1 **INTERIM RESOLUTION 2021-003** 2 3 REQUESTING THE ARKANSAS LEGISLATIVE COUNCIL TO RECOGNIZE 4 SEPTEMBER 2021 AS "SICKLE CELL DISEASE AWARENESS MONTH" IN 5 ARKANSAS. 6 7 WHEREAS, "sickle cell anemia" and "sickle cell disease" refer to a 8 group of inherited disorders that affect the red blood cells; and 9 10 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 11 12 and that do not last as long as normal, round red blood cells, which causes 13 anemia; and 14 WHEREAS, the sickle cells also get stuck in blood vessels and block 15 16 blood flow, resulting in vaso-occlusive crises, which can cause pain and 17 organ damage; and 18 19 WHEREAS, sickle cell anemia is a genetic disorder in which individuals 20 with the disease are born with two (2) sickle cell genes, each inherited from 21 one (1) parent while sickle cell disease is a genetic disorder in which 22 individuals with the disease are born with one (1) sickle cell gene and 23 another abnormal gene; and 24 25 WHEREAS, an individual who inherits one (1) sickle cell gene and one 26 (1) normal gene has "sickle cell trait", which occurs in one (1) out of every 27 twelve (12) African Americans and in one (1) out of every one hundred (100) 28 Latinos in the United States; and 29 30 WHEREAS, the Centers for Disease Control and Prevention estimates that 31 sickle cell disease affects approximately one hundred thousand (100,000) 32 Americans and occurs among about one (1) in every three hundred sixty-five 33 (365) Black or African-American births and one (1) out of every sixteen 34 thousand three hundred (16,300) Hispanic-American births, and it is estimated that more than one thousand fifty (1,050) Arkansans have sickle cell disease; 35 36 and

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2 WHEREAS, the National Institutes of Health is working on innovative 3 genetic therapies that could someday cure sickle cell disease; and 4 5 WHEREAS, the United States Food and Drug Administration has granted 6 orphan drug designation to sickle cell therapies to provide incentives and 7 encourage the development of therapies for rare diseases; and 8 9 WHEREAS, sickle cell disease is a chronic condition that can affect any 10 organ, including the kidneys, lungs, and spleen, and research indicates that patients experience many severe complications, including stroke, infection, 11 12 and pulmonary embolism, and have a shorter life expectancy than the general 13 population; and 14 15 WHEREAS, vaso-occlusive crises are a common painful complication of 16 sickle cell disease in adolescents and adults that may occur several times a 17 year, typically last several days, and are the leading cause of 18 hospitalizations of patients with sickle cell disease; and 19 20 WHEREAS, these recurrent episodes induce severe pain, decrease quality of life, can cause life-threatening complications, including stroke, are the 21 22 primary cause of hospitalizations of patients with sickle cell disease, and 23 are associated with increased mortality; and 24 25 WHEREAS, sickle cell disease can be a life-threatening condition 26 leading to a twenty-five- to thirty-year reduction in life expectancy, and 27 access to comprehensive care may be limited by social, economic, cultural, 28 and geographic barriers to obtaining quality care and improving their quality 29 of life; and 30 31 WHEREAS, these barriers include limitations in geographic access to 32 comprehensive care, the varied use of effective treatments, the high reliance 33 on emergency care and on public health programs, and the limited number of 34 healthcare providers with knowledge and experience to manage and treat sickle 35 cell disease; and 36

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           WHEREAS, while there is no widely available cure for sickle cell
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     disease, one-time gene therapies, including gene editing therapeutic
     approaches, are being developed and may offer potential cures for some
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     patients; and
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           WHEREAS, one-time, potentially curative therapies for sickle cell
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     disease may offer substantial savings over the patient's lifetime by helping
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     patients avoid the cost of future health services,
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    NOW THEREFORE,
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     BE IT RESOLVED BY THE ARKANSAS LEGISLATIVE COUNCIL OF THE NINETY-THIRD
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    GENERAL ASSEMBLY OF THE STATE OF ARKANSAS:
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           THAT the Arkansas Legislative Council recognize September 2021 as
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     "Sickle Cell Disease Awareness Month" in Arkansas.
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    Respectfully submitted,
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    Representative Fredrick J. Love
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    District 29
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    Representative Reginald Murdock
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    District 48
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    Prepared by: JMB/JMB
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