



Our Vision

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



Our Mission

Work together to **present a united voice to the public and policy makers** in order to improve the care of people with serious or life-limiting illnesses.



Our Values

- **Patients, Families and Caregivers** are why we exist and who we ultimately serve.
- **Stronger and Better Together** is our fundamental belief that we can accomplish more together than apart.
- **Communication, Coordination, Collaboration, Trust and Transparency** exemplify our intentional efforts to achieve specific goals.



Message from Our Board President and Executive Director

Welcome to the Coalition's inaugural impact report! The purpose of this report is to let you know who we are, what we represent and how we are making a difference.

To start, what we do is collaborate and focus on national health care policies, programs and strategies that will improve the care of people living with serious or life-threatening illnesses and their loved ones.

We have been in existence since 2001 when the Coalition was founded by the leading hospice and palliative care organizations to better communicate, coordinate and collaborate on issues and activities of importance to the field.

The Coalition is now an independent 501c3 organization comprised of 12 national organizations dedicated to improving access and quality of palliative care and hospice. *Every member is critical to our collective impact and voice.*

Our goals are to improve high quality palliative care for people living with serious illness and hospice care for those facing the end of life by:

- **Coordinating** and **communicating** a shared national vision,
- **Educating** the public and policy makers,
- **Collaborating** on public policies, and
- **Establishing** national clinical practice guidelines.

Specifically, this report will provide an overview of our work and accomplishments in five strategic priority areas: **Advocacy, Payment, Quality, Research, and Workforce;** plus other **education** and **communication** activities.

We invite you to learn more about us by visiting our newly designed website at www.nationalcoalitionhpc.org, joining us on Twitter @Coalitionhpc and subscribing to our *Coalition Edition* to receive bi-monthly updates.

Thank you for your interest and support of our collective work and we look forward to another productive year in 2020 (and beyond) together!



