



# Georgia Sickle Cell Education, Awareness & Advocacy Program

NATIONAL BLACK CHURCH INITIATIVE

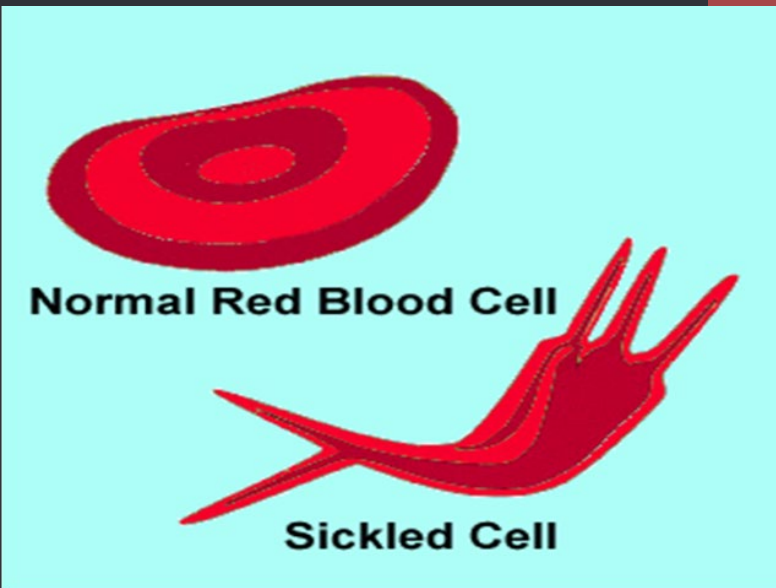


Dr. Lakiea Bailey  
Sickle Cell Consortium



# SICKLE CELL DISEASE

- SCD is a genetic disease affecting 70,000 – 100,000 Americans, primarily of African descent <sup>1</sup>
  - Most common genetic disease among blacks
  - SCD occurs in 1 of every 500 black births
- 1:1,100 Hispanics (eastern states)
- 1:32,000 Hispanics (western states)
- SCD occurs in many other ethnic groups, including Northern Europeans and those that live in the Middle Eastern Countries
- 1:12 African-Americans are carriers (trait) for the disorder



