SICKLE CELL DATA COLLECTION

SCD Glossary

Your go-to guide for understanding Sickle Cell Disease, created by CA SCDC.

Sources: CDC, NIH, SCDAA, MedlinePlus, and other community health organizations. Adapted by CA SCDC for clarity and accessibility.

Core Medical Terms

Anemia (uh-NEE-me-uh)

A condition where the body has too few red blood cells or not enough hemoglobin, the protein that helps carry oxygen. This leads to fatigue, weakness, and other symptoms due to reduced oxygen flow to organs. Severe anemia can cause serious health problems or even death.

Chronic Pain (KRAH-nik PAYN)

Pain that persists for 3 months or more, occurring on most days and often limiting daily life or work activities.

Fatigue (fuh-TEEG)

A persistent feeling of weariness, tiredness, or lack of energy (not the same as drowsiness) that can be physical, mental, or both, and may interfere with daily activities.

Hemoglobin (HEE-muh-glow-bin)

An iron-rich protein in red blood cells responsible for transporting oxygen from the lungs to tissues and carrying carbon dioxide back to the lungs.

Hemoglobin S (HbS) (HEE-muh-glow-bin ess)

A type of hemoglobin that's shaped differently from normal. It can cause red blood cells to change shape and not work properly, which happens in sickle cell disease.

Pain Crisis (PAYN KRY-sis) | **Vaso-occlusive Crisis (VOC)** (VAY-soh uh-KLOO-siv KRY-sis)

A sudden episode of severe pain, common in people with sickle cell disease. It happens when misshaped blood cells block blood flow.

Red Blood Cells (red bluhd sells)

The cells in your blood that carry oxygen. They normally look like soft, round discs and move easily through your body.

Sickling (SIK-ling)

When red blood cells change from their normal round shape into a hard, curved shape like a sickle or banana. This makes it hard for them to flow through their blood vessels.

Sickle Cell Disease (SCD) (SIK-uhl sel duh-ZEEZ)

An inherited blood disorder where red blood cells become sickle shaped. These cells don't last as long and can cause pain, infections, and other health problems.

Sickle Cell Trait (SCT) (SIK-uhl sel trayt)

A condition where a person inherits one normal hemoglobin gene and one sickle cell gene. People with the trait usually don't have symptoms but can pass the gene onto their children.

Diagnosis & Treatment

Blood Transfusion (bluhd tranz-FYOO-zhun)

A procedure where you receive healthy blood from someone else through a vein. It helps replace red blood cells and treat symptoms like anemia or severe pain.

Bone Marrow Transplant (bohn MAIR-oh trans-plant) **| Stem Cell Transplant** (stem sel trans-plant)

A treatment that replaces damaged bone marrow with healthy stem cells. It can potentially cure sickle cell disease but is usually used in severe cases and requires a close match from a donor.

Chelation Therapy (kee-LAY-shun THER-uh-pee)

A medicine used to remove extra iron from the body. It's often needed after many blood transfusions, which can cause iron to build up and harm organs.

Exchange Transfusion (eks-CHAYNJ tranz-FYOO-zhun)

A special type of blood transfusion where some of the sickled red blood cells are removed and replaced with healthy ones. It helps reduce symptoms and prevent complications.

Gene Therapy (jeen THER-uh-pee)

A new and advanced treatment that changes or replaces the faulty gene that causes sickle cell disease. It aims to provide a long-term or even permanent fix.

Hydroxyurea (hy-DROK-see-yoo-REE-uh)

A daily medicine that helps the body make healthier red blood cells. It can reduce pain episodes, hospital visits, and the need for blood transfusions in people with sickle cell disease.

Iron Overload (EYE-urn OH-ver-lohd)

A condition where too much iron builds up in the body, often from repeated blood transfusions. Too much iron can damage organs like the liver and heart.

Newborn Screening (NOO-born SKREE-ning)

A simple blood test done shortly after birth to check for serious conditions like sickle cell disease. It helps doctors find and treat problems early, even before symptoms appear.

Possible Symptoms & Conditions

Acute Chest Syndrome (uh-KYOOT chest SIN-drohm)

A serious lung problem that happens when sickled cells block blood flow in the lungs. It can cause chest pain, fever, coughing, and trouble breathing, and needs immediate medical care.

Infection Risk (in-FEK-shun risk) **| Immunocompromised** (ih-MYOO-noh-KOM-pruh-myzd)

People with sickle cell disease have weaker immune systems, especially if their spleen isn't working well. This makes it easier to get infections and harder to fight them off.

Leg Ulcers (leg UHL-sers)

Open sores that form on the lower legs, usually around the ankles. They can be painful and slow to heal, especially in people with sickle cell disease.

Organ Damage (OR-guhn DAM-ij)

When sickled cells block blood flow over time, they can hurt major organs like the heart, kidneys, liver, and brain, which may lead to long-term health issues.

Pulmonary Hypertension (PUL-muh-nair-ee HY-per-ten-shun)

High blood pressure in the blood vessels of the lungs. It makes it harder for the heart to pump blood and can cause shortness of breath and tiredness.

Splenic Sequestration (SPLEE-nik sek-wes-TRAY-shun)

A sudden event where sickled red blood cells get trapped in the spleen, causing it to swell and drop the red blood cell count quickly. This is dangerous and most common among young children.

Stroke (strohk)

A medical emergency that happens when blood flow to the brain is blocked. In sickle cell disease, it can be caused by sickled cells clogging brain vessels, leading to long-term problems with movement, speech, or learning.

Vision Problems (VIZH-un PRAH-bluhmz) | **Retinopathy** (ret-ih-NOP-uh-thee)

Damage to small blood vessels in the eyes caused by sickled cells. It can lead to blurry vision or even blindness if not treated.