Diane E. Meier, MD, FACP, FAAHPM
Board President



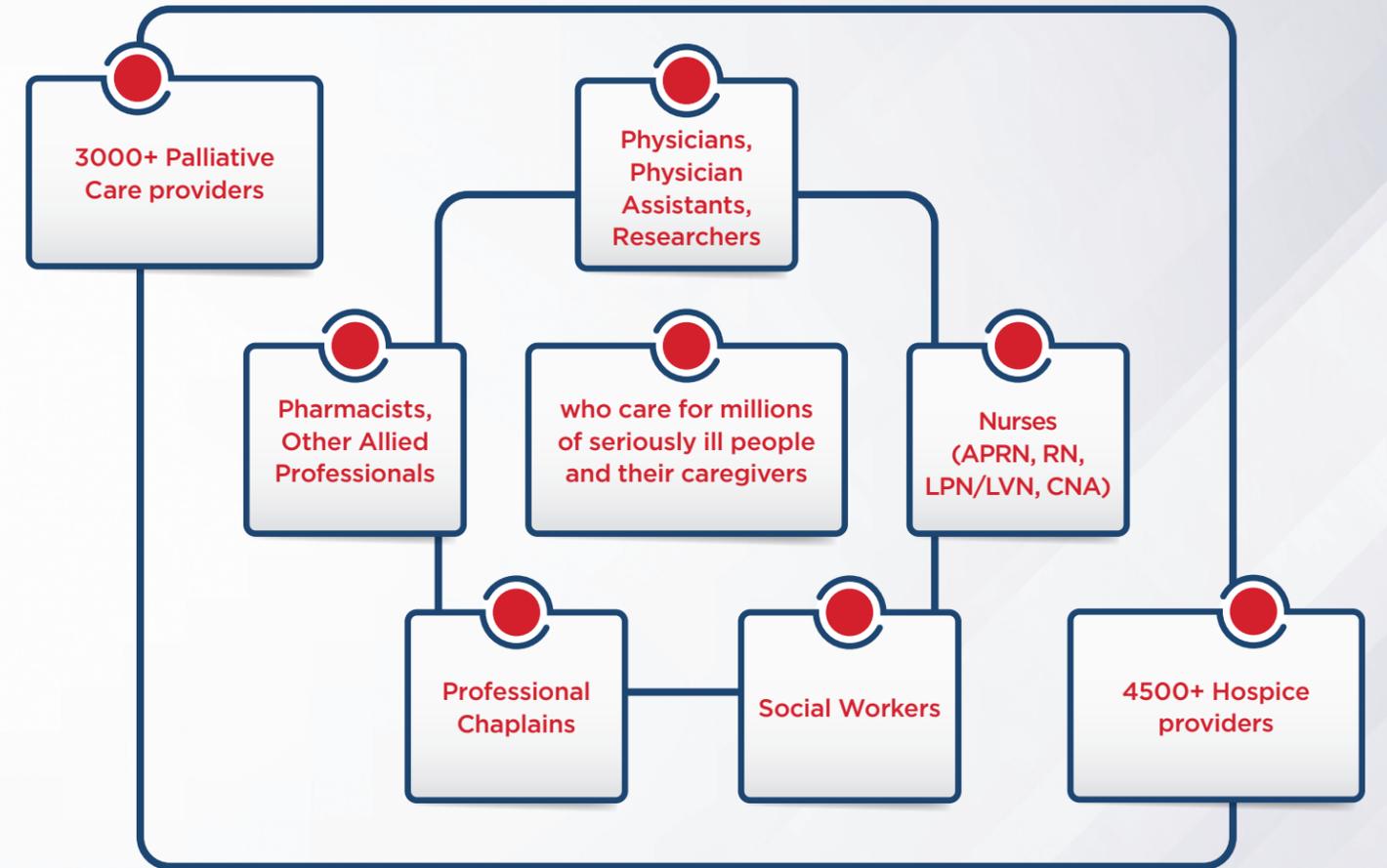
Amy Melnick, MPA
Executive Director

Our Members



Who We Represent

Our Coalition membership represents providers and the interdisciplinary team (IDT) in the palliative care field who work in multiple settings to improve serious illness care that includes:



“The Coalition allows the palliative care field to speak with one voice and to influence policy, quality standards, and public and professional awareness. We are so much stronger together!”



Diane Meier, MD, testifies before PTAC on behalf of the Coalition in support of a new Medicare serious illness payment model.

Diane E. Meier, MD, FACP, FAAHPM, Coalition Board President, and Director, Center to Advance Palliative Care

Our History



Coalition launched with five national organizations (AAHPM, CAPC, HPNA, NASW, NHPCO)



Published NCP's *Clinical Practice Guidelines for Quality Palliative Care, first edition*

Began monthly meetings to collaborate on advances for the hospice and palliative care field



Published NCP's *Clinical Practice Guidelines for Quality Palliative Care, third edition*

Hired first Executive Director, Amy Melnick, MPA

Communicated key policy positions on:

- [CMS Advanced Primary Care Model Concepts](#)
- [National Policy Proposals for Medicare patients with chronic conditions](#)
- [CMS Part B Payment Policies re: Physician Fee Schedule](#)

Expanded membership, APC and SWHPN join



Received grant from the Gordon and Betty Moore Foundation to expand national guidelines for palliative care.

Hosted [NCP Strategic Directions Stakeholder Summit](#)

Commented on:

- [Senator Ted Cruz's mention of palliative care during a CNN Town Hall debate](#)
- [Administration for Community Living, HHS, Principles for a Person-Centered Approach to Serious or Advanced Illness](#)
- [CMS New Direction for the Innovation Center](#)

Supported AAHPM's [Patient and Caregiver Support for Serious Illness payment model](#)

Expanded membership, PAHPM joins

Received 501c3, non-profit status



2001

2004

2013

2015

2017

2002

2009

2014

2016

2018



FOR QUALITY PALLIATIVE CARE

Formed National Consensus Project for Quality Palliative Care (NCP) to create national palliative care guidelines.



