

# Pediatric Palliative Care

# Field Guide

*A Catalog of Resources,  
Tools and Training to  
Promote Innovation,  
Development and Growth*



*Children are not small adults...*

## FORWARD

While the goals of pediatric and adult palliative care are the same – to relieve suffering for seriously ill patients and their families – clinical delivery of pediatric palliative care (PPC) differs fundamentally from adult delivery.

PPC has experienced notable growth over the past decade - this resource guide compiles current information for all PPC team members to support the field's further advancement. It's intended as a first stop for practical, non-clinical information on program development, access, quality, awareness, coordination and expansion. Resource information is organized under four categories:

**PPC's Value Proposition: Making the Case**

**Building and Expanding Integrated Programs**

**Collaborating with the Research Community**

**Advocating for System-Level Change**

**Responding to input from the frontlines of the PPC field, this guide synthesizes information from multiple sources.** It is intended to be a continually evolving hub with resources that will be updated often. We are interested in your feedback about this guide and ideas for improving it. **Please share your thoughts**, and let us know about new resources and initiatives that emerge or identify key pieces that may be missing by contacting Rebecca Kirch ([rakirch12@gmail.com](mailto:rakirch12@gmail.com)) or Brynn Bowman ([brynn.bowman@mssm.edu](mailto:brynn.bowman@mssm.edu)).

**Many special thanks** to the professionals who contributed input in developing this inaugural edition of the PPC field guide and devoted time to its review, including: Erica Kaye, Danielle Jonas, Janet Duncan, Conrad Williams, Kate Detwiler, Betsy Hawley, Erin Denney-Koelsch, Christina Ullrich, Justin Baker, Sarah Friebert, Renee Boss, Chris Feudtner, and Joanne Wolfe.

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## Central Players in Promoting Pediatric Palliative Care

Four core organizations provide the [main scaffolding](#) to strengthen and advance the pediatric palliative care (PPC) field, with other professional organizations also playing important roles. Specific contributions are summarized in this [Pieces of the Puzzle](#) article<sup>1</sup> with additional details immediately below and throughout this resource guide.



*“Ultimately, as the field of pediatric palliative care matures, I suspect no single organization will rise to the top, serving as a one-size-fits-all comprehensive provider of all our professional needs.*

*[We] will need to take pieces of what every organization has to offer... making the best use of each as we progress forward in our individual careers and as a collective field of interdisciplinary colleagues.”*

—Chris Feudtner, MD, PhD, MPH, FAAP  
AAP Chair, Section on Hospice and Palliative Medicine

**American Academy of Hospice and Palliative Medicine (AAHPM)** has an active [Pediatric Special Interest Group](#) for information exchange and strategic coordination of initiatives. AAHPM also embeds pediatric representation among its volunteer [workgroups, committees](#) and [Board of Directors](#).

**American Academy of Pediatrics (AAP)** has a PPC-focused [Section on Hospice and Palliative Medicine](#) (SOHPM) that fosters a strong community of dialogue and support, including its [listserv](#) and [newsletter](#). Affiliate Membership is available for non-physicians.

**Center to Advance Palliative Care (CAPC)** has [pediatric-specific resources](#) to support program development, marketing and making the business case that are accessible to all PPC team members through one [CAPC membership](#). PPC program participation in the [National Palliative Care Registry](#)<sup>TM</sup>, which is open to all and [does not require membership](#), enables teams to generate individualized performance reports on program structure and operations, as well as comparisons to other PPC programs.

**National Hospice and Palliative Care Organization (NHPCO)** has a [Children's Project on Palliative/Hospice Services](#) (ChiPPS) advisory council that contributes expertise to equip hospice and palliative care organizations in caring for children. It also produces an [e-Journal](#) newsletter for pediatric professionals.

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<sup>1</sup>Feudtner C. American Academy of Pediatrics Chair, Section on Hospice and Palliative Medicine; June 2016 newsletter.

**The following professional organizations also play important roles in the PPC field:**

Organization	Offerings
<a href="#">Hospice and Palliative Nurses Association (HPNA)</a>	<p>HPNA offers a pediatric nursing certification examination in hospice and palliative care and a wealth of educational material for RNs, APNs and Clinical Assistants. HPNA also hosts a <a href="#">Pediatric SIG</a> and participates in the:</p> <ul style="list-style-type: none"><li>• <a href="#">National Pediatric Hospice and Palliative Care Collaboration (NPHPCC)</a>, a partnership of national organizations that promotes inter-organizational communication and coordination to advance the field of pediatric hospice and palliative care</li><li>• <a href="#">ELNEC-Pediatric Palliative Care (ELNEC-PPC)</a>, a training program geared toward nurses that focuses on the unique needs of children and their families, including perinatal and neonatal content</li></ul> <p>Association of Pediatric Hematology and Oncology Nurses (APHON), which offers <a href="#">resources</a> specific to PPC for the oncology patient</p>
<a href="#">Social Work Hospice and Palliative Care Network (SWHPN)</a>	<p>SWHPN provides information, professional resources, policy updates and new and emerging education and research best practices in palliative and hospice care for its network of psychosocial care professionals. SWHPN hosts its <a href="#">General Assembly</a> in conjunction with AAHPM/HPNA's annual conference, providing an opportunity for palliative social workers to come together with peers.</p>
<a href="#">Association of Pediatric Oncology Social Workers (APOSW)</a>	<p>APOSW is a collaborative that advances pediatric psychosocial oncology care through clinical social work practice, research, advocacy, education and program development, including <a href="#">APOSW's Palliative Care SIG</a>.</p>
<a href="#">Child Life Council (CLC)</a>	<p>CLC provides child life specialist members with professional development programs and resources, facilitates exchange of professional knowledge and best practices and distributes information about the needs of children.</p>
<a href="#">Association of Professional Chaplains (APC)</a>	<p>APC serves chaplains in all types of health and human service settings. Info specific to PPC role of chaplains is described in:</p> <ul style="list-style-type: none"><li>• <a href="#">The role of professional chaplains on pediatric palliative care teams: perspectives from physicians and chaplains.</a> (Fitchett et al. 2011)</li><li>• <a href="#">A survey of chaplains' roles in pediatric palliative care: integral members of the team.</a> (Lyndes et al. 2012)</li></ul>

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## Value Proposition: Making the Case

### A. Pediatric Palliative Care is Unique and Essential

There are [significant differences](#) across a number of dimensions in what constitutes effective palliative care for adults versus infants and children. Infants and children needing palliative care range in age from prenatal to young adult, and interdisciplinary PPC teams care for patients and families with wide-ranging diagnoses and disease trajectories, often for many years. PPC teams must involve parents in decision-making and are adept at addressing the diverse developmental stages of the children they serve. Perinatal palliative care has evolved to serve women with high-risk pregnancies and families in need of support after the diagnosis of a life-limiting condition in utero.

The [American Academy of Pediatrics recommends](#) by expert consensus the initiation of PPC at diagnosis and its integration throughout the illness course to help improve quality of life (QOL), reduce suffering<sup>2</sup> and support goals of care<sup>3</sup> for the more than [400,000 pediatric patients and families](#) estimated to be living with life-threatening or serious health conditions in the US.<sup>4</sup>

Given limitations in our data stratifying age and disease categories, it's challenging to characterize with precision the full range of infants, children and families that might be appropriate or eligible for PPC services. Consequently, estimates of the population in need of PPC services vary widely.

Yet we do know that the numbers are sizable:

- **Children with medical complexity are increasing in prevalence** because of increased survival rates of infants born prematurely, with congenital anomalies and/or with chronic conditions, as well as improved treatments for acute illness in fields such as intensive care and oncology.<sup>5</sup>
- **More than half of childhood deaths occur in infancy**, and approximately half to two-thirds of these deaths occur in the neonatal period – most due to congenital and chromosomal anomalies and/or prematurity. In 2014, the infant mortality rate was 5.82 infant deaths per 1,000 live births in the US – a total of 23,215 deaths occurring in children under age 1 year.<sup>6</sup>
- **Estimates on the prevalence of US children currently living with life threatening or chronic, complex conditions such as congenital and chromosomal abnormalities, diseases of the nervous system or cancer, range from 400,000 and up, and more than 40,000 infants and children die annually.**<sup>7</sup>
- **As many as 17 million adults are serving as caregivers to a seriously ill child.**<sup>8</sup>

These statistics, and the stories behind them, underscore the priority to invest in PPC research, professional training and program expansion that meet rising demand for high quality palliative care to support infants, children and families across all care settings and transitions.

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<sup>2</sup> Wolfe J, Hammel JF, Edwards KE, et al. Easing of suffering in children with cancer at the end of life: is care changing? *J Clin Oncol*. 2008;26(10):1717-1723.

