in the SCD space to expand their resources to this population, starting with access to materials in Spanish. It is important to have these materials professionally translated, as the quality of automated translations, such as Google Translate, tends to be unreliable.

Additionally, there is a need for the healthcare community at large to learn about who is impacted by SCD. The idea that SCD is a condition that only impacts Black and African Americans not only leads to race-based medicine against this population, but it also leads to race-based medicine against other populations that do not identify or present as Black or African American, like many individuals within the Hispanic SCD population.

Finally, there is an opportunity for general education about SCD within the broader Hispanic community and within Hispanic health efforts. Much like how SCT testing is offered at many historically black colleges and universities, through the Black Panther party, and in other community spaces, an effort to reach Hispanic individuals and offer SCT testing should be conducted through larger partnerships that are culturally appropriate.

3. Roundtable Discussion

On August 18th, 2021, Sick Cells hosted a multi-stakeholder roundtable discussion with individuals from the Hispanic community who live with sickle cell disease (SCD) or care for loved ones with SCD. The glimpses that our SMEs gave us into the experiences of Hispanic SCD warriors guided the direction of our roundtable agenda and the themes we explored during this discussion. The objective of the roundtable discussion (RTD) was for stakeholders from the Hispanic SCD community to share their unique experiences as SCD warriors or caregivers, and to include additional voices in our search to understand the perception and awareness of SCD within the Hispanic community. The focus of the discussion was to identify key educational gaps, create targeted educational tools to fill those gaps, and inform Sick Cells' recommendations for stakeholders. All materials from the RTD are provided in Appendix A.

3.1 Recruitment

The roundtable participants included four SCD warriors, two SCD caregivers, and one SCD provider. Sick Cells staff participated as moderators for the discussion. A full list of all attendees is provided in Appendix A. We recruited participants through the Sick Cells Ambassador Program, Sick Cells' network of individuals, and the SMEs. We ensured that diverse ages, ethnicities and cultural backgrounds, and types of SCD were represented. We also included a diverse group of geographic locations: participants were from Florida, North Carolina, California, New Jersey, and Texas. The RTD was conducted over two hours. The team completed four of the five themed discussions. All participants except the provider were compensated for their time.

3.2 Roundtable Discussion Materials

In preparation for the RTD, we created an agenda and a discussion guide. The agenda included four sessions. We translated the discussion guide into Spanish and prepared a presentation to facilitate conversation from the RTD participants. The RTD was conducted in English and Spanish. Our Moderator for the RTD was bilingual and asked questions first in Spanish, then repeated them in English.

Participants were encouraged to respond in whichever language they felt most comfortable. The agenda and discussion guide are provided in Appendix A.

The roundtable participants shared their knowledge and personal experiences as Hispanic individuals living with SCD or caring for someone with SCD. We discussed five overarching themes:

- Need for more Awareness:
    - In the Hispanic community about SCD
    - In the SCD community about Hispanic individuals with SCD
    - In the medical community at large
- Need for more Support:
    - From the Hispanic community
    - Available in Spanish regarding SCD
    - From providers
- Racial Bias in Healthcare:
    - Pain management
    - Overall administration of care
- Communication Barriers
- Mistrust of medical providers

3.3 Summary of Themes

3.3.1 Session 1: Understanding the Diversity Within the Community

Terminology - The RTD began by asking participants to share what term they are most familiar with when referring to SCD in Spanish. The discussion was consistent with our environmental result findings (see Table 1). Most participants agreed that “anemia falciforme” is the most commonly used term for SCD in Spanish. Two participants who were from the Dominican Republic pointed out that the terms “anemia drepanocítica” or “drepanocitosis” are the more commonly used term there, and that the term “mogote” is only used in some regions of the Dominican Republic.

