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(Original Signature of Member)

117TH CONGRESS
1ST SESSION

H. RES.

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

IN THE HOUSE OF REPRESENTATIVES

Ms. LEE of California submitted the following resolution; which was referred to the Committee on _____

RESOLUTION

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

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 sickle cell disease occurs in about 1 out of every 365 Black or African-American births and 1 out of every 16,300 Hispanic-American births;

Whereas individuals who have sickle cell trait have a 50-percent chance of passing on the abnormal sickle cell gene to future offspring and a 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 during the 115th Congress, Public Law 115–327 reauthorized a sickle cell disease prevention and treatment demonstration program and provided for sickle cell research, surveillance, prevention, and treatment;

Whereas following the enactment of Public Law 115–327, the National Institutes of Health launched the Cure Sickle Cell Initiative aimed at bringing genetic therapies into first-in-human clinical trials within 5 years and moving newly developed genetic therapies, including gene-editing approaches, into clinical research;

Whereas communication of a screening result consistent with sickle cell trait should always be accompanied by appropriate counseling on the implications, provided by an in-

dividual 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; and

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 health care provider, prior to a person's reproductive years: Now, therefore, be it

1 *Resolved*, That the House of Representatives—

2 (1) recognizes the importance of ensuring that
3 people in the United States can make informed deci-
4 sions as a result of awareness of their sickle cell
5 trait status;

6 (2) recognizes the ongoing challenges in ad-
7 dressing health outcomes among people with sickle
8 cell trait and sickle cell disease;

9 (3) recognizes the importance of the develop-
10 ment of, and access to, new treatments for sickle cell
11 disease;

12 (4) encourages the medical community, in co-
13 ordination with State and Federal government, to
14 work to ensure that all individuals are made aware
15 of their sickle cell trait status by developing a com-
16 mon strategy for dissemination of screening results,

1 education, and counseling to parents and families in
2 collaboration with all 50 States' newborn screening
3 programs;

4 (5) calls on the Department of Health and
5 Human Services, in collaboration with experts, to
6 develop a surveillance and public awareness cam-
7 paign regarding the importance of knowing one's
8 sickle cell trait status and to gain knowledge on
9 sickle cell disease for all racial and ethnic groups in
10 the United States;

11 (6) commits to build on the progress of Public
12 Law 115-327, which reauthorized a sickle cell dis-
13 ease prevention and treatment demonstration pro-
14 gram and provided for sickle cell research, surveil-
15 lance, prevention, and treatment;

16 (7) calls on the Department of Health and
17 Human Services to expand access for screening and
18 appropriate counseling for carriers of sickle cell
19 trait;

20 (8) calls on the Department of Health and
21 Human Services to support comprehensive patient
22 care in sickle cell centers, including coordination of
23 care services between the Federal Government, State
24 governments, medical institutions, community health
25 workers, public and nonprofit entities, including

1 community-based organizations, and community
2 health workers;

3 (9) commits to ensuring support for research
4 that expands our understanding of the health out-
5 comes and other implications of sickle cell trait and
6 the health outcomes associated with sickle cell dis-
7 ease; and

8 (10) commits to ensuring equitable access
9 among economic, racial, and ethnic groups to new
10 treatments in order to improve health outcomes for
11 those with sickle cell disease.