

# THE SICKLE CELL FOUNDATION OF TENNESSE (SCFT)

Reginald French, CEO

This project was supported by a grant  
from Novartis STEP (Solutions to  
Empower Patients) Program™



SCDCARE FOR  
SCDCARE



Practical resilience strategies for caregivers of individuals with sickle cell disease (SCD) from birth through young adults.



---

The SCD CARE for SCD CARE module is a guide to practical resilience strategies and resources for caregivers of individuals with sickle cell disease (SCD) from birth through young adults. This is an interactive SCD Caregiver Resilience Educational Module.



Resilience is the ability to function effectively in the face of adversity. The effectiveness of resilience strategies has been demonstrated in many disease processes. SCD caregivers develop numerous resilience strategies throughout the years.

## PROJECT BACKGROUND



This project provides SCD caregivers with resilience strategies. The strategies were obtained from SCD caregivers sharing tools that have helped them successfully care for their child with SCD. A list of caregiver resources was developed along with a caregiver educational module.





Resources ... A Way of Life

*Chris Bridges (Father of teens with SCD)*



# Focus Groups Member Discussions

Three focus groups were held with parents of children with SCD from 11 months to 20 years old.

Caregivers were asked to discuss:

How having a child with SCD impacted them and their family?

To talk about the emotional impact of having a child with SCD?

To share how they established support systems, and to

Discuss what strategies they used to successfully navigate caring for a child with SCD?





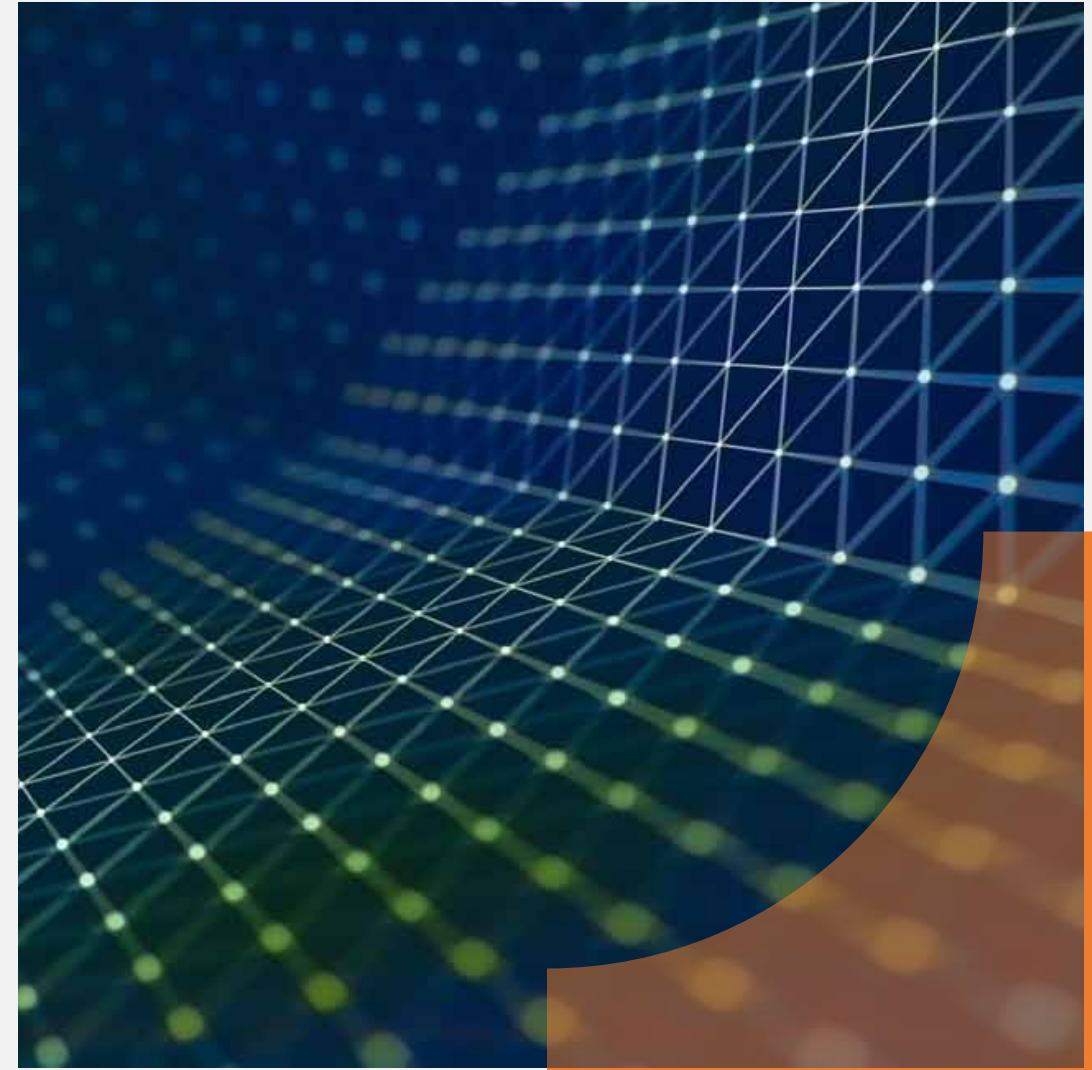
# Four Main Themes EmergEd from the Focus Group Discussions