Perception of SCD within the Hispanic Community - Participants explained that, although they rely heavily on their support systems, SCD is not understood by everyone in their family. While caregivers to someone with SCD tend to be well informed about SCD, their extended family and the Hispanic community at large is often uninformed or misinformed about SCD. They explained that there is a reluctance to speak about SCD due to cultural customs around privacy. Some participants expressed that as warriors or caregivers, the responsibility to educate often lies on them. The participants discussed the three common misconceptions previously identified by our SMEs (see section 2.4.1.) and spoke about often encountering these misconceptions within their respective communities as well.
To improve awareness about SCD, participants discussed the need for more funding, educational events such as seminars, and using social media as a tool to spread awareness. Participants also emphasized that they themselves are passionate about advocating and educating about SCD.

3.3.2 Session 2: Finding Out the Needs of the Community

The next session explored the resources available to the Hispanic SCD community and what resources are still needed. The goal was to identify gaps and use the discussion as a guide to make recommendations.

Participants expressed the need for more educational materials about SCD in Spanish. Multiple participants mentioned never having found or been offered any resources for SCD in Spanish. They mentioned there is a need for this type of content to be found on social media as well. Some cited informative virtual seminars as another educational resource that would be especially beneficial for people who live far away from major cities and are therefore less likely to have available resources near them.

Other suggested tools include:

- A registry of Spanish-speaking physicians to make it easier for Hispanic individuals to find a doctor
- A registry of Spanish-speaking advocates to accompany patients at the hospital during crises or regular visits
- Partnerships with community health organizations and SCD community-based organizations, as this information sharing would be beneficial to both raise awareness of SCD and help locals be aware of other projects and programs in their area.

3.3.3 Session 3: Healthcare Barriers

In the third session, we explored multiple themes related to healthcare and the challenges that Hispanic SCD patients face. We asked about barriers people in the Hispanic SCD community experience both from the provider and the patient perspective. Additionally, we asked about best practices to serve as a starting point for healthcare providers when engaging with this community.

The presence of racial biases was a constant theme in every story from this session. Two participants shared jarring stories of being stigmatized and labeled as drug addicts due to the fact that SCD treatment requires administration of opioids. They expressed that this type of treatment is commonplace for all SCD patients, and that they believe racial bias is a component in these situations.

Implicit bias also came up as a barrier in communication in the healthcare setting. Participants discussed the fact that often providers may hold biases and ideas based solely on the fact that a family or patient is Hispanic or speaks Spanish. They noted that these biases negatively affect the communication between the provider and the patient. Some participants noted that for example, if a provider encounters a Hispanic patient, the provider may wrongly assume that the patient or caregiver has low education, that they are religious, or that they do not believe in Western medicine.

As mentioned in previous sections, a common story told by the participants was that Hispanic patients with SCD are not believed to have SCD in healthcare settings. They attribute this to their race and not being racially identified as Black or African American.

Another barrier that RTD participants mentioned was the lack of awareness and education about SCD for medical providers. Participants expressed the frustration that comes with seeking medical treatments and being treated by doctors or nurses who only have a basic understanding of the disease. They explained that when this is the case, they end up having to educate the providers, and that the role of advocacy on the part of the caregiver becomes very important in these situations.

Participants expressed frustration with the overall administration of care and its inefficiency. The medical protocols and processes that patients must go through when seeking care can make it very difficult for SCD patients, especially in the middle of a pain crisis.

Although not discussed in depth, financial barriers were mentioned in the case of immigrant families coming to seek care in the United States.

3.3.4 Session 4: Successes and Best Practices

When we asked about what *has* worked in encounters with medical providers, participants expressed that their positive experiences were when they felt their providers listened to them. Multiple participants noted that when providers incorporated the patient and the caregiver into the discussion and took their insights into account when making decisions about their care, they felt heard and like they received better care. Thus, participants suggested a collaborative effort between the patient and the providers as the best practice when caring for patients with SCD.

When discussing communication, participants identified health literacy as a barrier. Based on the discussion, the complexity of the disease and understanding the nuances of medicine and treatment can be difficult. This is the case, even when we assume that appropriate interpreting services have been procured. Thus, health literacy is an area where education resources can make a large impact.

3.4 Opportunities for Further Discussion

There were a number of questions Sick Cells staff was unable to ask during the RTD due to time constraints. Future RTDs or focus groups should explore the impacts of public discourse about immigration on the Hispanic SCD population and their experience seeking care. We also would suggest discussing access to new and current treatments, clinical trials, and supplemental therapies (i.e., physical therapy and mental health services).