Published NCP's *Clinical Practice Guidelines for Quality Palliative Care, second edition*

Expanded membership, NPCRC joins

Advocated for hospice access and accurate media portrayal:

- [Medicare Part D Payment for Drugs in Hospice](#)
- [Inaccurate and negative hospice media coverage](#)

Supported recommendations:

- [Senate Finance Committee's Chronic Care Working Group Policy Options](#)
- [AHRQ's Assessment Tools for Palliative Care](#)
- [IOM's Report: Dying in America](#)

Expanded membership, HCCN joins



Partnered with CAPC's [Mapping Community Palliative Care](#) project

Commented on:

- [H.R. 5041, Safe Disposal of Unused Medication Act](#)
- [Opioid Crisis Response Act of 2018](#)
- [CMS FY 2019 Hospice Rule](#)



Selected for stakeholder engagement on a federal cooperative agreement with AAHPM's [Palliative Care Quality Measures Project](#)

Published [Clinical Practice Guidelines for Quality Palliative Care, fourth edition](#), and conducted a systematic review of the research evidence

Expanded membership to 10 national organizations, SPPCP joins



Key Partnerships

We believe it is very important that in any conversation around healthcare, the voices and expertise of our Coalition members need to be represented to ensure the best care for people living with serious illness and their families.

Our members work together to respond to various national [advocacy](#), [payment](#), [quality](#), [research](#) and [workforce](#) opportunities and challenges on behalf of the field.

Each month representatives from our membership meet to discuss various issues of interest and concern and determine what course of action is needed.

In addition, we are involved in [key partnerships](#) with external organizations beyond our membership to participate in national public policy initiatives that will advance access and quality of care for people living with serious illness, including:



Strategic Priorities

In 2019, the Coalition determined five specific strategic priorities to achieve our collective vision:

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

“Through combined efforts, the interdisciplinary partner organizations of the Coalition are making a significant difference in the specialty of Hospice and Palliative Care. We are able to accomplish more by working together and supporting each other.”

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

“National Patient Advocate Foundation regards the Coalition as one of THE most innovative and inclusive leaders in embracing collaborative initiatives that truly put people at the heart of health care.”

Rebecca Kirch, JD, Executive Vice President, National Patient Advocate Foundation

“Members of the Coalition share a common vision for the highest quality of care for people facing serious illness and a professional community that supports one another and strives to make access and innovation commonplace within and outside of organizations.”

Edo Banach, JD, Coalition Board Secretary and President & CEO, National Hospice and Palliative Care Organization

Edo Banach, JD, works on the Coalition's strategic plan.



Advocacy

Collaborates to Influence National Policy Agendas

The Coalition works together to formulate policy positions, meets with policy makers and formally submits comments on various regulatory, legislative and other issues. In 2019, our advocacy activities included:

- Endorsing the [Provider Training in Palliative Care Act](#), S. 1921, to improve access to hospice and palliative care
- Promoting the Bi-Partisan [Congressional Comprehensive Care Caucus](#)
- Expressing concerns re: [MedPAC March 2019 Recommendation](#) for hospice reductions
- Sharing concerns with payment changes in the [2020 Hospice Proposed Rule](#), plus supporting [Physician Assistants Prescribing Authority as Hospice Attending Physicians](#)
- Commenting on [2020 Medicare Physician Fee Schedule Proposed Rule](#)
- Communicating consensus recommendations as Congress considered hospice legislation re: [Hospice Integrity Initiatives](#)
- Commending the House Passage of Palliative Care Hospice Education & Training Act (PCHETA), [H.R. 647](#)



Senator Rosen (D-NV) speaks at the launch of the new Congressional Comprehensive Care Caucus.

Additionally, we strategically determine opportunities for experts from the Coalition to be nominated to serve on federal and national advisory bodies. Examples of our success included:

- The National Academies of Sciences, Engineering, and Medicine [Roundtable on Quality Care for People with Serious Illness](#)
- National Quality Forum [Geriatrics and Palliative Care Portfolio Standing Committee](#)
- National Quality Forum [MAP Hospital Workgroup](#)
- National Quality Forum [Opioid and Opioid Use Disorder Technical Expert Panel](#)
- [Patient Quality of Life Coalition](#) Steering Committee
- CMS [Hospice Quality Reporting Program](#) Patient Assessment Instrument and Quality Measure Development Panel

“The national efforts of the Patient Quality of Life Coalition and the National Coalition together amplify the collective voice of patients, researchers, providers, insurers, and health systems on the importance of greater patient access to palliative care.”

Keysha Brooks-Coley, Vice President, American Cancer Society Cancer Action Network, Inc.

