Message from Our Board President and Executive Director

2020: “Unprecedented, new normal, uncertain, pivot, doom scrolling”... We can probably all agree that we want to retire these words in 2021. This time last year when we published our inaugural 2019 Impact Report, we had no idea what events would unfold and transform every aspect of our personal and professional lives.

Through it all, we are enormously proud of our Coalition and how we and each of our 13 members faced many extraordinary challenges to provide guidance, technical assistance and tools to health care providers on the COVID-19 front lines, provided essential information to the field, and sent recommendations to Congress and the Administration which led to significant policy changes.

Our Coalition, more than ever, recognized that by cooperating, communicating, and collaborating we could accomplish so much more for people with serious and life-limiting illness. Remarkable highlights from this past year include:

- The COVID-19 pandemic changed the way care is delivered. Our members did everything possible to provide the critical resources, training, skills, and guidance to anyone caring for people with COVID-19 and their families. Our Coalition successfully worked together to provide a series of recommendations to Congress and the Administration regarding the critical role of hospice and palliative care providers during the pandemic.

- Coalition members also unanimously pledged to work together to take specific antiracist action and to address implicit and unconscious bias re: diversity, equity and inclusion within hospice and palliative care delivery and the profession itself. Read our full statement.

As for 2021, we would like to lean on the wisdom of Maya Angelou: “Hope and fear cannot occupy the same space. Invite one to stay.” We are inviting hope.

Thank you for the selfless service each of you continue to provide no matter what. It is because of you and our work together that can and will help heal our communities.

This report provides an overview of our work and accomplishments from this past year as well as other activities included in our strategic priorities.

Tribute to Coalition Founder and Visionary, Diane E. Meier, MD

2020 marked the end of Diane Meier’s term as the Coalition’s first President since our organization was formally incorporated in 2017. As one of the Coalition’s original founders, Diane’s vision of “always striving to improve coordination, cooperation and collaboration as a field, patient care will improve” will be forever embedded as the ultimate goal of our Coalition.

We thank Diane for her extraordinary service, dedication and commitment to the Coalition which has led to improving serious illness care for millions of patients, families, and caregivers.

Our Mission, Values, Vision

Two of the most important issues that emerged in 2020, the twin epidemics of COVID-19 and institutional and systemic racism resulted in a renewed commitment for the Coalition to be more diverse, equitable and inclusive that is now reflected in our updated mission, values, and vision.

Mission & Purpose

To present a united, yet diverse voice to the public and policy makers on behalf of providers, professionals and other organizations who are interested in working together to advocate for equitable health care policies and programs that will improve the care of patients and families living with serious or life-threatening illnesses.

Principles & Values

- Patients and Family Caregivers - Why we exist and who we ultimately serve regardless of race, gender, gender identity, sexual orientation, age, religion, ethnicity, socioeconomic status, or disability
- Stronger and Better Together - Fundamental belief that we can accomplish more together than apart
- Communication – Persistence in sharing information with each other, the field, and key stakeholders
- Collaboration, Trust and Transparency - Intentional effort to work together in an environment of trust, transparency, and inclusion to achieve specific goals
- Inclusive Leadership – Modeling positive and creative leadership that encourages, respects, and enables new leaders and encourages innovative ideas

Vision

All patients, family and caregivers who need it will have access to quality hospice and palliative care.

“...The Coalition serves as a place where individuals from all fields relating to hospice and palliative care can come together and engage in dialogue, share their perspectives and best practices to help the field and their care recipients improve and thrive in one of the most difficult moments of life.”

Patricia F. Appelhans, JD, Chief Executive Officer, Association of Professional Chaplains, Board Member

Our Mission

To provide a united, yet diverse voice to the public and policy makers on behalf of providers, professionals and other organizations who are interested in working together to advocate for equitable health care policies and programs that will improve the care of patients and families living with serious or life-threatening illnesses.
Our Members

Our Coalition membership now includes 13 leading national organizations who represent hospice and palliative care providers and the interdisciplinary team (IDT).