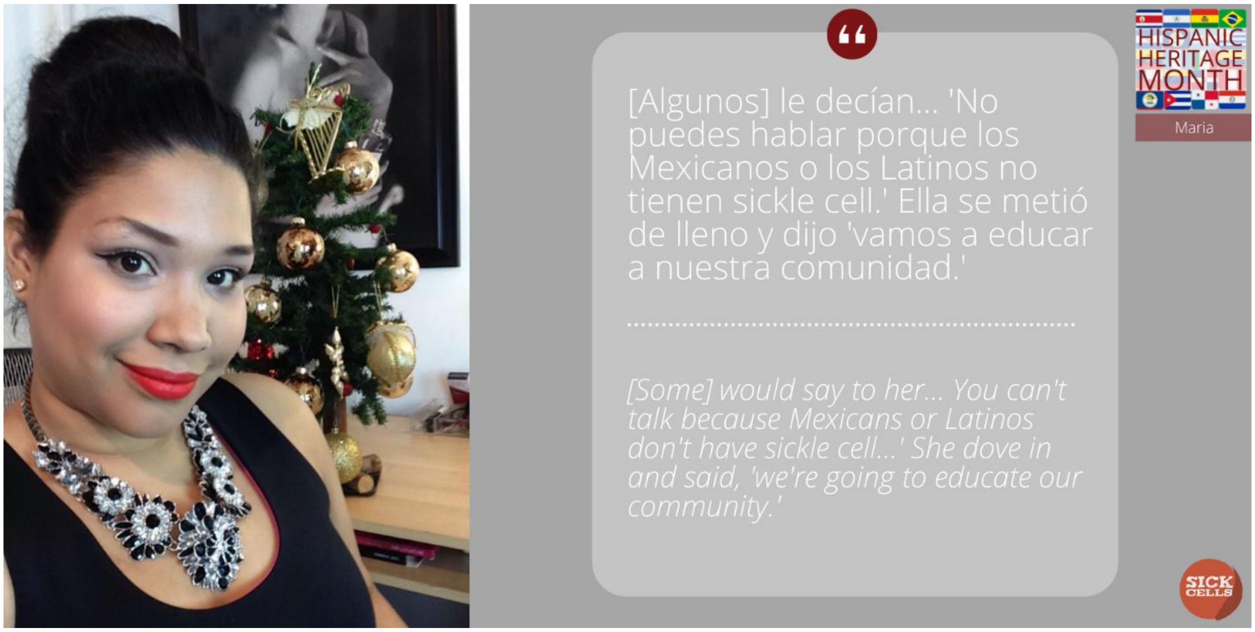
In future discussions, we would like to ask participants about their experiences with coverage and reimbursement. The SMEs expressed that at times, they are unable to get SCT testing covered or prescribed because of the educational void about SCD existing in the Hispanic population. We would like to explore if this experience applies to other services required to care for someone with SCD.

After the RTD, participants requested that we explore the topic of available bone marrow transplant donors and blood donations. We understand that there is always a need for more Black blood donors for the SCD community, and participants expressed the same applies for the Hispanic SCD community.

Finally, while participants expressed that communication with medical providers was a major determinant of their healthcare experience, we did not discuss inadequate or unavailable interpreter services and how this negatively impacts patients' care.

4. Social Media Campaign and Hispanic Heritage Month

From October 1 - October 15, 2021, Sick Cells launched a social media campaign on Instagram to feature the stories of two SCD warriors and one SCD caregiver from the Hispanic community. Each post featured a quote from the participants in both English and Spanish. In addition to the social media posts, the Sick Cells team published one HOPE Project blog in both English and Spanish and published a Spanish version of a previous blog about COVID-19 vaccines. To find the full series of posts, please visit our [website]() or find them on [Instagram]() and [Facebook]().



[Algunos] le decían... 'No puedes hablar porque los Mexicanos o los Latinos no tienen sickle cell.' Ella se metió de lleno y dijo 'vamos a educar a nuestra comunidad.'