# SCD COMMON GENOTYPES

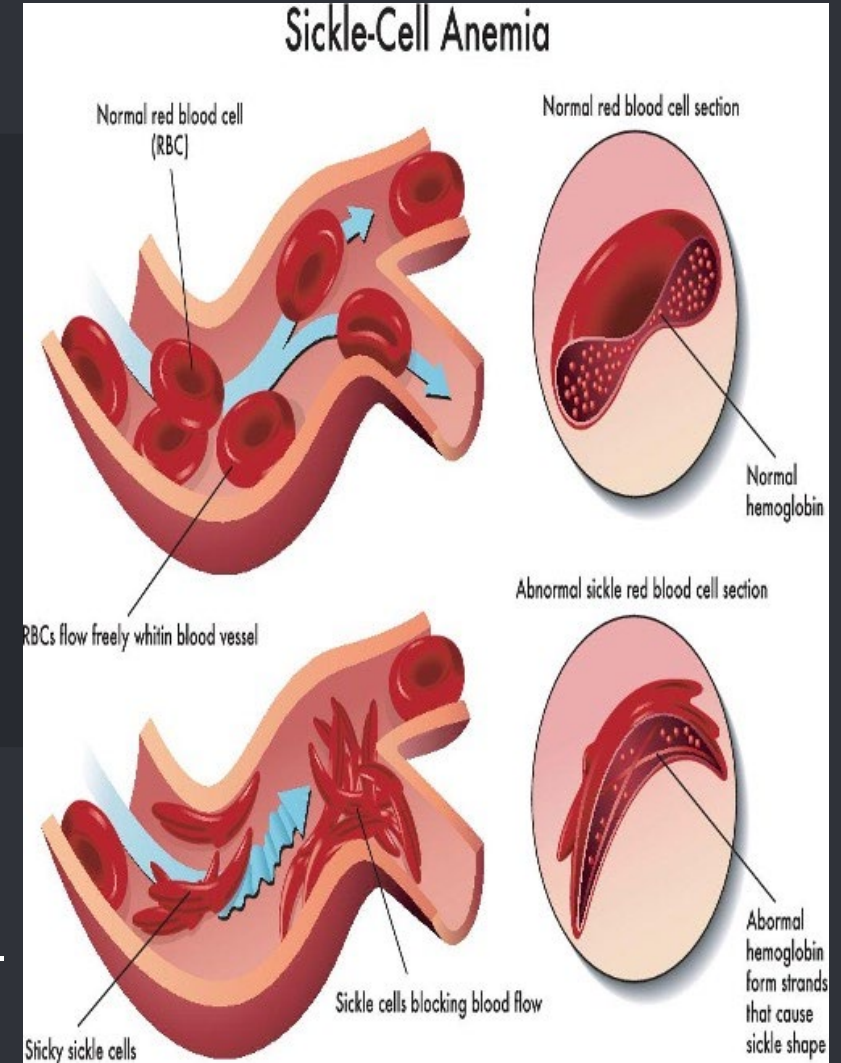
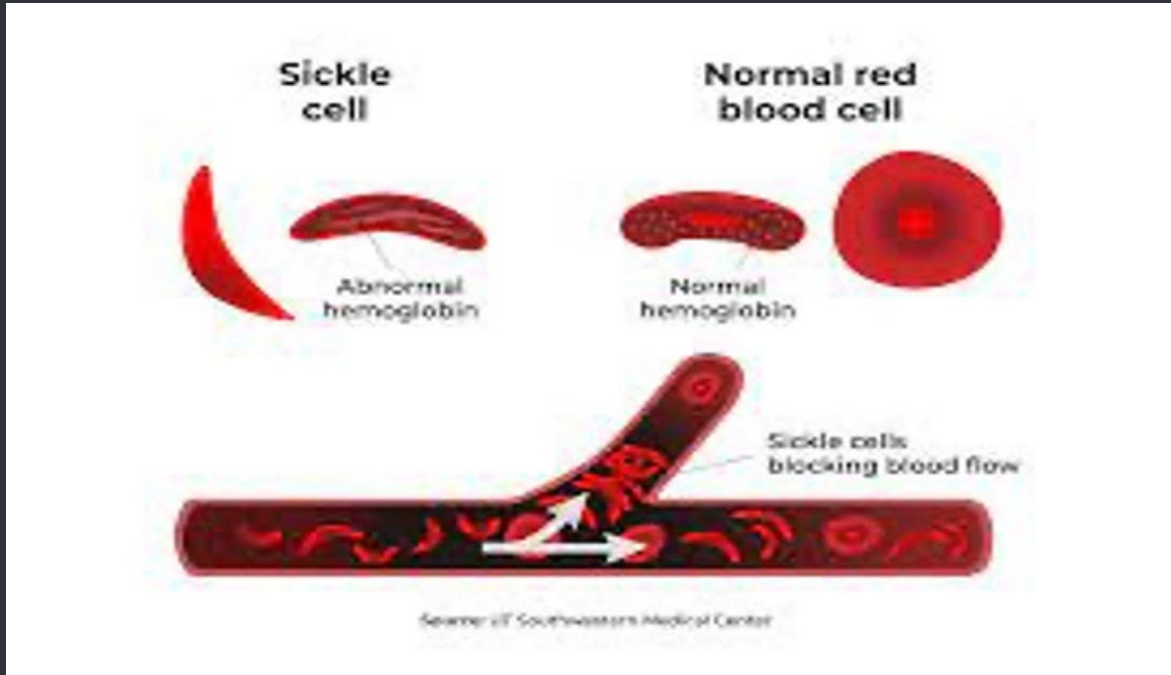


## GENOTYPE

## APPROXIMATE % OF US PATIENTS

- Sickle cell anemia (SS, most severe form) 65 %
- Sickle/Hb C disease (SC, lesser severity, but can still have pain episodes, and life-threatening complications) 25 %
- Sickle/Beta plus thalassemia ( $S\beta^+$  thalassemia, similar to SC) 8 %
- Sickle/Beta zero thalassemia ( $S\beta^0$  thalassemia, similar to SS) 2 %