<sup>3</sup> American Academy of Pediatrics, Section on Hospice and Palliative Medicine and Committee on Hospital Care. Pediatric palliative care and hospice care commitments, guidelines, and recommendations. *J Pediatrics* 2013; 132:966-72.

<sup>4</sup> Field JF, Behrman RE. When children die: Improving palliative and end-of-life care for children and their families. Washington, DC: National Academies Press; 2003.

<sup>5</sup> Cohen E, Kuo DZ, Agrawal R, et al. Children with Medical Complexity: An Emerging Population for Clinical and Research Initiatives. *J Pediatrics*. 2011;127(3):529-538.

<sup>6</sup> KD Kochanek, SL Murphy, J Xu, B Tejada-Vera. Centers for Disease Control and Prevention National Center for Vital Statistics. Deaths: Final Data for 2014 (65) 4 (June 30, 2016). [http://www.cdc.gov/nchs/data/nvsr/nvsr65/nvsr65\\_04.pdf](http://www.cdc.gov/nchs/data/nvsr/nvsr65/nvsr65_04.pdf)

<sup>7</sup> Xu J, Murphy SL, Kochanek KD, Bastian BA. Centers for Disease Control and Prevention. Deaths: Final Data for 2013 (64) 2 (February 16, 2016). Available at: [http://www.cdc.gov/nchs/data/nvsr/nvsr64/nvsr64\\_02.pdf](http://www.cdc.gov/nchs/data/nvsr/nvsr64/nvsr64_02.pdf)

<sup>8</sup> Kuhlthau K, Kahn R, Hill KS, Gnanasekaran S, Ettner SL. The wellbeing of parental caregivers of children with activity limitations. *Matern Child Health J* 2010;14(2):155–63.

## B. Trends in Pediatric Serious Illness and Palliative Care

[NHPCO's 2015 Facts & Figures Report](#) on *Pediatric Palliative & Hospice Care in America* describes the current state of PPC in the US, identifies children who may be in need of support and details existing gaps in service.

Some key trends detailed in the report:

### **Children with serious illness and complex health care needs are living longer.**

- The overall prevalence of children with life-threatening conditions is increasing due to advances in pediatric medical/surgical care; meanwhile, the number of deaths in children with complex chronic conditions declined between 1989 and 2003.<sup>9</sup>

### **Numbers of children with special health care needs that could potentially benefit from PPC continue to increase.**

- Approximately 27% of children living with special health care needs have conditions that affect their activities usually, always or a great deal,<sup>10</sup> and an estimated 8,600 children with complex chronic conditions are eligible for and would benefit from palliative care on any given day.<sup>11</sup>

### **Growth in service capacity enables provision of grief and bereavement support services to patients and families affected by trauma or sudden serious illness and death, which accounts for about one-fourth of childhood deaths.**

- PPC traditionally has served only the three-quarters of pediatric deaths classified as not preventable.<sup>12</sup>

### **Parents who planned a location for their child's death were more likely to be comfortable with that setting and less likely to have preferred a different location.<sup>13</sup>**

- The place where death occurs is not an appropriate quality of care indicator for PPC,<sup>14</sup> and existing data do not currently indicate whether children are dying in their family's preferred location.

### **PPC teams have increased over the past decade, but expansion is essential to include all [pediatric hospitals](#), general hospitals where children are cared for and [community-based care settings](#).**

- Only about half of all US children's hospitals have a PPC program; staff composition and services are highly variable.<sup>15</sup>
- NHPCO's 2013 national summary of hospice care showed that only about 14% of participating hospice agencies had formal PPC services with specialized staff.

<sup>9</sup> Feudtner C, et al. Shifting place of death among children with complex chronic conditions in the United States, 1989-2003. *JAMA* 2007; 297(24): 2725-32.

<sup>10</sup> US Department of Health and Human Services, Health Resources and Services Administration, Maternal and Child Health Bureau. The National Survey of Children with Special Health Care Needs Chartbook 2009-2010. Rockville, Maryland: US Department of Health and Human Services.

<sup>11</sup> National Hospice and Palliative Care Organization. ChiPPS White Paper: A call for change: recommendations to improve the care of children living with life-threatening conditions. October 2001

<sup>12</sup> Osterman MJ, et al. Annual summary of vital statistics: 2012-2013. *J Pediatrics* 2015; 135(6).

<sup>13</sup> Dussel V, et al. Looking beyond where children die: determinants and effects of planning a child's location of death. *JPSM* 2009; 37(1):33-42.

<sup>14</sup> American Academy of Pediatrics, Section on Hospice and Palliative Medicine and Committee on Hospital Care. Pediatric palliative care and hospice care commitments, guidelines, and recommendations. *J Pediatrics* 2013; 132:966-72.

<sup>15</sup> Feudtner C, Womer J, Augustin R, Remke S, Wolfe J, Friebert S, Weissman D. Pediatric palliative care programs in children's hospitals: a cross-sectional national survey. *J Pediatrics* 2013; 132(6):1063-70.

## C. Messaging Matters

### 1. What's in a name: Explaining Pediatric Palliative Care

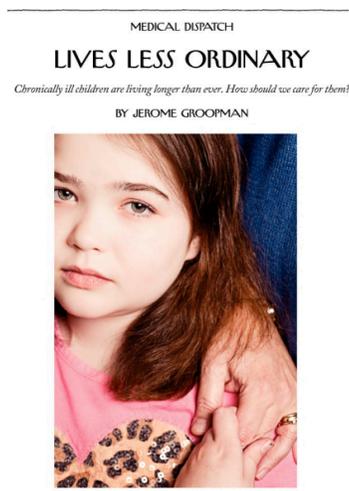
The use of consistent and clear messages to explain PPC really matters. A [consumer research study](#) commissioned by CAPC in 2011 revealed that 7 in 10 Americans are “not at all knowledgeable” about palliative care. Yet an overwhelming majority of people polled (92%) said that they would want palliative care for themselves or their loved ones and believe it should be accessible in our nation’s hospitals when it was explained using key messages that were developed through focus groups and interviews with patients and caregivers:

- Palliative care helps to provide the best possible quality of life for patients and their families.
- Palliative care helps patients and families manage the pain, symptoms and stress of serious illness.
- Palliative care is a partnership of patient, family and all of the medical specialists.
- Palliative care provides an extra layer of support for families and patients with serious illness.
- Palliative care is appropriate at any age and at any stage of a serious illness and can be provided along with curative treatment.

Ninety-two percent of respondents in the above study also said they believe patients should have access to this type of care at hospitals nationwide. Using these same consumer-derived messages to describe PPC, the American Childhood Cancer Organization informally surveyed its pediatric parent constituency in October 2014 to reveal [similar findings](#). Among 275 responding parents,

- **86%** would be likely to consider PPC for their child during cancer treatment, and
- **89%** think it's important that PPC services are available in all hospitals caring for children.

Not only does the term “palliative care” remain relatively unfamiliar to lay people, many clinicians still associate palliative care with terminal prognosis and believe it to be primarily useful near the very end of life. The erroneous association of palliative care with “giving up hope” or hospice remains one of the largest barriers preventing patients and families from accessing the benefits of palliative care.



Using consistent messages from the consumer-driven research highlighted above can help the field address this [identity problem](#).

A particularly poignant and relatable patient description of PPC appeared in *The New Yorker* "[Lives Less Ordinary](#)" January 20, 2014 medical dispatch article by Jerome Groopman. Then 11-year-old Gwen Lorimier, cared for by the Boston Children’s Hospital and Dana-Farber Cancer Institute Pediatric Advanced Care Team (PACT), explained succinctly what PACT meant to her:

*“It’s like when you’re filling in concrete. The transplanters are the people who put the layer down, then PACT are the people who go after and fill the holes, so the whole thing doesn’t start to crumble. But if it does start to crumble they’re the people who actually go with the hard hats and fix it.”*

