June 26, 2020

The Honorable Lamar Alexander
Chairman
Senate Committee on Health, Education, Labor, and Pensions
428 Dirksen Senate Office Building
Washington, DC 20510

Dear Chairman Alexander:

The Patient Quality of Life Coalition (PQLC) welcomes the opportunity to offer comments on the Whitepaper: Preparing for the Next Pandemic. The PQLC was established to advance the interests of patients and families facing serious illness. The coalition includes over 40 organizations dedicated to improving quality of care and quality of life for all patients from pediatrics to geriatrics, as well as supporting public policies that improve and expand access to quality palliative care and appropriate pain management. PQLC members represent patients, caregivers, health professionals, and health care systems.

As the impact of the COVID-19 pandemic continues to grow, there are many lessons we have already learned from this crisis. Therefore, we are grateful for the critical eye you are taking to improve our nation’s response to future pandemics. We write to express the need for greater improvements to our public health infrastructure and more training for the health care and public health workforce, especially in the area of palliative care.

Palliative Care Education and Training

Preparing for the Next Pandemic outlines the nation’s current public health capabilities and considers what changes to our public health infrastructure are necessary to improve state and local capacity to respond. The need for palliative care education and training among those on the front lines is urgent. We have an existing shortage that patients, families, and health care providers are now feeling as systems are overwhelmed as a result of the pandemic. We must act now to alleviate these stresses, as this pandemic will have lasting impacts on the palliative care and hospice workforce. We also must invest in building the public health infrastructure and workforce now to address these shortages in the unfortunate event of another pandemic.

There is an existing gap between the number of health professionals with palliative care training and the number required to meet the needs of the expanding population of patients with serious illness or multiple chronic conditions. The COVID-19 pandemic has shined a bright light on the existing palliative care workforce shortage and amplified the need for our nation’s health care workforce – beyond those who will specialize in the field – to have training in basic palliative care to ensure all patients facing serious illness or at the end of life can receive high-quality care.

We believe enacting legislation that responds to public health workforce challenges - the Palliative Care and Hospice Education and Training Act (PCHETA), S. 2080 - could provide immediate assistance in addressing the current, as well as any future pandemics. For example, PCHETA would allow the Secretary of Health and Human Services to disseminate information to inform patients, families, and health professionals about the benefits of palliative care throughout the continuum of care for patients with serious or life-threatening illnesses, including infectious diseases such as COVID-19.
Palliative care is specialized care that focuses on preventing and treating the debilitating effects of serious illness, with clinicians trained to assess and manage physical, psychological, and other sources of suffering. This includes relieving pain and other distressing symptoms, such as shortness of breath or unrelenting nausea. Palliative care seeks to anticipate, prevent, and treat physical, emotional, social, and spiritual suffering, as well as to help facilitate and support the goals and values of patients. This education is urgent for the health professionals who do not have palliative care training but are on the front lines of caring for individuals infected with diseases like COVID-19 and facing life and death decisions. Dr. Sean Morrison of the Icahn School of Medicine at Mount Sinai in New York previously testified in support of PCHETA before the House Energy and Commerce Committee. Regarding the current stresses on the New York health system due to the coronavirus, he stated: “Palliative care is everyone’s job. Everyone who comes in with severe COVID-19 is going to have breathlessness and respiratory symptoms.” A goal of any future pandemic preparedness legislation should be to support health care workers and improve patient care.

Training in palliative care also focuses on learning how to have detailed and skilled communication with patients and families to elicit goals and preferences. In the midst of a pandemic like COVID-19, this knowledge is essential. Members of the American Academy of Hospice and Palliative Medicine have shared how the lack of such training is stressing interdisciplinary palliative care teams that are already stretched thin. A palliative medicine physician at the University of Kentucky College of Medicine notes: “A lack of basic training in advance care planning leads to uncertainty about how to take care of most patients during the COVID crisis. The health system is facing a surge of very ill patients who have never discussed their health care goals with their families and feel anxious, and clinicians who are uncertain about how to best care for patients.” A leading palliative care expert who directs post-graduate education in palliative care at the University of Maryland School of Pharmacy adds, “I speak to friends every day who are spending their time desperately trying to quickly teach their colleagues about these conversations.”

The CARES Act (PL 116-136) recognized the importance of addressing health professional training and included the reauthorization of the Title VII health professions programs, the Title VIII nursing programs, and the geriatric training programs. PCHETA will work to address the critical shortage of health professionals with knowledge and skills in palliative care that can no longer be ignored. PCHETA is designed to build the evidence base for serious illness care and to educate all who care for patients like those now flooding our nation’s emergency departments, hospitals, and ICUs. PCHETA will not only help strengthen the palliative care workforce but also help ensure that, going forward, patients and providers are aware of the benefits of palliative care. According to the Institute of Medicine, there is a “need for better understanding of the role of palliative care among both the public and professionals across the continuum of care.”

Congress has long worked on a bipartisan basis to support and advance this bill. The House has passed it twice with overwhelming support. S. 2080 has the support of 38 bipartisan senators and is supported by more than 50 national organizations and 35 state organizations. There is no better time than now to demonstrate Congress’ commitment to ensuring all Americans facing serious or life-threatening illness can receive high-quality care and to providing our health care professionals with what they need to meet this pandemic moment, and ones sure to come.
As Congress considers measures to improve our nation’s pandemic preparedness, our organizations welcome the opportunity to discuss our views with you. If you have any questions, please contact Keysha Brooks-Coley, Vice President, Federal Advocacy, American Cancer Society Cancer Action Network and Chair of the Patient Quality of Life Coalition, at 202-661-5720 or Keysha.Brooks-Coley@cancer.org.

Sincerely,

American Academy of Hospice and Palliative Medicine
American Cancer Society Cancer Action Network
Association of Pediatric Hematology/Oncology Nurses
Cancer Support Community
Center to Advance Palliative Care
Hospice and Palliative Nurses Association
Leukemia & Lymphoma Society
National Brain Tumor Society
National Coalition for Hospice and Palliative Care
National Hospice and Palliative Care Organization
National Patient Advocate Foundation
Oncology Nursing Society
Physician Assistants in Hospice and Palliative Medicine
ResolutionCare Network
Social Work Hospice and Palliative Care Network
Supportive Care Coalition
Trinity Health