Who We Represent

Members serve 3,000+ palliative care and 4,500+ hospice providers who care for millions of seriously ill people and their caregivers.

“The Coalition’s membership represents the full complement of clinical disciplines and entities that have a stake in ensuring the provision of high-quality palliative care.

Our combined strength is born of our diverse experience, as collectively we represent the full breadth and depth of hospice and palliative care expertise.”

William “Bill” Dombi, Esq, President, National Association for Home Care & Hospice
2020 Accomplishments

Overview

This past year brought new challenges and opportunities to address within our strategic priorities. A summary of the major issues we addressed, and our accomplishments include:

Diversity, Equity, and Inclusion

- Committed to Addressing Disparities and Inequities
- Created an Online Hub of DEI Tools and Resources
- Submitted Request to the Incoming Biden Administration to Rescind Executive Order Combatting Race and Sex Stereotyping

Pediatric Palliative Care

- Received a Grant from the Cameron and Hayden Lord Foundation
- Established a National Pediatric Palliative Care Task Force to Align Disciplines and Organizations

Community-Based Palliative Care Advocacy

- Requested Congress and HHS Improve Access to Community-Based Palliative Care
- Disseminated NCP Guidelines, 4th edition

Details of our activities are featured on the following pages.

Strategic Priorities

- Advocacy: Coordinate an advocacy agenda to improve the ability to speak with a more consistent voice to Congress and federal agencies.
- Payment: Help prepare the field for a risk-bearing reimbursement environment and present a unified message.
- Quality: Lead the strategic implementation of national palliative care guidelines and other activities with key stakeholders to drive quality.
- Research: Develop a coordinated research advocacy strategy with key partners to increase investments in federal palliative care research.
- Workforce: Develop an interdisciplinary workforce assessment and strategy to ensure access.

COVID-19

- Coordinated Palliative Care and Hospice Advocacy Efforts with COVID Legislation
- Hosted Free Virtual COVID-19 Town Hall Series
- Created COVID-19 Resource Webpage

Palliative Care Quality Measures

- Engaged Stakeholders to Gain Input for New Palliative Care Measures

Public Messaging

- Joined a National MessageLab Initiative
- Hosted Series of Messaging Workshops for Members and Stakeholders to Improve Message Alignment

Diversity, Equity and Inclusion

Committed to Addressing Disparities and Inequities

The Coalition publicly condemned the killing of George Floyd at the hands of Minneapolis law enforcement and others who lost their lives simply because of the color of their skin.

Our members united to commit to supporting legislative and regulatory policies that address disparities and inequities in our healthcare system and working with others and acknowledging our responsibility to develop specific plans to dismantle structural racism and bias within the field, including within our own workplaces. Read our full statement.

While we recognize this work is long overdue, not easy, and will require dedicated and multi-faceted commitments and resources for years to come, in the short term, our Coalition:

- Assessed our current strategic priorities and projects to ensure our work holds to the standards of diversity, equity and inclusion as we continue to ensure that patients, families and caregivers who need it will have access to equitable quality hospice and palliative care;
- Recruited Black, Indigenous, (and) People of Color (BIPOC) leaders and individuals within the Coalition for leadership and speaking opportunities;
- Sought diverse voices and representation for external nomination opportunities;
- Worked together to define actionable and specific diversity, equity, and inclusion goals; and
- Surveyed our membership and reviewed work currently underway in the field in this area.

Created an Online Hub of DEI Tools and Resources

We are proud of all the resources our members created this past year to help us and those in our field learn and self-reflect on issues surrounding health and racial equity.

While this is an ongoing effort, we will continue to provide an online hub to help our field learn, challenge ourselves, and have the hard conversations with our peer groups, our colleagues and within our institutions.

Submitted Request to the Incoming Biden Administration to Rescind Executive Order Combatting Race and Sex Stereotyping

On January 20, 2021, the Coalition submitted a letter to newly elected President Biden to immediately rescind the Trump Administration’s Executive Order 13950, which places harmful restrictions on the ability of federal contractors, grantees, and civilian and military personnel to engage in essential training necessary to understand and address factors contributing to disparities in healthcare access and outcomes, including based on race, ethnicity, gender, gender identity, and sexual orientation.