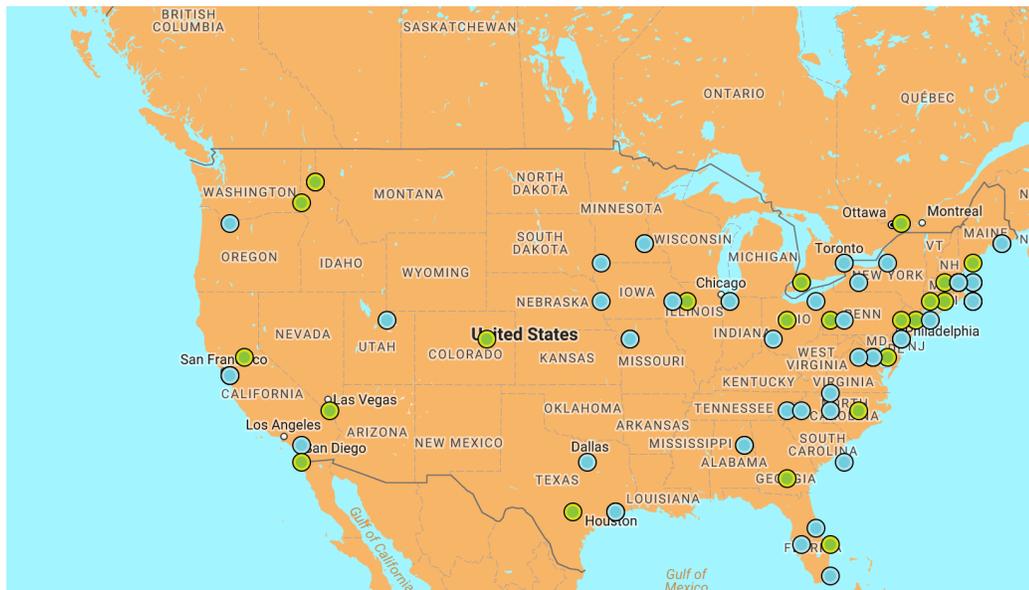
A related public radio interview featuring Drs. Gropman and Joanne Wolfe, "[Helping Chronically Ill Children](#)," describes the history behind the field's emergence and expansion, highlighting effective messages about PPC benefits:

- PPC adds an extra layer of support to these children and their families, using an interdisciplinary team approach to provide holistic, compassionate and individualized care.
- Through this partnership, PPC adds value not only to the children and families, but also to the multiple primary and subspecialty clinicians caring for them. A key part of PPC expertise involves knowing how to negotiate these complex waters to improve communication and collaboration to ultimately better care for the child and family.

[Courageous Parents Network](#) (CPN), an organization dedicated to bringing PPC everywhere, has created a powerful visual depicting PPC's national reach that is updatable in real time as information is added. This [interactive map](#) helps families caring for a seriously ill child find others in their community in similar situations, as well as locate PPC professionals/services in their area.

PPC professionals can use the link below to add their individual and institutional information to the growing network of professionals and parents. Entering data takes just a couple minutes, and populating the map helps demonstrate how the field is making its mark on the national landscape. The map is also a useful tool to help illustrate to institution administrators, policymakers and potential funders the need for increased investment in PPC to extend the field's reach.

JOIN the Network and get on the map!.



### Put PPC on the Map!

Use this link to [Join CPN network](#) and put your institution/yourself on the PPC network national map.



The CPN website is a superb resource to share with families. The table below features other resources available to explain PPC to families, professional colleagues and any other audience interested in PPC principles, themes or resources.

Organization	Description	Links
National Institute for Nursing Research Palliative Care: Conversations Matter® Campaign	NINR developed these web resources to raise awareness of and improve communications and understanding about PPC.	<a href="#">Conversations Matter campaign materials</a> for health care providers and for families that have children living with serious illnesses <a href="#">Spanish campaign materials</a>
Courageous Parents Network	CPN provides web and mobile resources that educate and support parents caring for seriously ill children, providing on demand access to coping tools, community and resources that promote family resilience.	<a href="#">Provider resources</a> <a href="#">Free CME Module on PPC for pediatric practitioners</a> One-hour, on demand course includes 4 sections plus parent perspectives: What is Pediatric Palliative Care; Advanced Care Planning; Initiating Difficult Conversations; Transitioning to End-of-Life/Bereavement <a href="#">Online video library</a> includes 260+ videos of parents talking about their experiences and of therapists addressing end-of-life issues – helpful for parent support and as teaching tools for clinicians <a href="#">Guides for Parents</a> topics include helping siblings cope; navigating the hospital; parent self-care; strengthening parenting partnership
Get Palliative Care	CAPC's consumer-focused website provides specific content explaining PPC, its definition, benefits and more.	<a href="#">Pediatric palliative care information for families</a> <a href="#">Distinctions: adult and pediatric palliative care</a> <a href="#">PPC team members</a>
American Childhood Cancer Organization (ACCO) "Parent's Guide to Enhancing Quality of Life in Children with Cancer"	Written by PPC experts and with parents' personal perspectives, this 261-page paperback is available to families for free through ACCO.	<a href="#">Parent's QOL Guide order info</a> <b>Healing happens here.</b> For families facing childhood cancer, consider recommending camp! <a href="#">Care camps map</a> or <a href="#">Children's Oncology Camps locator list</a>
National Hospice and Palliative Care Organization	NHPCO provides information and support for families about advance care planning, talking with child about serious illness, talking with doctors, caregiving, hospice and palliative care, grief and loss.	<a href="#">Brochures for families - in English and Spanish</a> – print on demand free pediatric-focused resources series that is part of NHPCO's <a href="#">Caring Info</a> program
PerinatalHospice.org	Website that provides professional information and resources for parents facing pregnancy affected by a life-limiting diagnosis.	<a href="#">Perinatal PC caregiver resources</a> <a href="#">Perinatal PC resources for parents</a> <a href="#">List of US and International Programs</a>

## 2. PPC Delivers Value That Warrants Focused Investment

Palliative care has become one of the [fastest growing medical specialties](#) in the United States, spurred by its ability to meet patients and families where they are and to accompany them as they move through the labyrinthine process of a serious illness. This approach demonstrably and measurably improves care quality and clinical outcomes – and by helping patients and families avert the need for 911 calls and repeated hospitalization, it also reduces costs. These benefits are recognized by hospital administrators, policymakers, payers and providers for their value in achieving the Institute for Healthcare Improvement's [Triple Aim Framework](#) to improve the patient experience of care and health of populations while reducing the per capita cost of health care.

PPC can use this momentum in the broader field to also expand its reach.

With increasing health system focus on value-based care and associated payment reforms, communicating about PPC and its benefits to various audiences is becoming a bigger part of every inter-professional clinician's job. Successfully embedding PPC services into organizational culture will take effective advocacy, backed by evidence, to support staffing and resource requests required to meet current PPC program needs and foster future growth potential.

**Philanthropic support continues to be the fundamental funding stream supporting PPC, but it is neither a sufficient nor a sustainable model.** The sections below feature resources available to help build and make the business case for PPC programs, including evidence-based talking points the field can use as a consistent message to expand and amplify understanding of PPC's ability to improve quality and meet the triple aim in the context of caring for infants, children and families. The advocacy section of this field guide identifies public policy and coalition activities currently underway to help address these system-level shortfalls.

### Pitch Points: PPC Helps Deliver the Best Care Possible Aligned with Achieving the Triple Aim

- **PPC provides an evidence-based solution supporting QOL and improved clinical outcomes** for seriously ill infants, children and families throughout the care continuum,<sup>16 17 18</sup> including improving the likelihood that children and families have fun and enjoy experiences that add meaning to life.<sup>19</sup>
- **Provision of PPC improves patient and family experience and satisfaction**, helps reduce parent caregiver burden, reduces needless hospital admissions through effective care coordination and symptom management and **through these gains in quality, also reduces costs.**<sup>20 21</sup>
- **PPC programs are becoming more common in children's hospitals** but most programs offer only inpatient services, and most only during the workweek.<sup>22</sup> Many are now also expanding to provide perinatal palliative care services.<sup>23</sup>

<sup>16</sup> Wolfe, J, Hammel, JF, Edwards, KE, et al. (2008). Easing of suffering in children with cancer at the end of life: Is care changing? *Journal of Clinical Oncology*, 26(10), 1717–1723.

<sup>17</sup> Hays, RM, Valentine, J, Haynes, G, et al. (2006). The Seattle Pediatric Palliative Care Project: Effects on family satisfaction and health-related quality of life. *J Palliat Med* 9(3), 716–728.

<sup>18</sup> Gans D, Hadler MW, Chen X, et al. Impact of a pediatric palliative care program on the caregiver experience. *J Hosp Palliat Nurs* 2015;17:559-565.

<sup>19</sup> Friedrichsdorf SJ, Postier A, Dreyfus J, Osenga K, Sencer S, Wolfe J. Improved quality of life at end of life related to home-based palliative care in children with cancer. *J Palliat Med*.

<sup>20</sup> Gans D, Hadler MW, Chen X, et al. Cost Analysis and Policy Implications of a Pediatric Palliative Care Program. *JPSM* 2016 (in press) DOI: <http://dx.doi.org/10.1016/j.jpainsymman.2016.02.020>

<sup>21</sup> Postier A, Chrastek J, Nugent S, Osenga K, Friedrichsdorf SJ. Exposure to home-based pediatric palliative and hospice care and its impact on hospital and emergency care charges at a single institution. *J Palliat Med*. 2014;17(2):183-188.

