Comprehensive Education Program Specifically for Sickle Cell Trait (SCT)

General Public

CHRIS "CJ" JOHNSON FOUNDATION

Chris “CJ” Johnson Foundation

The Chris “CJ” Johnson Foundation was founded in November 2012 by Ritchie Johnson, in loving memory of her son, Chris, who tragically passed away from renal medullary carcinoma (RMC), an aggressive kidney cancer closely linked to sickle cell trait (SCT) . Based in Sugar Land, Texas, this 501(c)(3) nonprofit is dedicated to raising awareness, advocating for equitable healthcare, educating families and providers, supporting RMC patients worldwide, and advancing life-saving research through annual contributions to UT MD Anderson Cancer Center.

The Foundation’s mission is to build a global community focused on eliminating health disparities, improving care accessibility, and ultimately finding a cure for RMC all by leveraging powerful storytelling, policy engagement, and collaboration with medical partners and advocacy networks.

For more information, visit our website here.

About the Toolkit

This toolkit was developed to support our mission of raising awareness, advocating for change, and providing support to individuals and families impacted by sickle cell trait. Whether you are living with sickle cell trait, have a loved one who carries it, or simply want to learn more, this guide offers clear, accessible information and resources. Our goal is to inform, empower, and inspire action by helping you understand your health, ask the right questions, and share knowledge within your community.

Toolkit Objectives

1. Awareness

- Increase understanding of SCT and its potential health complications, including sudden death in athletes, kidney issues, and exertional collapse.
- Dispel myths and misinformation through community campaigns and events.

2. Education

- Provide fact-based, up-to-date information on SCT through accessible formats.
- Offer continuing education modules for medical professionals and informative materials for schools and community organizations.

3. Advocacy

- Equip individuals and families with the knowledge and confidence to advocate for better healthcare practices, genetic screening, and policy changes.
- Engage with legislators and stakeholders to recognize SCT as a public health priority.

4. Support

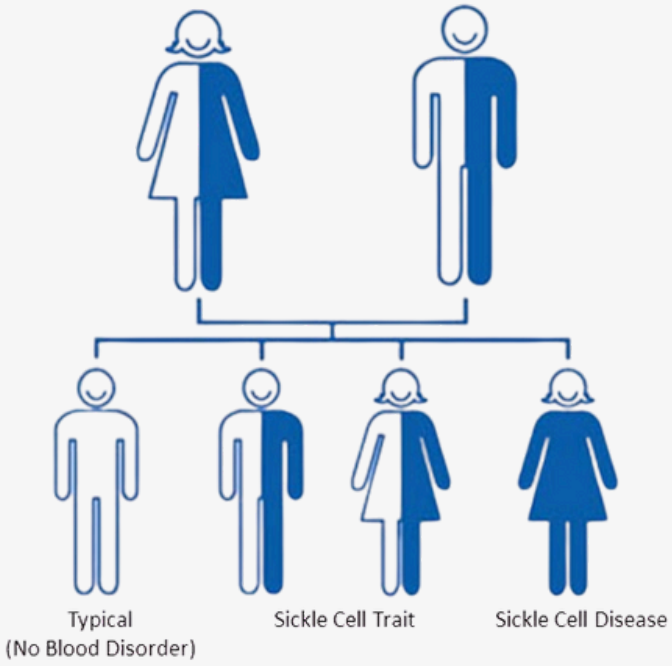
- Provide access to community support groups, peer networks, and mental health resources.
- Offer guidance on navigating life with SCT, including fitness, family planning, and career advice.

What is Sickle Cell Trait (SCT)?

Sickle Cell Trait (SCT) is a genetic condition. It means a person inherited one normal hemoglobin gene and one sickle hemoglobin gene. It's not the same as Sickle Cell Disease (SCD), which requires two sickle genes, one from each parent.

If you have SCT, you usually don't have the painful symptoms of Sickle Cell Disease. In fact, many people with SCT live healthy, active lives but it's still important to know your trait status because it can be passed on to your children, and in some cases, it may affect your health.

How SCT Is Inherited:



- Each parent passes down one gene.

- If both parents have SCT:
  - 25% chance the child will have Sickle Cell Disease.
  - 50% chance the child will have SCT.
  - 25% chance the child will have no sickle gene.

Knowing your trait status helps you make informed decisions about family planning and your health. SCT is diagnosed with a simple blood test. People at risk of having SCT can talk with a doctor or health clinic about getting this test.

Health Implications of SCT

While SCT often doesn't cause symptoms, it can still pose health risks especially under certain conditions like intense physical activity or dehydration.

