Comprehensive Education Program Specifically for Sickle Cell Trait (SCT)

Medical Professionals

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 impacted by sickle cell trait. Designed specifically for healthcare providers, this guide highlights key clinical considerations, red flags, and best practices for patient care. Whether you are in primary care, emergency medicine, nephrology, hematology, or another specialty, this resource equips you with concise, evidence-based tools to recognize potential complications, counsel patients effectively, and advance awareness within the medical community.

Toolkit Objectives

1. Clinical Awareness

- Recognize that sickle cell trait (SCT) is not always benign and can present with serious health implications.
- Stay informed on current evidence linking SCT to complications such as exertional collapse, renal issues, and RMC.

2. Testing & Counseling

- Implement appropriate screening protocols and confirmatory testing when SCT is suspected.
- Provide clear, compassionate counseling to patients and families about SCT status and implications.

3. Early Recognition & Management

- Identify red flags such as exertional heat illness, hematuria, unexplained flank pain, or collapse during exercise.
- Develop care plans that include risk mitigation strategies for athletes, military recruits, and high-risk patients.

4. Advocacy & Collaboration

- Partner with athletic trainers, schools, and community organizations to support individuals with SCT.
- Promote SCT education and awareness within your practice, hospital system, and broader medical community.

Clinical Awareness

Sickle Cell Trait (SCT) is often mischaracterized as “benign,” but emerging evidence shows that under specific conditions it can lead to serious complications.

Medical professionals should be aware of:

- **Health risks**:
  - exertional Rhabdomyolysis
  - rhabdomyolysis
  - venous thromboembolism
  - renal complications (**RMC**, hyposthenuria, CKD,)

- **At-risk populations**:
  - athletes
  - military recruits
  - pregnant women
  - individuals with co-morbid conditions like hypertension or diabetes

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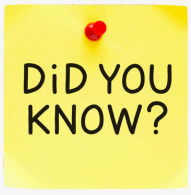

Individuals with sickle cell trait are up to 20–30 times more likely to develop **renal medullary carcinoma (RMC)**, a very aggressive kidney cancer, compared to the general population. Early recognition of unexplained hematuria or flank pain is critical.

Testing & Counseling

Proper testing and counseling are essential for early detection, patient safety, and informed decision-making.

- **Screening & Confirmation**: Hemoglobin electrophoresis or high-performance liquid chromatography (HPLC) are the gold standards for confirming SCT. While the sickle solubility test can serve as a quick screen, it should always be confirmed with electrophoresis. Screening should be considered for newborns, student-athletes, military recruits, patients with a family history of hemoglobinopathies, and individuals presenting with unexplained hematuria, hyposthenuria, or renal complications. **Routine documentation of SCT status in the medical record is crucial for continuity of care.**

- **Patient Counseling**: Providers should clearly explain the difference between SCT and sickle cell disease, emphasizing that SCT is usually asymptomatic but carries potential risks. Counseling should cover inheritance patterns, reproductive considerations (e.g., risk of having a child with SCD if both parents are carriers), and lifestyle or environmental factors that may increase risk (e.g., extreme exercise, dehydration, high altitude). Encourage referrals to genetic counselors for families or individuals seeking more detailed guidance.

Newborn Screening Overview

Newborn screening for sickle cell disease is critical for early intervention. Prompt identification enables timely initiation of prophylactic antibiotics, vaccinations, and comprehensive care, significantly reducing morbidity and mortality in affected infants.

- Mandated in all 50 U.S. states.
- Heel-stick sample collected at 24–72 hours of life.
- Methods: High-performance liquid chromatography (HPLC) or capillary electrophoresis.
- Identifies both SCD and SCT; follow-up protocols may vary by state.

Result Interpretation

- SCD: Requires confirmatory testing, referral to comprehensive care, initiation of penicillin prophylaxis, and parental education.
- SCT: Carrier status; important for genetic counseling, family testing, and reproductive planning.

Why It Matters

- This early detection allows for timely intervention and care, significantly improving outcomes for affected children.

Early Recognition & Management

Early identification of complications can prevent serious outcomes and improve patient safety.

Recognizing Red Flags:

Be alert for hematuria, unexplained flank or abdominal pain, exertional collapse, rhabdomyolysis, severe fatigue during exercise, and symptoms of venous thromboembolism (e.g., leg swelling, shortness of breath).

Renal medullary carcinoma (RMC) may present with hematuria, flank pain, unexplained weight loss, or an abdominal mass often diagnosed late due to subtle early symptoms.

Management Strategies:

For patients with SCT, recommend proactive measures such as adequate hydration, gradual progression in exercise or athletic training, heat and altitude acclimatization, and avoidance of extreme exertion without proper supervision.

For athletes, implement emergency action plans and ensure staff are trained to respond to exertional collapse or rhabdomyolysis. Patients presenting with renal symptoms should be referred promptly to nephrology or urology for evaluation, and any unusual laboratory findings (e.g., hematuria or reduced kidney function) should be closely monitored.

Advocacy & Collaboration

Medical professionals play a key role in bridging awareness, education, and policy.

- **Interdisciplinary Collaboration**: Work with athletic trainers, school nurses, sports medicine teams, military medical staff, genetic counselors, and community health organizations to ensure patient safety and education. Ensure that emergency protocols for exertional sickling are in place in schools, colleges, and athletic programs.

- **Promoting Awareness and Policy Change**: Educate patients and their families on SCT risks, encourage routine testing where appropriate, and advocate for institutional policies that protect individuals with SCT during high-risk activities. Participate in community outreach, health fairs, and professional workshops to raise awareness and provide education to both peers and the general public.

Sickle Cell Trait (SCT): Quick Reference for Medical Professionals

Testing & Diagnosis

- **Screen**: newborns, athletes, military recruits, patients with unexplained hematuria/renal issues, couples with family history.
- **Confirm**: Hemoglobin electrophoresis or HPLC (gold standard).

Note: Sickle solubility test (SST) is only a screening tool.

Clinical Red Flags

- **Renal**: hematuria, hyposthenuria, CKD, renal medullary carcinoma (RMC).
- **Vascular**: ↑ risk of VTE (esp. in pregnancy or with risk factors).
- **Exertional**: collapse, rhabdomyolysis, sudden death risk in extreme exertion/heat.
- **Pregnancy**: ↑ UTIs, ↑ VTE, genetic counseling needed.
- **Other**: splenic infarction at high altitudes.

Key Takeaway

SCT is not always benign. Early recognition, patient education, and proactive monitoring can prevent life-threatening complications.

Immediate Action Triggers

⚠️ Gross/microscopic hematuria
⚠️ Flank pain or abdominal mass
⚠️ Exertional collapse or rhabdomyolysis
⚠️ Suspected VTE (leg swelling, chest pain, SOB)
⚠️ Signs of RMC (hematuria + weight loss + pain)

Best Practices

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✅ Document SCT status clearly in medical record.
✅ Counsel on inheritance (25% SCD risk if both parents have SCT).
✅ Refer for genetic counseling when relevant.
✅ Educate athletes/military: hydrate, acclimate gradually, avoid extreme exertion.
✅ Monitor kidney function if renal symptoms present.
✅ Early referral to nephrology/urology if hematuria or renal impairment.

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.