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**August 1, 2024**

Representative Diana DeGette

2111 Rayburn House Office Building

Washington, DC 20515

Representative Larry Bucshon

2313 Rayburn House Office Building

Washington, DC 20515

Dear Representatives DeGette and Bucshon,

The Coalition to Improve Access to Cancer Care (CIACC) appreciates the opportunity to provide feedback as you build on the reforms in the 21st Century Cures Act.

CIACC is a patient organization-led coalition representing patients, healthcare professionals, healthcare centers, and the life sciences industry. The coalition works to ensure that life-saving anticancer medicines are affordable to patients. While scientific breakthroughs have dramatically changed the way cancer is treated, public policy has often not kept pace with these innovations. Specifically, insurance benefit design has not adapted to the reality of how many patients are now treated with oral and self-administered anticancer medicines.

When Congress passed the 21st Century Cures Act the goals were to help advance biomedical research and foster new medical innovations for some of the worst diseases, like cancer. The reality still remains that outdated cost-sharing policies have limited patients’ abilities to access some of these new lifesaving drugs.   
  
In your letter to stakeholders, you stated that *“*Cures 2.0 aimed to build on the success of 21st Century Cures by focusing on ways we can modernize coverage and access to life-saving cures. In crafting legislation to build on existing work in the 21st Century Cures initiative, we are reminded that a modernized system of developing new cures will require a delivery system capable of getting them to patients in need.*”* We couldn’t agree more.

For decades, intravenous (IV) delivery was the primary method for administering the medications used to treat cancer. But today, more anticancer medications come in the form of a pill or are self-injectable. Typically, anticancer medications that are administered intravenously are covered under a health plan’s medical benefit. For many patients, this means having to pay a moderate co-pay or, in some cases, no cost-sharing for their medication.

But self-administered anticancer medications are usually covered under a health plan’s pharmacy benefit. When it comes to anticancer medications, pharmacy benefits typically require the patient to cover a percentage of the drug’s overall cost. Since anticancer drugs are typically very expensive, this type of cost-sharing creates serious barriers to care for patients prescribed to treat their cancer.

Consequently, many patients that have insurance coverage through employer-sponsored health plans face unmanageable co-insurance, paying thousands of dollars per month for their medications. Many choose not to take their anticancer medications because they cannot pay.

In a recent call to a CIACC coalition member’s nurse hotline, a patient facing this situation asked:

“*What do I do? I could sell our house and use our retirement assets to pay for my treatment or I could forgo treatment and allow my wife and kids to have the future we worked so hard to plan. What kind of a husband and father am I if I use the money?”*

Unfortunately, this sentiment is not uncommon. According to a study published in the Journal of Oncology Practice, 10% of patients choose not to fill their initial prescriptions for oral anticancer medications due to high co-pays, with the abandonment rates being even higher for therapies with the most expensive co-pays.[[1]](#footnote-1)

Additionally, the problem has been exacerbated by the growth of patient-administered cancer therapies. It has become the standard of care for many types of cancer. Anticancer medications taken orally accounts for approximately 25% of the oncology development pipeline, according to a study by the [*National Community Oncology Dispensing Association*](http://www.ajmc.com/journals/supplement/2016/improving-patient-access-to-critical-therapies-in-the-age-of-cost-sharing/in-office-dispensing-of-oral-oncolytics-a-continuity-of-care-and-cost-mitigation-model-for-cancer-patients).[[2]](#footnote-2) More importantly, many cancer medicines taken orally do not have an alternative that is injected or administered by IV. That means these oral medications are the only option for some cancer patients. As these treatments become more prevalent, we must ensure the out-of-pocket costs to patients are as affordable as their IV counterparts.

Our solution is the Cancer Drug Parity Act (H.R. 6301/S. 2039), legislation with a history of overwhelming bipartisan support in both the House and the Senate. This builds on robust support at the state level. In fact, 44 states and the District of Columbia have taken action to solve this disparity for patients that are on state-regulated health plans.

The Cancer Drug Parity Act would ensure that federally-regulated group health plans provide coverage for cancer treatments, allows patients taking self-administered anticancer medicines to benefit from the same level of cost-sharing as they would have if they were administered an IV, port administered or injected cancer medication. This bill addresses the outdated insurance benefit designs and seeks to lower out-of-pocket costs for all cancer treatments, regardless of how they are administered. Health insurance cost-sharing designs should not create barriers for cancer patients to access potentially life-saving medicines or undermine the doctor-patient relationship by forcing physicians to place patients on less-effective treatments based solely on costs.

Historically, Congress has acknowledged the need to reduce out-of-pocket spending for Medicare beneficiaries and has enacted legislative measures to address this issue. The Cancer Drug Parity aims to extend this cost relief to patients covered under federal-regulated group health plans. Health insurance cost-sharing should not create barriers for cancer patients or force doctors to prescribe less-effective treatments based on cost. It is essential to modernize insurance benefit designs to include equitable coverage for self-administered anticancer medications.

**We have seen the tremendous, life-changing treatments facilitated by CURES - we must now ensure that they are accessible. We urge you to include the Cancer Drug Parity Act in any reforms to the 21st Century Cures Act.**

For further questions about this bill, please contact Danielle Doheny, Director of Policy and Advocacy for the International Myeloma Foundation, at ddoheny@myeloma.org.

Respectfully,

Association for Clinical Oncology

Cancer*Care*

Cancer Support Community

Fight Colorectal Cancer

GO2 for Lung Cancer

Hematology/Oncology Pharmacy Association

International Myeloma Foundation

LUNGevity Foundation

Lymphoma Research Foundation

Oncology Nursing Society

Ovarian Cancer Research Alliance

Patient Empowerment Network

Triage Cancer

1. https://ascopubs.org/doi/10.1200/JOP.19.00016 [↑](#footnote-ref-1)
2. [In-Office Dispensing of Oral Oncolytics: A Continuity of Care and Cost Mitigation Model for Cancer Patients (ajmc.com)](https://www.ajmc.com/view/in-office-dispensing-of-oral-oncolytics-a-continuity-of-care-and-cost-mitigation-model-for-cancer-patients) [↑](#footnote-ref-2)