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December 16, 2019

The Honorable Diana DeGette
U.S. House of Representatives
2111 Rayburn House Office Building
Washington, D.C. 20515-4329

The Honorable Fred Upton
U.S. House of Representatives
2183 Rayburn House Office Building
Washington, D. C. 20515-4329

Dear Congresswoman DeGette and Congressman Upton:

I am writing on behalf of GO₂ Foundation for Lung Cancer (a recent merger of Lung Cancer Alliance and Bonnie J. Addario Lung Cancer Foundation), which has a mission of transforming survivorship by saving, extending and improving the lives of those vulnerable, at risk and diagnosed with lung cancer, to thank you for leading and following up on your initial call to action that five years ago gave us the 21st Century Cures Act of 2016 (Cures). Your commitment to build upon the current progress and your desire to work in a bipartisan way to make improvements and further dedicate investments to a patient-valued healthcare delivery system has inspired our community.

As you move forward, GO₂ Foundation for Lung Cancer is committed to working with you to ensure that the needs of the lung cancer community are taken into account as this process continues. Historically, patients with lung cancer have experienced an exceptionally low survival rate (five-year survival rate of just over 19%) due to the overarching stigma and lack of early detection and treatment options. But recent exciting and dramatic breakthroughs, including life-saving screening and approval of more personalized and targeted drug therapies, have resulted in a transformative shift in the management of the disease, patient quality of life during treatment, and increased survivorship.

Since becoming law, Cures has improved our healthcare arena, but we agree there's more work to be done to promote new breakthrough treatments and access to life-saving cures. As you move forward with your discussions, we look forward to participating to underscore the specialized needs of the more than ten million Americans at risk or living with lung cancer to usher in a more

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patient-centered system that brings choice and greater access to high-quality care in an affordable and equitable way to all patients in all communities.

Given the objective of Cures to serve as healthcare reform predicated by stakeholder input, GO₂ Foundation for Lung Cancer recommends that the following healthcare principles to be included in the Cures 2.0 Legislation.

Patient Valued Care Delivery System

Healthcare delivery should be patient centered. As we continue the transition from the traditional fee-for-service health care delivery system model to a “value” based care model, we must ensure that “value” is defined by the patient not third party interests.

Access to Quality Care

Healthcare should preserve patient and physician decision making about what treatments are “medically necessary” for and valued by the patient and should include access to all appropriate cancer care specialists, palliative care, support services and new lifesaving drugs and therapies.

The healthcare delivery system must recognize that each of us has individual needs, unique characteristics and personal preferences that factor into our healthcare decisions and that do not fit neatly into one-size-fits-all models and assessments that drive certain clinical decisions on benefits, cost, and effectiveness of treatments. Therefore, as we continue to transform healthcare delivery, we must ensure a people-centered healthcare system that works to match the right care deemed necessary by the individual and their physician, no matter where the individual works or lives.

Preventive Services, Early Detection and Treatment for Lung Cancer

The healthcare delivery system must recognize that in order to reduce lung cancer mortality—the leading cause of cancer death among men and women, every racial and ethnic group, and with a higher incidence rate among women and the military—that early detection and research must be linked to prevention efforts in a continuum of care.

Cures 2.0 should streamline and expedite the federal structure and process responsible for review and implementation of new preventive services to ensure benefits reach people more rapidly and efficiently. The system must be reformed to be more adaptive and agile to transition from scientific breakthrough to a national public health implementation plan.

The law should continue to support, reward and incentivize prevention, wellness, early detection and earlier intervention strategies to reverse costly and late stage management of disease. We urge you to guard against risking possible critical advancement in disease prevention and detection and treatments as is found under the current structure that does not promote the practice of precision medicine.

Precision Medicine and Providing the Best Treatments for Every Individual Patient

Patients now have more options as compared to a decade ago. Newer drugs such as targeted therapies are extending and improving lives, but it is imperative that patients receive timely diagnosis and testing so they receive the right drug at the right time. Lung cancer is a good example as it is not just one disease but many diseases, often with high rate of mutations or tumor changes. Patients face enormous challenges around misdiagnoses, delays in diagnosis, single gene test coverage over guideline-based comprehensive testing, disparities in access to testing, and financial considerations. Within the current system, different coverage policies exist between Medicare and private insurers and most tests are only covered once, while biomarker testing needs to be done multiple times throughout therapy in order to adapt treatment based on specific tumors or changes.

We know very well the consequences of being given wrong treatment due to lack of or insufficient testing – it negatively impacts a patient’s survival outcome. If we don’t know who should be given specific types of therapies, the medical innovation envisioned by Cures 2.0 will not work despite the new therapies available to help patients. To ensure continued progress we strongly advocate to advance precision medicine and high-quality science for care delivery by removing the access barriers to specialty care, comprehensive biomarker testing and the patient’s own healthcare data.

Clinical Trials, Drug Parity, and Women and Lung Cancer

To further address patient access issues, we recommend the inclusion of [the Clinical Treatment Act \(HR 913\)](#) to increase clinical trials participation and coverage for Medicaid patients. Also, as new treatment options become available, we must ensure the out of pocket costs to patients are affordable; therefore, we recommend the inclusion of [the Cancer Drug Parity Act \(H.R. 1730\)](#). To stimulate more research into underrepresented patient subtypes such as women and never smokers and to increase the five year survival rate of lung cancer, we recommend the inclusion of the provisions of [the Women and Lung Cancer Research and Preventive Services Act \(H.R. 2222\)](#). This is supported by scientific findings of higher incidence rates of lung cancer among women and indication that the rate of never-smoking lung cancer is increasing.

Digital Health to Improve Patient Care

We support Cures 2.0's focus on digital health and recommend the promotion and adoption of telehealth across the nation. This requires removing the current barriers of interstate licensure to allow access and ability to practice telehealth and expanding coverage and payment parity for same services across all payers. Removing barriers in digital information and data exchange could also promote innovation in medical research. Similarly, structural changes that would allow clinical trials to be done more efficiently across state lines and in community settings (such as central Institutional Review Board (IRB) oversight and more efficient, secure digital information flow) could help with trial participation and bring medical research to those who need it most.

Health Literacy, Transportation and Financial Resources

In addition, we agree on the need to improve the ability of families and caregivers to support their loved ones by increasing health literacy to better inform them of options for treatment and services as well as associated cost vs. surprise billing. We receive high call volume on our HelpLine about other critical issues—transportation and financial resources to access treatment. Providing financial assistance and greater community resources to navigate patients to where they can receive help will help remove these constraints to care.

Again, thank you for the opportunity to comment on the development of Cures 2.0 Legislation. As we further our mission of transforming survivorship for the lung cancer community, we look forward to working with you on next steps. Your staff may contact Elridge Proctor, Senior Director of Government Affairs at 202-742-1427 (Eproctor@go2foundation.org) with any questions or updates.

With Sincere Regards,



Laurie Fenton Ambrose
Co-Founder, President & CEO
GO₂ Foundation for Lung Cancer