PATIENT
QUALITY OF LIFE
COALITION

May 9, 2018

Congressman Greg Walden
Chair, Energy & Commerce
Committee
U.S. House of Representatives
2185 Rayburn House Office Building
Washington, DC 20515

Congressman Frank Pallone
Ranking Member, Energy & Commerce
Committee
U.S. House of Representatives
237 Cannon House Office Building
Washington, DC 20515

Dear Chairman Walden and Ranking Member Pallone,

On behalf of the Patient Quality of Life Coalition, we wish to express our sincere thanks for your support of H.R. 1676, the *Palliative Care and Hospice Education and Training Act* (PCHETA). This important piece of legislation will make a difference in the lives of millions of Americans suffering from serious illness, as well as their families and caregivers. PCHETA has strong bipartisan support with 269 cosponsors – that represents a majority of the House of Representatives and includes more than half the members of the House Energy and Commerce Committee. We urge you to consider this bill for a markup in the Health Subcommittee and the full Committee, and to advance PCHETA to the House floor during the second session of the 115th Congress.

Despite a high level of medical treatment, many seriously ill individuals still experience troubling symptoms, fragmented care, poor communication with their health care providers, unmet psychological and personal care needs, and enormous strains on their family caregivers. Numerous studies have shown that palliative care can improve pain and symptom control, quality of life, and patient and family satisfaction with care.

Palliative care is an interdisciplinary model of care focused on relief of the pain, stress and other debilitating symptoms of serious illness, such as cancer, cardiac disease, respiratory disease, kidney failure, Alzheimer's, AIDS, ALS, and MS. The goal of palliative care is to relieve suffering and provide the best possible quality of life for patients and their families. Palliative care can be offered from the point of diagnosis forward, simultaneously with life-prolonging and curative therapies for persons living with serious, complex, and eventually terminal illness and includes hospice care. Palliative care is patient-centered care — translating patient goals to appropriate treatments.

With its focus on expanding the interdisciplinary palliative care workforce, promoting awareness of the benefits of palliative care among patient and providers, and improving the evidence base for this care, H.R. 1676 would address key barriers that prevent patient access to palliative care today. First, delivery of high-quality palliative care cannot take place without a sufficient number of health care professionals with appropriate training and skills. Students graduating from medical, nursing or health care professional schools today receive little, if any, training in the core precepts of pain and symptom management, advance care planning, communication skills, and care coordination for patients with serious or life-threatening illness. Further, there is a large gap between the number of health care professionals with palliative care training and the number required to meet the needs of the expanding population of seriously ill patients. PCHETA would begin to bridge this gap by establishing education centers and career incentive awards to improve the training of doctors, nurses, physician assistants, social workers, pharmacists, chaplains and other health professionals in palliative care.

PCHETA also aims to strengthen clinical practice and improve health care delivery for patients living with serious or life-threatening illness, as well as their families, by directing existing funds toward palliative care research. Research funding for palliative care and pain and symptom management comprises less than 0.1 percent of the annual budget at the National Institutes of Health. PCHETA would encourage an expansion and intensification of research in these important areas.

Finally, more must be done to ensure 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." PCHETA would direct the implementation of a national education and awareness effort so that patients, families, and health professionals understand that palliative care can help ensure higher-quality care for individuals facing serious or life-threatening illness.

Again, we appreciate your support and look forward to working with you to move this legislation forward to a markup in the Energy and Commerce Committee Health Subcommittee and the full Committee, and to advance it to the House floor before the end of the year. If you would like additional information regarding PCHETA, please do not hesitate to contact Keysha Brooks-Coley, Chair of the Patient Quality of Life Coalition, at keysha.brooks-coley@cancer.org.

Sincerely,
Academy of Integrative Pain Management
Alzheimer's Association
Alzheimer's Impact Movement
American Academy of Hospice and Palliative Medicine
American Cancer Society Cancer Action Network
American Heart Association | American Stroke Association
American Psychological Association
American Psychosocial Oncology Society
American Society of Clinical Oncology
Association of Oncology Social Work
Association of Pediatric Hematology/Oncology Nurses
C-Change
The California State University Institute for Palliative Care
Cambia Health Solutions
Cancer Support Community
Catholic Health Association of the United States
Center to Advance Palliative Care
Children's National Health System
Coalition for Compassionate Care of California
Colorectal Cancer Alliance
Courageous Parents Network
ElevateHOME
The George Washington Institute for Spirituality and Health
Hospice and Palliative Nurses Association
Leukemia & Lymphoma Society
Lung Cancer Alliance
Motion Picture & Television Fund
National Alliance for Caregiving
National Coalition for Cancer Survivorship
National Coalition for Hospice and Palliative Care
National Comprehensive Cancer Network
National Palliative Care Research Center
National Patient Advocate Foundation
National POLST Paradigm
Oncology Nursing Society
Partnership for Palliative Care
Pediatric Palliative Care Coalition
Physician Assistants in Hospice and Palliative Medicine
Prevent Cancer Foundation
St. Baldrick's Foundation
Supportive Care Coalition
Trinity Health