Learn more at www.nationalcoalitionhpc.org/dei.

“...One of the accomplishments I am most proud of is the statement the Coalition made on racism and the killing of George Floyd. Despite limited resources, we were able to pull together various resources posted and statements made in the wake of George Floyd’s death. It was powerful to see the commitment to racial justice and equity from Coalition partners.”

Wendy-Jo Toyama, MBA, CAE, CEO & Executive Director, American Academy of Hospice and Palliative Medicine, Board Secretary.
Coordinated Palliative Care and Hospice Advocacy Efforts with COVID Legislation

As soon as the COVID-19 global pandemic surfaced in March, the Coalition immediately began coordinating advocacy efforts re: palliative care and hospice, including:

- Recommended Swift Passage of Senate COVID-19 Legislation: Families First Coronavirus Response Act (March 16, 2020)
- Advocated for the Inclusion of Palliative Care Content in the NIH COVID-19 Treatment Guidelines (April 30, 2020)
- Sent Urgent Letter to the National Governors Association to Advocate for PPE (April 30, 2020)
- Submitted Recommendations for Phase 4 COVID-19 Legislation (May 5, 2020)
- Provided Recommendations for NIH Treatment Guidelines to include Palliative Care Services (June 25, 2020)
- Supported Congressional Effort to Prioritize Future Palliative Care Training (June 26, 2020)
- Submitted additional resources and recommended best practices in the Palliative Care Technical Assistance response document published by HHS/ASPR/TRACIE (July 2, 2020)

Hosted Free Virtual COVID-19 Town Hall Series

The Coalition sponsored a series of four virtual Town Halls:

- **Town Hall I**: Addressed the current impact of the pandemic on hospice and palliative care providers and information on associated policy and legislative changes. (April 2, 2020)
- **Town Hall II**: Addressed how the pandemic has changed the delivery of palliative care and hospice, with special emphasis on the role of chaplaincy and the need for psychosocial support. (June 11, 2020)
- **Town Hall III**: Addressed interdisciplinary changes in response to the pandemic, how to best serve communities of color, and how to prepare for the continuation and shifting of the pandemic around the country. (July 27, 2020)
- **Town Hall IV**: Addressed health disparities with communities of color and coping with stress. (September 21, 2020)

Created COVID-19 Resource Webpage

The Coalition created a COVID-19 Resources webpage, that combined helpful links, fact sheets and other resources to provide information and guidance to the hospice and palliative care field, including:

- **COVID-19 Blog**: Chaplaincy in the Time of COVID-19: Challenges and Opportunities (by HealthCare Chaplaincy Network)
- **COVID-19 Toolkit**: Top Communication and Symptom Management Tools (for the non-palliative care specialist): “Top 6” resources developed by experts that cover advance COVID-19 planning, symptom management, communication in difficult situations and providing emotional support for people living with seriously ill.
- **COVID-19 Resources for Hospice and Palliative Care Professionals**: A combined list of all the resources created by our member organizations to provide information and guidance to professionals in the hospice and palliative care field on the outbreak of COVID-19.

Learn more at [www.nationalcoalitionhpc.org/covid19](http://www.nationalcoalitionhpc.org/covid19).

“One of the accomplishments of the Coalition that I am most proud of this past year are our Interdisciplinary Covid-19 webinars. We heard from our members that these webinars made a significant impact on them.”

Virginia (Ginger) Marshall, MSN, ACNP-BC, ACHPN, FPCN, Hospice and Palliative Nurses Association, Board Member

“Despite the lack of touch and face to face meetings, the caring doesn’t stop.”

Joe Rellota, MD, American Academy of Hospice and Palliative Medicine

“In response to the pandemic, change was accelerated in a rapid way…we went from high touch to high tech. We had to train all the disciplines in a very short time on how to be able to communicate in a virtual space.”

