

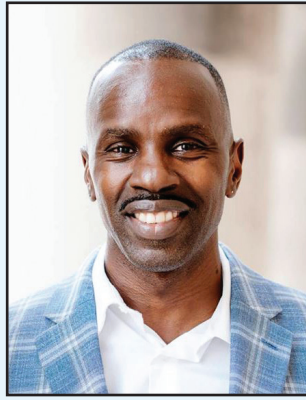
# Take Charge Of Your Health Today. Be Informed. Be Involved.

## Sickle cell disease and pain management

*This month's overview focuses on two converging topics: Sickle cell disease (SCD) and pain management — both of deep relevance to our Black community. In this overview, Dr. Charles Jonassaint, PhD, MHS (a researcher specializing in pain management and mental health care for people who are underserved) emphasizes the importance of acknowledging how stress con-*

*tributes to pain crises for people with sickle cell disease. We asked Carlos T. Carter, President & CEO at the Urban League of Greater Pittsburgh, why it's important to understand the link between stress and increased pain for SCD patients.*

We learned from the overview that stress plays a considerable role in triggering pain in sickle cell disease (SCD) patients. This is insightful research



CARLOS T. CARTER

and I encourage sufferers of this disease to be advocates for their own health. I am always concerned about the wellbeing of others; I want people to have the best quality of life, so it is critical to understand this link.

Stress reduces quality of life for a healthy individual and for those patients with SCD. It further exacerbates their condition and increases their pain levels to a point that could require hospitalization

and/or a lengthy recovery period. Understanding this link and developing strategies to manage and reduce stress can greatly improve the quality of life for Black people battling this chronic disease.

*Dr. Jonassaint has developed a mobile intervention to help reduce stress among people with SCD. Why might mobile applications like this be helpful for the Black community?*

Any mobile application

can be helpful if it is easy to access. This particular mobile application is helpful in building a community of support among other sufferers. I'm hopeful that it will provide tools and resources that SCD patients can have at their fingertips to navigate their own pain management in a constructive way. I'm also optimistic that SCD patients will take advantage of this to alleviate their pain and improve the quality of their life.

## Reducing sickle cell disease pain in the digital age

mHealth tool could help SCD patients lower stress and manage pain — without opioids.

In previous features on sickle cell disease, we've focused on SCD's impact on Black people who suffer more with this inherited blood disorder than any other group.

According to the CDC, SCD happens in about 1 out of every 365 Black births. About 1 in 13 Black babies is born with sickle cell trait (SCT).

Like other medical conditions, such as diabetes, cancer, and heart disease, Black people with SCD face racial health disparities that impact their physical care and mental health.

When you combine that inequality with Black people's general mistrust of the medical community and mental health stigma, it's easy to understand why many SCD patients find it hard to stay on top of their ongoing treatment.

But there's good news. SCD patients are living longer, more productive lives, thanks to new treatment, advances, and medical care.

However, these individuals are still struggling with pain that can move from chronic to acute and back again.

Acute pain can send SCD patients to the ER and take a toll on their mental health and quality of life.

According to recent research by Dr. Charles R. Jonassaint published in the British Journal of Haematology, 8% of study participants reported at least one mental health disorder. Six percent noted a mood disorder, while 7% had an anxiety disorder.

What triggers a pain crisis?

According to Dr. Jonassaint, who is a University of Pittsburgh assistant professor of medicine, social work and clinical translational science — and member of UPMC's Sickle Cell Disease team — “stress” is second only to “weather” in triggering severe pain.

“Here's just one example,” he explains. “A patient — who's already dealing with chronic SCD pain — loses a beloved family member. That grief, and the stress associated with it, will trigger a pain crisis that sends them to the ER and may include a hospital stay and a lengthy recovery period.”

A pain crisis may also involve standard treatment with opioids/narcotics despite what we now know about addiction. “Whatever we can do to lessen a patient's dependence on opioids is a priority,” Dr. Jonassaint adds.

It makes sense then to help SCD patients understand the signs of stress and give them ways to lower it. “If patients can change their behavior in a way that reduces stress, the hope is that they will avoid a pain crisis and suffer less overall,” he continues.