[Some] would say to her... You can't talk because Mexicans or Latinos don't have sickle cell...' She dove in and said, 'we're going to educate our community.'

Example: Maria Rivera's quote (Caregiver) with a photo of her daughter, Jazmine Rivera (SCD Warrior)

5. Limitations and Recommendations

Limitations: The project was funded by the Global Genes Health Equity Grant. With $15,000 of funding, we were able to conduct a systematic review of the online resources available to individuals living with SCD from the Hispanic community. While our findings are telling and insightful, we were limited in the number of hours spent on the environmental scan, individuals we could interview and hours to review content. We see this as an opportunity to continue this work and create more-detailed recommendations to improve the quality of care and support for the Hispanic SCD population.

Recommendations: Our findings from this project underscore the need for a focus on the Hispanic SCD population. We want to emphasize that when focusing on equity and inclusion, organizations should add more Hispanic voices, in addition to the existing voices, in the SCD space. This section provides recommendations on straightforward interventions to begin this process.

Education - There is a need for more education about SCD in the Hispanic community, stakeholders across the healthcare spectrum, advocacy organizations, legislators, and in the general public. We also hypothesize that by increasing representation, stigma associated with SCD, and race-based diagnosis can be reduced.

Language Resources - To increase reach, insurance and pharmaceutical companies, state health departments, federal agencies, and large organizations should have language options on their websites. This will allow individuals who speak languages other than English to feel included and engage with the provided content.

- Advocacy Tools - SCD and other health organizations should make select advocacy tools available in Spanish. These are items that go beyond disease education, such as toolkits, events, conference materials, and more.
- Disease Management - SCD and other health organizations, hospitals, manufacturers, payers, and other vested stakeholders in the SCD space should have more Spanish-language education about SCD available. This information should also focus on genetics, SCT, and what services are available to individuals and families living with SCD. These entities should also offer information about existing and new treatments in Spanish
- Terminology - Materials about SCD should use common terms that describe the disease depending on who the target audience is. We hypothesize that, due to the limited information available in Spanish about SCD, no standardized term for the disease has been used. Because of this, we suggest using the top one or two Spanish-language terms for SCD and providing a key to other terms until the community becomes more familiar with the disease overall.

Representation - To increase awareness about SCD in the Hispanic community, storytelling that features Hispanic caregivers and individuals living with SCD should be incorporated into existing work, campaigns, educational materials, and beyond.

- Storytelling Campaigns - Sick Cells understands the power of storytelling and suggests that the more entities can engage with the Hispanic population, the more the SCD community will become representative of the population that is affected by the disease.

- Culturally Competent Materials - We learned that the level of understanding about SCD in the Hispanic population varies. Materials made to educate this community should be made in partnership with Hispanic individuals living with SCD and go through rounds of focus groups. This is to truly understand what education is truly required.

Partnerships - To reach the broader Hispanic community, we suggest partnerships with organizations that focus on health and health literacy for the Hispanic population. We also suggest working with Congress and local legislators that focus on Hispanic issues to educate them about the importance of sickle cell trait testing, disease education, and the stories from various Hispanic communities about SCD.

Appendix A

Sick Cells prepared the following materials for the RTD: Invitations, Agenda, and Summary. Most materials were available in English and Spanish.

A.1 Invitations

Roundtable on Diversity within the Sickle Cell Disease Community

On behalf of Sick Cells, we invite you to participate in a roundtable discussion focused on identifying educational gaps in the Hispanic community regarding Sickle Cell Disease on August 18 from 1-3PM EST. **The goal of the meeting is to collaborate and develop resources that can provide practical help, support and information for Hispanic individuals living with SCD and their caregivers.** Our facilitated discussion will include 7-10 participants, representing SCD warriors and caregivers from the Hispanic population living with SCD. Topics that will be explored during this discussion include: The awareness of SCD in the Hispanic community, mental and physical health concerns, resources currently available, the impact of racism, stigma, and discrimination, and best practices.

Through this rich dialogue we seek to identify actionable next steps to support those individuals living with SCD and bring awareness of their stories to both the Hispanic community and healthcare providers at large. The output of this roundtable will be resources that will be developed by the Sick Cells team and will be the main subject of an educational campaign, which will be launched in September.