# Prolonged Sickling of RBC's



- After recurrent episodes of sickling
  - membrane damage occurs
  - cells not capable of resuming biconcave shape upon re-oxygenation
- Deformed sickle cells stick to other blood cells and blood vessels

# Acute and Chronic Manifestations

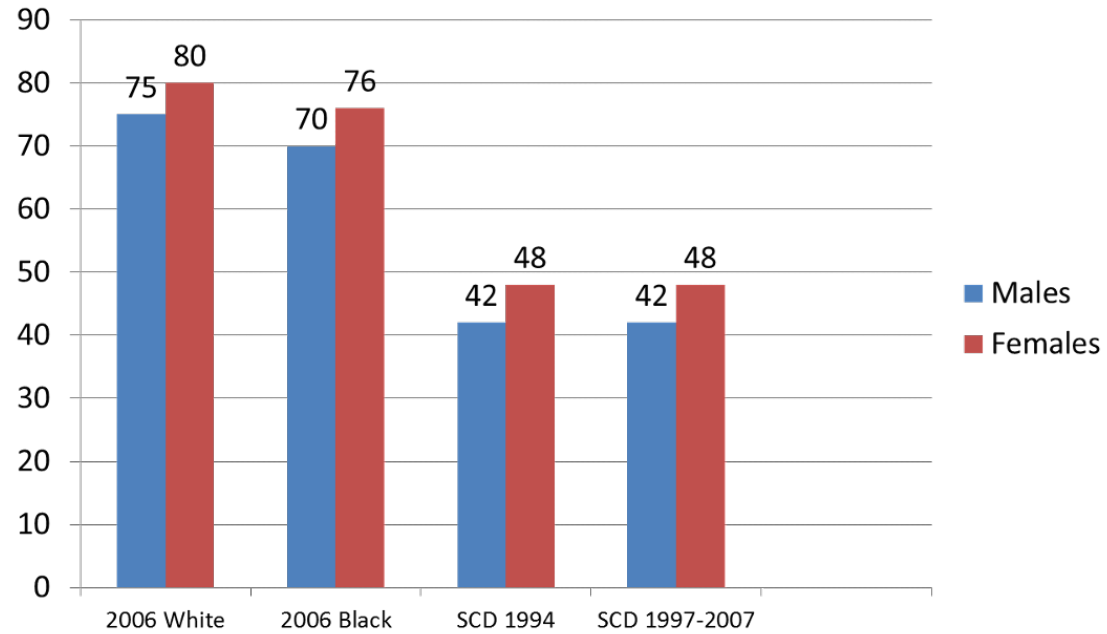


## Acute Manifestations

- Bacterial sepsis or meningitis\*
- Recurrent vaso-occlusive pain (dactylitis, musculoskeletal or abdominal pain)
- Splenic sequestration\*
- Aplastic crisis\*
- Acute chest syndrome\*
- Stroke\*
- Priapism
- Hematuria, including papillary necrosis

## Chronic Manifestations

- Anemia
- Jaundice
- Splenomegaly
- Functional asplenia
- Cardiomegaly and functional murmurs
- Hyposthenuria and enuresis
- Proteinemia
- Cholelithiasis
- Delayed growth and sexual maturation
- Restrictive lung disease\*
- Pulmonary hypertension\*
- Avascular necrosis
- Proliferative retinopathy
- Leg ulcers
- Transfusional hemosiderosis\*



# Comparison of Life Expectancy US Population vs. Sickle Cell Disease



**THE POWER  
OF THE  
COLLECTIVE**



# SICKLE CELL CONSORTIUM

## MISSION

The Sickle Cell Community Consortium is a national collaborative of sickle cell Warriors, caregivers, community-based organizations (CBOs), community partners and medical/research advisers working collectively to equip and empower the sickle cell community to be full participants, and lead the charge, in sickle cell advocacy, education, research, legislation and policy.

