**MESSAGE FROM OUR BOARD PRESIDENT AND EXECUTIVE DIRECTOR**

First and foremost, our deepest gratitude goes to all of you who have worked for years, and especially this past year, to improve the care of people with serious illness.

At the beginning of 2021, our Coalition members focused on sharing our goals to provide equitable high quality hospice and palliative care to all those that need it with the new Biden administration and Congress.

Although we were (and still are) in the midst of a world-wide pandemic, our Coalition came together to unite and speak with one voice to improve serious illness care. Despite the ongoing challenges posed by COVID-19, the enormous changes facing the field and the losses we have experienced, our Coalition remains hopeful for the future that we will continue to do what we do best: Cooperate, Communicate, and Collaborate.

We were grateful for the availability of the COVID-19 vaccinations in early 2021 and issued a statement urging all hospice and palliative care professionals, volunteers, patients, and caregivers to get a vaccine unless contraindicated.

We continued our commitment to being a more diverse, equitable, and inclusive (DEI) Coalition by forming our new Equity and Inclusion Workgroup, revising our strategic plan through a DEI lens, and influencing our National Pediatric Palliative Care Task Force membership and work.

Another tremendous accomplishment from this past year was completing a three year Palliative Care Measures Project that the Coalition was fortunate to serve as a collaborative partner under the leadership of the American Academy of Hospice and Palliative Medicine. This was a monumental effort and the first of its kind for the palliative care field.

A heartfelt huge thank you to all who have helped, contributed, and participated in our Coalition work this past year! We look forward to continuing to serve and represent you and the thousands of interdisciplinary team members working each day to improve serious illness care.

Edo Banach, JD
Board President

Amy Melnick, MPA
Executive Director

**INSIDE THIS REPORT LEARN HOW WE:**

1. Are moving forward with our new three-year strategic plan
2. Represent the field
3. Convene our members
4. Increase access to palliative care and hospice
5. Embed equity and inclusion in our work
6. Elevate patient and caregiver voices
7. Improve access to pediatric palliative care
8. Share information
9. Govern and work internally to make it all happen

**OUR NEW STRATEGIC PLAN**

This past year, we embarked on a strategic planning process, led by our Coalition Board, that included a dynamic methodology to identify current and future environmental, programmatic and operation opportunities and challenges and review input from Coalition members to create a realistic, creative, and strategic set of goals.

Specifically, we:

- Collected information from internal and external stakeholders including those outside the field;
- Facilitated discussions with our Coalition members;
- Made strategic decisions based on our mission, vision and values, while considering what’s missing and what’s possible; and
- Wrote the final plan to organizationalize our work.

During this period, we specifically acknowledged the work needed to address issues related to diversity, equity, and inclusion (DEI) in all our Coalition initiatives. The result is a new three-year strategic plan for 2022-2024 that aligns with our values and intended impact and is accompanied by specific strategies to achieve our goals.

**OUR MISSION**

Improve the care of people with serious or life-limiting illnesses by convening the field, advocating for equitable policies and improved health outcomes, establishing best practices, and sharing resources.

**OUR VISION**

All patients, families and caregivers will have equitable access to quality hospice and palliative care.

**WE BELIEVE**

We believe that patients, families, and caregivers, (regardless of race, gender, gender identity, sexual orientation, age, religion, ethnicity, socioeconomic status or disability) are always the intended beneficiaries of our work.

We believe as a Coalition our best role is to convene, advocate and streamline access and information regarding innovative and inclusive best practices and quality standards.

We believe that patient voices are essential to the quality of care and seek partnerships to have them guide our work.

**OUR STRATEGIC FRAMEWORK**

Patients need equitable access to quality hospice and palliative care regardless of location, race, gender, gender identity, sexual orientation, age, religion, ethnicity, socioeconomic status or ability.

- We will advance health equity for patients with serious illness and their caregivers.

Patients deserve a primary and specialty workforce and universal quality standards to meet their hospice and palliative care needs.

- We will disseminate best practices, research, and data to advance the field.

All people with serious and/or life-limiting conditions should have access to the full scope of palliative care regardless of where they are.

- We will advocate for legislative and regulatory policy changes to advance the field of hospice and palliative care practice.

The Coalition will be the lead convener for the organizations within the hospice and palliative care field.

- We will create a sustainable foundation for the Coalition.

**“The best way to find yourself is to lose yourself in the service of others.”**

- Mahatma Gandhi

Wendy-Jo Toyama, MBA, CAE, American Academy of Hospice and Palliative Medicine, Coalition Board Secretary
WE IMPROVE THE CARE OF PEOPLE WITH SERIOUS OR LIFE LIMITING ILLNESSES BY... CONVENING THE FIELD

HOW WE CONVENE
Being the lead convener for the organizations within the hospice and palliative care field, it "takes a village" to fulfill our mission and goals. In addition to Coalition leaders who attend our monthly meetings, we are especially grateful for our four active workgroups - Advocacy, Communications, Equity and Inclusion, and Quality - each comprising of representatives from our member organizations.