Being Organized

Establishing A Support System

Finding Faith and Spirituality

Recognizing the Impact of Mental Health





## Being Organized

- *"I actually created a binder when we first found out that my son had sickle cell. And it was, it was different things from, what do you do if he has a fever? What do you do if he's lethargic? What do you do if he seems a little pale and ... , I also had ... resources in there that I was given, literature resources that I was given from the partners at the hospital. His medical records, I kept records of all of his appointments, anything that he had, his lab work." Caregiver of Child with SCD*





# Being Organized – Tips!

---

- Keep a Journal
- Put appointments in your phone
- Have an emergency hospital bag ready at all times
- Establish a routine
- Have important numbers easily visible
- Schedule “Me” time
- Make To Do Lists
- Remember this is a journey – forgive yourself for any missteps along the way



# Establishing a Support System



# Ask for HELP!

---

**Don't be afraid to ask for help**

**Prepare ahead of time**

**Make a plan that you can follow during emergencies**

**Make a list**

**Be specific with your request**

**Share responsibility**

**Ask several people for help**

**Show appreciation to those that help you**

**Think outside the box**







## Finding Faith/Spirituality

- *"I just ... believe in God and, ,, , they pray along with me, they just started getting ... (on their) knees at night, even though I know they don't know what to say to God, ... just trusting God."* Caregiver of a child with SCD.





