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June 6, 2019

The Honorable Chuck Grassley  
Chairman  
Senate Finance Committee  
219 Dirksen Senate Office Building  
Washington, DC 20510

The Honorable Ron Wyden  
Ranking Member  
Senate Finance Committee  
219 Dirksen Senate Office Building  
Washington, DC 20510

Dear Chairman Grassley and Ranking Member Wyden:

I am writing on behalf of GO<sub>2</sub> Foundation for Lung Cancer, (a recent merger of Lung Cancer Alliance and the 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. We wish to express our strong support for the reauthorization of the Patient-Centered Outcomes Research Institute (PCORI) and to encourage the Senate to take up H.R. 3030, the Patient-Centered Outcomes Research Extension Act of 2019.

As you may know, Lung cancer is the leading cause of cancer deaths across all states, genders, and ethnic groups, claiming nearly 150,000 lives each year. In 2019 alone, an estimated 228,150 people will be diagnosed with lung cancer and as many as 142,000 more will die in the next year. Despite recent advancements in the treatment and care of lung cancer, the disease's five-year survival rate is at a low 18%.

PCORI shares our mission to help patients and caregivers improve their care by empowering them with trustworthy information to take charge of their healthcare. As an independent nonprofit, nongovernmental organization that was authorized by Congress in 2010, PCORI is working with a community of patients and healthcare stakeholders to identify critical research questions and answer them through comparative clinical effectiveness research, or CER, focusing on better healthcare decisions and, ultimately, improved patient outcomes.

PCORI funded research supports personalized care and advances clinically effective care by comparing which treatment approaches work best, for which patients, given their needs and preferences. It incorporates outcomes that matter most to patients in cost and wellness through its patient-centered outcomes research that engages patients throughout the research process, including the design in order to capture the outcomes that matters to patients, to improve health care decisions and inform the government on how the healthcare system can be more efficient.

**Empower Everyone.  
Ignore No One.**

As of December 2018, PCORI has awarded more than \$2.4 billion dollars in grants to more than 600 research projects in 44 states across the U.S. Several of these funded projects have generated particularly promising evidence for improving care and patient outcomes areas. The PCORI portfolio includes a number of studies that advance quality care for our community of patients with lung cancer and their caregivers. Two notable studies include a study comparing the effectiveness of telehealth versus in-person palliative care and a longitudinal cohort study to compare the effectiveness of less versus more frequent CT screening for the monitoring of nodules detected either through routine screening or as incidental findings. These two examples show the full continuum of care that PCORI covers -- one study that will help doctors find lung cancer early, when it is most treatable and one that can help advanced cancer patients and their caregivers with palliation and end-of-life care, while potentially addressing social determinants of health through use of telehealth technologies.

Unless Congress acts now or before the September deadline, PCORI will not be authorized to continue its work toward achieving high quality and evidenced based care that will reduce costs in the health care system. Research is a long-term commitment, which requires sufficient time and continued investment to conclude studies, disseminate the findings and develop implementation tools. In order for PCORI funded research to be most impactful, stability in PCORI's funding is essential and Congress must reauthorize PCORI for another 10 years.

As you consider the recommendations provided by the Friends of PCORI and other stakeholders, we encourage Congress to exclude quality-adjusted life years (QALY) from PCORI supported studies in order to remain patient-centric, as QALY could lead to potential bias and discrimination against certain vulnerable patients such as lung cancer. Thank you for your commitment to empower patients to make informed decisions and to drive innovation and value in our health care. With any questions or comments, you may contact, Elridge Proctor, Senior Director of Government Affairs & Public Policy at 202-742-1427 or [Eproctor@go2foundation.org](mailto:Eproctor@go2foundation.org).

Sincerely,



Laurie Fenton Ambrose  
Co-Founder & CEO  
GO<sub>2</sub>Foundation for Lung Cancer

[go2foundation.org](http://go2foundation.org)

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