

# THE HANGOUT UPDATE

## MARCH SESSION

3/23/2023



**TAISHA MATHIEU**  
*Health & Wellness Coordinator*

In March, we completed our monthly session of **“THE HANGOUT - A support group for individuals impacted by Sickle Cell Disease.”** The topic was **“Intimacy and Sexuality”**. Thanks to everyone who joined in! If you were unable to participate in The Hangout this month, please enjoy this summary of the discussion.

### **GROUP NORMS**

We want the Hangouts to be a safe, supportive space for all participants. We reviewed group norms briefly at the start of the session, and as always, if you have any questions or concerns about the norms, feel free to contact Taisha Mathieu at [taisha@mythreesicklers.org](mailto:taisha@mythreesicklers.org).

### **TOPIC**

This month’s topic focused on the importance of how to efficiently express emotions when negating life with Sickle Cell disease. Participants felt that for change to be in motion and effective within the Sickle Cell community advocating and voicing opinions, concerns, and challenges will provide more awareness and solidarity. For instance, a member shared a quote by Audre Lorde “Caring for myself is not self-indulgence, it is self-preservation, and that is an act of political warfare.” The group extrapolated that individuals should have the right to care for themselves without being guilted, judged, and ashamed. Battling for a life of peace and normalcy for a sickle cell warrior must never be placed in the hands of those who do not choose to learn or want to understand the challenges that one faces on the daily basis. Self-advocacy presents individuals with the chance to voice what has been muted and empathize with what has been looked upon minutely.

We had the opportunity on behalf of a nonprofit organization based in New Jersey, Caring Contact to have guest speaker Crisis Line Director, Michelle Habayeb. Mrs. Habayeb discusses how the organization is a listening and crisis hotline community. There are currently 100 volunteers and small paid staff combating the sufferings that individuals face daily which are not being heard. Although, the organization is based in New Jersey calls are received nationwide. She explains that calls every day vary from individuals dealing with anxiety, depression, grief, loneliness, suicidal thoughts, and mental and physical illness. She empathized that this community focuses on ensuring the caller is safe for now and is in an environment that provides true empathy, and genuine and nonjudgmental engagement. Those in the SCD community may be dealing with other challenges aside from physical ailments which include feeling hopeless, helpless, guilty, relying on food or possibly alcohol for coping, and experiencing irritability and anger.

It is vital that society come together in unity to listen, comfort, and support those who are going through daily hardships whether within the Sickle Cell Disease community or others. It is essential that a person can be in a space to distress and share their story because every story is unique and deserves to be voiced. When citizens can have their emotions identified it allows them to be empowered and have control of their thoughts, feelings, and behaviors.

Advocacy not only impacts self but also groups collectively pushing to strive for effective and successful change that will enhance the lives of SCD individuals. For example, some participants discussed what it would be like if they could create policies that would impact the lives of SCD citizens for the better. Participants have come up with a few policy suggestions that only touch the surface of the changes that need to change within the SCD community. Examples, include providing SCD citizens with more affordable medications. The medications that SCD citizens take are in price ranges that at times discourage the person from wanting to maintain a healthy well life. The ranging pricing with or without insurance creates a battle internally within the individual of choosing if he or she should want to have treatment monthly. Second, providing SCD individuals with home care services. This policy would assist individuals who may be suffering from severe pain and fatigue that restricts them from doing their daily routines throughout the day. It can be very worrisome having to manage one's strength but also having to manage the home all at once without a helping hand to make the trials less daunting. Next, life insurance rates were another factor that brought up shared concerns. SCD citizens feel that their premiums should not be rated solely due to having Sickle cell. It can be very frustrating trying to prepare for the future and still being reminded because of a disease one has puts you in a category that demands more expense and less room to focus on providing for loved ones. Finally, another suggestion for the SCD community would be to have an SCD card like cancer patients. In addition, having a medical card for hospitals and medical facilities to have more updated data information and health records of citizens who have Sickle Cell.

Members shared how beneficial it would be for SCD to have specific cards that provide essential health information, support, and resources for individuals as well as for local clinics and work-related locations. Those with SCD should not be marginalized and ignored when it comes to social and medical competency. Next, there was a member who shared a horrifying and traumatic experience from a lack of support and attentiveness from the Emergency department. The participant stated, "I went into the ER because of the amount of pain I was enduring from my sickle cell crisis, and I ended up waiting for 8 hours to receive treatment". Healthcare personnel and administrators must consider that pain is not subjective but an objective matter. The reason is when people feel pain it can cause a lack of focus, and restrictions in daily living, and more importantly it can negatively impact the self-esteem of individuals. There must be more advocacy for the well-being of people living with SCD and there must be a place for feelings to be shared freely.

Overall, the SCD community continues to combat the challenges that limit the progress of warriors living healthy lives.



**SPECIAL GUEST**

**MICHELLE HABAYEB**  
Crisis Line Director