Potential Health Complications:

- **Exertional Rhabdomyolysis** (breakdown of muscle tissue): increase risk during intense exercise or military training, especially without prosper hydration and rest; may experience musicle pain, weakness, dark colored urine and fatigue
- **Splenic Infarction** (blockage of blood supply to the spleen): triggered by high altitudes (flying or mountain climbing), low oxygen environments, or dehydration; may experience sharp pain in the left side of the abdomen, fever and nausea
- **Blood Clots:** higher risk for blood clots in certain situations
- **Eye Complications**: SCT can affect blood vessels in the eyes; sickle cell retinopathy (changes to the retina); retinal detachment (retina can detaach from the back of the eye)

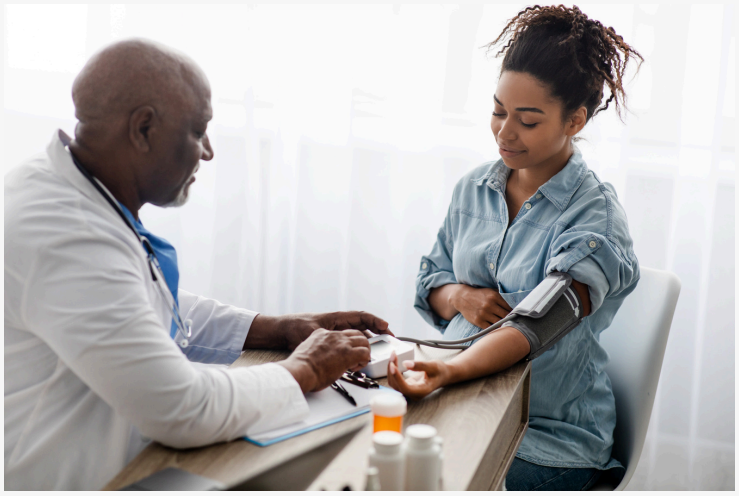
Kidney Related Complications:

- **Hematuria** (blood in the urine): often painless and may be intermittent; caused by sickling of the red blood cells in the renal medulla which leads to bleeding in the urinary tract

Health Implications of SCT (con’t)

- **Hyposthenuria**: a reduced ability to concentrate urine
- **Chronic Kidney Disease (CKD):** emerging evidence suggest SCT may increase the risk of developing CKD; risk is further elevated with co-morbid conditions like hypertension and diabetes
- ***Renal Medullary Carcinoma (RMC)***: a very aggressive kidney cancer almost exclusively seen in individuals with SCT; usually affects young people (teens to 30's); often diagnosed late due to lack of symptoms until full blown (flank pain, blood in urine, unexplained weight loss and abdominal mass); awareness and early intervention are critical

Together, these conditions highlight why knowing your SCT status is so important. Staying informed allows for early detection, proactive care, and timely intervention. Regular check-ups, open conversations with healthcare providers, and increased awareness can make a lifesaving difference.



Genetic Counseling: Why It Matters

If you or your partner has SCT, speaking with a genetic counselor can help you understand your reproductive options and what SCT means for your children. These conversations are not just for couples and it's helpful information for anyone with SCT to know.

Genetic Counseling Can Help You:

- Understand how SCT is passed down.
- Explore testing options for your partner or children.
- Make informed family planning decisions.
- Learn about early interventions and care if your child is at risk.

Tip: Ask your primary care doctor or OB-GYN for a referral to a genetic counselor or find one through a local hospital or community health center.

Newborn Screening for Sickle Cell

Newborn screening for sickle cell disease is a simple test that can save lives. Detecting sickle cell early allows babies to get the care they need right away, preventing serious health problems and helping them live healthier, longer lives.

- All babies in the U.S. are tested soon after birth with a small heel-prick blood sample.
- The test checks for sickle cell disease (SCD) and sickle cell trait (SCT).
- Early detection means children with SCD can start treatment right away, improving health and survival.

What the Results Mean

- Sickle Cell Disease (SCD): Your baby has the disease. A special medical team will contact you to confirm and begin care.
- Sickle Cell Trait (SCT): Your baby is a carrier. This does not cause disease but is important for your child’s future health and family planning.

Why It Matters

- Early detection allows the parents to be informed of potential complications of SCT
- Children who start care early have healthier outcomes and a better quality of life.

Advocacy and Resources

There’s power in knowing and sharing stories by advocating for SCT education and better healthcare, you can help save lives and improve outcomes for future generations.

How You Can Get Involved:

- **Raise awareness:** Share your story or facts about SCT on social media.
- **Join events**: Participate in local health fairs, walkathons, or SCT awareness days.
- **Support policy change**: Encourage schools, colleges, and athletic programs to screen for SCT and offer appropriate support.
- **Connect with community**: Join a support group or attend SCT-focused workshops.

Resources You Can Access:

- Local SCT support groups (in-person and online)
- Free or low-cost SCT testing centers
- Mental health and peer support
- The Chris “CJ” Johnson Foundation events and advocacy campaigns

You are not alone. The SCT community is growing stronger and you're a vital part of it.

SCT & Athletes: Staying Active Safely

Some people with SCT have been shown to be more likely than those without SCT to experience heat stroke and muscle breakdown when doing intense exercise, such as competitive sports or military training under unfavorable temperatures (very high or low) or conditions (such as high humidity).

Studies have shown that the chance of this problem can be reduced by avoiding dehydration and not getting too hot during training.