When and Where

Date and Time: August 18th 12 – 2 PM CT

Location: Zoom Conferencing

Compensation

We will provide $200 of compensation for your time.

RSVP

Please contact Karla Sintigo via e-mail at ksintigo@sickcells.org if you are able to join us (please RSVP by August 13th, 2021)

About the Hosts

This Roundtable will be hosted by the Sick Cells team with support provided through Global Genes RARE Foundation Alliance. Sick Cells is a patient advocacy organization that seeks to elevate the voices of the sickle cell disease (SCD) community and our stories of resilience. In highlighting the grave disparities the SCD community faces, Sick Cells seeks to influence decision-makers and propel change.

We thank you in advance for your consideration of this invitation.

A.2 Roundtable Discussion Agenda (English and Spanish)

Health Equity Project Roundtable

August 18th, 12:00 PM – 2:00 PM CT

Goal of the Roundtable:

- Develop educational and advocacy resources for people in the Hispanic/Latinx community with SCD
- Understand the experience of people who are Hispanic/Latinx and have SCD

Time (CT)	Agenda Item	Moderator
12:00 – 12:20	**Welcome and Introductions** ● Introduction of Sick Cells ● Introduce “Health Equity” Project ● Icebreaker Activity ● Introduce environmental scan results	**Ashley Valentine** Sick Cells **Karla Sintigo** Sick Cells
12:20 – 12:45	**Understanding the diversity within the community:** ● What is the perception/understanding of SCD within your own family/community? ● What name do you use to refer to SCD in Spanish? ● How do you think awareness and understanding of SCD could be improved in your community?	**Karla Sintigo** Sick Cells
12:45 – 12:55	**Finding out the needs of the community:** ● What resources have been available to you regarding SCD? Have these resources been available in Spanish? ● What types of information, education, or support does the Hispanic/Latinx community need regarding SCD? ● Can you share a story that highlights a major challenge or barrier that you face as a Hispanic/Latinx SCD patient (or a caregiver as well)?	**Karla Sintigo** Sick Cells
12:55 – 1:05	**Finding out barriers from the provider perspective:** *Questions for the SCD Clinical Providers*: ● Where do significant disconnects or communication challenges exist between health care providers and caregivers? ● Can you share a personal story that highlights any of these issues?	**Karla Sintigo** Sick Cells

1:05 - 1:15	**Trust of medical providers:** ● How has your experience overall with doctors been? ● What resources have you used to find your provider? ● In your encounters with doctors, what has worked, what has gone well? ● What experiences in particular have led to your personal feelings about providers?	**Karla Sintigo** Sick Cells
1:15 – 1:20	Break	
1:20 – 1:50	**Healthcare barriers:** ● When accessing healthcare, have you felt limited by language barriers? How has language affected your experience? ● What other barriers have you experienced while navigating the healthcare system?	**Karla Sintigo** Sick Cells
1:50 – 2:00	Summarize Feedback on What We Learned Adjourn	**Karla Sintigo** Sick Cells

Grupo de Enfoque - Proyecto para la Equidad en Salud

18 de Agosto, 12:00 PM – 2:00 PM CT

Metas del grupo de enfoque:

- Desarrollar recursos de educación y apoyo para las personas Hispanas/Latinas con Anemia Falciforme
- Entender más sobre la experiencia de las personas Hispanas/Latinas con Anemia Falciforme

Hora (CT)	Artículos de Agenda	Facilitadora
12:00 – 12:20	**Bienvenida e introducciones** ● Introducción de Sick Cells ● Introducción del Proyecto ● Actividad rompehielos ● Introducción de los resultados de la investigación de los medios	**Ashley Valentine** Sick Cells **Karla Sintigo** Sick Cells
12:20 – 12:45	**Comprendiendo la diversidad de la comunidad:** ● ¿Cuál es la percepción o entendimiento sobre la Anemia Falciforme en su familia y comunidad? ● ¿En cuál nombre se refiere a la enfermedad? ● ¿Cómo cree que se podría aumentar el conocimiento y la comprensión sobre la Anemia Falciforme en su comunidad?	**Karla Sintigo** Sick Cells
12:45 – 12:55	**Investigando las necesidades de la comunidad:** ● ¿Cuales recursos ha tenido disponibles sobre la anemia falciforme? ¿Han estado disponibles en Español? ● ¿Qué tipos de información o recursos de educación y apoyo necesita la comunidad Hispana sobre la Anemia Falciforme? ● ¿Puede compartir una anécdota que demuestra un obstáculo mayor que usted ha enfrentado siendo Hispano/a con Anemia Falciforme? (O siendo cuidador de una persona con Anemia Falciforme)	**Karla Sintigo** Sick Cells