Palliative Care & Hospice Education and Training Act

H.R. 1676 / S. 693

Background

Palliative care improves quality of life, enhances patient and family satisfaction with care, and controls costs for the rapidly expanding population of individuals with serious illness or multiple chronic conditions. In 2000, less than 25% of U.S. hospitals had a palliative care program, compared with 75% in 2015. Yet, not all these programs have in place the interdisciplinary team necessary to provide comprehensive, high-quality palliative care. At the same time, palliative care is increasingly being provided in community settings. This growth comes in response to the increasing numbers and needs of Americans living with serious or complex chronic illnesses and the realities of the care responsibilities faced by their families. Palliative care is a relatively new medical specialty, and more must be done to ensure patients and providers understand its benefits and that an adequate, appropriately trained workforce is available to provide the pain and symptom management, intensive communication and level of care coordination that addresses the episodic and long-term nature of serious and complex chronic illness.

Bill Summary

PALLIATIVE CARE AND HOSPICE EDUCATION CENTERS

Establishes Palliative Care and Hospice Education Centers to improve the training of interdisciplinary health professionals in palliative care; develop and disseminate curricula relating to palliative care; support the training and retraining of faculty; support continuing education; provide students with clinical training in appropriate sites of care; and provide traineeships for advanced practice nurses.

PHYSICIAN TRAINING

Authorizes grants or contracts to schools of medicine, teaching hospitals and graduate medical education programs to train physicians (including residents, trainees, and fellows) who plan to teach palliative medicine. Such programs will provide training in palliative medicine through a variety of service rotations, such as consultation services, acute care services, extended care facilities, ambulatory care and comprehensive evaluation units, hospice, home health, and community care programs. Programs will be required to develop specific performance-based measures to evaluate the competency of trainees.

ACADEMIC CAREER AWARDS

Establishes a program to promote the career development of physicians who are board certified or board eligible in Hospice and Palliative Medicine and have a junior (non-tenured) faculty appointment at an accredited school of medicine. Eligible individuals must provide assurance of a full-time faculty appointment in a health professions institution and commit to spend a majority of funded time teaching and developing skills in interdisciplinary education in palliative care.

WORKFORCE DEVELOPMENT

Establishes fellowship programs within the new Palliative Care and Hospice Education Centers to provide short-term intensive courses focused on palliative care. Supporting the team approach to palliative care, the fellowships will provide supplemental training for faculty members in medical schools and other health professions schools, including pharmacy, nursing, social work, chaplaincy and other allied health disciplines in an accredited health professions school or program (such as a physician assistant education program) so providers who do not have formal training in palliative care can upgrade their knowledge and skills for the care of individuals with serious or life-threatening illness as well as enhance their interdisciplinary teaching skills.

CAREER INCENTIVE AWARDS

Provides grants or contracts for eligible health professionals who agree to teach or practice in the field of palliative care for at least 5 years. Eligible individuals include: advanced practice nurses, social workers, physician assistants, pharmacists, or students of psychology who are pursuing a doctorate, masters, or other advanced degree with a focus in palliative care or related fields in an accredited health professions school.

NURSE TRAINING

Creates special preferences in existing nurse education law for hospice and palliative nursing, in education, practice and quality grants, workforce development, and nurse retention projects.

PALLIATIVE CARE EDUCATION AND AWARENESS

Provides for the establishment of a national campaign to inform patients, families and health professionals about the benefits of palliative care and the services that are available to support patients with serious or life-threatening illness. Directs the dissemination of information, resources and materials about palliative care services to health professionals and the public in a variety of formats, in consultation with professional and patient stakeholders.

ENHANCED RESEARCH

Directs the National Institutes of Health to use existing authorities and funds to expand palliative care research to advance clinical practice and improve care delivery for patients with serious or life-threatening illness.