More information is available at www.nationalcoalitionhpc.org/advocacy.

Payment

Impacts New Medicare Payment Model for Serious Illness

In 2019, CMS released new Medicare [alternative payment model](#) options including those that serve [the seriously ill population](#). The Coalition worked with our member organizations to jointly analyze these options and reach consensus on its impact and implications for hospice and palliative care providers and most importantly, for patients and families. The Coalition Advocacy Workgroup also provided input by engaging directly with CMS as stakeholders through meetings, discussions and written communication.

Our impact for the Primary Care First-Serious Ill Population (SIP) Option included:

- [Strongly recommending to CMS to move forward with the SIP Model](#) (Dec. 2018)
- [Commending the new HHS Primary Care First Model that included a Serious Illness 'Track'](#) (Apr. 2019)
- [Meeting with CMMI to discuss implications of a new payment model for patients and families living with serious illness](#) (May 2019)
- Hosting a free [webinar](#) plus a [virtual town hall meeting](#) for palliative care programs and hospices interested in the new Medicare payment options. (Nov. and Dec. 2019)

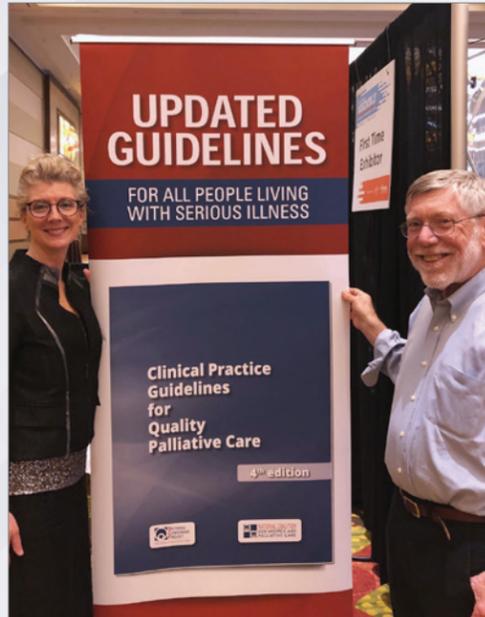
More information is available at www.nationalcoalitionhpc.org/payment.



Joe Rotella, AAHPM Chief Medical Officer and Coalition Advocacy Workgroup member, responds to questions from the Physician-Focused Payment Model Technical Advisory Committee regarding a potential new serious illness model.



Coalition Leaders meet with CMMI to discuss implications of the new Serious Illness Payment Model.



Gwynn Sullivan, NCP Project Director, and Rev. George Handzo, Healthcare Chaplaincy Network Coalition member and NCP Steering Committee member, promote the newly published NCP Guidelines, 4th edition.

Leads Broad Dissemination and Implementation of National Guidelines for Quality Palliative Care

Clinical Practice Guidelines for Quality Palliative Care, 4th edition, (NCP Guidelines), published by the Coalition in November 2018, established a comprehensive foundation for quality palliative care for all people living with serious illness, regardless of their diagnosis, prognosis, age or setting.

Key dissemination and implementation achievements in 2019 included:

93 national organizations endorsed and supported	90,000+ views of NCP webpage	22,000+ copies downloaded online or purchased
10,000+ health care professionals reached via national/ regional conferences	450,000+ impressions from Coalition tweets (#NCPGuidelines)	36,000,000+ estimated audience impressions from 35 media placements

Additionally, the 4th edition continues to inform:

- New CMS payment models
- National accreditation organizations' palliative care standards
- National multi-payer workgroup efforts
- Palliative care measure development projects
- Research agendas
- National public engagement initiatives

More information is available at www.nationalcoalitionhpc.org/ncp.



Amy Melnick facilitates a keynote panel discussion re: the NCP Guidelines at the AAHPM/HINPA 2019 Assembly with NCP Co-Chairs, Drs. Martha Twaddle and Betty Ferrell, and Dr. Shantanu Agrawal, NQF President and CEO.

Expands Stakeholder Engagement for Palliative Care Quality Measure Development

The Coalition was selected in 2018 as a subrecipient and partner of the American Academy of Hospice and Palliative Medicine's (AAHPM)



[Palliative Care Quality Measures Project](#) to be responsible for stakeholder engagement because of our central position, leadership expertise and longstanding relationships with key stakeholders in the palliative care field.