# Ways to Use Faith/Spirituality

Prayer

Silent  
Meditation

Forgive  
Yourself

Don't judge  
others

Attend  
support/prayer  
groups

Remain  
hopeful

Stay positive

Perform acts  
of kindness for  
others



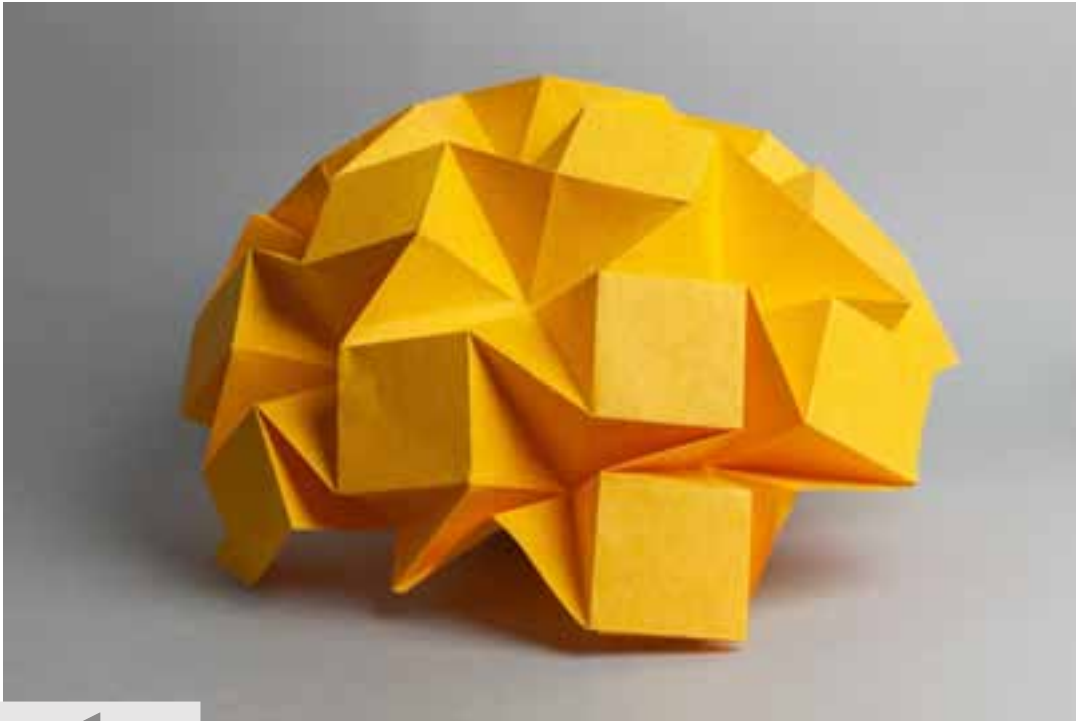




Recognizing the Impact of Mental Health



# MENTAL HEALTH



*"You say, how do you, how do you manage your emotions? I mean, your emotions are good as long as they're good, but as many times as they've been in the hospital, I've gone through the guilt trip. I, ... I've been in my highs, and I've been at my lows."* Caregiver of Child with SCD

*"I know if they see me stressed or if I lose my head about it, they give up too. They break down and I don't want them to feel like that, ..."* Caregiver of Child with SCD



# Mental Health Tips

## Get

- Get connected - Join support/caregivers groups

## Set

- Set realistic expectations

## Ask

- Ask for family/support to relieve you for a couple hours a week

## Take

- Take care of your health; make doctor's appointments; exercise





Knowledge and Understanding  
Helps Us Move Forward

*Nichole Bridges (parent of teens  
with SCD)*





# Resources

## Resilience Support

Caregivers Need to Care for Themselves as well

<https://www.focusonthefamily.com/get-help/caregivers-need-to-care-for-themselves-as-well/>

Practicing Mindfulness to Relieve Caregiver Stress

<https://www.vnsny.org/article/practicing-mindfulness-to-relieve-caregiver-stress/>

Caregivers, Let's Talk About Caring for Yourself

<https://www.mindful.org/caregivers-lets-talk-about-caring-for-yourself/>

## Exercises

- Exercise reorganizes the brain to be more resilient <https://www.princeton.edu/news/2013/07/03/exercise-reorganizes-brain-be-more-resilient-stress>
- Exercising to relax <https://www.health.harvard.edu/staying-healthy/exercising-to-relax>
- Exercise: A healthy stress reliever <https://www.apa.org/news/press/releases/stress/2013/exercise>







## Thank You to Novartis and Our SCD Caregivers

- Thank you to all of the caregivers that participated in the focus groups and project evaluation.
- Thanks to Novartis for funding this grant and making this project possible.



# THANK YOU To The Team Members

Reginald French, CEO, SCFT  
Dr. Jerlym Porter  
Dr. Artangela Henry  
Yvonne Carroll, RN, JD





# Contact Us

## **MEMPHIS Advisory Council**

**680 Oakleaf Office Lane  
Suite 101**

**Memphis, TN 38117**

**(901) 552-4267**

## **NASHVILLE Advisory Council**

**P.O. Box 330575**

**Nashville, TN 37203**

**(615) 240-7263**

