



# IMPACT REPORT

**Cooperation.**  
**Communication.**  
**Collaboration.**





## MESSAGE FROM OUR BOARD PRESIDENT AND EXECUTIVE DIRECTOR

### REFLECTIONS FROM THIS PAST YEAR

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 heart-felt 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

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

– Mahatma Gandhi

## 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 operationalize our work.

During this process, 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.

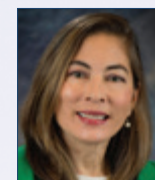
- **We will disseminate best practices, research, and data to advance the field.**

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.**



I am most proud of the Coalition’s thoughtful and committed approach to diversity and inclusion. After last year’s racial reckoning, we knew we needed to do more, and we ensured that this work is a part of our strategic planning process moving forward.

– **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 REPRESENT THE FIELD

Our membership includes **13 leading national organizations**:

- Who represent over **4,500 palliative care and 3,000 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 F. 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

### 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!*

#### ADVOCACY WORKGROUP

- Jackie Kocinski (AAHPM)\*\*\*
- Joe Rotella (AAHPM)\*\*\*
- Sue Ramthun (AAHPM)\*
- Cindy Moon (AAHPM)\*\*\*
- Phil Rodgers (AAHPM)\*
- Kyle Christiansen (APC)
- Allison Silvers (CAPC)\*
- Diane Meier (CAPC)\*
- Stacie Sinclair (CAPC)
- Lucas Swanepoel (CHA)
- George Handzo (HCCN)\*\*
- Charles James Parker (HCCN)\*\*
- Virginia Marshal (HPNA)\*\*
- Chad Reilly (HPNA)
- Jessica Barker (HPNA)
- Christopher Rorick (HPNA)
- Clare Chmiel (HPNA)\*
- Caitlin Brennan (HPNA)\*
- Theresa Forster (NAHC)\*\*\*
- Katie Wehri (NAHC)\*\*\*
- David Baird (NAHC)\*\*\*
- Calvin McDaniel (NAHC)
- Judi Lund Person (NHPCO)\*\*\*
- Lori Bishop (NHPCO)\*\*\*
- Hannah Yang Moore (NHPCO)\*
- Logan Hoover (NHPCO)
- Annie Acs (NHPCO)\*
- Sean Morrison (NPCRC)
- Nadya Dmitrov (PAHPM)

- Betsy Fricklas (PAHPM)
- Jeff Myers (PAHPM)
- Jon Nicolla (PCQC)
- Kelly McKenna (PCQC)
- Sarah Friebert (PPCTF)
- Jenni Linebarger (PPCTF)
- Jennifer Bartz (PPCTF)
- Jessica Strong (SWHPN)\*\*
- Jennifer Hirsch (SWHPN)
- Suzanne Marmo (SWHPN)\*\*
- Michelle Krishbaum (SPPCP)
- \*Advocacy Strike Team
- \*\*Hospice Strike Team

#### COMMUNICATIONS WORKGROUP

- Allison Lundberg (AAHPM)
- Kyle Christiansen (APC)
- Emily Muse (AAHPM)
- Lisa Morgan (CAPC)
- Melissa Scholl (CAPC)
- Denise Hess (CHA)
- George Handzo (HCCN)
- Brittney Stock (HPNA)
- Theresa Forster (NAHC)
- Tom Threlkeld (NAHC)
- Jon Radulovic (NHPCO)
- Holly Pilewski (PAHPM)
- Maddy Giella (PCQC)
- Kelly McKenna (PCQC)
- Laura Meyer-Junco (SPPCP)
- Allison Shukraft (SWHPN)
- Jessica Strong (SWHPN)
- Natalie Kovacic (SWHPN)

#### EQUITY AND INCLUSION WORKGROUP

- Sonia Malhotra (AAHPM)
- Linda Sterling (AAHPM)
- Inetta Reddell (APC)
- Brittany Chambers (CAPC)
- Brynn Bowman (CAPC)
- Kathleen Curran (CHA)
- Rev. Sharondalyn Dupree (HCCN)
- Todd Hultman (HPNA)
- Davis Baird (NAHC)
- Ben Marcantonio (NHPCO)
- Toby Weiss (NHPCO)
- Stacey Orloff (PPCTF)
- Sarah Friebert (PPCTF)
- Suzanne Marmo (SWHPN)

- Jeffrey Garland (APC)
- Stacie Sinclair (CAPC)
- Denise Hess (CHA)
- George Handzo (HCCN)
- Joy Goebel (HPNA)
- Theresa Forster (NAHC)
- Katie Wehri (NAHC)
- Ben Marcantonio (NHPCO)
- Lori Bishop (NHPCO)
- Nadya Dimotrov (PAHPM)
- Betsy Fricklas (PAHPM)
- Lorie Weber (PAHPM)
- Angela Marks (PCQC)
- Kelly McKenna (PCQC)
- Holly Davis (PPCTF)
- Kathryn Walker (SPPCP)
- Anne Kelemen (SWHPN)

#### QUALITY WORKGROUP

- Katherine Ast (AAHPM)
- Joe Rotella (AAHPM)
- Cindy Moon (AAHPM)

**“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**, MSN, 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](#))
- Hosted virtual town hall, **Conversation with Coalition Leaders: The Biden Administration and the 117th Congress** - What Lies Ahead & How We Can Make an Impact ([April 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 (PCHETA)** provisions incorporated in the Congressional Reconciliation Package ([September 2021](#))

- Endorsed the bipartisan **Provider Training in Palliative Care Act** (S. 2890) ([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 Marmo**, LCSW, PhD, APHSW-C, Equity and Inclusion Workgroup Member, Social Workers Hospice & Palliative Care Network

I am proud that the Coalition has a centralized and unique Equity and Inclusion workgroup. We are diverse across ethnicities, mindsets and work cultures which lends itself to rich collaboration.