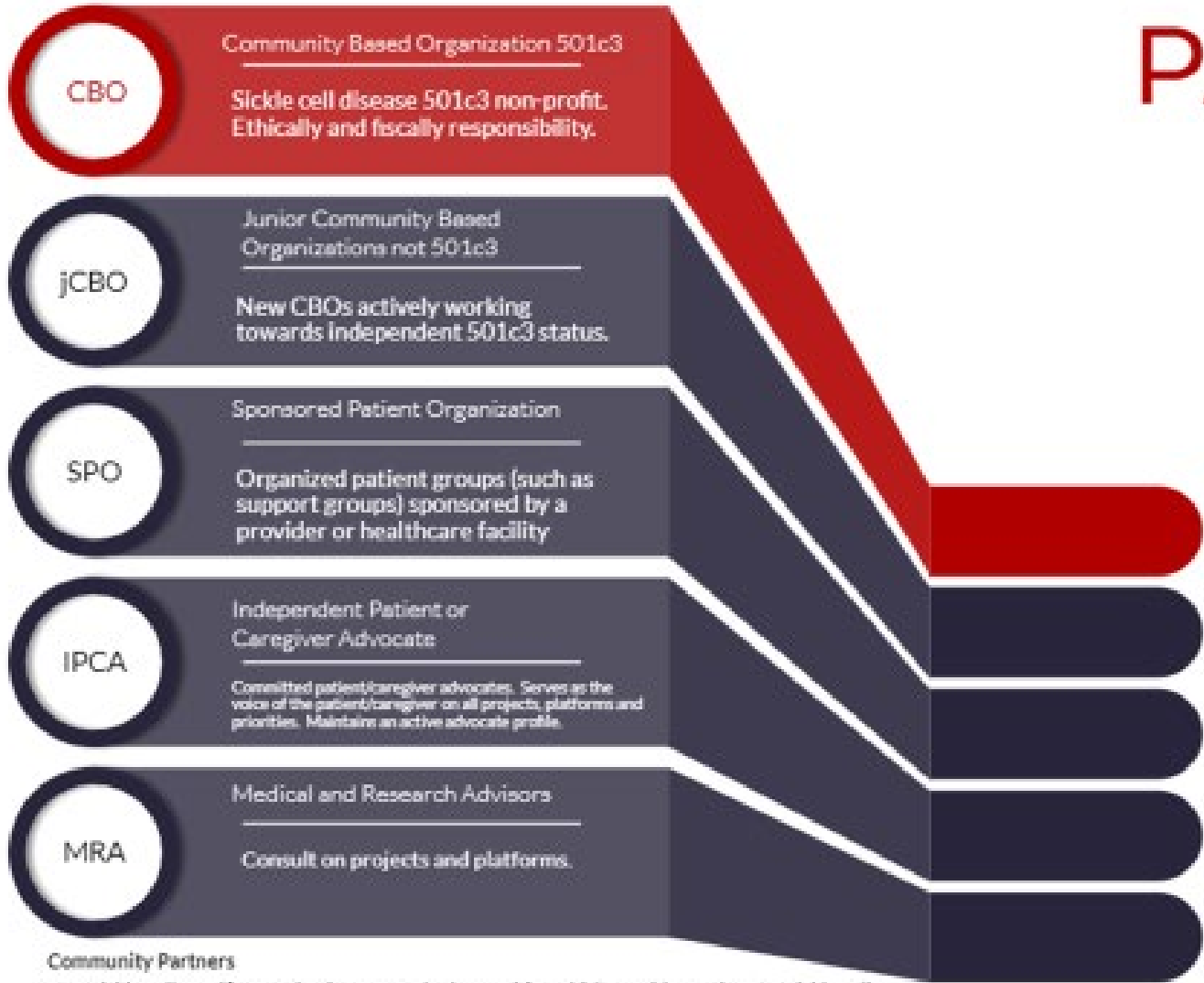


# SICKLE CELL CONSORTIUM



## CORE GOALS

- To provide sickle cell community-based organizations (CBOs) with the necessary infrastructure, support, training and resources to build and maintain strong, effective CBOs.
- To provide a platform to harness and amplify the sickle cell patient voice through Collective Impact to enable sickle cell patients and stakeholders to identify and address needs and gaps and implement collaborative, multi-stakeholder-directed solutions through patient powered and patient-centered projects, research and outcomes.



