

116TH CONGRESS
1ST SESSION

H. R. 1966

To direct the Comptroller General of the United States to complete a study on barriers to participation in federally funded cancer clinical trials by populations that have been traditionally underrepresented in such trials.

IN THE HOUSE OF REPRESENTATIVES

MARCH 28, 2019

Mr. CUMMINGS (for himself, Mr. SARBANES, and Mr. RUPPERSBERGER) introduced the following bill; which was referred to the Committee on Energy and Commerce, and in addition to the Committees on Armed Services, and Veterans' Affairs, for a period to be subsequently determined by the Speaker, in each case for consideration of such provisions as fall within the jurisdiction of the committee concerned

A BILL

To direct the Comptroller General of the United States to complete a study on barriers to participation in federally funded cancer clinical trials by populations that have been traditionally underrepresented in such trials.

1 *Be it enacted by the Senate and House of Representa-*
2 *tives of the United States of America in Congress assembled,*

3 **SECTION 1. SHORT TITLE.**

4 This Act may be cited as the “Henrietta Lacks En-
5 hancing Cancer Research Act of 2019”.

1 **SEC. 2. FINDINGS.**

2 Congress finds as follows:

3 (1) Only a small percent of patients participate
4 in cancer clinical trials, even though most express an
5 interest in clinical research. There are several obsta-
6 cles that restrict individuals from participating in-
7 cluding lack of available local trials, restrictive eligi-
8 bility criteria, transportation to trial sites, taking
9 time off from work, and potentially increased med-
10 ical and nonmedical costs. Ultimately, about 1 in 5
11 cancer clinical trials fail because of lack of patient
12 enrollment.

13 (2) Groups that are generally underrepresented
14 in clinical trials include racial and ethnic minorities
15 and older, rural, and lower-income individuals.

16 (3) Henrietta Lacks, an African-American
17 woman, was diagnosed with cervical cancer at the
18 age of 31, and despite receiving painful radium
19 treatments, passed away on October 4, 1951.

20 (4) Medical researchers took samples of Hen-
21 rietta Lacks' tumor during her treatment and the
22 HeLa cell line from her tumor proved remarkably
23 resilient.

24 (5) HeLa cells were the first immortal line of
25 human cells. Henrietta Lacks' cells were unique,
26 growing by the millions, commercialized and distrib-

1 uted worldwide to researchers, resulting in advances
2 in medicine.

3 (6) Henrietta Lacks' prolific cells continue to
4 grow and contribute to remarkable advances in med-
5 icine, including the development of the polio vaccine,
6 as well as drugs for treating the effects of cancer,
7 HIV/AIDS, hemophilia, leukemia, and Parkinson's
8 disease. These cells have been used in research that
9 has contributed to our understanding of the effects
10 of radiation and zero gravity on human cells. These
11 immortal cells have informed research on chromo-
12 somal conditions, cancer, gene mapping, and preci-
13 sion medicine.

14 (7) Henrietta Lacks and her immortal cells
15 have made a significant contribution to global
16 health, scientific research, quality of life, and patient
17 rights.

18 (8) For more than 20 years, the advances made
19 possible by Henrietta Lacks' cells were without her
20 or her family's consent, and the revenues they gen-
21 erated were not known to or shared with her family.

22 (9) Henrietta Lacks and her family's experience
23 is fundamental to modern and future bioethics poli-
24 cies and informed consent laws that benefit patients
25 nationwide by building patient trust; promoting eth-

1 ical research that benefits all individuals, including
2 traditionally underrepresented populations; and pro-
3 tecting research participants.

4 **SEC. 3. GAO STUDY ON BARRIERS TO PARTICIPATION IN**
5 **FEDERALLY FUNDED CANCER CLINICAL**
6 **TRIALS BY POPULATIONS THAT HAVE BEEN**
7 **TRADITIONALLY UNDERREPRESENTED IN**
8 **SUCH TRIALS.**

9 (a) IN GENERAL.—Not later than 2 years after the
10 date of enactment of this Act, the Comptroller General
11 of the United States shall—

12 (1) complete a study that—

13 (A) reviews what actions Federal agencies
14 have taken to help to address barriers to par-
15 ticipation in federally funded cancer clinical
16 trials by populations that have been tradition-
17 ally underrepresented in such trials, and identi-
18 fies challenges, if any, in implementing such ac-
19 tions; and

20 (B) identifies additional actions that can
21 be taken by Federal agencies to address bar-
22 riers to participation in federally funded cancer
23 clinical trials by populations that have been tra-
24 ditionally underrepresented in such trials; and

1 (2) submit a report to the Congress on the re-
2 sults of such study, including recommendations on
3 potential changes in practices and policies to im-
4 prove participation in such trials by such popu-
5 lations.

6 (b) INCLUSION OF CLINICAL TRIALS.—The study
7 under subsection (a)(1) should include review of cancer
8 clinical trials that are largely funded by Federal agencies,
9 including the National Institutes of Health, the Depart-
10 ment of Defense, the Department of Veterans Affairs, the
11 Agency for Health Research and Quality, the Food and
12 Drug Administration, and such other Federal agencies as
13 the Comptroller General of the United States may iden-
14 tify.

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