<sup>22</sup> Feudtner C, Womer J, Augustin R, Remke S, Wolfe J, Friebe S, Weissman D. Pediatric palliative care programs in children's hospitals: a cross-sectional national survey. *J Pediatrics*. 2013 Dec;132(6):1063-70.

<sup>23</sup> Denney-Koelsch E, Black BP, Cote-Arsenault D, Wool C, Kim S, Kavanaugh K. A Survey of Perinatal Palliative Care Programs in the United States: Structure, Processes, and Outcomes. *J Palliat Med*. 2016.

- **Despite this steady program expansion, millions of infants and children in the US still lack access to quality PPC** from the point of diagnosis throughout the course of illness, and PPC team staffing and capacity vary tremendously.<sup>22</sup>
- **Resources for PPC program development and fellowship training of the next generation are essential** to build teams and their capacity to improve care quality for infants, children and families.
- **Outpatient and community-based PPC services are just beginning to develop.**<sup>24 25</sup> Investment in building community-based PPC is essential to bridge from hospital to home.
- **PPC research funding lags far behind what is invested in adult palliative care.** Outside of pain, there are relatively few studies that can guide clinicians in the treatment of common symptoms in children (e.g., fatigue, nausea, breathlessness, anxiety, depression). Key research priorities for PPC have been identified.<sup>26 27</sup>
- **Educating and training all pediatric professionals in pain and symptom management, communication and care coordination are also important** so that all clinicians caring for children with serious illness and their families in the community and hospitals have a uniform set of core (“generalist”) palliative care knowledge and skills, and refer to PPC specialty teams for the more complicated or nuanced situations.<sup>28</sup>

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<sup>24</sup> Kaye EC, Rubenstein J, Levine D, Baker JN, Dabbs D, Friebert SE. Pediatric palliative care in the community. *CA: A Cancer Journal for Clinicians*. 2015;65(4):315-333.

<sup>25</sup> Rabow MW, O’Riordan DL, Pantilat SZ. A statewide survey of adult and pediatric outpatient palliative care services. *J Palliat Med* 2014;17(12):1311-1316.

<sup>26</sup> Ullrich C, Morrison RS. Pediatric Palliative Care Research Comes of Age: What We Stand To Learn from Children with Life-Threatening Illness. *J Palliat Med*. 2013;16(4):334-336.

<sup>27</sup> Baker JN, Levine DR, Hinds PS, et al. Research Priorities in Pediatric Palliative Care. *The Journal of Pediatrics*. 2015;167(2):467-470.

<sup>28</sup> Quill TE, Abernethy AP. Generalist plus Specialist Palliative Care — Creating a More Sustainable Model. *New England Journal of Medicine*. 2013; 368(13): 1173-1175.

## Building and Expanding Integrated Programs

PPC is a rapidly growing medical subspecialty designed to meet the needs of seriously ill infants, children and their families, and has become an integral part of quality of care in US hospitals. This section features practical resources available to support PPC teams in start-up and/or program development and expansion, with particular focus on gathering and using program and other data to help make the best value-based case and monitor program progress.

### Customary Phases of Institutional PPC Acceptance and Program Maturation



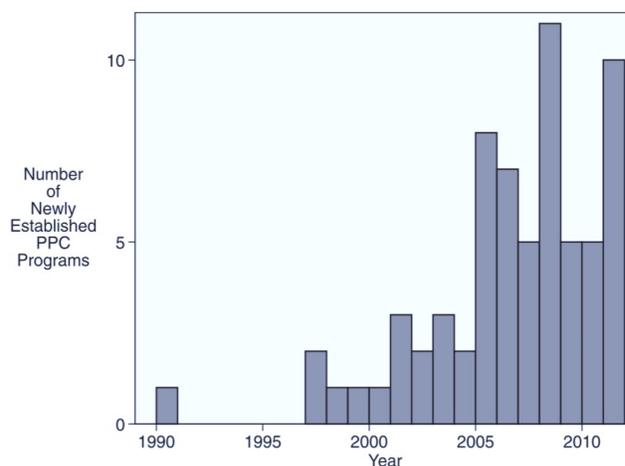
PPC programs typically transform across a trajectory over time. This recent [interview blog with Justin Baker](#) features practical tips to support successful PPC program progression:

- Identify the palliative care champions within your institution
- Pilot the program: Look for low-hanging fruit at first, and build on small wins
- Build on successes and learn from failures
- Identify appropriate screening triggers for palliative care with input from specialist and other colleagues
- Provide organization-wide training, which is critical to early palliative care involvement
- Find a 'carrot' – what you can do that the institution can't live without. For example, St. Jude predicated having access to the home-based care team that clinicians and families wanted on consulting with the PPC service.

### A. Prevalence

#### 1. Children's Hospitals PPC National Survey 2013

In summer of 2012, 226 US [children's hospitals were surveyed](#) on whether the institution had a PPC program as well as characteristics including staff composition, range of services offered, financial support, and frequency of consultations. At the time, sixty-nine percent (112) of the 162 hospitals responding had a PPC program.



**FIGURE 2**  
Establishment of new hospital-based PPC programs over time.

#### Key Survey Findings

(Feudtner, et al. *Pediatrics* 2013):

- Rate of new PPC program creation peaked in 2008, with 12 new programs created that year, and 10 new programs in 2011
- Most programs offer only inpatient services, and most only during the workweek
- Number of consults annually varied substantially across programs, positively associated with hospital bed size and number of funded staff
- PPC programs are often highly dependent on hospital funding

## Perinatal PPC National Survey 2016

Palliative care programs are also expanding to include perinatal care services. [Denney-Koelsch et al.](#) recently surveyed 136 existing perinatal palliative care programs in 42 states to glean insights on the structure, process and outcomes of care currently offered, including program alignment with [National Consensus Project for Quality Palliative Care](#) domains. Among 75 responding programs from 30 states representing different settings:

- Most programs (70%) had been operating for less than 10 years, and 38% used formal measures of quality assessment (the table in the next section highlights several sources for quality metrics); and
- Programs were in four types of settings: academic centers, community hospitals, local hospice or palliative care organizations and community-based support systems.

### A. Culture of Quality

The development of any new PPC program should begin with a needs assessment process, which is used to identify gaps in patient and family services and to assess the priorities of the program's stakeholders. Payers may be among this list of stakeholders – for more information about how payers can support palliative care, see the CAPC [Payer-Provider Partnerships Toolkit](#). CAPC's website provides needs assessment and program start-up [tools](#) to support the development of new PPC programs. As a companion to this Field Guide, CAPC's website also provides a [slide deck](#) available for free to all that explains PPC, its value proposition, and benefits for children and families.

The AAP provides guidelines for the delivery of PPC that serve as a framework upon which to build the pediatric palliative care program. Start-up programs may choose to phase growth over time, using these guidelines as a roadmap. For example, PPC programs often begin with only a few team members, and subsequently increase staff and services as program resources expand. To ensure quality and safety, [AAP guidelines](#) specify that mature teams should:

- Include physicians, nurses, social workers, case managers, spiritual care providers, bereavement specialists and child life specialists;
- Have an adequate number of dedicated, trained staff who are available for consultation 24-7 and are paid specifically to provide PPC,
- Bridge their consultative activities across multiple physical locations to support patients, ranging from provision of services in homes or schools to clinics, hospitals and other partnering facilities; and
- Conduct ongoing quality improvement reviews and projects aimed at improving patient and family experiences and outcomes.

### 1. Table of Standards, Guidelines and Measures Sources

The AAP's PPC-specific parameters align with other palliative care guidelines and standards (*see table below*) that aim to build a culture of quality, standardization and accountability as access to palliative care grows.

