

115TH CONGRESS
1ST SESSION

H. RES. 539

Calling for sickle-cell trait research, surveillance, and public education and awareness.

IN THE HOUSE OF REPRESENTATIVES

SEPTEMBER 26, 2017

Ms. LEE (for herself, Mr. BURGESS, Ms. NORTON, Ms. WILSON of Florida, Mrs. WATSON COLEMAN, Mr. GRIJALVA, Mr. EVANS, Mr. HASTINGS, Ms. JACKSON LEE, Mr. ELLISON, Mr. MEEKS, and Mr. PAYNE) submitted the following resolution; which was referred to the Committee on Energy and Commerce

RESOLUTION

Calling for sickle-cell trait research, surveillance, and public education and awareness.

Whereas sickle-cell disease is the most common inherited blood disorder in the United States, affecting approximately 100,000 people in the United States;

Whereas more than 3,000,000 people in the United States have the sickle-cell trait, and many are unaware of their status;

Whereas in 2010, the total number of babies born with sickle-cell trait was estimated to have exceeded 60,000, and the total United States incidence estimate was 15.5 cases per 1,000 births;

Whereas African Americans (1 in 12) and Hispanic Americans (1 in 100) are most at risk for carrying the sickle-cell trait, and the trait has been found in persons of Greek, Italian, East Indian, Saudi Arabian, Asian, Syrian, Turkish, Cypriot, Sicilian, and Caucasian origin;

Whereas individuals who have sickle-cell trait have a 50-percent chance of passing on the abnormal sickle-cell gene to future offspring and 25-percent chance of having future children with sickle-cell disease if both parents have the trait;

Whereas sickle-cell disease can be identified before birth by testing a sample of amniotic fluid or tissue from the placenta;

Whereas individuals with sickle-cell trait have the same life expectancy as the general population, but are at risk for certain conditions, including blood in the urine, kidney cancer, complications with trauma to the eye, and tissue death in the spleen at high altitudes, or may have a false positive A1C test;

Whereas according to a 2007 study in the American Journal of Medical Genetics, all States have been required to screen for sickle-cell disease/trait since 2006; however, most States lack a protocol for disseminating results of trait status, with parents being notified only 37 percent of the time;

Whereas communication of a screening result consistent with sickle-cell trait should always be accompanied by appropriate counseling on the implications, provided by an individual with adequate training and understanding of the information;

Whereas the limited research on the communication of sickle-cell trait test results to patients demonstrates that there is a high prevalence of misleading information being communicated during counseling sessions for sickle-cell trait following newborn screening by clinicians;

Whereas no studies have examined whether information on sickle-cell trait test results is being accurately transmitted to an individual, whether by a family member or healthcare provider, prior to a person's reproductive years; and

Whereas Congress recognizes the importance of ensuring that people in the United States can make informed decisions as a result of awareness of their sickle-cell trait status: Now, therefore, be it

1 *Resolved*, That the House of Representatives—

2 (1) recognizes the ongoing challenges in ad-
3 dressing health outcomes among people with sickle-
4 cell trait and sickle-cell disease;

5 (2) encourages the medical community, in co-
6 ordination with the State and Federal Government,
7 to work to ensure that all individuals are made
8 aware of their sickle-cell trait status by developing
9 a common strategy for dissemination of screening
10 results, education, and counseling to parents and
11 families in collaboration with all 50 States' newborn
12 screening programs;

13 (3) calls on the Department of Health and
14 Human Services, in collaboration with experts, to

1 develop a surveillance and public awareness cam-
2 paign regarding the importance of knowing one's
3 sickle-cell trait status and to gain knowledge on sick-
4 le-cell disease for all racial and ethnic groups in the
5 United States;

6 (4) calls on the Department of Health and
7 Human Services to expand access for screening and
8 appropriate counseling for carriers of sickle-cell
9 trait; and

10 (5) commits to ensuring support for research
11 that expands our understanding of the health out-
12 comes and other implications of sickle-cell trait and
13 the health outcomes associated with sickle-cell dis-
14 ease.

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