



NATIONAL
PEDIATRIC
PALLIATIVE CARE
TASK FORCE

An Initiative of the National Coalition for Hospice and Palliative Care

2020

APRIL 2020

Coalition receives 2-year grant from the Cameron & Hayden Lord Foundation to develop a national pediatric palliative care task force

SUMMER 2020 LEADERSHIP

Rachel Thienprayoon & Cheryl Ann Thaxton are named co-chairs

SETTING THE COURSE

Task Force adopts Mission, Vision, and Goals

PRIORITIZE OPPORTUNITIES

Task Force identifies 3 Priority Areas: Payment & Financing, Needs Assessment, and Knowledge & Awareness

BUILDING THE TEAM

The National Pediatric Palliative Care Task Force is established with representatives from 16 organizations and parent advocates

SEPTEMBER 2020

Task Force hosts its inaugural meeting



**NATIONAL
PEDIATRIC
PALLIATIVE CARE
TASK FORCE**

An Initiative of the National Coalition for Hospice and Palliative Care

2021

TASK FORCE BUILDING

- Logo created
- Launched PPC Now e-newsletter
- @PedsPCTask

SERVE AS SUBJECT MATTER EXPERTS

- Provide expertise & input on core resources & opportunities for protecting state access to pediatric concurrent care
- Partnered with CAPC to develop PPC Multi-Disciplinary Clinical Training Recommendations & Learning Pathways

ASSESS NEEDS

Surveyed member organizations about PPC. Wow! 13 of 15 don't have a standardized definition of PPC

RAISING AWARENESS

- Present on the Task Force at AAHPM/HPNA Annual Assembly, Boston Children's Grand Rounds, and National Coalition member meeting

INFLUENCE AND DEVELOP PARTNERSHIPS

- Pediatric representatives seated on the Coalition's Communication, Quality, & Advocacy Workgroups
- PPC Now content partners include Courageous Parents Network & ChiPPs

ADVOCATE FOR POSITIVE CHANGE

- Advocated in writing for CMS to develop pediatric patient-reported measures and caregiver proxy tools
- Presentation for Blue Cross Blue Shield Association on concurrent care and state PPC initiatives & payment models



**NATIONAL
PEDIATRIC
PALLIATIVE CARE
TASK FORCE**

An Initiative of the National Coalition for Hospice and Palliative Care

2022

LEADERSHIP

Rachel Thienprayoon named Chair with Holly Davis as Chair Elect & Cheryl Ann Thaxton as Past Chair for 2-year terms

SERVE AS SUBJECT MATTER EXPERTS

- Family advocate, Dannell Shu is a panel expert and closing speaker at the NASEM family caregiving workshop
- Jori Bogetz seated on NASEM Roundtable on Quality Care for People with Serious Illness, ensuring pediatrics is always part of the conversation & decision-making
- Toluwalase Ajayi is a panel expert on NASEM's roundtable on improving research in the pregnant population

ASSESS NEEDS

Members Kristin James & Danielle Eaves develop and disseminate an international child life hospice and palliative needs assessment survey

DEVELOP PARTNERSHIPS

- Informed CAPC's development of a PPC Billing and Business Development toolkit
- Informed the development of Illinois' Medicaid PPC benefit guidelines

INFLUENCE

- NAHC develops pediatric member listserv and reestablishes a Pediatric Council & Medicaid Committee
- Pediatric representative seated on the Coalition's DEI workgroup

ADVOCATE FOR POSITIVE CHANGE

- Task Force collaborates with AAP to talk with Senator Jackey Rosen about potential PPC legislation
- TF members champion for children's PPC at PQLC's virtual advocacy day on Capitol Hill
- Publish PPC Guiding Principles in response to Dobbs v Jackson ruling



**NATIONAL
PEDIATRIC
PALLIATIVE CARE
TASK FORCE**

An Initiative of the National Coalition for Hospice and Palliative Care

2023

INFLUENCE

- AAHPM establishes a Pediatric Palliative Care Council
- Develop PPC definition and host open comment period for input
- PCQC establishes a PCQ-Peds, likely to become Pediatrics Committee & absorbs Pediatric Palliative Improvement Network into their efforts

DEVELOP PARTNERSHIPS

- Collaborating with C-TAC and AAP to explore opportunities to expand Medicaid palliative care access
- Engage NHPCO and PCQC in a collaboration to share pediatric programmatic data to inform the 2023 edition of Pediatrics Facts and Figures

**Prepare for the
next chapter!**

SERVE AS SUBJECT MATTER EXPERTS

Chair Rachel Thienprayoon is a panel expert in NASEM's 2-day workforce sustainability workshop

ADVOCATE FOR POSITIVE CHANGE

Met with AHRQ to provide pediatric input on their proposed Interventions to Improve Care of Bereaved Persons

TASK FORCE ANNUAL MEETING

Task Force Annual Meeting held in Chicago in June