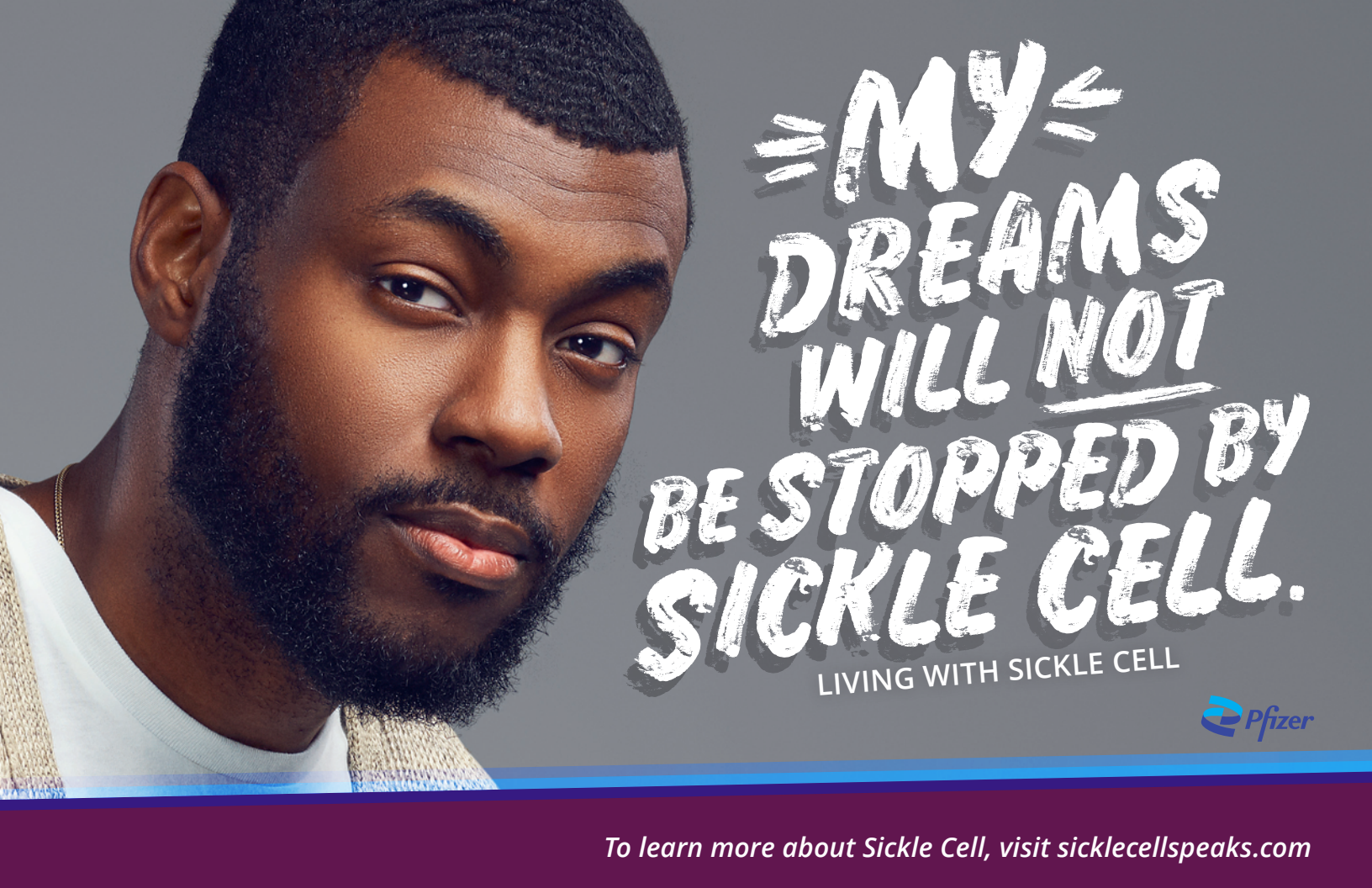
MY DREAMS WILL NOT BE STOPPED BY SICKLE CELL.
LIVING WITH SICKLE CELL
Pfizer
To learn more about Sickle Cell, visit sicklecellspeaks.com

OUR MISSION

Sickle Cell Speaks exists to bring together a community of people, from patients to caregivers to friends and relatives, whose lives are affected by Sickle Cell. Our intent is to dispel misconceptions about Sickle Cell, break down stigmas and inspire hope. We will offer Sickle Cell resources, and build a platform to share your stories and read the stories of others with Sickle Cell so that the voices of Sickle Cell can be heard. It is not our intent to provide medical advice. Please talk to your doctor about any questions you have or for medical advice.

WHAT IS SICKLE CELL

Red blood cells are responsible for carrying oxygen throughout the body. Sickle Cell is an inherited condition where healthy, round red blood cells become shaped like crescents. These rigid crescents are not able to get through small blood vessels and break down easily that may lead to anemia, fatigue, episodes of pain and organ damage.

GENETICS

In order to have Sickle Cell Disease, a person must inherit two Sickle Cell genes, one from each parent. Having Sickle Cell Trait (SCT) doesn't mean you have Sickle Cell Disease. People with Sickle Cell Trait have inherited a Sickle Cell gene from one parent and a normal gene from the other parent.

WHO IT AFFECTS

About 100,000 people in the United States have Sickle Cell. People of African descent make up 90% of the population with Sickle Cell in the United States. Sickle Cell also affects people of Hispanic, South Asian, Southern European, and Middle Eastern ancestry. Sickle Cell affects people whose ancestors came from parts of the world where malaria is common.