**Community Partners**

Non-sickle cell specific orgs, businesses and other entities which provide services for sickle cell community or whose purpose or mission aligns with the collective goal of the Consortium.

# PARTNERS





# PARTNERS

● ● ● sickle cell community consortium



# Patient, Caregiver, CBO Agenda for Georgia

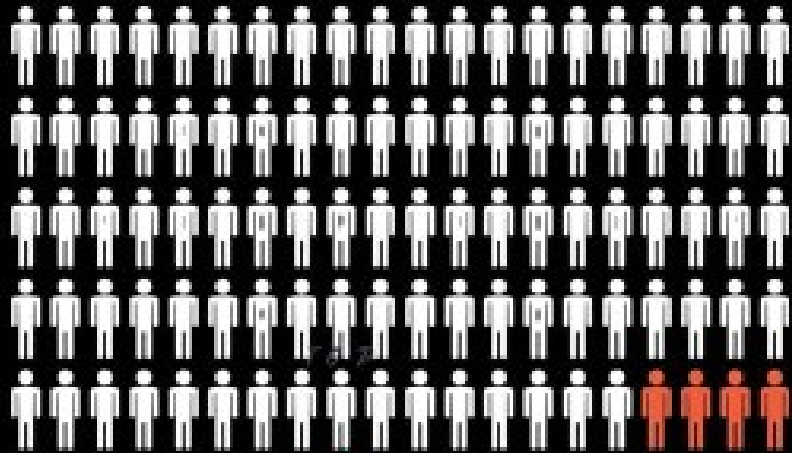


1. Blood & Marrow Donation
2. Emergency Department Discrimination & Access to Care
3. Legislative Action in GA Schools and GA Jobs
4. Mental Health Awareness, Support & De-stigmatization
5. Sickle Cell Education



