



Introduced Version

**HOUSE CONCURRENT
RESOLUTION No. _____**

DIGEST OF INTRODUCED RESOLUTION

A CONCURRENT RESOLUTION raising awareness for
sickle cell disease.

Porter

_____, read first time and referred to Committee on

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HC 1029/DI 140



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RESOLUTION No. _____**

1 A CONCURRENT RESOLUTION raising awareness for
2 sickle cell disease.

3 *Whereas, Sickle cell disease is a severe, life-shortening,*
4 *inherited disease that affects the red blood cells and impacts*
5 *predominantly people of color, particularly African-Americans;*

6 *Whereas, Sickle cell disease is a disease in which a person's*
7 *body produces abnormally shaped red blood cells that resemble*
8 *a crescent or sickle, and that do not last as long as normal*
9 *round red blood cells, which leads to anemia. The sickle cells*
10 *also get stuck in blood vessels and block blood flow, resulting*
11 *in vaso-occlusive crises that can cause pain and organ damage;*

12 *Whereas, Individuals living with sickle cell disease experience*
13 *severe pain, anemia, organ failure, stroke, and infection. In one*
14 *recent study, more than 30% of those diagnosed experienced*
15 *premature death, and another recent study estimates that the*
16 *life expectancy for individuals with sickle cell disease is 54*
17 *years;*

18 *Whereas, While the Centers for Disease Control and*
19 *Prevention estimates that sickle cell disease affects more than*
20 *100,000 people in the United States, the exact number of people*
21 *with sickle cell disease is unknown, so there is a need for*
22 *comprehensive and coordinated data collection efforts to better*
23 *understand and quantify the scope and impact of sickle cell*
24 *disease on patients, communities, states, and the nation;*

25 *Whereas, In the more than 100 years since the underlying*
26 *cause of sickle cell disease was discovered, the lack of focus on*



1 *this racially-specific illness has contributed to a minority*
 2 *patient community receiving relatively little attention and has*
 3 *resulted in delays in the development of effective treatment*
 4 *options;*

5 *Whereas, Individuals living with sickle cell disease encounter*
 6 *barriers to obtaining quality care and improving their quality*
 7 *of life, and these barriers include limitations in geographic*
 8 *access to comprehensive care, the varied use of effective*
 9 *treatments, the discrimination of being labeled "drug seekers"*
 10 *when seeking care during a crisis, the high reliance on*
 11 *emergency care, and the limited number of health care*
 12 *providers with knowledge and experience to manage and treat*
 13 *sickle cell disease;*

14 *Whereas, After decades of relatively little progress being*
 15 *made in therapeutic innovations for sickle cell disease, several*
 16 *therapies for sickle cell disease have been approved in the last*
 17 *few years, providing patients and their physicians with new*
 18 *therapeutic options to manage and treat their condition; and*

19 *Whereas, With several rapidly progressing, one-time genetic*
 20 *therapies in clinical development, we are now on the verge of*
 21 *a potential cure for some patients living with sickle cell disease,*
 22 *and while these investigational approaches are still being*
 23 *evaluated in clinical trials, such therapies have the potential to*
 24 *revolutionize the practice of medicine and transform the lives*
 25 *of individuals living with sickle cell disease: Therefore,*

26 *Be it resolved by the House of Representatives*
 27 *of the General Assembly of the State of Indiana,*
 28 *the Senate concurring:*

29 SECTION 1. That the Indiana General Assembly recognizes
 30 the progress being made on research into treatments of sickle
 31 cell disease and the effect this disease has on those who live
 32 with it.

33 SECTION 2. That the Principal Clerk of the House of
 34 Representatives shall transmit copies of this resolution to State
 35 Representative Gregory Porter for distribution.