We greatly appreciate the time each workgroup member volunteers in addition to their already full-time job to help the Coalition best represent the interdisciplinary field and advocate for quality hospice and palliative care. Thank you!

HOW WE REPRESENT THE FIELD
Our membership includes 13 leading national organizations:

- Who represent over 4,500 palliative care and 1,000 hospice providers, and thousands of interdisciplinary health care professionals, including:
  - Physicians
  - Physician Assistants
  - Social Workers
  - Researchers
  - Nurses (APRN, RN, LPN/LV, CNA)
  - Chaplains
  - Pharmacists
  - Other Allied Professionals
- Who care for millions of seriously ill people and their caregivers in multiple and varied settings.

WHAT OUR MEMBERS SAY...
One of the greatest benefits of the Coalition is it truly reminds us of the interprofessional nature of our field and highlights the needs and strengths of our collegial organizations which is what creates the unique nature of our work.

- Allie Shukraft, MSW, MAT, APHSW-C, Social Workers Hospice & Palliative Care Network

Being a Coalition member, our organization can work collectively to advance the knowledge, best practices, and value that this field brings to the larger public.

- Patricia P. Appelhans, JD, Association of Professional Chaplains, Coalition Board Member

The Coalition brings together a wide variety of stakeholders who are deeply committed to the mission of hospice and palliative care and allows all participants to gain perspective from the various viewpoints, and a deeper understanding and appreciation of the field.

- William A. Dombi, Esq., National Association for Home Care & Hospice

ADVOCACY WORKGROUP
Jackie Kocinski (AAHPM)**
Joan Corcell (PCQN)
Kelly McKenna (PCQG)
Sarah Friebert (PPTCF)
Jenni Linebarger (PPTCF)
Bryan Bowman (CAPC)
Kathleen Curran (CHA)
Rev. Sharondalyn Dupree (HCCN)
Todd Hultman (HPNA)
Kathy Gueck (APC)

EQUITY AND INCLUSION WORKGROUP
Sonia Malhotra (AAHPM)
Linda Sterling (AAHPM)
Inetta Reddel (APC)
Brittany Chambers (CAPC)
Bryan Bowman (CAPC)
Kathleen Curran (CHA)
Rev. Sharondalyn Dupree (HCCN)
Tod Doerman (HPNA)
Davis Baird (NAHC)
Ben Marcantoni (NHPCO)
Lori Bishop (NHPCO)
Nadya Dmitrov (PAHPM)
Betsy Fricklas (PAHPM)
Jeff Myers (PAHPM)
Joni Nicola (PCQG)
Joy Goebel (HPNA)
George Handzo (HCCN)
Priscilla Marmo (SWHPN)
Michelle Krashbaum (SPCPC)
Advocacy Strike Team
**Hospice Strike Team

COMMUNICATIONS WORKGROUP
Allison Lundberg (AAHPM)
Kyle Christiansen (APC)
Emily Mue (AAHPM)
Lisa Morgan (CAPC)
Melissa Scholl (CAPC)
Denise Hess (CHA)
George Handzo (HCCN)
Brittany Stock (HPNA)
Theresa Forster (NAHC)
Tom Theile (NAHC)
For the Coalition (NHPCO)
Holly Pilewski (PPTCF)
Suzanne Marmo (SWHPN)
Collin McDaniel (NAHC)
Spencer Stolarski (HPNA)
Suzanne Marmo (SWHPN)

QUALITY WORKGROUP
Katherine Ast (AAHPM)
Joe Rotella (AAHPM)
Cindy Moon (AAHPM)
Jeffrey Garland (APC)
Stacie Sinclair (CAPC)
Denise Hess (CHA)
George Handzo (HCCN)
Joy Goebel (HPNA)
Theresa Forster (NAHC)
Kathleen Curran (CHA)
Rev. Sharondalyn Dupree (HCCN)
Tod Doerman (HPNA)
Davis Baird (NAHC)
Ben Marcantoni (NHPCO)
Lori Bishop (NHPCO)
Nadya Dmitrov (PAHPM)
Betsy Fricklas (PAHPM)
Lone Weber (PAHPM)
Angela Marks (PCQG)
Kelly McKenna (PCQG)
Holly Davis (PPTCF)
Kathryn Walker (SPCPC)
Anne Kelemen (SWHPN)

“The Coalition is a cohesive group of dedicated interdisciplinary professionals working together to improve care for patients and families dealing with serious illness.”