Initiative	Description	Resource Links
National Consensus Project for Palliative Care	NCP Clinical Practice Guidelines for quality palliative care defines optimal program components in eight domains, including structure and processes for the interdisciplinary team.	<a href="#">National Consensus Project</a> <a href="#">NCP Clinical Practice Guidelines 3rd Edition</a>
AAHPM/HPNA Measuring What Matters	AAHPM/HPNA jointly produced a consensus set of hospice and palliative care quality indicators intended as a foundation for standard, valid internal quality measurement for US settings.	<a href="#">JPSM April 2015 article</a> <a href="#">AAHPM project website</a>
The Joint Commission Advanced Certification for Palliative Care	TJC standards specify that all hospitals currently certified or seeking initial certification will be required to implement data collection for five standardized measures after January 1, 2017.	<a href="#">TJC Certification for palliative care programs</a> <a href="#">CAPC support materials</a>
NHPCO Standards of Practice	The NHPCO Standards of Practice for hospice and palliative care programs has an associated Pediatric Standards Supplement for providing care to infants, children, adolescents and their families in the home, hospital and long-term care and respite facilities.	<a href="#">Overview article on NHPCO pediatric standard supplement</a> <a href="#">NHPCO Pediatric Supplement</a> <a href="#">NHPCO standards</a>
Interdisciplinary palliative care team member certifications	CAPC's website provides information regarding specialty certifications for physicians, nurses, social workers and chaplains.	<a href="#">List with links for IDT professional certification</a>
National Quality Forum (NQF) Palliative Care Endorsed Measures and Preferred Practices	In 2006 NQF issued a report detailing 38 Preferred Practices for Palliative and Hospice Care Quality. As with the The Joint Commission certification standards, these preferred practices use the NCP Guidelines for Quality Palliative Care as their foundation.	<a href="#">Crosswalk of NQF palliative care preferred practices</a> <a href="#">NQF Endorses Palliative Care and EOL Measures</a>
American College of Surgeon's Commission on Cancer Accreditation Standards (2016 edition)	Commission on Cancer (CoC) clinical standard 2.4 requires cancer programs to provide palliative care services either onsite or by referral; this particular standard and the larger complement of patient-centered standards apply to pediatric cancer programs that are CoC accredited.	<a href="#">Standards home page</a> <a href="#">Standards book 2016</a>
Pediatric Psychosocial Oncology Care Standards (2015)	15 standards for social and psychological aspects of oncology care appear in Dec 2015 special issue of <i>Pediatric Blood &amp; Cancer</i> .	<a href="#">PDFs of standards</a> <a href="#">Pediatric Blood and Cancer Special Issue</a>

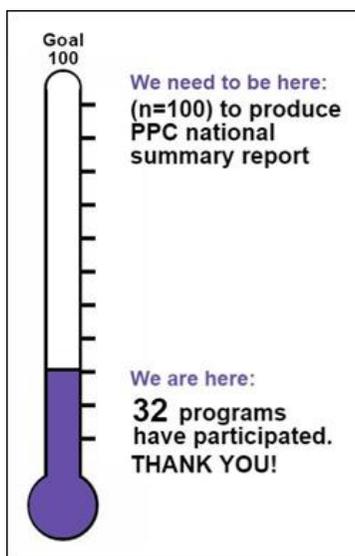
## 2. Measuring and Monitoring PPC Program Impact: Using the National Palliative Care Registry

Access to program-level data is crucial for developing, sustaining or expanding a service, and PPC programs need a plan for measuring and monitoring impact to improve quality, secure influence and garner support. The [National Palliative Care Registry™](#) was developed by CAPC and NPCRC in response to this field need, and extensive revisions have been made this year to the hospital survey with PPC expert input in order to ensure that the Registry is responsive to the unique elements of PPC. Participation in the Registry is free to all palliative care programs. You do not need to be a member of CAPC to participate.

The Registry has also added surveys for community-based palliative care settings this year – home based, office/clinic and long-term care – and provides definitions for key measures and detailed guidance for specific questions. The Registry allows programs to compare their data to those of peers, including patient population (e.g., pediatrics), hospital size, care setting, degree of penetration (percent of annual admissions seen by palliative care) and staffing level. Programs can enter data for one or more service settings and all members of the palliative care team can join the Registry, enter and update data and view reports.

**PPC programs can use the Registry to measure their progress and track their operational capacity and reach.** There is **NO** cost to participate or to receive data reports. **Robust** program participation will strengthen the ability to create pediatric-specific reports, and will enable further evolution of the database over time to better address the needs of pediatric programs. The PPC program participation “call to action” that circulated by e-mail via AAP, SOHPM and PPCRN in summer 2016 is excerpted below. **If you’ve not already done so, please enter your 2015 data!**

### National Palliative Care Registry™



The [National Palliative Care Registry™](#) is now collecting 2015 data for hospital PPC programs.

**Participation in the Registry is free and open to all programs.**

Submitting PPC program data offers immediate access to individualized performance reports and will add your program data to the national profile of PPC. PPC-specific tips for completing the hospital survey are provided below.

Thirty-two programs have already submitted their program data and fifteen more have registered – but we will need to reach 100 programs in order to have numbers sufficient for reliable data on the state of pediatric palliative care.

Tips for PPC programs appear below. Contact the Registry helpdesk with any questions at [registryhelpdesk@capc.org](mailto:registryhelpdesk@capc.org) or 212-201-2689

## Registry Tips and Guidance for PPC Programs

- Download the hospital survey questions [here](#) to help save you time in collecting your data.
- You do not have to be able to complete all questions to participate. Your responses can be updated and edited as you collect more data in the future.
- Hospital PPC programs can participate by completing the hospital survey. A question has been added to Module 1 to identify pediatric programs. If you have already submitted data, please go back and check that this question is marked yes.
- Module 1. Hospital Metrics, Patient Demographics: Q3. Is this hospital a children's hospital? This question is pre-populated using data from the American Hospital Association (AHA), which reports only on freestanding hospitals. If your facility is a children's hospital – freestanding or not – please select yes.
- Q6-10. Hospital Metrics (admissions, beds, ADC, deaths, discharges): Please limit to the children's population at your hospital. For example, for beds, include only neonatal and pediatric beds.
- Q11. Is your program at this service site primarily a pediatric program? This question was added to clearly identify pediatric programs. A subsequent question asks about patient age groups. This question was retained based on the recognition that many pediatric programs see young adults over the age of 18, and some may see other patient populations.

### 3. Program Development and Maturation

Several new [PPC-specific tools and templates](#) have been developed by CAPC this year to support PPC program development, marketing and making the business case, with more to come. All are accessible to CAPC members via CAPC Central, providing a range of palliative care tools, training and technical assistance resources available for every level of experience – whether an institution is just thinking about getting started in building a PPC team, or already has a team fully integrated within its hospital or health system.

[CAPC membership](#) is open to organizations, including hospitals, health systems, hospices and community health care organizations, and provides unlimited access to all CAPC resources that support palliative care delivery and quality across the continuum. One membership fee covers the cost of training, tools, hands-on technical assistance and expert resources for the entire staff of each member institution. Many hospitals are already CAPC members, and some of these institutions secured financial support for their membership through third-party payers and/or philanthropic funding.

**CAPC membership information contact:** Rosie Aponte at 212 824-9574 or [membership@capc.org](mailto:membership@capc.org)

### 4. Leadership and Training

The table below highlights information on various leadership and educational training opportunities for PPC professionals.

**American Academy of Pediatrics  
[Young Physicians' Leadership Alliance](#)**

**A 3-year training program designed to develop leaders and build a leadership community among early career pediatricians and pediatric subspecialists**

**[AAHPM Leadership Forum](#)**

An innovative collection of new training opportunities developed in partnership with the [American Association for Physician Leadership](#)

[AAHPM Ignite](#): A full-day preconference offered at Annual Assembly

[AAHPM Ascend](#): An intensive two-day program offered at Summer Institute

[AAHPM Elevate](#): Web-based self-study courses include ethical challenges, quality improvement, negotiation tactics, strategic thinking, decision making and finance in health care organizations.

**[CAPC Palliative Care Leadership Centers](#)**

Intensive hands-on training and a full year of mentoring, including designing and launching a successful program – [PCLC Pediatric](#)

**[Resilient Clinician project for preventing burnout and promoting well-being](#)** tailored to the needs of PC clinicians

This [article](#) details a paradigm for approaching clinician resilience, the conceptual model, and curriculum for a workplace resilience intervention for hospital-based PC teams. The curriculum is based on training in eight resilience skills that are useful for common challenges faced by clinicians.

**Education in Palliative and End-of-Life Care Program ([EPEC](#)) – Pediatrics**

EPEC offers a pediatric-specific conference curriculum designed to provide in person training on effective teaching strategies as well as access to comprehensive educational materials

**Program in Palliative Care Education and Practice ([PCEP](#)) – Pediatric Track**

An in person, intensive conference focusing on advanced topics in PPC offered through Harvard Medical School's Center for Palliative Care

**[AAHPM Fellowship Training Directory](#)**

AAHPM's Pediatric SIG has compiled a list of pediatric-specific fellowship training sites that can be accessed using this [link](#).

The Pediatric Advanced Care Team (PACT), the pediatric palliative care service at Boston Children's Hospital and the Dana Farber Cancer Institute, offers the first ever full-time, yearlong [PPC social work fellowship](#).

