

Congress of the United States
Washington, DC 20515

Chairman Pallone, Ranking Member Walden, and Members of the Committee:

We submit this statement today regarding H.R. 1966, the Henrietta Lacks Enhancing Cancer Research Act, legislation that honors the extraordinary life and legacy of Henrietta Lacks and takes steps to ensure that vital cancer research is inclusive of all individuals.

Henrietta Lacks, a Black woman, died of cervical cancer in 1951. During her cancer treatment, doctors took samples of her tumor, and from this the HeLa cell line was created. Without her or her family's knowledge, her cells were used in medical research and helped lead to some of medicine's most important breakthroughs, including the development of the polio vaccine, along with treatments for cancer, HIV/AIDS, leukemia, and Parkinson's disease. Her cells have made a significant contribution to the areas of global health, scientific research, quality of life, and patient rights.

Despite the progress that Lacks' cells helped to achieve, many communities still face glaring health disparities in many areas, including cancer. For example, while cancer incidence rates are highest among non-Hispanic White females, non-Hispanic Black females have the highest death rates. In addition, non-Hispanic Black males are most likely to develop prostate cancer and are roughly twice as likely to die from the disease than any other racial or ethnic group.¹

Clinical trials are a key component to advancing cancer research and treatment, and ultimately reducing disparities. The Henrietta Lacks Enhancing Cancer Research Act would direct the Government Accountability Office to study and publish a report regarding barriers to participation in federally funded cancer clinical trials by populations that have been traditionally underrepresented in such trials.

Currently, about 1 in 5 cancer clinical trials fail because of lack of patient enrollment, with racial and ethnic minorities, and older, rural, and lower-income Americans generally underrepresented in such trials. There are many factors that may lead to an individual being unable to participate in a clinical trial including lack of available local trials, transportation to trial sites, restrictive eligibility criteria, taking time off from work, and potentially increased medical and nonmedical costs. The purpose of this legislation is to ensure that Congress has the necessary information to find solutions that adequately address these barriers and help reduce health disparities.

This bill is an important step in making sure that all individuals are able to benefit from cancer research. We urge the Committee to consider this important legislation. Thank you.

ELIJAH E. CUMMINGS
Member of Congress

C.A. DUTCH RUPPERSBERGER
Member of Congress

¹ American Cancer Society Cancer Action Network, *Cancer Disparities: A Chartbook* (2018), <https://www.fightcancer.org/policy-resources/cancer-disparities-chartbook>.