— Virginia (Ginger) Marshall, MEN, ACHPN, FPCN, Hospice and Palliative Care Nurses Association, Coalition Board Treasurer
WE IMPROVE THE CARE OF PEOPLE WITH SERIOUS OR LIFE LIMITING ILLNESSES BY... ADVOCATING FOR EQUITABLE POLICIES AND IMPROVED HEALTH OUTCOMES

HOW WE INCREASE ACCESS TO PALLIATIVE CARE AND HOSPICE

One of the Coalition’s signature strengths is aligning the field and speaking with one amplified voice to national policy makers.

In 2021, we worked through our Advocacy Workgroup and Strike Teams to advocate for increased access to palliative care and hospice. Together, we utilized both regulatory and legislative strategies to achieve the following:

- Submitted request to the Biden Administration to rescind Executive Order combatting race and sex stereotyping (January 2021)
- Submitted comprehensive policy recommendations to the New Biden Administration and Congressional Leaders (February 2021)
- Provided recommendations re: Hospice Survey Reform to the Centers for Medicare & Medicaid Services (CMS) (March 2021)
- Submitted recommendations for the Home and Community Based Services (HCBS) Access Act (April 2021)
- Endorsed Creating Opportunities Now for Necessary and Effective Care Technologies for Health Act of 2021 (CONNECT Act) (April 2021)
- Submitted comments and recommendations re: the FY 22 Medicare Hospice Program Proposed Rule to CMS (June 2021)
- Endorsed bipartisan Expanding Access to Palliative Care for Seniors Act (S. 2565) (July 2021)
- Submitted comments re: the Home Health Proposed Rule to CMS (August 2021)
- Supported the Palliative Care Hospice Education and Training Act (PCHTA) provisions incorporated in the Congressional Reconciliation Package (September 2021)
- Endorsed the bipartisan Provider Training in Palliative Care Act (S. 2893) (September 2021)
- Submitted consensus policy recommendations re: high priority quality measures for people with serious illness to the Centers for Medicare and Medicaid Innovation (CMMI) (September 2021)
- Submitted recommendations to National Institute of Nursing Research (NINR) re: their new strategic plan to encourage continued palliative care research focus (December 2021)

The Coalition enables a united and powerful advocacy voice across the full range of hospice and palliative care disciplines that brings together wisdom to vet issues and formulate responses.

- The Reverend George Handzo, APBCC, CSSBB, HealthCare Chaplaincy Network

The Coalition brings a synthesis of broad perspectives into logical recommendations for federal regulators and legislators.

- Allison Silvers, MBA, Center to Advance Palliative Care

It’s been wonderful to collaborate with other health care organizations which has allowed our voice to be heard by elected representatives and policy makers.

- Kathy Kemle, MS, PA-C, DFAAPA, Physician Assistants in Hospice and Palliative Care

HOW WE EMBED EQUITY AND INCLUSION IN OUR WORK

Last year began with strengthening our commitment to address diversity, equity, and inclusion (DEI) issues within the Coalition and our field as a key priority – and ended with more specific tasks slated for 2022 through our strategic planning process.

Working closely with representatives of the national organizations, allowed me to see that we all want to promote a more equitable field of hospice and palliative care and work together to eliminate disparities and improve patient care.

- Suzanne Marano, LCSW, PhD, APHSSW-C, Equity and Inclusion Workgroup Member, Social Workers Hospice & Palliative Care Network

Here’s what we were able to accomplish this past year and our work is just beginning:

- Revised our Mission & Purpose, Principles & Values, Vision, and Strategic Priorities through a DEI lens;
- Compiled DEI resources from our members to share their organization’s statements, promote best practices, encourage more efforts, and avoid duplication;
- Sent a letter requesting to rescind the previous administration’s Executive Order 13950, which if implemented would have curtailed federally funded diversity training; and
- Increased greater representation for national leadership nominations, speakers, and nominations for National Quality Forum committees as well as the Coalition’s Pediatric Palliative Care Task Force members.

We also established a new Equity and Inclusion Workgroup that is comprised of representatives appointed from each member organization.

The purpose of the workgroup is to:

1. Advise, recommend, and take specific action on DEI issues related to regulatory, legislative, quality, workforce, research, national leadership nominations and other arenas as identified;
2. Discuss questions, comments, or concerns in support of DEI within the hospice and palliative care field; and
3. Share best practices amongst the Coalition member organizations.

In the next three years, we plan to advance health equity for hospice and palliative care patients by:

- Creating a multi-year strategy of focus informed by the Equity and Inclusion Workgroup;
- Establishing consensus regarding the Coalition’s definition of DEI;
- Creating inclusive common, patient-centered language to share with the field; and
- Making recommendations for more consistent data collection throughout the field regarding DEI.

The Coalition brings together wisdom to vet issues and formulate responses.