**University of Colorado Denver [Interprofessional Master of Science](#) in Palliative Care (MSPC) and Palliative Care Certificate Programs**

The MSPC prepares physicians, nurses (including BSN and APN), physician assistants and pharmacists as Palliative Care Community Specialists who provide high quality palliative consultation and care to patients and families in their own communities.

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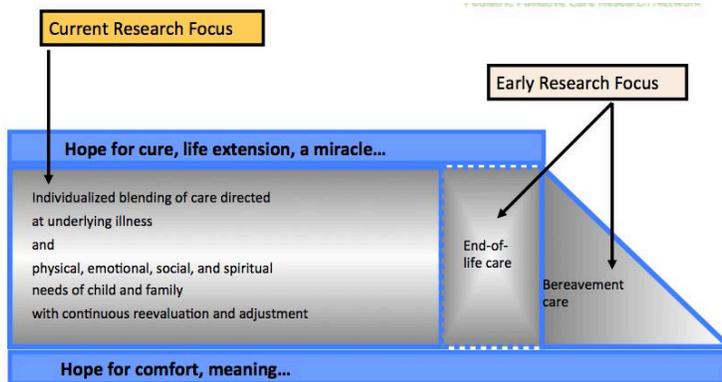
## Collaborating with the Research Community

*“In pediatrics, we suffer from a practice gap in that there remains such a dearth of evidence-based research for much of our clinical practice. So we rely on anecdotal evidence, or fly by the seat of our pants.” - Sarah Friebert, MD*

### A. Research Focused Specifically On Children Is Imperative

PPC is considered a cornerstone of patient care safety and quality, and the [Institute of Medicine in 2003](#) championed the urgency for developing PPC training programs, guidelines, protocols and priorities for research.<sup>29</sup> Yet more than a decade later, the current state of the science in PPC research that guides clinical practice is still largely limited to descriptive case studies and reports. As a result, decisions in pediatric palliative care practice too often rely on anecdote, or alternatively, on extrapolations of the experience and knowledge gleaned from the study of adult populations.

Dedicated investment supporting rigorous research studies is essential to advance knowledge and understanding in the field and ultimately to improve the outcomes of PPC interventions and policies. Current initiatives fostering coordination and a community of support for robust PPC research are highlighted in this section, starting with resources that frame guidance for PPC research priorities and future directions.



**Current trend in PPC research that supports more integrated care in practice:**

Increasing focus on acceptance of providing PPC and disease-directed treatment at the same time, starting PPC early in the course of illness and continuing throughout the care continuum and transitions.

AAP expressly emphasizes in its [PPC commitments](#) the importance of rigorous research and continuous quality improvement in all aspects of interdisciplinary care, including specifically:

- Evaluation of specific pharmacologic and non-pharmacologic interventions to alleviate symptoms;
- Medical and psychosocial interventions to improve quality of decision making and quality of life for patients and family members;
- Education and training to improve clinicians' knowledge, attitudes, skills and behaviors; and
- Different program or service delivery models to improve access, outcomes and cost-effectiveness.

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<sup>29</sup>Institute of Medicine (US) Committee on Palliative and End-of-Life Care for Children and Their Families; Field MJ, Behrman RE, editors. When Children Die: Improving Palliative and End-of-Life Care for Children and Their Families. Washington (DC): National Academies Press (US); 2003.

In [Pediatric Palliative Care Research Comes of Age: What We Stand to Learn from Children with Life-Threatening Illness](#), Ullrich and Morrison identify several specific priority PPC research topics in two major categories:

<b><u>Pediatric-specific research</u></b>	<b><u>Broad application research across ages</u></b>
<ul style="list-style-type: none"><li>• Developmental considerations for how children perceive and understand their illness experience and participate in their care to devise and evaluate age-appropriate interventions and support</li><li>• Support for parents holding responsibility to make the best possible decisions on behalf of the child</li><li>• Support strategies for families facing life-threatening condition in utero during the perinatal period</li><li>• Support strategies for adolescents and young adults grappling with issues around independence, peer acceptance and self-image</li><li>• Patterns of symptoms experienced by children and development of instruments to accurately assess symptoms in developmentally appropriate manner, particularly non-pain symptoms and testing interventions to relieve them</li><li>• Understand family member experience to devise supportive interventions benefiting child's entire family, with particular emphasis on gender balance to include fathers in research samples</li></ul>	<ul style="list-style-type: none"><li>• Development and study of models of care and support strategies for families who hold multiple, concomitant goals of care involving curative or life-prolonging therapies in the face of uncertainty</li><li>• Support strategies to effectively explore goals of care and implement curative or life-prolonging treatments in line with stated goals</li><li>• Study effects of federal concurrent care provision and state-level initiatives promoting PPC delivery</li><li>• Study PPC delivery patterns to inform efforts to provide palliative care earlier in course of illness and over longer time horizon</li><li>• Investigate models of effective PPC provision in the community and related outcomes</li></ul>

Subsequently, Baker and colleagues used Delphi methodology with PPC providers and parents to identify and prioritize consensus [Research Priorities in Pediatric Palliative Care](#), generating a list of 20 priorities that are thematically grouped as decision making, care coordination, symptom management, quality improvement and education. The top five priorities are:

- 1) Develop and evaluate strategies to help families make difficult decisions, particularly about end of life
- 2) Compare outcomes for patients and families who have early access to PPC programs with outcomes for patients and families referred late in the illness trajectory
- 3) Develop strategies to teach clinicians how to help parents make difficult decisions (particularly end-of-life) and evaluate the impact of this education on relevant clinical outcomes
- 4) Develop and validate evidence-based practice guidelines in PPC
- 5) Study strategies for integrating quality palliative care practices into the ongoing care of seriously ill children in a variety of care settings and evaluate the impact of these strategies on relevant care processes and outcomes.

Gelfman and Morrison have examined and reported the status of [federal grant support](#) of palliative care research over time, finding steady improvement in numbers of palliative care investigators receiving National Institutes of Health funding between 2001 and 2010. Yet despite improvement, the total funding for palliative care research still rounds up to *less than one percent of the NIH budget*, and PPC

research support is only a tiny fraction of that. Another update looking at 2011-2015 is currently underway.

Significantly, the Institute of Medicine has consistently called for substantial increases in palliative care research investment that support more integrated care, *including calling out PPC research emphasis specifically*:

[Comprehensive Cancer Care for Children and Their Families: Summary of a Joint Workshop](#) (2015) proceedings and its [companion highlights journal article](#) call for increased clinical research and support for pediatric palliative care and psychosocial care studies.

[Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life](#) (2015) consensus report finding that “pediatric-related research needs may be especially pressing,” particularly comparative effectiveness studies on symptom management and bereavement support; analyses of care in various settings; and studies on staffing, managing and financing hospital-based pediatric palliative and community-based pediatric hospice services.

Through its current [Roundtable on Quality Care for People with Serious Illness](#), the National Academies of Sciences Engineering and Medicine (formerly known as the Institute of Medicine) will build on these earlier findings using a series of workshops over the next three years to press for more progress, including specific emphasis addressing the needs of seriously ill infants and children and the families who care for them.

Three palliative care-focused networks offer infrastructure for a collaborative research community and coordination opportunities to help PPC investigators gain ground.

## 1. Pediatric Palliative Care Research Network (PPCRN)



[PPCRN](#) includes a dedicated and [growing group](#) of researchers from a number of sites across North America that is working individually and collaboratively to advance the science of pediatric palliative care. PPCRN coordinates PPC research projects with multiple sites and organizations to support the development of PPC research, and holds monthly calls for investigators to share study plans, insights and feedback. The group also meets annually in person at the AAHPM/HPNA national assembly.

PPCRN Info Contact: Madeline Bilodeau at [madeline\\_bilodeau@dfci.harvard.edu](mailto:madeline_bilodeau@dfci.harvard.edu)

## 2. National Palliative Care Research Center (NPCRC)



The [NPCRC](#) is committed to stimulating, developing and funding research directed at improving care for seriously ill patients and their families.