THE FOUR MAIN TYPES OF SICKLE CELL DISEASE ARE:

Hemoglobin SS disease
Hemoglobin SS disease is the most common and most severe type of Sickle Cell Disease. It occurs when you inherit the hemoglobin S gene mutation from both parents.

Hemoglobin SB 0 (beta-zero) thalassemia
Hemoglobin sickle beta-zero thalassemia occurs when you inherit the hemoglobin beta S gene from one parent and a hemoglobin beta 0 thalassemia gene from the other parent.

Hemoglobin SC disease
Hemoglobin SC disease is the second most common type of Sickle Cell Disease. It occurs when you inherit the hemoglobin beta S gene from one parent and the hemoglobin C gene from the other.

Hemoglobin SB+ (beta) thalassemia
Hemoglobin SB+ (beta) thalassemia occurs when you inherit the hemoglobin beta S gene from one parent and a hemoglobin beta plus thalassemia gene from the other parent.

Hemoglobin SD, hemoglobin SE, and hemoglobin SO
These types of Sickle Cell Disease are less common and are usually less severe.

Join the conversation, follow Sickle Cell Speaks on social

Meet Dalilah | *Sickle Cell Patient*

"When I was younger, I kind of felt like the odd fox, because no one really understood what Sickle Cell was because no one else had it."

Sickle Cell can be different for everyone. Dalilah discusses how it mainly affects her lungs. She expresses how she has overcome challenges with Sickle Cell, and how she uses dance as a creative outlet.

Meet Julian | *Sickle Cell Patient*

"I keep a lot of things relating to Sickle Cell to myself because a lot of people don't really understand."

Julian manages his pain the best way that he can. He tries to keep his stress low, drink plenty of water, and rest when he needs it. He discusses the importance of talking to your doctor about how to best manage your pain and his excitement for starting college and becoming an adult.

Meet Thea | *Sickle Cell Caregiver (Julian's Mom)*

"I was a hover ("helicopter") mom when trying to just keep him well. I'm trying to share knowledge so he can learn to take care of himself."

When she was pregnant with her son Julian, Thea didn't know that her husband carried the Sickle Cell Trait. She knows that living with Sickle Cell can be difficult but was confident that she could give her son a good life. Thea has worked to prepare Julian for adult life. Her wish is that Julian has a robust life, family, and career.

Find more stories of strength at SickleCellSpeaks.com

COMMON MISCONCEPTIONS

There are many misconceptions associated with Sickle Cell. Here is a list of common ones:

Misconception 1: Sickle Cell is contagious.
Fact: Sickle Cell is not contagious. It is inherited.

Misconception 2: Sickle Cell only impacts Black people or people of African descent.
Fact: Sickle Cell predominately affects Black people or people of African descent in addition to people of other races and ethnic origins including people of Hispanic, South Asian, Southern European and Middle Eastern Ancestry.

Misconception 3: If people do not look like they are in pain – they must not be in pain.
Fact: People with Sickle Cell may have high pain tolerance or they may be masking their pain.

Misconception 4: People living with Sickle Cell are lazy.
Fact: People with Sickle Cell often suffer from symptoms of fatigue or tiredness – this is not laziness.

Misconception 5: All Sickle Cell patients are opioid drug seekers.
Fact: Opioids are commonly prescribed to help with the pain that comes with Sickle Cell. This doesn't mean that all Sickle Cell patients are "drug seekers".

Helping educate others about Sickle Cell can make a big difference in overcoming stigmas and correcting misconceptions about Sickle Cell.

WHY ARE THERE DIFFERENT TYPES OF SICKLE CELL?

"Sickle Cell Disease" is a term used to describe a group of genetic diseases that affect the body's hemoglobin. Sickle Cell Disease is caused by a mutation in the beta-globin gene, resulting in abnormal hemoglobin called sickle hemoglobin, or Hb S.

Different types of Sickle Cell Disease arise based on whether the hemoglobin beta S gene is inherited with another beta S gene or with a different beta gene mutation.

Meet Mekhi | *Sickle Cell Patient*

"If you see a classmate who has Sickle Cell, maybe ask some questions, but don't badger them about it."

Having Sickle Cell can make school even more challenging. Hear from Mekhi as he shares advice with students living with Sickle Cell as well as teachers and other students.

TIPS FOR LIVING WELL WITH SICKLE CELL

Here are some general tips for living with Sickle Cell. Talk to your doctor to see if these tips are right for you.

1. **Stay hydrated.** Staying hydrated may help prevent pain.
2. **Maintain a balanced body temperature.** It is important not to get too hot or too cold. Physical activity should be part of your life, but don't overdo it.
3. **Reduce stress and stay positive.** Stress may make your Sickle Cell worse. Talk to your doctor about your stress, and also if you are depressed.
4. **Get enough sleep.** With Sickle Cell, you may experience fatigue if not enough oxygen is getting to your body. It is important to get plenty of sleep.
5. **Practice good hygiene.** Common illnesses can be harmful to people with Sickle Cell. Make sure you are fully vaccinated and practice good hygiene (like washing your hands) and food safety.
6. **Find a good healthcare team.** It is important to find a doctor that understands Sickle Cell. It also may be good to include a hematologist (blood specialist) as part of your care team.
7. **Surround yourself with support.** Your family and friends can help monitor your health and listen to you. Also, patient support and community based organizations may be able to provide support and resources.