- The Reverend George Handzo, APBCC, CSSBB, HealthCare Chaplaincy Network

The Coalition enables a united and powerful advocacy voice across the full range of hospice and palliative care disciplines that brings together wisdom to vet issues and formulate responses.

- The Reverend George Handzo, APBCC, CSSBB, HealthCare Chaplaincy Network
In 2018, the Coalition, along with RAND Health Care, was contracted by the American Academy of Hospice and Palliative Medicine as a subrecipient and partner of the Palliative Care Measures Project to be responsible for stakeholder engagement deliverables because of our central position, leadership expertise and longstanding relationships with key stakeholders in the palliative care field.

The following two measures are now available for palliative care and other healthcare clinicians to implement in their practice:

1. How much patients felt heard and understood; and
2. If patients got the help they wanted for their pain.

NCP GUIDELINES, 4TH EDITION, STILL MAKING AN IMPACT!

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

87,000+ copies downloaded or purchased
137,500+ viewed NCP Guidelines website

“I appreciate the Coalition’s many accomplishments in advancing hospice and palliative care, and I’m most proud of its publishing the NCP Guidelines.”

– Joe Rotella, MD, MBA, HMDC, FAAPHM, American Academy of Hospice and Palliative Medicine

HOW WE IMPROVE ACCESS TO PEDIATRIC PALLIATIVE CARE

In April 2020, the Coalition was awarded a two-year grant from the Cameron and Hayden Lord Foundation to establish a National Pediatric Palliative Care Task Force. Additional grant support from the Cambia Health Foundation supported the Task Force’s convening efforts.

Our mission is to activate interdisciplinary collaborations and create real-world solutions to continuously improve equitable access to high quality pediatric palliative care (PPC).

Here’s what the PPC Task Force accomplished this year:

• Established three workgroups (Payment and Finance, Needs Assessment, Knowledge and Awareness)
• Appointed pediatric representatives to the Coalition’s workgroups (Advocacy, Communication, Equity & Inclusion, and Quality)
• Developed and adopted operating guidelines to govern and direct the work of the Task Force
• Partnered with the Center to Advance Palliative Care to develop new national PPC training standards (adapted from the NCP Guidelines, 4th edition)
• Distributed a national pediatric hospice and palliative care survey (in partnership with NHPCO)
• Integrated language specific to pediatrics (for the Coalition’s response to the draft Home and Community-Based Services Act and to hospice regulatory comments)
• Provided strategic guidance on proposed federal and state legislation specific to pediatric palliative care (in partnership with our member organizations)
• Created a quarterly e-newsletter, PPC NOW
• Established strategic partnerships (Courageous Parents Network and NHPCO Pediatric Advisory Council)

Looking towards 2022, our goals are to:

1. Advance the workgroup initiatives and activities;
2. Secure the long-term sustainability of the Task Force; and
3. Strengthen the Task Force’s influence, engagement, and leadership in supporting and developing national and state policies and legislation that increases children’s access to pediatric palliative care.
How We Share Information

In 2020, the Coalition received a subrecipient award from the University of Washington Cambia Palliative Care Center of Excellence to expand stakeholder engagement and dissemination of the *Messaging Principles for Serious Illness Care* over a two-year timeframe that was funded by The John A. Hartford Foundation and Cambia Health Foundation, and spearheaded by Dr. Anthony (Tony) Back.

In 2021, we achieved our goal of hosting four workshops with representatives from each member organization to align our public messaging for serious illness care, as well as an Insider’s Briefing for other national organizations.

The outcome of implementing the messaging principles within the Coalition was the revision and redesign of our bi-monthly newsletter, *Coalition Edition*, that now focuses on how we communicate information to the field, as well as how we “invite dialogue” from the field. (See ‘Pulse Check’ from our November 2020 issue.)

Our collaboration with our members and stakeholders will continue as we seek to communicate a more unified voice!

Messaging Principles for Serious Illness Care

1. **Talk up the benefits.**
   - Show how these services and care improve peoples’ lives. (Don’t lead with dying.)
2. **Present choices for every step.**
   - At every stage of an illness, emphasize that people have choices. (Laypeople often assume a doctor will tell them what they ‘have’ to do.)
3. **Use stories.**
   - People want to hear from people like them. Be positive and aspirational. (Trying to scare them into doing something to avoid a bad outcome doesn’t work.)
4. **Invite dialogue—and not just once.**
   - The call to action is to talk with someone—friend, family, or clinician. (Most people welcome a chance to interact but don’t want to be lectured.)
5. **Invoke a new team.**
   - Patients, people who matter to them, health care providers, & community all have a role. (Many people think they are on their own.)

The Coalition shares 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

“The time is always ripe to do right.”

– Martin Luther King Jr.