

THE HANGOUT UPDATE

JULY SESSION

7/27/2023



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

Fortunately, during this month's session particularly the topic discussed centered around the significance of life outside of sickle cell disease. Summer is a season that brings time to spend with family and loved ones, and a chance to center the focus of life outside of school and work. SCD warriors deal with the daily hassles of work, school, family obligations, and maintaining a stable and healthy mind frame after experiencing an unhealthy crisis. The warriors should have the opportunity to recognize the minute details that can positively or negatively affect their lives. Individuals with SCD must not stop learning and embracing the journey of what life offers while managing the upheavals of this chronic illness.

A participant expressed that “Progress does not have to equate to perfection”. Individuals must understand overall whether one is a Sickle cell Diseased warrior, caretaker, friend, spouse, or even a peer life is not meant to be perfect but the choices one chooses to make in the now is what counts.

Participants engaged in a brief reflective exercise that was tailored towards expressing the downfalls and uplifting steps of living a life outside of chronic illness. The first statement began with "When I get out of bed I" opened the session with participants stating they praise God for being able to live and see the day. Additionally, individuals shared the feelings of being grateful to have spouses and loved ones to check on them while they are in a space of delight or when they are not feeling well. The second statement is "When motivation kicks in I can do the daily chores without feeling overwhelmed, read, smile, and play loud music. When SCD warriors are motivated, they demonstrate strength, triumph, and victory in things that most would consider to be trivial. Nothing is impossible if you believe that the sky is the limit.

Participants voiced that being motivated takes a lot of inner patience but more importantly support from loved ones but also from themselves. At times, when one is overwhelmed with the factors of the world around them and the trials of physical pains it can become very exhausting to find space for a reason to think with exuberance. The next statement states, "When I feel safe and secure I. The participants have mentioned that they begin to feel a sense of vulnerability, trust, and confidence in being able to express themselves with those around them but also being able to let go of judgments and insecurities that the world tends to project. For example, when an SCD warrior misses a social gathering, they are labeled "the sick one" or the one that never wants to socialize. Unfortunately, individuals tend to assume that chronic illness chooses when to turn on and off. Likewise, when a warrior begins to feel ridiculed or even stigmatized the individual will begin to isolate themselves and demonstrate signs and symptoms of mental health illness and depression. That is why when one attends an event or even becomes more involved in the workplace peers, colleagues, and family need to be considerate of the effort that the warrior was able to achieve.

Finally, my support system allows me to feel like I matter, I am important, I am capable, I am acknowledged, and I can do anything. When an SCD warrior has a support system it provides space to be free of the trials that the world brings, it gives room for the individual to be able to share concerns, fears, and even accomplishments without being belittled. The purpose of the support system is to empower warriors when they have felt defeated, neglected, and discouraged. Maccabees 1 Chapter 2 Verses 62 and 64 states, "Do not fear the words of a sinful man, for his glory ends in corruption and worms. Children! Be courageous and strong in keeping the law, for by it you shall be glorified." A participant shared that this bible verse is a reminder to stand strong even when they are struggling from the pains and difficulties of every life. It is also a reflection of how to follow the path of righteousness even when at times it is easy to give into society's perceptive of how to live a life while having a chronic illness how to demonstrate happiness while being considered disabled, how to embrace serenity while having to listen to constant judgment and stigmas of being ill. Meanwhile, everyone gets criticized for behaviors and interests, and more SCD warriors need to continue to advocate for themselves so they can live healthy and stable lives. For instance,

a parent of Sickle Cell warrior mentioned that her child embraces time to herself playing and watching movies alone and not with the caretaker. The warrior stated, "I feel satisfied being able to be in my space". The parent shared her feelings of guilt and shame for not spending more time with her child but also conflicted with the notion that the warrior may not want to share the moments of laughter and positivity with the caretaker. It can be difficult at times to respect the wishes of those who are so very loved, but it is imperative that as SCD advocates we allow the warriors to feel and know that they are heard.

Participants have shared that they have been told that they are demonstrating too much arrogance, lack of consideration of the feelings of others, and overthinking too much about the disaster to even think of having survival prep kits for natural disasters. It can be difficult to maintain good health and try to constantly follow the desires of others. SCD warriors have voiced that demonstrating strength and fortitude should not be confused with arrogance because at times they feel weak, and depleted, from the medications, and pains that they manage daily so when a time arises for them to embrace their sense of empowerment, they choose to ignore the noise of others. In addition, to ignoring the negative noise from others, having survival kits in case of disasters allows some participants to feel at ease for the unknown. Ironically like a crisis a sickle cell warrior may develop spontaneously or even through a stressful environment it is up to the warrior to prepare for the possible outcome of having to deal with the pain, taking more medication, or even having to arrive at a local emergency room for further treatment.

Furthermore, people will always try to limit one from progressing especially when they do not experience progression within themselves. The issue of traveling and having a passion for dance, for example, has come up in discussions. The idea that a person with Sickle Cell should only be allowed to stay in one place and not embrace the freedom to live merry is absurd. People do not believe in implementing more resources, outreach, or support. In addition to SCD warriors managing with daily criticism, the factors that have been tossed away from the social media discussions that require more advocacies include education, gun violence, and lack of voting within the African American community. Sickle cell warriors are at a disadvantage because of the lack of social, cultural, and political awareness involved in all these factors. People need to understand what decisions are being made to promote the wellness and safety of their communities. When individuals do not take a stand on issues that not only affect the lives of those who are suffering how can change move forward? How can a promising future be even when leaders, educators, and citizens do not take a stance on advocating and engaging in assemblies town hall meetings or even voting? The insurance to living a stable and healthy life starts with educating and protecting the lives of those who have been outcast and scrutinized. Essentially, sickle cell disease is not the only contribution to the lives of warriors but also the many decisions and questions about how to work together within society when it comes to progression and solidarity.

There is a saying that states a picture is worth a thousand words. Evidently, to the

participants that is true. Art can depict the thoughts, emotions, feelings, and challenges that people and even society may endure. Furthermore, art provides people with a place where they can express themselves and have a space where they can share vulnerabilities, receive support, and advocate for themselves. Participants shared various quotes such as "The mind is a terrible thing to waste" by the late Dr. Martin Luther King. The second quote that brought a lot of emphasis was from Nelson Mandela, "I believe that in the end, it is kindness and generous accommodation that are the catalysts for real change". When knowledge and education come together the society can collaborate on making the world a better place for everyone. If there is more destruction, prejudice, marginalization, and cruelty on display, it is very difficult for the idea of change to even be a light at the end of the tunnel that portrays inhumanity as a source of inspiration.