By the end of year one of the project (Sept. 2019), the Coalition:

- Assisted with establishing and convening the project's [Technical Expert Clinical User Patient Panel \(TECUPP\)](#) which represents 17 national organizations to ensure a broad range of stakeholder input;
- Hosted the first educational webinar, [Measuring Up! New Palliative Care Quality Measures Project](#) to gain public input;
- Developed a variety of [communication materials](#) about the project; and
- Assisted with the outreach and recruitment of [test sites](#).

This three year project will develop and test two patient experience measures assessing core patient-centered and patient-reported outcomes in palliative care:

1. The adequacy and appropriateness of symptom management – particularly pain; and
2. The experience of feeling heard and understood by the palliative care provider and team.

A public comment period for the two measures will be held in 2021.

More information is available at www.nationalcoalitionhpc.org/macra.

“This Coalition is the central place where organizations that represent individuals and families with serious illness come together to advance quality palliative and hospice care. We always accomplish more when we work together and are able to leverage the collective wisdom and experience of this incredibly diverse and intelligent group of healthcare leaders.”

Steve Smith, MS, CAE,
Coalition Board Treasurer and CEO & Executive Director, American Academy of Hospice and Palliative Medicine



MACRA Palliative Care Quality Measures Project Team Kick-off Meeting, AAHPM Headquarters, Chicago, IL

Thank you!

The *NCP Guidelines, 4th edition*, was made possible by funding from the **Gordon and Betty Moore Foundation** with additional support for the systematic review provided by the:

- Gordon and Betty Moore Foundation
- Gary and Mary West Foundation
- The John A. Hartford Foundation
- Stupski Foundation

2019 ACCOMPLISHMENTS

Research

Spearheads a Research Advocacy Agenda



R. Sean Morrison, MD, speaks at a Congressional briefing.

In 2018, the Labor and Health and Human Services (L/HHS) Appropriations bill urged the National Institutes of Health (NIH) to expand and intensify national research programs in palliative care to address quality of care and quality of life for the rapidly growing population of individuals in the United States living with a serious illness.

Our Coalition, representing patients, families, health care providers, organizations and the research community, identified that further research advocacy efforts are needed to develop the evidence base for palliative care.

Under the leadership of Sean Morrison, MD, Director, National Palliative Care Research Center, our Coalition partnered with the Patient Quality of Life Coalition (PQLC) in 2019 to spearhead a research advocacy strategy to influence NIH to increase their investments in palliative care research by recommending the following three activities:

1. **Increase career development awards for early stage investigators;**
2. **Increase dedicated research funding for palliative care research through a trans-institute strategy; and**
3. **Increase palliative care representation on internal study sections.**

More information is available at www.nationalcoalitionhpc.org/research.

“The Coalition is a critical contributor to advancing the care of persons living with serious illness and their families. It is the exemplar of diverse organizations working in concert to achieve a shared goal of critical importance to all Americans.”

R. Sean Morrison, MD, Coalition Board Member and Director, National Palliative Care Research Center

2019 ACCOMPLISHMENTS

Workforce

Advocates for Passage of the Palliative Care Hospice Education and Training Act (PCHETA)

After years of support and advocacy by the Coalition and our member organizations, on Oct. 24 2019, the US House of Representatives passed, by unanimous voice vote, the Palliative Care Hospice Education and Training Act (PCHETA), [HR 647](#). This legislation seeks to increase the number of trained hospice and palliative care professionals, raise awareness of palliative care and increase research funding for palliative care.

Our advocacy efforts for PCHETA in 2019 included:

- Educating our members about PCHETA and the various ways to get involved in the legislative process;
- Sharing regular updates via social media posts, news releases and Coalition meetings;
- Attending the Patient Quality of Life Coalition’s Lobby Day, June 2019;
- Publicly [commending](#) the house passage; and
- Continuing to promote the passage of the Senate companion bill, [S. 2080](#).

