

# The Sickle Cell Oregon Globe

**Supporting Families \* Building Community \* Sharing Hope** 

Serving The Pacific Northwest & Hawaii

# **Sickle Cell Community Update**

- This month: sickle cell myth-busting!
- Blood donations urgently needed
- Sickle cell trait: tips and tidbits

- 2 million Americans have sickle cell trait
- Sickle cell trait is not limited to any one ethnic group
- High altitudes can be life-threatening to trait carriers



### A Message from the **Executive Director**

Pastor Marcia Taylor, MA Executive Director/CEO Sickle Cell Anemia Foundation of Oregon & PNW

# **Setting the Record Straight: Myths About Sickle Cell Disease**

Misinformation about sickle cell disease can be harmful. Let's set the record straight on two common misunderstandings about SCD.

#### Myth #1:

#### **Only Black People Get Sickle Cell Disease**

SCD does not discriminate based on ethnicity or skin color. Anyone of any ethnicity can have SCD. Whether children are born with SCD depends only on their parents' SCD status, not their ethnicity. In fact, SCD is also found in people of Indian, Middle Eastern, Hispanic, and Mediterranean ethnicities. SCD results when one inherits a sickle gene from each parent at the time of conception.

#### Myth #2:

**Sickle Cell is a Contagious Blood-Borne Disease** SCD is a genetic condition present at birth.

People only have SCD if they inherit a sickle cell gene and an abnormal hemoglobin gene from each parent. Therefore, children can only have SCD if both parents have an abnormal hemoglobin gene. It is not possible to get infected with the blood of someone who has SCD. SCD is not contagious, and you cannot "catch" SCD.

## **GIVE THE GIFT OF LIFE** —GIVE BLOOD

Blood transfusions are one of the most critical treatments for sickle cell patients, but less than 10% of Americans donate blood. Sickle cell patients benefit most from blood transfusions from people of the same race or similar ethnicity, but only five percent of blood donors are of African ancestry. Help us make a difference for SCD patients by pledging to donate blood this month.

#### **Important Information for SC Trait Carriers**

If you have sickle cell trait, you should know the risks that can lead to serious complications. Understanding the basics of SCT is the first step to protecting yourself.

#### What Is Sickle Cell Trait?

Sickle cell trait (SCT) means you have inherited one sickle cell gene from one parent and one normal gene from the other parent. In sickle cell disease, you have inherited one sickle cell gene, and one abnormal gene from the other parent.

#### Who Gets Sickle Cell Trait?

Sickle cell trait is found in people of many different ethnic backgrounds. The trait developed in areas where malaria was common because it provides some protection against malaria.

#### **Important Facts About Sickle Cell Trait**

Many people have sickle cell trait and do not know it. If you have the trait, you may have already passed it on to your children. If two people who have sickle cell trait have children together, their child could be born with sickle cell disease. This is why knowing your status is critical—not just for your health, but for your family planning decisions.

While most people with sickle cell trait live normal lives without painful episodes, some carriers have a high percentage of sickle cells. Under certain conditions—such as dehydration, cold temperatures, stress, low oxygen levels, infections, or surgeries—these individuals can suffer a sickle cell crisis.

The most common type of crisis is vaso-occlusion, which occurs when sickle-shaped red blood cells block small blood vessels. This can cause sudden and extreme pain in the affected areas.

**The Good News:** There are medications and treatments available to help manage these episodes.

# **Tips for People with SCT**

- Avoid high altitudes
- Avoid extreme temperatures
- · Stay well hydrated at all times
- Know your sickle cell percentage
- Tell ALL your doctors about your SCT
- Get genetic counseling for pregnancy
- Know the warning signs

#### **Know the Warning Signs**

If you experience any of these symptoms, seek medical help immediately:

- · Severe, unexplained pain
- · Extreme fatigue
- Shortness of breath
- Blue-tinged nails or lips
- Sudden weakness
- Swollen hand and feet

#### **Don't Ignore Your Experience**

If you have sickle cell trait and you've experienced pain episodes, hospitalizations, or other complications—you are not imagining it. Your experience is real and valid. Don't let anyone tell you that "trait carriers don't have problems." Some do, and you deserve proper medical care.

#### The Bottom Line

Sickle cell trait can cause serious problems in some people, especially under certain conditions. The key is knowing your status and understanding your risks.