Dr. Jonassaint's research at Pitt focuses on improving pain and mental health care for people who live in underserved communities.

He and his team believe that one way to lower stress for SCD patients is to use technology to teach them relaxation techniques.

With that in mind, Dr. Jonassaint is currently conducting a study called CaRISMA, a clinical trial built for the SCD community

by the SCD community.

“CaRISMA is our name for a mobile, technology-based program that treats SCD pain in a way that doesn't rely on medications,” he explains. “It stands for Cognitive Behavioral Therapy and Real-Time Pain Management Intervention for Sickle Cell via Mobile Applications,” he says laughingly. “You can see why we shortened it.”

“From a research standpoint, we know that people who suffer from



DR. CHARLES JONASSAINT, PHD, MHS

other diseases can use behavioral techniques to better manage their pain without the use of drugs. So why not people with SCD?”

What is CaRISMA? It's a current research study involving SCD patients with chronic pain.

These patients use their smartphones to access a popular social media app that serves as a health tracking system, teaching center, and support group. Patients continue

taking their prescribed medications as indicated.

When CaRISMA participants are chosen, they're split into two groups. One group learns more about SCD via video education lessons and facts created by Sickle Cell 101.

The other group learns about cognitive behavioral therapy (CBT) and how it can be used to lower stress.

“Participants learn how CBT can help them recognize unhelpful thoughts and behaviors that may trigger an SCD pain crisis,” says Dr. Jonassaint.

Once patients can recognize the behaviors, CaRISMA teaches them ways to change their negative thoughts and lower stress thru methods like distraction, activity scheduling, and relaxation.

“It's a toolkit for understanding how our thoughts and emotions affect our actions,” he says.

Both the education and CBT groups check-in regularly with a personal health coach via phone, text or both.

Many of these coaches are adults living with SCD. All of them provide weekly emotional and informational support.

“Empathy is important for everyone's mental health, but especially people who suffer with chronic pain,” says Dr. Jonassaint.

CaRISMA also features:

- “Celia,” a chat bot that's available 24/7. Celia provides healthy lifestyle tips and facts about SCD and helps users apply what they've learned.

- An online SCD support group of people who face similar challenges and who support each other thru virtual meet-up activities.

- A pain diary that records and tracks trends in a participant's daily pain and mood.

- Toolbox and badges that let participants access content from previous lessons.

