

Proclamation

by Governor Jim Justice

- Whereas,** "Sickle cell anemia" and "sickle cell disease," used interchangeably, refer to a group of inherited disorders that affect the red blood cells; and
- Whereas,** Sickle cell disease 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; and
- Whereas,** the sickle cells also get stuck in blood vessels and block blood flow, resulting in vaso-occlusive crises, which can cause pain and organ damage; and
- Whereas,** Sickle cell disease is a genetic disorder where individuals with the disease are born with two sickle cell genes, each inherited from one parent; and
- Whereas,** an individual with only one sickle cell gene has a "sickle cell trait," which occurs in 1 out of every 13 African Americans and in 1 out of every 100 Latinos in the United States; and
- Whereas,** The United States Centers for Disease Control and Prevention estimates that sickle cell disease affects approximately 100,000 Americans, and occurs among about 1 in every 365 Black or African-American births and 1 out of every 16,300 Hispanic-American births, and it is estimated that more than 200 West Virginians have sickle cell disease; and
- Whereas,** The National Institutes of Health is working on innovative genetic therapies that could someday cure sickle cell disease; and
- Whereas,** The United States Food and Drug Administration has granted orphan drug designation to sickle cell therapies to provide incentives and encourage the development of therapies for rare diseases; and
- Whereas,** Sickle cell disease is a chronic condition that can affect any organ, including the kidneys, lungs, and spleen, and research indicates that patients experience many severe complications, including stroke, infections, and pulmonary embolism, and have a shorter life expectancy than the general population; and
- Whereas,** Vaso-occlusive crises are a common painful complication of sickle cell disease in adolescents and adults which may occur several times a year, and these recurrent episodes induce severe pain; decrease quality of life; can cause life-threatening complications, including stroke; are the primary cause of hospitalizations in sickle cell disease; and are associated with increased mortality; and
- Whereas,** Vaso-occlusive crises typically last several days and are the leading cause of hospitalizations of patients with sickle cell disease; and
- Whereas,** Sickle cell disease can be a life-threatening condition leading to a 25 to 30-year reduction in life expectancy, and access to comprehensive care can be limited by social, economic, cultural, and geographic barriers; and
- Whereas,** individuals living with sickle cell disease encounter barriers to obtaining quality care and improving their quality of life, and 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 disease; and
- Whereas,** while there is no widely available cure for sickle cell disease, one-time gene therapies, including gene editing therapeutic approaches, are being developed and may offer potential cures for some patients; and
- Whereas,** one-time, potentially curative therapies for sickle cell disease may offer substantial savings over the patient's lifetime by avoiding the cost of future health services.

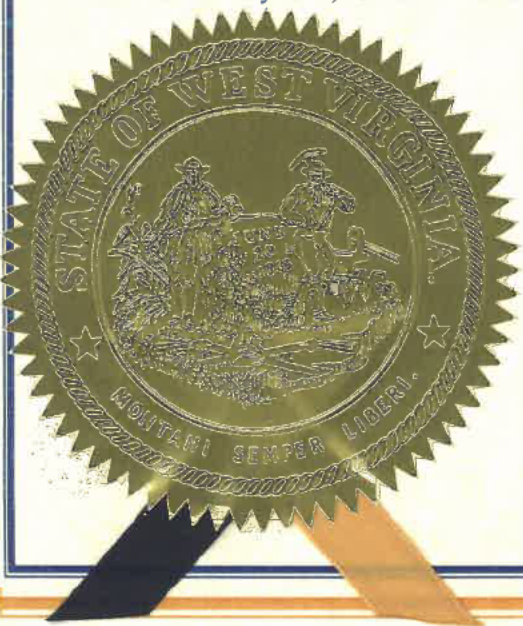
Now, Therefore, Be it Resolved that I, Jim Justice, Governor of the Great State of West Virginia, do hereby proclaim **September 2022** as:


Sickle Cell Disease Awareness Month

in the Mountain State and encourage all citizens to join me in this observance.

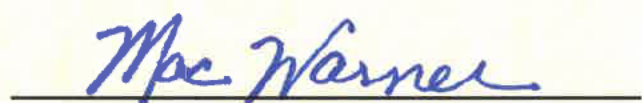
In Witness Whereof, I have hereunto set my hand and caused the Great Seal of the State of West Virginia to be affixed.

Done at the Capitol, City of Charleston, State of West Virginia, this the Twenty-Fifth day of August, in the year of our Lord, Two Thousand Twenty-Two, and in the One Hundred Sixtieth year of the State.




Jim Justice
Governor

By the Governor:


Mac Warner
Secretary of State