Sponsors NASEM’s Workshop on Building the Workforce to Care for People with Serious Illness

The Coalition served as one of the sponsors for The National Academies of Sciences, Engineering and Medicine’s (NASEM) [Roundtable on Quality Care for People with Serious Illness](#) public workshop, [Building the Workforce We Need to Care for People with Serious Illness](#), Nov. 2019. Representatives from the Coalition and several member organizations also served on the workshop’s planning committee. This important workshop examined the workforce needed to care for people with serious illness, including physicians, nurses, social workers, chaplains, community-based workers, and home health care workers, and presented possible solutions to the workforce crisis.

More information is available at www.nationalcoalitionhpc.org/workforce.



Coalition and National Patient Advocate Foundation representatives meet with Rep. Ben Cline (R-VA) to discuss the need for PCHETA bill passage.

“The Coalition has been an integral member of the NASEM’s Roundtable on Quality Care for People with Serious Illness since its inception, and continues to serve as a valuable contributor providing critical insights into the various issues the Roundtable is focusing on to improve care for people facing serious illness.”

Laurie Graig, Activities Director, The National Academies of Sciences, Engineering and Medicine

2019 ACCOMPLISHMENTS

Education

Free Webinars

The Coalition's webinars focus on issues important to the field and draw a cross-section of the palliative care and hospice interdisciplinary team.

This past year, we hosted four complimentary webinars totaling over 1,500 participants.

- **National Coalition Virtual Town Hall** re: new Medicare alternative payment models
- **New Medicare Alternative Payment Models: Options and Opportunities for Hospices and Palliative Care Programs**, both payment webinars were in collaboration with the American Academy of Hospice and Palliative Medicine, Center to Advance Palliative Care, Hospice and Palliative Nurses Association and the National Hospice and Palliative Care Organization
- **Measuring Up! New Palliative Care Quality Measures Project**, in collaboration with American Academy of Hospice and Palliative Medicine and RAND Health
- **Clinical Practice Guidelines for Quality Palliative Care, 4th edition**

Recordings and handouts for each webinar are available at www.nationalcoalitionhpc.org/webinars.

“
Stellar faculty and the webinar reflected immense stakeholder involvement. Congratulations!

“
Thank you! Excellent resources shared. GREAT work by all presenters. I learned so much!

“
Excellent overview, in a very understandable manner, of the measure development process and the importance of this project. Thank you!

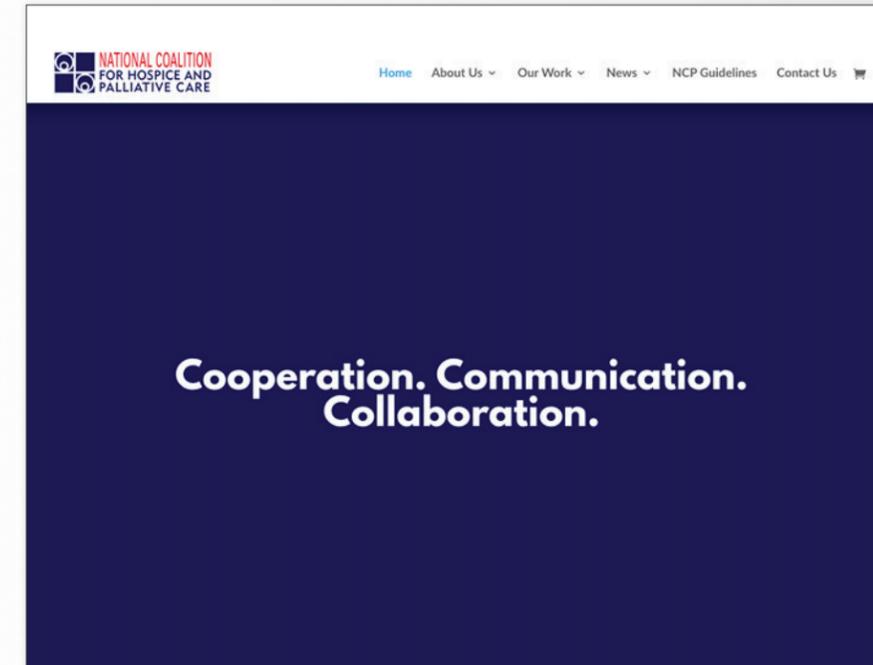
“
Appreciate the quality of the program delivery, printable slides and smooth coordination between speakers. Well done!

