

THE HANGOUT UPDATE

JUNE SESSION

6/22/2023



TAISHA MATHIEU

Health & Wellness Coordinator

In June, we completed our monthly session of **“THE HANGOUT - A support group for individuals impacted by Sickle Cell Disease.”** The topic was **“Managing Sickle Cell Disease...Together”**. 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.

TOPIC

This month’s topic was how we manage sickle disease together. Although the physical and mental parts of the SCD warrior may be exhausted and overwhelmed, relief comes from maintaining faith and a strong support team. Essentially, resonating with the idea that SCD should not mean suffering alone and being overlooked. During the session, we did an exercise that voiced out the hardships, frustrations that one must tackle to have a stable mindset in having a healthy life. The exercise provides a sentence, and participants fill in the remainder with their personal feelings and experiences. For instance, when I feel denied I ... get frustrated, get upset, feel unworthy, and question my life. Those are reflective thoughts and feelings that demonstrate SCD severity. Luke chapter 1 verse 37 states that nothing is impossible. For example, SCD warriors have emphasized that family, co-workers, and society sometimes ignore feelings and concerns about having such a draining and imbalanced disease.

Sickle Cell is imbalanced because there are no specific times announced when pain, lack of sleep, or absent days from work or school will occur. However, participants talked about how aligned details do not mean one is not worthy of living a full and abundant life. The second sentence began with When I lose control I... shut down, feel defeated, run, do not have any medication, go into crisis, try my very best to practice self-care using heating pads, having a backup plan if the schedule for the day must change. "The Lord give me strength" is the statement participants share that brings comfort in their dark moments of despair and depletion. "My grace is sufficient for you, for power is made perfect in weakness." I will rather boast most gladly of my weaknesses, so that the power of Christ may dwell with me. (2 Corinthians chapter 12 verse 9). Warriors must face moments when control is out of their hands, and they must drop everything and leave everything to God. For instance, one participant said, "Why get upset when you have the next day to conquer?" When SCD breaks down emotionally and physically, we tend to forget that tomorrow will be the day to reexamine that inner being. When I am not in pain I... praise God, feel good, sleep, enjoy the plans of the day and or festivities, looking forward to tackling work that the day may bring.

Participants have expressed that they feel strong, empowered, and worthy of handling daily hassles without restriction. They are also reminded of the anchor SCD holds on to in their lives. Sickle cell warriors must embrace the moments we take for granted since the liberty of living life without pain is not as consistent as one would imagine.

The remainder of the session has questions that identify milestones struggles, and healthy strategies to sustain a whole person while dealing with the chronic demands of Sickle cell. Participants have shared the struggles of Avascular necrosis (AVN) occurring within the shoulders and hips. AVN is a disruption taking place within the blood supply of a person with Sickle cell. The idea of having-to-having surgery on the shoulders and possibly ending up without having a range of motion (ROM) sounds very depleting and worrisome. One form of alleviation can be to practice aerobiotic in the heated pools of the gym if they are offered. It allows the body to practice a full range of motion and allows the warrior to feel strengthened and not overwhelmed by the surmounting pain. Second participants have shared that when insurance coverage does not effectively take place fear begins to overpower them. For example, having to take medication for pain and being told that the fee is insurmountable to obtain can not only place fear but also judgment on the SCD warrior. In addition, to learning looking for treatments & physical therapies receiving and providing education about this disease is beneficial for the individual as well. Participants have stressed the importance of having an advocate who can voice their pains and health challenges when they go to healthcare facilities such as a hospital. Tobit chapter 1 verse 3 states, I, Tobit, have walked in the paths of truth and good works all the days of my life. I have given alms to my brothers and fellow country folk, exiled like me to Nineveh. SCD warriors cried about the horrific experiences they have dealt with when entering a healthcare institution. Participants have shared why would individuals who are supposed to provide care, and understanding and good faith demonstrate the opposite. Those who go to

the hospital are not people who are seeking to harm themselves or others but receive treatment so that they can go back to living their lives and provide helping hands to those who are in need through volunteerism and more. When the stigmas of drug seeking take into effect the treatments received from the medical professional become horrendous and appealing. The lack of trust, compassion, cultural competency, and empathy destroys the morale of Sickle cell warriors who are only trying to seek help and medical attention. The members shared tips that have helped prevent a crisis and or keep from having to go to the hospital. Participants explored various forms of healthy coping mechanisms. For instance, avoid intake of caffeine, and alcohol, and go to high-elevation locations. Next, taking medications on time, and drinking more fluids like water. last practicing self-care through spiritual practice such as praying, attending church, and removing oneself from stressful conversations or circumstances that could create a crisis. Participants expressed a variety of exercises and holistic approaches that help to prevent triggering a crisis in their personal lives. Some examples include using the treadmill every day, attending Zumba and yoga classes, drinking teas such as turmeric & black tea, walking, and meditating. Overall, warriors need to find the balance that helps them personally to succeed and have a healthy and stable life. A poem written by the late Dr. Maya Angelou “ Alone” extrapolates the significance of what life should not be for any who is living a life with Sickle cell. Because having sickle cell should never isolate or outcast citizens but it should bring forth more solidarity, education, and support.

Lying, thinking
Last night
How to find my soul a home
Where water is not thirsty
And bread loaf is not stone
I came up with one thing
And I don't believe I'm wrong
That nobody,
But nobody
Can make it out here alone.

Alone, all alone
Nobody, but nobody
Can make it out here alone.

There are some millionaires
With money they can't use
Their wives run round like banshees
Their children sing the blues
They've got expensive doctors
To cure their hearts of stone.

But nobody
No, nobody
Can make it out here alone.

Alone, all alone
Nobody, but nobody
Can make it out here alone.

Now if you listen closely
I'll tell you what I know
Storm clouds are gathering
The wind is gonna blow
The race of man is suffering
And I can hear the moan,
'Cause nobody,
But nobody
Can make it out here alone.

Alone, all alone
Nobody, but nobody
Can make it out here alone.