**Specifically, the NPCRC is providing a mechanism to:**

- Establish priorities for palliative care research
- Develop a new generation of researchers in palliative care
- Coordinate and support studies focused on improving care for patients and families living with serious illness
- Rapidly translate these findings into clinical practice in partnership with CAPC

[NPCRC grant funding opportunities](#) include the range of mechanisms below in three [areas of interest](#): (1) pain and symptom management; (2) communication; and (3) models of health care delivery. Information on the website details the [grant schedule](#), eligibility and [how to apply](#). In a collaborative parallel initiative with the NPCRC, the American Cancer Society (ACS) also supports pilot projects in [palliative care and cancer](#) modeled on the NPCRC's program.<sup>30</sup>

<a href="#">Pilot and Exploratory Project Support Grant</a>
<a href="#">Junior Faculty Career Development Award</a>
<a href="#">Transition to Independence Award</a>
<a href="#">Research Design/Statistical Support Grant</a>
<a href="#">Infrastructure Support for Collaborative Studies</a>

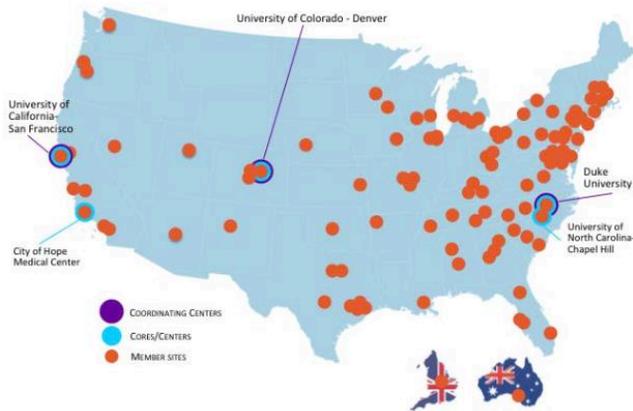
Every fall, [grantees](#) come together with leaders in the field for the Kathleen Foley Palliative Care [Research Retreat and Symposium](#), which includes dedicated pediatric sessions to foster the community of PPC researchers.

To date, NPCRC has invested over \$1.75 million to fund 10 pediatric palliative care investigators in the US. These studies have focused on treating distressing symptoms, enhancing communication among children, their parents and siblings and their doctors, developing care models for children with non-cancer diseases, and enhancing care in the neonatal and pediatric ICU.

NPCRC Info Contact: Lily Chiu, Program Assistant at [lily.chiu@mssm.edu](mailto:lily.chiu@mssm.edu)

<sup>30</sup> A number of other oncology grant mechanisms are also open to palliative care projects in the area of pediatric oncology, including for example: [Conquer Cancer Foundation](#), [Rally Foundation](#), [St. Baldrick's Foundation](#), [The Pablove Foundation](#), and [Alex's Lemonade Stand Foundation](#).

### 3. Palliative Care Research Cooperative Group



[PCRC](#) was established in 2010 with a primary goal of helping investigators overcome the many challenges of conducting multi-site research in order to advance the field of palliative care.

The [PCRC members network](#) creates a community of palliative care providers who can engage in research discovery. At latest count, the network includes 261 members representing 106 sites. PCRC is actively engaged now to bring PPC research into its fold.

PCRC funds [pilot awards](#) to provide seed funding for future research activities through PCRC. The awards offer opportunities for investigators to participate in investigator development activities and be mentored and coached by senior investigators in the field. Topics of interest include:

- Experience and outcomes of caregivers in hospice and palliative care
- Trajectories of symptom experience, patient functioning and relationship to interventions delivered in hospice and palliative care settings
- Portfolios of non-pharmacologic interventions used in hospice and palliative care
- Definitions of patient populations in the PCRC that can be enrolled in future studies
- Pilot testing of interventions and study procedures in preparation for future PCRC studies

PCRC's website also provides a helpful, frequently updated chart of multiple available palliative care research [funding opportunities](#). Visit these links for information on becoming a PCRC [member](#) or to view PCRC [newsletters](#).

PCRC Info Contact: Jordan Elizabeth Lodato at [jordan.lodato@duke.edu](mailto:jordan.lodato@duke.edu)

## B. Opportunities for Sharing Research Scholarship Across the Field

In addition to the initiatives detailed above, several other opportunities exist for PPC professionals to learn and share new scholarly work with the field:

**AAHPM's [PC-FACS](#)** (Fast Article Critical Summaries) provides summaries and insightful commentaries on the most important findings from nearly 100 medical and scientific journals. It offers the field a useful channel for disseminating PPC research, as well as opportunity to gain valuable [editorial leadership](#) experience.

**[PCNOW Fast Facts and Concepts](#)** provides concise, practical, peer-reviewed and evidence-based summaries on key palliative care [topics](#) important to clinicians and trainees. In 2015, the entire library of Fast Facts was updated and revised, and content is also available via mobile apps for [iPhone](#) and [Android](#).

**AAP** sponsors two major meetings:

- (1) The Pediatric Academic Societies ([PAS meeting](#)) each spring includes research, quality improvement and educational offerings, and is widely recognized in academic circles by both generalists and subspecialists
- (2) The National Convention and Exhibition ([NCE in the fall](#)) offers educational programs largely intended for the general pediatrician audience. SOHPM mounts a special program at NCE each year, with opportunities to present abstracts on case reports, descriptions of novel programs, quality improvement projects and research findings. Abstract prizes are awarded, with particular emphasis given to early-career clinicians.

**AAHPM's** and **HPNA's** combined [annual national assembly](#) brings together the full range of age and specialty in HPM clinical care, research and quality improvement. Annual assembly includes multiple pediatric sessions and pediatric paper presentations, and the Pediatric SIGs and PPCRN also host in person meetings during assembly.

**SWHPN** hosts its [General Assembly](#) in conjunction with AAHPM/HPNA's annual conference, gathering hundreds of social work professionals to present and share in oral, poster and symposia presentations, as well as workshops, plenaries and networking opportunities.

**NHPCO** offers a [pediatric intensive](#) as part of its annual [clinical team conference](#).

**CAPC** offers a pediatric track at its annual [National Seminar](#) and supports intensive hands on training and mentorship through its [Pediatric Palliative Care Leadership Center](#).

**American Society of Clinical Oncology (ASCO)**, in partnership with AAHPM, hosts an annual Palliative Care in Oncology [Symposium](#). While earlier of these symposia have offered very little pediatric content, PPC has started taking some hold on the agenda and could potentially expand if PPC weighs in to build that demand.

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## Advocating for System Level Change

Advocacy amplifies patient and professional voices to move beyond individual solutions to create broader systemic change. Taking collective action through public policy advocacy is an essential step in accelerating growth of the PPC field, particularly as it relates to improving the regulatory and accreditation and payment landscape for PPC services in hospital, ambulatory and home settings by both private and public insurance.

In its [PPC guidelines and recommendations](#), AAP has called for regulatory reform that:

- Broadens hospice eligibility by expanding life expectancy criteria;
- Specifies that concurrent care includes all routine forms of life-prolonging care (e.g., home nursing care for children requiring life sustaining technologies) in addition to palliative care;
- Enables provision of respite care and other therapies that benefit the child by benefiting other members of the child's family; and
- Ensures adequate payment accompanies these and other regulatory changes.

A number of professional organizations provide advocacy training and opportunities for taking legislative or other public policy action, several of which are highlighted in the table that concludes this section. Many do so through coalitions focused on palliative care advocacy – with those initiatives featured immediately below.

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## State PPC Coalitions Provide Infrastructure

Several states have created coordinated Pediatric Palliative Care Coalitions to help advance the field through awareness, education and advocacy. This [chart](#) provides links and contact info for these important initiatives, currently active or developing in the following states (those without links do not yet have coalition websites):

<a href="#">California</a>	Maryland	<a href="#">New York</a>	South Carolina
<a href="#">Illinois</a>	<a href="#">Michigan</a>	Ohio	<a href="#">Texas</a>
Kansas	Minnesota	<a href="#">Pennsylvania</a>	Vermont

### A. Implementing Concurrent Care

Section 2302 of the Patient Protection and Affordable Care Act (ACA) created through federal law the opportunity for concurrent palliative and curative care for children enrolled in state Medicaid or Children's Health Insurance Program (CHIP), allowing PPC teams to become involved earlier in the trajectory of care. This provision spares families the difficult choice of foregoing curative treatment before receiving hospice benefits, but does not change Medicaid's eligibility stipulation requiring no more than a six-month life expectancy.

NHPCO developed helpful resources to support concurrent care implementation efforts and advocacy:

- [Concurrent care requirement information](#)
- [Implementation toolkit](#)

Children who qualify have access to benefits limited to the existing array of Medicaid hospice services and other existing Medicaid services covered by a state, but a child may be simultaneously enrolled in other programs that provide supplemental services such as home- and community-based service waivers. This [Briefing Document](#) on the concurrent care provision highlights examples of successful state activities implementing this approach.