12:55 – 1:10	**Investigando obstáculos desde la perspectiva del médico:** *Preguntas para proveedores de salud de Anemia Falciforme*: ● ¿Cuáles son los obstáculos más importantes en la comunicación entre los proveedores y los cuidadores de los pacientes? ● ¿Puede compartir una anécdota la cual demuestra estos problemas?	**Karla Sintigo** Sick Cells
	Confianza en los médicos: ● En general, ¿cómo ha sido su experiencia con los doctores? ● ¿Cuales recursos ha utilizado para encontrar su doctor? ● En sus encuentros con los doctores, ¿cuales cosas han sido exitosas o han trabajado bien? ● ¿Cuáles experiencias en particular han impactado sus opiniones sobre los proveedores?	**Karla Sintigo** Sick Cells
1:10 – 1:15	Descanso	
1:15 – 1:50	**Obstáculos en cuidados de salud:** ● En acceder a los servicios de salud, ¿Se ha visto limitado por las barreras de su idioma? En qué manera ha impactado su experiencia? ● ¿Cuáles otros obstáculos ha enfrentado al navegar el sistema de salud?	**Karla Sintigo** Sick Cells
1:50 – 2:00	Resumen de lo que aprendimos Fin de la reunión	**Karla Sintigo** Sick Cells

A.3 Summary and Attendee List (English)

Hispanic Outreach to Promote Equity (HOPE) Project Roundtable: Meeting Summary

Note: The summary will be made available in Spanish at a later date.

Overview: On August 18th, 2021, Sick Cells hosted a multi-stakeholder roundtable discussion with individuals from the Hispanic community who live with Sickle Cell Disease (SCD) or care for loved ones with SCD. The goal of the roundtable was to understand SCD within the Hispanic community, identify key educational gaps, and create targeted educational tools to fill those gaps. Additionally, based on the findings of our environmental scan and this roundtable, we will make recommendations to vested stakeholders regarding this population. Finally, we will launch a social media campaign which will aim at educating and spreading awareness of Hispanic individuals with SCD through storytelling. While we will launch a storytelling campaign this Hispanic Heritage Month, the effort will be ongoing for the remainder of 2021 and into 2022.

Objective: The objective of the discussion was for stakeholders to expand on their unique experiences as SCD warriors or caregivers, and to help us understand the perception and level of awareness about SCD within the Hispanic community. We relied on the expertise and experiences of these individuals to also assess what tools they think would best serve the community and what resources are available. The results of the discussion will guide us in creating resources in the future to better support Hispanic individuals with SCD and their families.

The roundtable was attended by four SCD warriors, two SCD caregivers, and one SCD provider. Sick Cells staff participated as moderators for the discussion. A list of all attendees is provided in Appendix A. This roundtable was conducted through the support of the Global Genes RARE Grant.

Summary of Themes: The roundtable participants shared their knowledge and personal anecdotes regarding their experiences as Hispanic individuals living with SCD or caring for someone who has SCD. We discussed the five overarching themes:

- Need for more Awareness:
    - In the Hispanic community about SCD
    - In the SCD community about Hispanic individuals with SCD
    - In the medical community at large
- Need for more Support:
    - From the Hispanic community
    - Little to no resources in Spanish regarding SCD
    - From providers
- Racial Bias in Healthcare:
    - Pain management
    - Overall administration of care
- Communication Barriers

- Mistrust of medical providers

Agenda Overview: The agenda was developed by Sick Cells and included 4 sessions.

