

Sickle cell anemia

- A disease of the red blood cells
- Blood cells appear *sickled* under a microscope; become rigid and block blood flow
- Causes pain, and can lead to organ failure and death
- Blood transfusion and pain medication among common treatments

Sickle Cell Trait

- The gene that carries the disease
- Not usually harmful, but can cause the disease in your children when both parents have it
- Discoverable by blood test, at birth, or when you give blood



THE GENE THAT CARRIES SICKLE CELL ANEMIA DOESN'T CARE WHAT COLOR YOUR SKIN IS. IT CAN PRODUCE THE DISEASE IN ANYONE.

Why we should all be concerned:

According to the National Institutes of Health National Library of Medicine:

- ...research has largely ignored how this devastating rare blood disorder specifically affects Latinx nationwide.
- Hispanics/Latinx are at increased risk for SCD and are the second most-prevalent racial/ethnic group carrying SCD, though **their risk for this disease and its complications is less understood.**
- **US-residing Latinx and mixed-race American populations with SCD is likely to increase.**
- However, few US-based studies have examined SCD within Latinx populations.

Non-black Americans with sickle cell disease:

Michael Loiacono – Italian American Sickle Cell Advocate

Tito Puente – Legendary Latin Jazz Percussionist

Sickle cell trait can also affect Hispanics, South Asians, Caucasians from southern Europe, and people from Middle Eastern countries. More than 100 million people worldwide have sickle cell trait. *American Society of Hematology*

Again, according to the National Institutes of Health National Library of Medicine:

- Ethnicity is a complex lens through which to view disease.
- Terminology changes over time, is not clearly defined or inclusive, and is not always accepted.

It's time we thought about sickle cell anemia as a genetic disease, not a racial disease.

What we need to do about it:

Get tested for sickle cell trait

- Newborn screening for sickle cell anemia became mandatory in all states in 2006, but all states never had guidelines for disclosing the information to families, and those guidelines are not consistent.
- Parents often are not educated about results
- Healthcare workers generally are not looking for disease in non-black patients and are not educated in discussing it with them.
- The gene has its roots in Africa, but African genetics ARE ALL OVER THE WORLD

We're all in this together

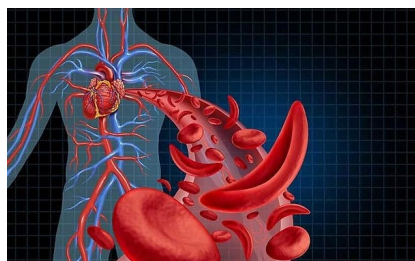
Get tested for trait! Blood banks regularly test new applicants and provide results. You will be doing yourself and your future generations a favor.

Blood transfusions

The American Red Cross receives thousands of requests each week for blood for sickle cell patients in need of blood transfusion. The recipient may or may not look like you, but may have matching blood properties.

Become a regular blood donor

When you self-identify as someone whose heritage might carry the gene, the American Red Cross can immediately match your blood with a sickle cell patient who needs it.



Sickled cells in the bloodstream

Our vision is of a world in which targeted blood donation exceeds the needs of every sickle cell anemia patient in the world

And everyone knows their trait status



The Risk of Disease with Sickle Cell Trait by Genotype

Parents with trait:

AS AS

Their Children:

AA AS AS SS

AS = Trait Carrier

AA = Normal Hemoglobin

SS = Sickle Cell Disease

One of four children per pregnancy can have sickle cell disease when both parents have sickle cell trait



TEAM AMBER

LIFE IS IN THE BLOOD



Raising awareness about sickle cell anemia and sickle cell trait in non-black Americans