2019 ACCOMPLISHMENTS

Communication

New Website

Check out our newly updated website at www.nationalcoalitionhpc.org.



E-Newsletter

Sign up to receive the **Coalition Edition**, our bi-monthly summary of news and updates impacting and influencing the field, [subscribe here](#) or send an email to info@nationalcoalitionhpc.org.



Social Media

Follow us [@CoalitionHPC!](https://twitter.com/CoalitionHPC)



Coalition Top Tweets in 2019

“
The #NCPGuidelines feature recommendations for integrating palliative care principles and best practices into health care delivery for all people with serious illness. #hpm #PalliativeCare #PalliativeMedicine

“
The #PalliativeCare & #Hospice Education & Training Act (#PCHETA, H.R. 647), if passed increases training for #hpm professionals, helps launch an awareness campaign & focuses federal research funding. Ask your Member of Congress to co-sponsor. #PQLCLobbyDay

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

This workgroup advises the Coalition on legislative and regulatory issues and makes recommendations for changes to public policies, legislation and regulation proposed by federal policy makers. Members in 2019 included:

- Jackie Kocinski (AAHPM)
- Virginia "Ginger" Marshall (HPNA)
- Sean Morrison (NPCRC)
- Cindy Moon (AAHPM)
- Clare Chmiel (HPNA)
- Nadya Dmitrov (PAHPM)
- Sue Ramthun (AAHPM)
- Christopher Rorick (HPNA)
- Elizabeth Fricklas (PAHPM)
- Phil Rodgers (AAHPM)
- Edo Banach (NHPCO)
- Jeff Myers (PAHPM)
- Joe Rotella (AAHPM)
- Lori Bishop (NHPCO)
- Judy Peres (SWHPN)
- Kyle Christiansen (APC)
- Lauren Drew (NHPCO)
- Gary Stein (SWHPN)
- Diane Meier (CAPC)
- Hannah Yang Moore (NHPCO)
- Benjamin Kematick (SPPCP)
- Allison Silvers (CAPC)
- Judi Lund Person (NHPCO)
- Stacie Sinclair (CAPC)
- Mark Slobodien (NHPCO)

Communications

This workgroup discusses communication opportunities, challenges and strategies and collaborates on messaging for the field. Members in 2019 included:

- Laura Davis (AAHPM)
- Chad Reilly (HPNA)
- Allison Shukraft (SWHPN)
- Kyle Christiansen (APC)
- Jon Radulovic (NHPCO)
- Natalie Kovacic (SWHPN)
- Lisa Morgan (CAPC)
- Holly Pilewski (PAHPM)
- George Handzo (HCCN)
- Benjamin Kematick (SPPCP)

Quality

This workgroup encourages the development of new quality and performance improvement measures and recommends experts from Coalition member organizations to serve on federal and other expert panels. Members in 2019 included:

- Katherine Ast (AAHPM)
- George Handzo (HCCN)
- Betsy Fricklas (PAHPM)
- Cindy Moon (AAHPM)
- Joy Goebel (HPNA)
- Kathryn Walker (SPPCP)
- Joe Rotella (AAHPM)
- Marika Haranis (HPNA)
- Stacie Sinclair (CAPC)
- Lori Bishop (NHPCO)

Our Board of Directors

The Coalition is honored to have a prominent Board of Directors who are devoted to advancing and elevating the hospice and palliative care field – nationally, regionally and locally. Our Board members are award winning, visionary thought leaders for our interdisciplinary field...*and together are committed to united action.* Specifically, the Board provides governance and guidance for the Coalition's strategic focus and activities.



Diane E. Meier, MD, FACP, FAAHPM
Board President, Center to Advance Palliative Care



Edo Banach, JD
Board Secretary, National Hospice and Palliative Care Organization



Steve R. Smith, MS, CAE
Board Treasurer, American Academy of Hospice and Palliative Medicine



R. Sean Morrison, MD
Board Member At Large, National Palliative Care Research Center



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

Our Team



Amy Melnick, MPA
Executive Director



Gwynn B. Sullivan, MSN
Project Director



Cozzie M. King
Manager



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