Janet Bull, MD, MBA, FAAHPM, HMDC, Palliative Care Quality Collaborative
Pediatric Palliative Care

Established a National Pediatric Palliative Care Task Force to Align Disciplines and Organizations

Grant Awarded

With support from the Cameron and Hayden Lord Foundation, the National Coalition for Hospice and Palliative Care has expanded its scope to actively advocate and support national initiatives to improve children’s access to pediatric palliative care (PPC). The Coalition was awarded a two-year grant in April 2020 to establish a national Pediatric Palliative Care Task Force to identify and promote feasible solutions and activities that will directly impact the way PPC is delivered and received.

Membership

The inter-professional membership is comprised of pediatric palliative care leaders from the Coalition’s 13 member organizations, American Academy of Pediatrics (AAP), American Psychological Association (APA), Association of Child Life Professionals (ACLP), and three family advocates. The members represent a diversity of knowledge and skills, disciplines, and backgrounds that speak to the breadth of the PPC experience.

Co-chaired by Rachel Thienprayoon, MD and Cheryl Ann Thaxton, DNP, the Task Force met four times in 2020 and will continue to meet monthly through spring 2022.

Strategic Focus

Mission: Activate interdisciplinary collaborations and create real-world solutions to continuously improve access to pediatric palliative care.

Vision: Equitable access to high-quality pediatric palliative care for everyone.

Key Priorities: Over the next year, the Task Force will assess, initiate, and promote critical actions in the following three areas to enhance and increase children’s access to high-quality pediatric palliative care services:

1. Payment and Financing
2. Assessment of Need and Capacity
3. Raising of Awareness and Demand

Learn more at www.nationalcoalitionhpc.org/pediatric.

Palliative Care Measures Project

Engaged Stakeholders to Gain Input for New Palliative Care Measures

In 2018, the Coalition was selected as a sub-recipient to partner with the American Academy of Hospice and Palliative Medicine on a three year Palliative Care Measures Project to be responsible for stakeholder engagement because of its central position, leadership expertise and longstanding relationships with key stakeholders in the palliative care field.

The overall goal of the project is to develop two patient-reported experience measures that assess the quality of care provided by palliative care teams working in doctor’s offices and clinics, specifically:

1. How much patients feel heard and understood, and
2. How much patients get the help they wanted for pain.

By the end of 2020, the Coalition completed the following stakeholder engagement tasks for the project:

- Convened two virtual meetings of the Technical Expert Clinical User Patient Panel (TECUPP).
- Planned a second educational webinar for February 1, 2021, co-sponsored by the National Patient Advocate Foundation. (A recording and handout for the first webinar held in 2019 is available here.)
- Established a strategy to obtain public comments from patients, caregivers, and clinicians on the importance of implementing the measures, held February 1-March 2, 2021.
- Created a strategic communications plan and materials to provide regular project updates to key stakeholders and promote project activities. See Frequently Asked Questions.

Learn more at www.nationalcoalitionhpc.org/macra.

Hear NPAF Volunteers discuss the importance of the two proposed measures.
Community-Based Palliative Care Advocacy

Requested Congress and HHS to Improve Access to Community-Based Palliative Care

The Coalition and National Hospice and Palliative Care Organization spearheaded a dual track advocacy effort to build administration support at the Centers for Medicare and Medicaid Innovation and in Congress to establish a community-based palliative care model.

Read the letter and comparison chart submitted to Capitol Hill leaders and HHS officials September 2020 that was signed by 13 Coalition members, and 27 national organizations and 34 state organizations. Additional related advocacy efforts included:

- Submitted consensus recommendations to improve Alzheimer’s care in the nation in response to the Senate Finance Subcommittee on Health Care’s request for information from stakeholders for suggested policy solutions.
- Provided input into the Hospice Act, “Helping Our Senior Population in Comfort Environments Act” that passed the House Ways and Means Committee on February 2020. Elements of this legislation passed into law in Comfort Environments Act” that passed the House Ways and Means Committee on December 22, 2020 and took into consideration Coalition input and feedback.
- Endorsed the Patient Quality of Life (POLC) palliative care payment principles to help drive policy recommendations that will be used to guide this broad-based Coalition’s work.

