

113TH CONGRESS
2D SESSION

H. RES. 510

Expressing the sense of the House of Representatives that the National Institutes of Health should develop a pilot program to improve medical trial participation, retention, efficiency, effectiveness, and diversity.

IN THE HOUSE OF REPRESENTATIVES

MARCH 11, 2014

Mr. KINGSTON submitted the following resolution; which was referred to the Committee on Energy and Commerce

RESOLUTION

Expressing the sense of the House of Representatives that the National Institutes of Health should develop a pilot program to improve medical trial participation, retention, efficiency, effectiveness, and diversity.

Whereas clinical trials are essential for improving our Nation's health;

Whereas economically disadvantaged individuals, the elderly, females, and ethnic and racial minority groups, especially African-Americans, Hispanic or Latino Americans, Native Americans or Native Alaskans, Asian or Pacific Islanders, are underrepresented in clinical trials, thereby threatening the applicability of trial results for the general population;

Whereas minority groups account for more than 30 percent of the United States population, yet collectively represented only 12.3 percent of all publically funded cancer trials from 2003 to 2005;

Whereas a 2012 study supported by the National Cancer Institute found that in patients 65 and older lower income predicted lower trial participation, even while being nearly universally covered by the Medicare program;

Whereas a national survey of cancer patients found that 85 percent of respondents were unaware that participating in a clinical trial was an option for them;

Whereas cancer patients with annual incomes of less than \$20,000 are 44 percent less likely and those with annual incomes of less than \$50,000 are 30 percent less likely to participate in clinical trials than cancer patients with higher incomes;

Whereas in a 2001 survey of African-American physicians, 93 percent of physicians cited lack of patient awareness as a possible factor contributing to low rates of African-American trial participants and 92 percent of physicians cited mistrust of the medical community;

Whereas lack of health insurance is a major concern for potential trial participants, with only 5.4 percent of all National Cancer Institute sponsored cancer treatment trial participants being patients who choose to participate despite not having health insurance;

Whereas a 2007 to 2011 study found that 53 percent of patients earning less than \$20,000 were concerned about how to pay for a trial, compared to 25 percent of patients that earned more than \$100,000;

Whereas the National Institute of Health Revitalization Act of 1993 requires applicants for Federal research funding to provide a strategy for inclusion of women and people of diverse racial and ethnic origins into clinical trials, but 21 percent of studies having received Federal research funding since then have failed to report sample sizes by racial or ethnic group; 64 percent did not provide any analysis by racial or ethnic group; and 75 percent did not report any outcomes by sex; and

Whereas increasing participation rates of underrepresented demographic groups in clinical trials would give physicians and researchers greater confidence that the results of those trials would apply as broadly as possible to all patients in the population: Now, therefore, be it

1 *Resolved*, That it is the sense of the House of Rep-
2 resentatives that—

3 (1) the National Institutes of Health is encour-
4 aged to use its existing budget and authority to es-
5 tablish a pilot partnership with nonprofit organiza-
6 tions that hold prior experience and expertise in di-
7 verse community outreach and trial accrual in order
8 to increase the efficiency and effectiveness of clinical
9 trials of the National Institutes of Health, increase
10 patient enrollment and retention in such trials, and
11 address the lack of diversity in such trials; and

12 (2) the goals of the pilot partnership should in-
13 clude, but should not be limited to, providing clinical
14 trial navigation services to help patients find, enroll,

1 and manage the logistical issues related to enroll-
2 ment and retention in federally supported clinical
3 trials, and to improve participation by populations
4 such as underrepresented and uninsured individuals
5 in appropriate clinical trials.

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