Session 1: Understanding the Diversity Within the Community

The roundtable discussion began by asking participants to share what term they are most familiar with when referring to SCD in Spanish. Most participants agreed that "anemia falciforme" is the most commonly used term for SCD in Spanish. Two participants who were from the Dominican Republic pointed out that the term "anemia drepanocitica" or "drepanocitosis" is the more commonly used term there, and "mogote" which is a term that is only used in the Dominican Republic.

Next, we discussed the perception of Sickle Cell Disease (SCD) within their own communities, and the best ways to improve awareness and understanding about SCD in their communities. Participants explained that although they rely heavily on their support systems, such as their parents, and they tend to be well informed about SCD, their extended family and the Hispanic community at large is often uninformed or misinformed about what SCD is.

They explained that there is a reluctance to speak about SCD and when the conversations do happen, there are many misconceptions that are held about the disease, and so they feel, as warriors or caregivers, the responsibility to educate as much as possible. The participants discussed three common misconceptions within the community:

- Given that the most common name in Spanish for SCD is "anemia falciforme," **people in the community often mistake the disease for iron deficiency anemia** and think it can be cured or helped with iron supplements.
- Participants expressed **having been doubted as having SCD due to not being Black** (this misconception was also discussed in the context of healthcare settings).
- **People in the community do not fully understand the genetics** of the disease and how it is passed down to an individual.

Overall, participants across the board agreed that there is very little to no awareness of SCD within the Hispanic community and that this shows in the low support they feel from the community regarding the disease. Participants also expressed the importance of increasing awareness of SCD at large, and how it is a crucial aspect in securing funding for research and development for new treatments. In other words, awareness and support go hand-in-hand.

To improve awareness about SCD, participants discussed the need for more funding, educational events such as seminars, and using social media as a tool to spread awareness. Participants also emphasized that they themselves are passionate about advocating and educating about SCD.

Session 2: Finding Out the Needs of the Community

The next session explored the resources available to the community and what resources participants felt the community needs. The goal was to identify gaps in resources and to use the discussion as a guide to make recommendations.

Participants expressed the need for more educational materials about SCD in Spanish. Multiple participants mentioned never having found any resources for SCD in Spanish. They mentioned the need for this type of content to be found in social media as well. Informative virtual seminars were mentioned as another option to have as an educational resource, which would be especially beneficial for people who live far away from major cities, where resources are likely less easy to come by. Other tools that were suggested include:

- A registry of Spanish-speaking physicians to make it easier for Hispanic individuals to find a doctor.
- A registry of Spanish-speaking advocates to accompany patients at the hospital during crises or regular visits.

Another suggestion was to create partnerships between organizations, as this sharing of information would be beneficial to both raise awareness and be aware of other projects and programs that are out there.

Session 3: Healthcare Barriers

In the third session, we explored multiple themes related to healthcare and the challenges that Hispanic patients face. We asked about barriers people in the community experience both from the provider and the patient perspective. Additionally, we tried to get a sense of best practices, by asking about positive experiences with healthcare providers.

Participants shared their experiences regarding barriers in healthcare settings, and racial bias came up multiple times. Two participants shared jarring stories of being stigmatized and mistreated as drug addicts, due to the fact that SCD treatment requires administration of opioids. They expressed that this type of treatment is commonplace for SCD patients and that they believe racial bias is definitely a component in these situations.

Implicit bias also came up as a barrier in communication in the healthcare setting. Participants discussed the fact that often providers may hold different biases and ideas based solely on the fact that a family or patient is Hispanic or speaks Spanish and that these biases negatively affect the communication between the provider and the patient. For example, the provider may wrongly assume that the patient/caregiver has low education, that they are religious, or that they do not believe in Western medicine.

Although not discussed in depth, financial barriers were mentioned in the case of immigrant families coming to seek care in the United States.

Another barrier that was mentioned was the lack of awareness and education about SCD for medical providers. Participants expressed the frustration that comes with having to go for treatments and be treated by doctors or nurses who only have a basic understanding of the disease. They explained that when this is the case, they end up having to educate the providers, and that the role of advocacy on the part of the caregiver becomes very important in these situations.