- **Rev. Inetta A. Reddell**, MACS, MDIV, BCC, Co-Chair, Equity and Inclusion Workgroup, Association of Professional Chaplains

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 to President Biden](#)** 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.





## WE IMPROVE THE CARE OF PEOPLE WITH SERIOUS OR LIFE LIMITING ILLNESSES BY... ESTABLISHING BEST PRACTICES

### HOW WE ELEVATE PATIENT AND CAREGIVER VOICES

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.



Over the course of three years, two patient reported experience measures were developed and rigorously tested “by the field for the field” with substantial input from patients and caregivers thanks to our unique partnership with the [National Patient Advocate Foundation](#).

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.

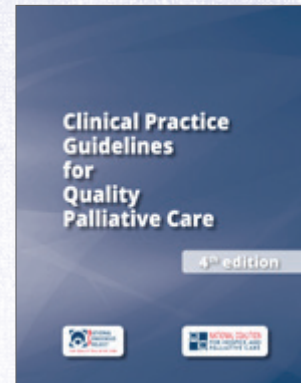
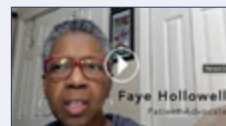
Here’s what the Coalition contributed the final year of the project in 2021:

- Created the [project website](#) to support continued dissemination efforts about the measures
- Collaborated with an innovative [Technical Expert Clinical User Patient Panel \(TECUPP\)](#) that included representatives from all 13 Coalition members, five other national organizations and patient/family representatives;
- Partnered with the [National Patient Advocate Foundation](#) to incorporate perspectives of patients and caregivers (and throughout the lifespan of the project);
- Hosted a free public webinar, [Launching the Future of Palliative Care: Patient-Reported Experience Measures](#), with 202 health care professionals attending; and
- Facilitated a public comment period to obtain specific feedback about the measures, both of which received strong support from 207 respondents that included clinicians, patients, family members, caregivers, and advocates.



This effort proved the importance of a team approach between the patient, their caregivers and clinicians, and how to treat the whole person.

– Faye Hollowell, National Patient Advocate Foundation Volunteer, and TECUPP member



### 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



We are most proud of our diversity and connectivity; as a team we are relational, coordinated, and motivated. Our sum is more than the whole of our parts.



– Rachel Thienprayoon, MD, and Cheryl Ann Thaxton, DNP, Co-Chairs, National Pediatric Palliative Care Task Force



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:

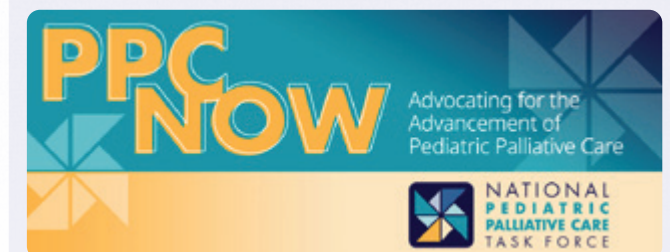
- Established three workgroups (Payment and Finance, Needs Assessment, Knowledge and Awareness)
- Appointed pediatric representatives to the Coalition’s workgroups (Advocacy, Communication, Equity & Inclusion, and Quality)
- Developed and adopted operating guidelines to govern and direct the work of 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](#))

- Submitted a letter of support for patient-reported measures (to advocate for CMS to fund a [Palliative Care Measures Project](#) for pediatrics)
- Hosted an annual meeting to review progress and set strategic goals for the coming year

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.

> SIGN UP TO RECEIVE PPC NOW!





# WE IMPROVE THE CARE OF PEOPLE WITH SERIOUS OR LIFE LIMITING ILLNESSES BY... **SHARING RESOURCES**

## 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.)

## OUR GOVERNANCE

Thank you to our exemplary **Board of Directors and Officers** who serve to provide strategic guidance for our work and activities.



**Edo Banach, JD**  
Board President (NHPCO)



**Wendy-Jo Toyama, MBA, CAE**  
Board Secretary (AAHPM)



**Virginia (Ginger) Marshall, MSN, ACNP-BC, ACHPN, FPCN**  
Board Treasurer (HPNA)



**Patricia F. Appelhans, JD**  
Board Member At Large (APC)



**Brynn Bowman, MPA**  
Board Member At Large (CAPC)



**R. Sean Morrison, MD**  
Board Member At Large (NPCRC)



**Jessica Strong**  
Board Member At Large (SWHPN)



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

– Edo Banach, JD, Board President

## OUR TEAM



**Amy Melnick, MPA**  
Executive Director



**Cozzie King**  
Manager, Operations and Special Projects



**Devon Dabbs**  
Project Director



**Gwynn Sullivan, MSN**  
Project Director

“The time is always ripe to do right.”

–Martin Luther King Jr.

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PALLIATIVE CARE