Disseminated NCP Guidelines, 4th edition

Since its publication two years ago, the National Consensus Project’s Clinical Practice Guidelines for Quality Palliative Care, 4th edition (NCP Guidelines), continues to be widely distributed.

By the end of 2020,

116,000+
viewed the NCP Guidelines website

44,000+
NCP Guidelines were downloaded online or purchased

Continues to be one of the most viewed guidelines at ECRI Guidelines Trust.

The NCP Guidelines are available at www.nationalcoalitionhpc.org/ncp.

“The promotion of the Guidelines continues to be the most important contribution of the Coalition to the field. We refer to it constantly in education and advocacy.”

The Rev. George Handzo, APBCC, CSSBB, Director, Health Services Research & Quality, HealthCare Chaplaincy Network

Public Messaging

Joined a National MessageLab Initiative

The Coalition joined a national “MessageLab” initiative spearheaded by Dr. Anthony (Tony) Back to increase the availability and public demand for high quality palliative care, hospice and advance care planning. Goals of the project include:

- Create more understanding within the field about public messaging and what works and doesn’t work when communicating to the public.
- Conduct consumer research and present latest findings to the field for action/reaction.
- Enable leading organizations to improve and revise messaging to eliminate confusion, contradictions and misunderstandings that the public widely experience.
- Engage the field in unifying how we communicate to the public.

Hosted Series of Messaging Workshops for Members and Stakeholders to Improve Message Alignment

Thanks to the generous support of The John A. Hartford Foundation and the Cambia Health Foundation, the Coalition sponsored a special virtual workshop series, Improving and Aligning Messaging to Build Public Engagement and Access to Palliative Care and Hospice. The Coalition hosted interactive working sessions for our members and invited stakeholders in 2020 to:

- Review the latest research and findings related to public messaging about the field.
- Understand the work behind new Messaging Principles developed by the field; and
- Consider how to integrate the new Messaging Principles to improve public understanding of serious illness and end-of-life care.

In 2021, the Coalition will sponsor workshops for members and a free public webinar to present findings and key recommendations regarding revising and improving serious illness communication.

“Having the Coalition monitoring policy and legislation at the Federal level has been very important. Being able to add our names in support or submitting a comment letter after receiving a notice from the Coalition is a huge benefit to the organization and our members.”

Jessica Strong, Executive Director, Social Work Hospice & Palliative Care Network

“The Coalition is a vibrant and crucial partner in improving the public messaging that our field uses to reach people who need us.”

Anthony L. Back, MD, Co-Director, Cambia Palliative Care Center of Excellence, University of Washington

Learn more about this broader effort.
Coalition Appointments for National Committees

Congratulations to the individuals and organizations that were nominated or endorsed by Coalition member organizations and selected to national committees in 2020.

NQF Geriatrics and Palliative Care Standing Committee
- Rev. Dr. Jeffrey T. Garland, DM, EdS, BCC (APC)
- Suzi Johnson, MPH, RN (NHPCO)

NQF Hospital Workgroup
- R. Sean Morrison, MD (NPCRC)

NQF Coordinating Committee
- American Academy of Hospice and Palliative Medicine (AAHPM)

NQF Post-Acute Care/Long Term Care Committee
- National Hospice and Palliative Care Organization (NHPCO)

CMS CMMI Days At Home Measure Technical Expert Panel
- David Casarett, MD, MACP; FAAHPM, HMDC (CAPC)
- Dana Lustbader, MD, FAAHPM (AAHPM)
- Rebecca Kinch, JD (CAPC)

National Quality Partners™ Action Team to Co-Design Patient-Centered Health Systems
- Cozzie King (Coalition)

National Quality Partners™ Leadership Consortium 2020
- Jennifer Kennedy, EdD, MA, BSN, RN, CHC (NHPCO)

“Congratulations to the individuals and organizations that were nominated or endorsed by Coalition member organizations and selected to national committees in 2020.