# BLOOD AND MARROW DONATION

22 MILLION ON THE REGISTRY,  
**ONLY 4% ARE BLACK.**



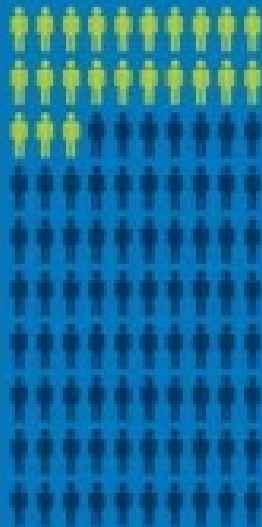
*We are the  
Cure*

TEXT SC3  
TO 61474

## ODDS OF FINDING A MATCH BASED ON ETHNIC BACKGROUND

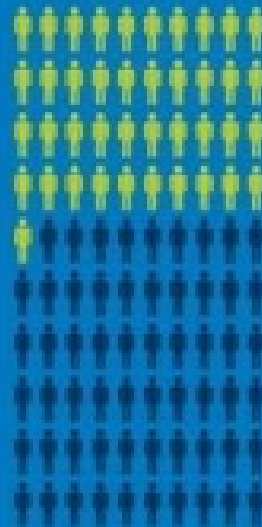
Black or African  
American

**23%**



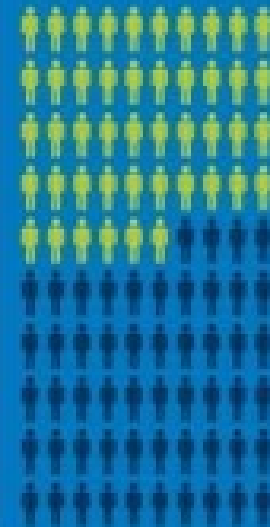
Asian or Pacific  
Islander

**41%**



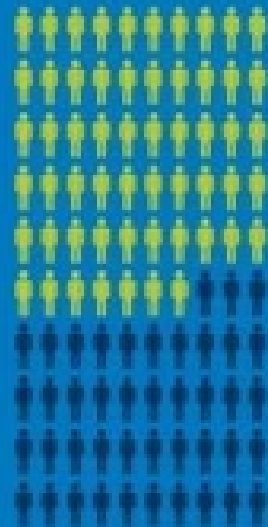
Hispanic  
or Latino

**46%**



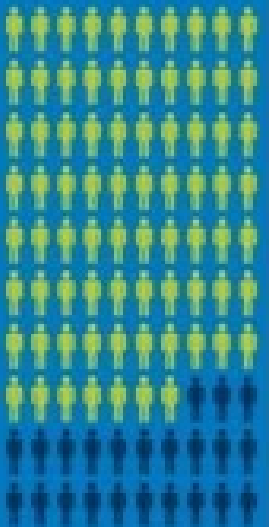
American Indian  
and Alaska Native

**57%**



White

**77%**



# BLOOD AND MARROW DONATION



American Red Cross

Meet the need

## SICKLE CELL FIGHTERS



SICKLE CELL COMMUNITY CONSORTIUM



EVERY TWO SECONDS,  
SOMEONE NEEDS BLOOD.

