



June 16, 2017

Dear Chairman Senator Lamar Alexander and Ranking Member Senator Patty Murray of the U.S. Senate Health, Education, Labor and Pensions (HELP) Committee:

The Union for Affordable Cancer Treatment (UACT) is a non-profit cancer patient group. We are a union of people affected by cancer, their family members and friends, people who take care of people with cancer, health care professionals and cancer researchers committed to increasing access to effective cancer treatment and care. We are particularly concerned about the rapidly escalating cost of cancer medication and seek to fight for cancer treatment and care to be affordable and available. More information about the group is available on <https://uact.org>.

We urge you to hold public hearings on how the proposed Senate bill that will end or modify the Affordable Care Act will affect cancer patients (particularly persons with pre-existing conditions) and to ensure that there are sufficient mechanisms to curb excessive prices for drugs and other health technologies, and to protect cancer patients from medically unnecessary restrictions on access to new anticancer drugs, diagnostic tools and treatments.

UACT is especially concerned that there will be gaps in insurance and/or medical needs covered for millions of cancer patients. We are asking the Committee to hear testimony on the extent of those gaps, and to consider changes that would improve coverage.

The nonpartisan Congressional Budget Office (CBO), estimated in May 2017 that the House of Representatives' version of a health-care reform bill, the American Health Care Act (AHCA) H.R. 1628, would lead to millions more Americans lacking health insurance by 2026:

CBO and JCT estimate that, in 2018, 14 million more people would be uninsured under H.R. 1628 than under current law. The increase in the number of uninsured people relative to the number projected under current law would reach 19 million in 2020 and 23 million in 2026. In 2026, an estimated 51 million people under age 65 would be uninsured, compared with 28 million who would lack insurance that year under current

law. Under the legislation, a few million of those people would use tax credits to purchase policies that would not cover major medical risks¹.

It is essential to determine and to discuss the possible gaps in the Senate bill before any vote.

Cancer is certainly a “major medical risk” and American cancer patients, their families and caregivers deserve more consideration and respect from the US Senate HELP Committee.

The information reported by the news media about the Senate bill has been limited due to the extreme secrecy of the process. We assume that as usual, special interests are well informed as regards the text of the proposals, but the general public has been treated with surprising contempt. This secrecy is an insult to persons who depend upon well functioning insurance markets the most. Persons living with cancer or other pre-existing conditions require treatments that are expensive and unaffordable without adequate risk sharing. We want to know who will be covered, and if policies will be good enough to adequately cover the essential health care benefits patients need.

We recognize that it is important to control the costs of health care. In this regard, we urge the Senate to ensure there are sufficient mechanisms to curb excessive prices for drugs and other health technologies. This should include more robust authority to grant compulsory licenses on drug patents and to end non-patent exclusivities such as the Orphan Drug exclusivity, when prices are excessive. In short, where prices are unreasonable, we want the Senate to put the monopoly at risk, rather than patients.

UACT also urges the Congress to consider broader long term reforms that involve the delinking of R&D costs (and incentives to invest) from drug prices. This can start with studies of the feasibility of ending legal monopolies on drugs, and replacing the incentive that such monopolies provide with alternative rewards or funding mechanisms, including but not limited to large market entry rewards, expanded subsidies for or public funding of clinical trials, and mechanisms such as the open source dividend to enhance access to knowledge, materials, data and technologies that benefit upstream innovation.

Thank you,

Sincerely



Dr. Manon Ress (stage 4 cancer patient)

Acting Director, UACT

¹ <https://www.cbo.gov/publication/52752>