**MEDICAID FACTS United States**

**What is Medicaid?**  
 Medicaid is the single largest health insurer for children. It is also the primary source of health care for low-income parents and other non-elderly adults, the elderly, and persons with disabilities. The Affordable Care Act (ACA) gives states the option to expand Medicaid eligibility for non-elderly adults earning up to 138 percent of the federal poverty level; even prior to the ACA, states generally provided Medicaid coverage to children with family income levels around or above this level.

**Why is Medicaid important to children?**  
 Medicaid is a critical health care program for low-income children and children with special health care needs.

- Medicaid covers 33 million children nationwide.
- Approximately 20 percent of children have special health care needs, and 44 percent of them are covered by public insurance.<sup>1</sup>
- 60 percent of children enrolled in Medicaid live in households where at least one household member works.
- Historically, children represent half of all Medicaid enrollees, but they account for only 29 percent of Medicaid spending.

**How is Medicaid different from Medicare?**

	MEDICAID	MEDICARE
<b>STRUCTURE</b>	A joint federal and state program. Each state establishes its own standards for Medicaid eligibility, benefits and provider payment rates under broad federal guidelines that establish certain minimum standards.	A federal health insurance program. The federal government sets all standards.
<b>FINANCING</b>	Costs shared by both the federal and state governments.	Paid for entirely by the federal government.
<b>ELIGIBILITY</b>	Serves low-income and disabled children, parents, program-needs and the elderly, as well as other disabled adults. Since 2014, states may expand Medicaid to low-income adults who had not been previously eligible.	Serves elderly and disabled people who receive Social Security, regardless of income.
<b>BENEFITS</b>	Provides the Early and Periodic Screening, Diagnosis, and Treatment (EPSDT) benefit, which ensures children covered by Medicaid receive all medically necessary care, including physician and hospital visits, well-child visits and treatment, immunizations, dental, vision, and hearing services.	Does not have a benefit package for children since Medicare was designed with adults, not children, in mind.

MARCH 2015

AAP partnered with the National Association of Children’s Hospitals to create a helpful series of [state-specific fact sheets](#) explaining the importance of the Medicaid program and how children rely on it for their health care.

This [2013 Policy Brief on Coverage of Palliative and Hospice Care for Pediatric Patients with a Life-Limiting Illness](#) describes the variety of state policy approaches that enabled inclusion of the concurrent hospice and curative care waiver for Medicaid reimbursement in the ACA.

Implementation of concurrent care and understanding reimbursement mechanisms for state-based services are important opportunities for collaborative PPC advocacy, particularly through State PPC Coalitions, to ensure sustained coverage of these services.

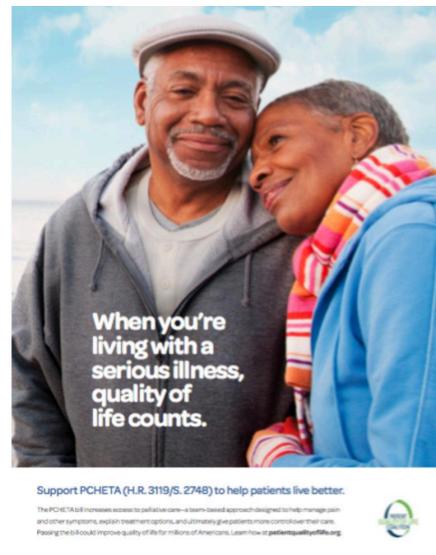
## B. Advancing Palliative Care Legislation: Patient QOL Coalition

Many of the professional organizations featured in this guide are active participants in the [Patient Quality of Life Coalition](#), formed in 2013 and currently comprised of more than 25 [member organizations](#) dedicated to improving quality of care and QOL for seriously ill adults and children through promotion of public policy that will improve and expand access to high quality palliative care.

In particular, the coalition is working to secure support and passage of the [Palliative Care and Hospice Education and Training Act](#) (H.R. 3119/S.2748).

Dr. Sean Morrison testified about PCHETA and the importance of palliative care before the US House Energy and Commerce Committee on September 8, 2016. You can view his written statement, testimony, and the extensive Q&A with Congressional Members using this link: <https://energycommerce.house.gov/hearings-and-votes/hearings/examining-legislation-improve-public-health>

Visit the PQOL [action center](#) to view coalition activities and learn how you can engage in the effort and take action as a volunteer advocate.



**When you're living with a serious illness, quality of life counts.**

Support PCHETA (H.R. 3119/S. 2748) to help patients live better.

The PCHETA increases access to palliative care—a team-based approach designed to help manage pain and other symptoms, explain treatment options, and ultimately give patients more control over their care. Passing the bill could improve quality of life for millions of Americans. Learn how at [patientqualityoflifecol.org](http://patientqualityoflifecol.org)

## C. Advocacy Training Resources

This chart provides links to training guides and other resources that lay out basic steps and information for engaging in federal, state and local advocacy activities.

Organization	Advocacy Resources Links
<p>American Academy of Pediatrics The Academy advocates for the health of all children, and works with government, communities and other national organizations to shape many child health and safety issues.</p>	<p><a href="#">Advocacy Info Page</a></p> <p><a href="#">Training Modules</a></p> <p><a href="#">Advocacy Guide</a></p>
<p>American Academy of Hospice and Palliative Medicine AAHPM engages in public policy advocacy to advance the field, promote the interests of palliative care and hospice patients and support the health professionals who care for them. The needs of patients and their families throughout the care continuum guide AAHPM's policy agenda.</p>	<p><a href="#">Advocacy Info Page</a></p> <p><a href="#">Public Policy Priorities</a></p> <p><a href="#">Legislative Action Center</a></p>
<p>Hospice and Palliative Nurses Association HPNA acts independently and with collaborating organizations to address hospice and palliative care issues at the national, state, local and regional levels.</p>	<p><a href="#">Public Policy Guiding Principles</a></p> <p><a href="#">Advocacy Resources</a></p> <p><a href="#">Take Action Page</a> promoting American Association of Colleges of Nursing (AACN)'s <i>Competencies and Recommendations for Educating Undergraduate Nursing Students: Preparing Nurses to Care for the Seriously Ill and Their Families</i></p>
<p>National Hospice and Palliative Care Organization Hospice Action Network (NHPCO HAN) NHPCO HAN is the Advocacy Arm of NHPCO, dedicated to preserving and expanding access to Hospice care in America.</p>	<p><a href="#">Advocacy Info Page</a></p> <p><a href="#">Hospice Action Network</a></p> <p><a href="#">Policy Resources</a></p> <p><a href="#">Advocacy Toolkit</a></p>
<p>National Coalition for Hospice and Palliative Care NCHPC is comprised of AAHPM, HPNA, NHPCO, CAPC, NPCRC, the Association of Professional Chaplains, and the Social Work Hospice and Palliative Care Network (SWHPN).</p>	<p><a href="#">Sign On Letters and Activities</a></p> <p>The coalition is designed to focus on common goals while recognizing that each organization has its own unique objectives that it may choose to pursue independently.</p>

## APPENDIX: Resources for Families

### A. Insurance, Employment and Financial Issues Assistance and Advocacy



Patient Advocate Foundation (PAF) was founded in 1996 to [safeguard families](#) confronting significant medical issues and the impact on their lives – including parents of children diagnosed with life-threatening illness.

Through effective mediation assuring access to care, maintenance or employment and preservation of financial stability, PAF operates with more than 200 caring case managers offering individualized and sustained services as active liaisons between patients or parents and their insurer, employers and/or creditors to resolve insurance, job retention and/or debt crisis matters. They are also assisted by doctors and health care attorneys. [Online resources](#) are also available.

PAF's advocacy affiliate, [National Patient Advocate Foundation](#), brings patient voices to health system delivery reform, developing and driving initiatives promoting equitable access to affordable quality health care through policy action and public and private partnerships.

Families can contact PAF at 1-800-532-5274 [or email an online case manager directly](#).

### B. Care Camps: Unique QOL Support For Pediatric Cancer Families



"It's a lot of fun once you get here, and you feel like you've never had cancer."

— Hannah Zarr  
Age 12

#### [Oncology Care Camps](#): Healing Happens Here

Care camps [make QOL happen](#) for sick kids, their siblings and their parents. Many offer camp experience for bereaved families as well.

Care camps are proven interventions for providing a medically supervised escape in a supportive environment where children and families participate in recreational activities to help [improve physical, psychological, and social functioning](#) while making memories that last lifetimes.

Use this link to [locate camps](#) near your institution.

### C. Other Programs for kids and families:

[Hole in the Wall Gang Camp](#) programs serving seriously ill children and families in the Northeast

[Make-A-Wish Foundation](#) for seriously ill children between ages 2 ½ and 18 at time of referral



Care camps receive support through a strategic partnership between Children's Oncology Camp Association International and [KOA Care Camps](#) donations.