# DONATE BLOOD & SAVE LIVES

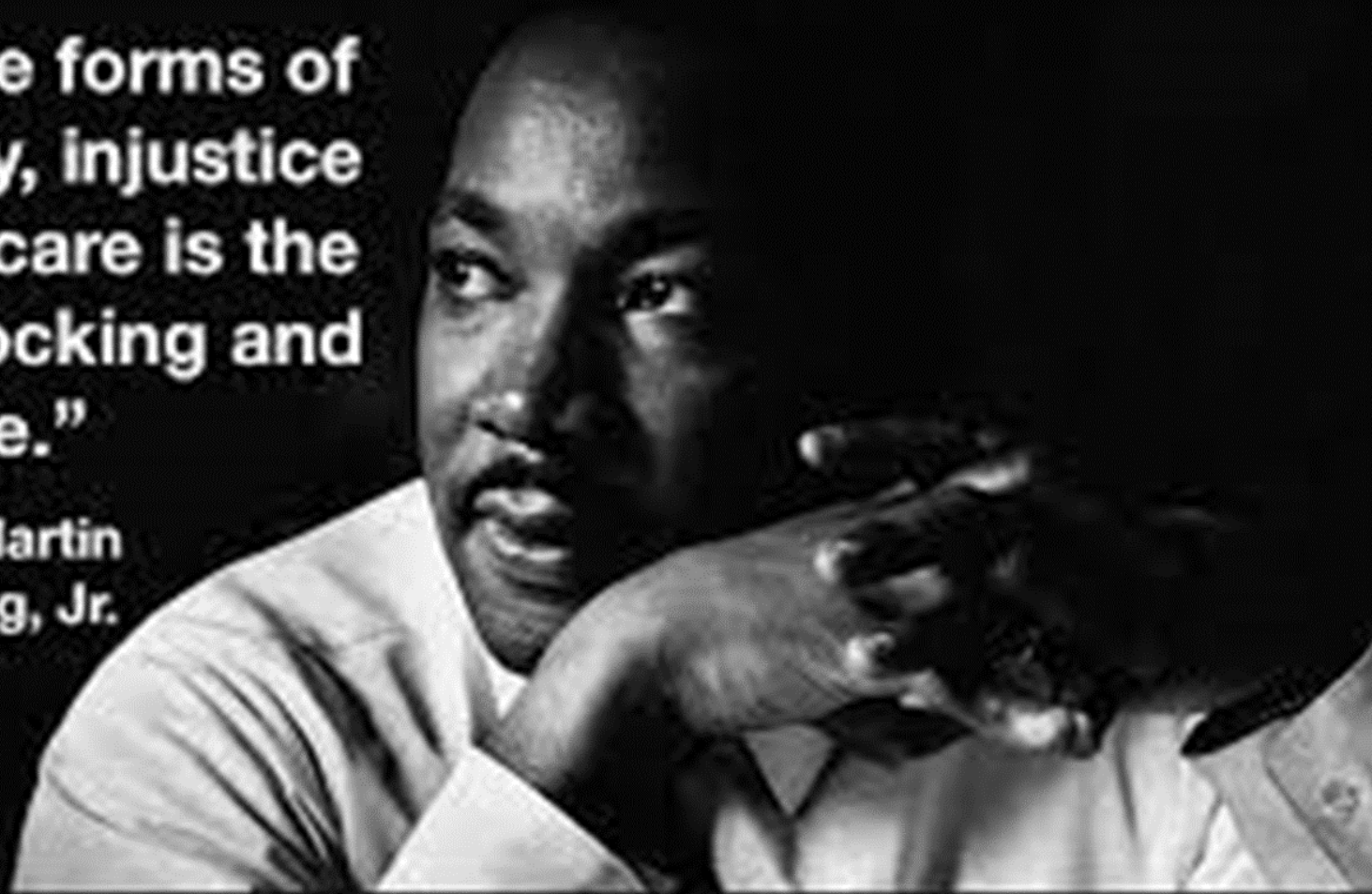
CHECK YOUR LOCAL  
BLOOD BANK



# EMERGENCY DEPARTMENT DISCRIMINATION

**“Of all the forms of inequality, injustice in healthcare is the most shocking and inhumane.”**

**— Rev. Dr. Martin Luther King, Jr.**



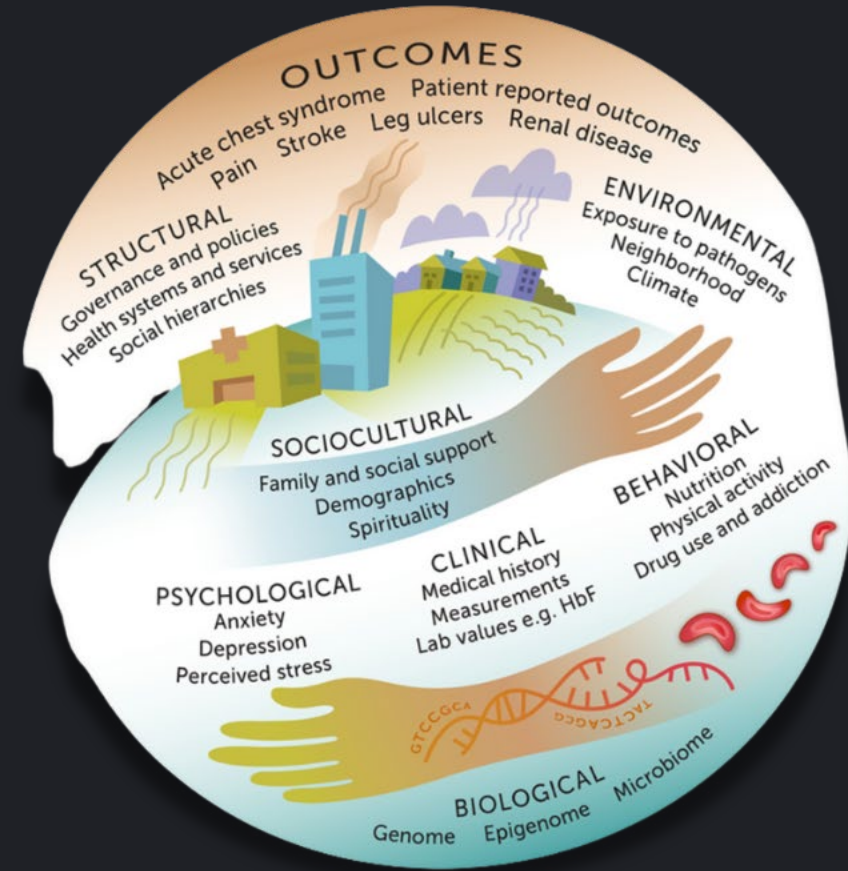
# GEORGIA JOBS & SCHOOLS







# Mental Health Awareness, Support & De- stigmatization



# Sickle Cell Education





# SKYDIVING





THANK YOU

