A RESOLUTION encouraging the Cabinet for Health and Family Services to study sickle cell disease and the establishment of a State Sickle Cell Registry.

WHEREAS, sickle cell anemia and sickle cell disease (SCD), used interchangeably, refer to a group of inherited disorders that affect the red blood cells; and

WHEREAS, sickle cell anemia is a disease in which a person's body produces abnormally shaped red blood cells that resemble a crescent or sickle, and that do not last as long as normal round red blood cells, which leads to anemia. The sickle cells also get stuck in blood vessels and block blood flow, which can cause pain and organ damage; and

WHEREAS, sickle cell anemia is a genetic disorder where individuals with the disease are born with two sickle cell genes, each inherited from one parent. An individual with only one sickle cell gene has a "sickle cell trait"; and

WHEREAS, according to the Centers for Disease Control and Prevention (CDC), the exact number of people living with sickle cell disease in the United States is unknown; and

WHEREAS, according to the CDC, it is estimated that SCD affects approximately 100,000 Americans, and occurs among about 1 out of every 365 African-American births and about 1 out of every 16,300 Hispanic-American births; and

WHEREAS, according to the CDC, it is estimated that sickle cell trait occurs about 73 out of every 1,000 African-American births, about 3 out of every 1,000 white births, and about 7 out of every 1,000 Hispanic-American births; and

WHEREAS, according to the United States Department of Health and Human Services Office of Minority Health, approximately two million Americans carry the sickle cell trait and, unlike most people with sickle cell anemia, most people who have sickle cell trait never know they have it and can live their entire lives without any complications from it; and

WHEREAS, the financial cost of SCD is high, both to people with the disease and

to the health care system; and

WHEREAS, according to the CDC, medical expenditures for children and adults with SCD averaged $10,704 for children to $34,266 for the 30 to 39 age group, with a high portion of the sickle cell disease costs associated with inpatient hospitalizations; and

WHEREAS, individuals living with sickle cell anemia encounter barriers to obtaining quality care and improving their quality of life. These barriers include limitations in geographic access to comprehensive care, the varied use of effective treatments, the high reliance on emergency care and on public health programs, and the limited number of health care providers with knowledge and experience to manage and treat sickle cell anemia;

NOW, THEREFORE,

Be it resolved by the House of Representatives of the General Assembly of the Commonwealth of Kentucky:

➔Section 1. The members of the House of Representatives encourage the Cabinet for Health and Family Services to study sickle cell disease and to establish a State Sickle Cell Registry. The registry shall be used to:

(1) Establish a central registry of patients diagnosed with sickle cell disease; and

(2) Compile statistical information and provide information to patients about counseling, intervention, educational services, and other resources that may be beneficial to the patient.

➔Section 2. The Clerk of the House of Representatives is directed to transmit a copy of this Resolution to Representative Reginald Meeks for delivery.