

116TH CONGRESS
2D SESSION

H. R. 1966

AN ACT

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,*

1 **SECTION 1. SHORT TITLE.**

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

4 **SEC. 2. FINDINGS.**

5 Congress finds as follows:

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

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

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

23 (4) Medical researchers took samples of Hen-
24 rietta Lacks’ tumor during her treatment and the
25 HeLa cell line from her tumor proved remarkably
26 resilient.

1 (5) HeLa cells were the first immortal line of
2 human cells. Henrietta Lacks' cells were unique,
3 growing by the millions, commercialized and distrib-
4 uted worldwide to researchers, resulting in advances
5 in medicine.

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

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

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

1 (9) Henrietta Lacks and her family’s experience
 2 is fundamental to modern and future bioethics poli-
 3 cies and informed consent laws that benefit patients
 4 nationwide by building patient trust; promoting eth-
 5 ical research that benefits all individuals, including
 6 traditionally underrepresented populations; and pro-
 7 tecting research participants.

8 **SEC. 3. GAO STUDY ON BARRIERS TO PARTICIPATION IN**
 9 **FEDERALLY FUNDED CANCER CLINICAL**
 10 **TRIALS BY POPULATIONS THAT HAVE BEEN**
 11 **TRADITIONALLY UNDERREPRESENTED IN**
 12 **SUCH TRIALS.**

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

16 (1) complete a study that—

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

24 (B) identifies additional actions that can
 25 be taken by Federal agencies to address bar-

1 riers to participation in federally funded cancer
2 clinical trials by populations that have been tra-
3 ditionally underrepresented in such trials; and
4 (2) submit a report to the Congress on the re-
5 sults of such study, including recommendations on
6 potential changes in practices and policies to im-
7 prove participation in such trials by such popu-
8 lations.

9 (b) INCLUSION OF CLINICAL TRIALS.—The study
10 under subsection (a)(1) shall include review of cancer clin-
11 ical trials that are largely funded by Federal agencies.

 Passed the House of Representatives December 9,
2020.

Attest:

Clerk.

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