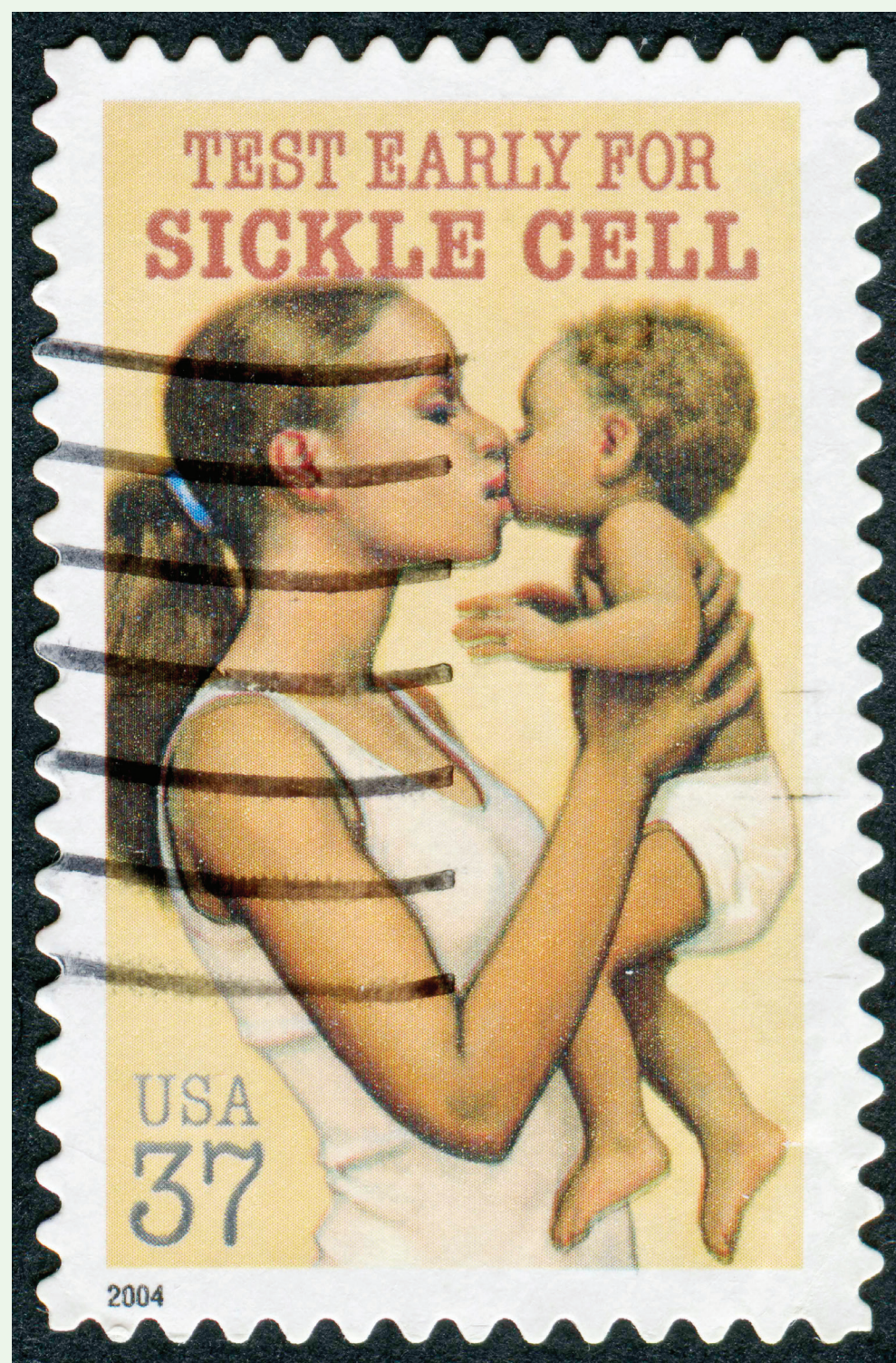
What's especially unique about CaRISMA is what Dr. Jonassaint calls “warrior stories.” He notes, “Warrior stories are teaching videos created by real SCD patients. They are not actors. They're open and honest as they discuss their experiences with SCD. They know what they're talking about.”

What does Dr. Jonassaint hope the study will tell him and his team? “We want to know which approach is more effective at helping SCD patients reduce pain — and the depression associated with the pain. Is that the smartphone digital CBT group or the education group?”

“Personally, we also hope that the knowledge and support patients received from CaRISMA will help them feel more confident, so they can advocate for themselves with health care professionals and family members.”

“People who suffer with SCD carry a heavy burden that impacts their mental health and quality of life in a profound way,” Dr. Jonassaint continues.

“Can we use smartphone technology and mHealth tools to empower these individuals to feel better without the need for opioids? I'm hopeful we can.”



## Sickle cell nerds: Sickle Cell 101 helps people understand SCD in simple, but powerful ways

Sickle Cell 101 (SC101) is a Silicon Valley-based non-profit whose team specializes in educating people about sickle cell disease (SCD).

Since its founding, SC101 has become a global force

for reliable, innovative, and easy-to-understand information for SCD patients, caregivers, health-care providers, and others.

On the organization's digital platforms, which includes social media,

you'll find info about SCD and sickle cell trait (SCT) that's evidence-based and patient friendly!

Their website sc101.org includes Sicklopedia, a web resource that explains sickle cell disorders, how

SCD is inherited, types of SCD, and more.

Additionally on their website, a blog tab includes recent and relevant articles about SCD, featuring experts and actual people who live with the

disease.

Most importantly on its digital platforms, you can “Ask an Expert” and receive evidence-based information from SC101's team of experts — in the comfort of your home.

You can follow SC101 on popular social media sites by searching “Sickle Cell 101.”