A common story told by the participants was that Hispanic patients with SCD are not believed to have SCD healthcare settings. They contribute this to their race and not being racially identified as Black or African American. Participants discussed having difficulties with medical providers because they doubted them as having the disease.

Participants expressed frustration with the overall administration of care and its inefficiency, as it can make it very difficult for SCD patients, especially in the middle of a pain crisis, to navigate the protocols and processes they must go through when seeking care.

Session 4: Successes and Best Practices

When we asked about what *has* worked in encounters with medical providers, participants expressed that in their positive experiences they had been listened to. The providers incorporated the patient and the caregiver into the discussion and took their insights into account when making decisions about their care. Thus, a collaborative effort between the patient and the providers was suggested as the best practice when caring for patients with SCD.

When discussing communication, the question of health literacy also was discussed briefly as a barrier. Based on the discussion, given that language itself is not an issue, either because there are appropriate interpreting services or the patient speaks English proficiently, the complexity of the disease and understanding the medicine and treatment can become a barrier, and this is an area where educational resources can make much of an impact in bridging that gap.

Unexplored Themes: While participants expressed that communication was a major determinant of their healthcare experience, we did not discuss the case when there are no inadequate or unavailable interpreter services and how this negatively impacts patients' care.

In future roundtables, we would also like to pose questions related to immigration issues, and whether fear of being deported or having their immigration status threatened is a challenge for individuals when it comes to seeking care.

Lastly, we would like to ask participants about their experiences with clinical trials and also about insurance and their experiences with payer policy.

Next Steps: As of September 2021, Sick Cells will create a resource map to highlight what educational tools will fill gaps for the Hispanic population. Along with these tools, we will highlight the stories of SCD warriors and caregivers through a social media campaign during Hispanic Heritage Month. The goal is to provide the Hispanic community with the resources that they need in order to empower them as patients and also to raise awareness about SCD within the Hispanic community, and about Hispanic patients with SCD within the Sickle Cell community and the medical community at large. Lastly, we will create a report which includes our environmental scan and the findings from this roundtable and make recommendations to vested stakeholders in order to further increase awareness and support for this population.

Acknowledgements: We are extremely thankful to each participant for their contribution in this roundtable discussion and for their commitment to advocate for SCD in their communities. Additionally, we thank Global Genes for their generous support of our work.

Roundtable Attendees

Name	**Stakeholder Group**
Servio Astacio	SCD Warrior
Doris Polanco	SCD Warrior
Stephanie Ramos	SCD Warrior
Nilda Navedo	SCD Warrior
Carmen Navedo	SCD Caregiver
Maria Rivera	SCD Caregiver
Dr. Titilope Fasipe	SCD Provider
Emma Andelson	Sick Cells Staff
Karla Sintigo	Sick Cells Staff
Abby Tainter	Sick Cells Staff
Ashley Valentine	Sick Cells Staff

A.4 Recommendations for Stakeholders

Stakeholder Group	Immediate	Future
SCD community (Nonprofits, community-based organizations, etc.)	Link to Spanish language resources on your website: - Sick Cells HOPE Project page with resources - SickleCell101es Instagram account - NIH NHLBI Spanish-language resources - CDC Spanish-language resources	Translate 1-2 blogs (or other organizational content) into Spanish Prioritize hiring bilingual staff, either full-time or part-time Offer community health worker (CHW) training in Spanish, or for the Spanish-speaking community Begin/increase outreach to non-Black communities of color affected by SCD
Government Agencies	Prioritize hiring full-time bilingual staff Translate entire website + materials into Spanish, link to existing materials in Spanish	Increase funding for SCD data collection in the Hispanic/Latinx community Make data reports and summaries available to the public
Policymakers	Prioritize hiring full-time bilingual staff Translate various medical materials into Spanish	Translate entire website + materials into Spanish
Medical community (Hospitals, clinics, medical providers, etc.)	Prioritize hiring full-time bilingual staff Educate interpreters on SCD in the Hispanic/Latinx community	Translate entire website + materials into Spanish Implement additional unconscious bias training about SCD for medical staff