Dear Representatives DeGette and Upton:

The International Myeloma Foundation appreciates the opportunity to provide feedback as you continue develop the legislative reforms included in Cures 2.0.

Founded in 1990, the International Myeloma Foundation (IMF) is the oldest and largest myeloma specific patient advocacy organization in the world. With more than 525,000 members in 140 countries, the IMF serves myeloma patients, family members, and the medical community. The IMF provides a wide range of programs in the areas of research, education, support, and advocacy. Multiple myeloma is the second most common form of blood cancer and it most frequently impacts individuals between the ages of 65 and 74 and our patient population will be heavily impacted this proposal or any additional proposed changes to Medicare Part B. There is not a cure for myeloma and while many treatments exist to manage the disease, access to innovative therapies have helped increase the quality and length of life of myeloma patients.

When you wrote and passed the 21st Century Cures Act your 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 The reality still remains that outdated cost-sharing policies have limited patients’ abilities to access some of these new lifesaving drugs.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 initial “Call to Action” letter you stated that “Cures 2.0 is an effort to modernize coverage and access to life-savings cures in the United States and across the globe. Patients from across the country continually remind us that a modernized system of developing new cures will require a modernized health care delivery system capable of delivering them to patients in need.” We couldn’t agree more.

The way we treat cancer is changing. But the way cancer care is covered is not. Insurance benefit design has not kept up with the pace of innovation in medicine and the growth of cancer treatments administered by patients, including orally administered treatments. Traditionally, intravenous (IV) and injected treatments were the primary methods to deliver chemotherapy. Most health plans tend to generously cover those treatments for patients under their medical benefit by requiring them to only pay a small co-pay for office visits, often between $20-$50.
Insurers do not offer comparable cost-sharing for many newer medicines administered by patients, including pills taken orally. Instead, most of those treatments are covered by a plan’s prescription benefit, which often require patients to pay much more out-of-pocket. In many cases, this means patients face extremely high, often-unmanageable co-insurance. Some patients pay thousands of dollars a month. The result of these high out-of-pocket costs is that 10% of patients choose not to fill their initial prescriptions for anticancer medicines taken orally. The rates are much higher for therapies with the most-expensive co-pays.

The problem is exacerbated by the growth of patient-administered cancer therapies. It has become the standard of care for many types of cancer. Chemotherapy taken orally accounts for approximately 25% of the oncology development pipeline, according to a study by the National Community Oncology Dispensing Association. 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, 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, 43 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.

The IMF is not alone in our support for this policy change. We lead a coalition called the Coalition to Improve Access to Cancer Care (CIACC) which coalesces around our support for this legislation. The CIACC is a cancer patient-focused coalition representing patients, healthcare professionals, care centers and the life sciences industry.

2 https://www.access2cancercare.org/
3 https://www.access2cancercare.org/about/coalition-members/
We thank you for considering our recommendation for inclusion in your Cures 2.0 and look forward to working with your offices. Should you or your staff wish to contact us directly, please contact Robin Levy of the International Myeloma Foundation at RLevy@myeloma.org or at 201-220-9137.

Sincerely,

Robin Roland Levy
Senior Director
Public Policy and Advocacy