People with SCT who participate in competitive or team sports (such as student athletes) should be careful when doing training or conditioning activities. To prevent illness, it is important to:

- Set your own pace and build your intensity slowly.
- Rest often in between repetitive sets and drills.
- Drink plenty of water before, during and after training and conditioning activities.
- Keep the body temperature cool when exercising in hot and humid temperatures by misting the body with water or going to an air-conditioned area during breaks or rest periods.
- Immediately seek medical care when feeling ill.

Source: CDC, National Center on Birth Defects and Developmental Disabilities (NCBDDD), 2025

Personal Stories: Real Lives, Real Impact

Sharing lived experiences brings SCT to life and inspires others to learn, test, and speak up. Here are a few voices from our community:

“I found out I had Sickle Cell Trait in high school, so when I got to college, I already knew how to take care of my body. I adjusted my workouts, stayed hydrated, and communicated with my coaches. Knowing my status early helped me compete safely and confidently.”

— Shanice Johnson, former collegiate track athlete and Sickle Cell Trait Advocate

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“In 2019, I was diagnosed with renal medullary carcinoma (RMC). Not only was I shocked to learn I had cancer, but I was equally stunned to discover that I carried sickle cell trait (SCT)—something no one had ever told me throughout my life. I served 17 years in the military without knowing I had SCT. I often wonder if, had I been informed about the trait and its potential complications, I might have been able to avoid some of the challenges I faced—and perhaps even prevented the cancer from developing. Today, I am proud to say that five years after my diagnosis, my cancer is in remission.”

– Andre Snead (Retired Captain in US Army), Conyers, Georgia, Volunteer for the Chris "CJ" Johnson Foundation, Inc.

Personal Stories: Real Lives, Real Impact

“It will forever weigh on me that my sickle cell trait status was passed on to my son, who lost his life to renal medullary carcinoma at just 20 years old. I often wish I had a time machine — that I could use the information in this toolkit to save not only my son, but also so many others who might still be with us today through early detection of RMC.”

— Milton Wade, father to a son who passed away from RMC and Sickle Cell Trait Advocate

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“As a teenager, I learned I had sickle cell trait because my mother was a carrier. Later, I discovered that my youngest son also carried the trait. As both a mother and a nurse, I was told that sickle cell trait was benign and nothing to worry about.

My son was a competitive athlete, and I had no idea that the intense physical activity he engaged in could put him at risk for developing renal medullary carcinoma (RMC)—a rare, aggressive, and often fatal form of kidney cancer. I had never even heard of RMC, and sadly, many physicians were unaware of it as well. This lack of awareness often leads to patients being misdiagnosed or diagnosed far too late.

That was the case for my son. By the time he began showing symptoms, his cancer had already advanced to Stage IV. He fought courageously but passed away just 15 months later, at the age of 39.”

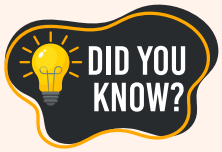
– Ritchie Johnson, President and Founder of the Chris "CJ" Johnson Foundation

General Public Infographic

Sickle Cell Trait: What You Need to Know

What is Sickle Cell Trait (SCT)?

Sickle cell trait means a person inherits one sickle cell gene and one normal gene. It is not the same as sickle cell disease. Most people with SCT live normal, healthy lives, but under certain conditions, SCT can lead to health complications.



About 1 in 13 African Americans and 1 in 100 Hispanic Americans are born with sickle cell trait. Many people don't even know they carry it.

Why Knowing Your Status Matters

- SCT is inherited—if both parents carry SCT, their child could be born with sickle cell disease.
- Knowing your status helps you make informed health and family planning decisions.
- Athletes and people with physically demanding jobs should be aware of SCT because of risks linked to intense exertion, dehydration, and heat.

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FOUNDATION

Possible Health Risks

While most people with SCT never have problems, some health risks include:

- Blood in urine (hematuria)
- Dehydration and heat-related illness during strenuous activity
- Rare risks: kidney complications (CKD, renal medullary carcinoma), venous blood clots, and splenic infarction at high altitudes

What You Can Do

- Get tested to know your SCT status (a simple blood test).
- Stay hydrated and avoid extreme overexertion.
- Share your status with your doctor and loved ones.
- Ask questions—advocacy starts with awareness!

Disclaimer

This toolkit has been developed to provide educational information about Sickle Cell Trait (SCT). It is designed to raise awareness, support community education, and serve as a resource for individuals, families, organizations and medical providers.

The information provided in this toolkit is for educational purposes only. It is not a substitute for professional medical advice, diagnosis, or treatment. Always seek the advice of a qualified healthcare provider with any questions you may have regarding your health, genetic status, or a medical condition.

This toolkit was created by the Chris “CJ” Johnson Foundation to support education and awareness efforts. The views and content expressed do not necessarily represent the official policy or position of any funding agency, partner, or affiliated organization.

Sickle Cell Trait can be a sensitive topic within families and communities. Please use this resource with cultural awareness, compassion, and respect for individuals and families affected by SCT.