Thank you to our three very active workgroups that are comprised of volunteers and staff from our Coalition member organizations. Our workgroups meet monthly or bi-monthly and advise on all recommendations for action that are approved by the full Coalition.”

R. Sean Morrison, MD, Director, National Palliative Care Research Center, Board Treasurer

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Our Dedicated Workgroup Members

Thank you to our three very active workgroups that are comprised of volunteers and staff from our Coalition member organizations. Our workgroups meet monthly or bi-monthly and advise on all recommendations for action that are approved by the full Coalition.

Advocacy Workgroup
- Jacqueline Kocinski (AAHPM)
- Cindy Moon (AAHPM)
- Sue Ramthun (AAHPM)
- Philip Rodgers (AAHPM)
- Joe Rotella (AAHPM)
- Kyle Christiansen (APC)
- Bryan Bowman (CAPC)
- Diane Meer (CAPC)
- Allison Silvers (CAPC)
- Stacie Sinclair (CAPC)
- Denise Hess (CHA)
- Indu Spagnard (CHA)
- George Handzo (HCCN)
- Virginia “Ginger” Marshall (HPNA)
- Chad Reilly (HPNA)
- Clare Chmiel (HPNA)
- Christopher Ronick (HPNA)
- Theresa Forster (NAHC)
- Calvin McDaniel (NAHC)
- Katie Wehri (NAHC)
- Annie Acs (NHPCO)
- Lori Bishop (NHPCO)
- Judi Lund Person (NHPCO)
- Hannah Yang Moore (NHPCO)
- Sydney Shepherd (NHPCO)
- Mark Slubber (NHPCO)
- Sean Morrison (NPCRC)
- Nadya Dimitrov (PAHPM)

Communications Workgroup
- Allison Lundberg (AAHPM)
- Emily Muse (AAHPM)
- Kyle Christiansen (APC)
- Lisa Morgan (CAPC)
- Melissa Scholl (CAPC)
- Denise Hess (CHA)
- George Handzo (HCCN)
- Britney Stock (HPNA)
- Theresa Forster (NAHC)
- RaShonda Riddle (NAHC)
- Tom Threlkeld (NAHC)
- Rodulous (NHPCO)
- Holly Pilewski (PAHPM)
- Kelly Mckenna (PCQC)
- Natalie Kovacic (SPPCP)
- Allison Shukraft (SWHPN)

Quality Workgroup
- Katherine Ast (AAHPM)
- Cindy Moon (AAHPM)
- Jeff Myers (PAHPM)
- Kelly Mckenna (PCQC)
- Michelle Krifbaum (SPPCP)
- Judy Peres (SWHPN)
- Jessica Strong (SWHPN)
- Jennifer Hirsh (SWHPN)
- Gary Stein (SWHPN)
- Katherine Forster (NAHC)
- Lori Wehri (NAHC)
- Jennifer Kennedy (NHPCO)
- Nadya Dimitrov (PAHPM)
- Betsy Fricklas (PAHPM)
- Angela Marks (PCQC)
- Kelly McKenna (PCQC)
- Kathryn Walker (SPPCP)
- Jessica Strong (SWHPN)
Our Board of Directors
The Coalition welcomes a new slate of Board of Directors and officers who will serve to provide governance and guidance for our strategic focus and activities during 2021-2022.

We are grateful to have award winning and visionary thought leaders who are devoted to advancing and elevating the field.

Our Team

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Sign up to receive and view archives of the Coalition Edition, our bi-monthly summary of news and updates impacting and influencing the field.

Follow Us @CoalitionHPC

With representation from all 13 @CoalitionHPC member organizations, the @AmerAcadPeds, and three family advocates, the @PedsPCTF is uniquely positioned to collaboratively drive forward the field of pediatric palliative care. Learn more bit.ly/34Q0VMj #PEDpc #hapc #hpm
2020 Impact Report

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