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
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

**INFLUENCE AND DEVELOP PARTNERSHIPS**
- Pediatric representatives seated on the Coalition's Communication, Quality, & Advocacy Workgroups
- PPC Now content partners include Courageous Parents Network & CHiPPs

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

**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
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

**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

**DEVELOP PARTNERSHIPS**
- Informed CAPC’s development of a PPC Billing and Business Development toolkit
- Informed the development of Illinois’ Medicaid PPC benefit guidelines

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

**NATIONAL PEDIATRIC PALLIATIVE CARE TASK FORCE**
An Initiative of the National Coalition for Hospice and Palliative Care
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

ADVOCATE FOR POSITIVE CHANGE
- Met with AHRQ to provide pediatric input on their proposed Interventions to Improve Care of Bereaved Persons

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

SERVE AS SUBJECT MATTER EXPERTS
Chair Rachel Thienprayoon is a panel expert in NASEM’s 2-day workforce sustainability workshop

TASK FORCE ANNUAL MEETING
Task Force Annual Meeting held in Chicago in June

Prepare for the next chapter!