

■ Lighting the Way

Impact Report





■ Mission and Goal

The mission of Pediatric Palliative Care Coalition (PPCC) is to provide resources to families, volunteers and medical professionals caring for children with life-limiting illnesses. Their goal is to light the way for children and their families coping with this difficult, life-altering experience.

■ Reach and Impact

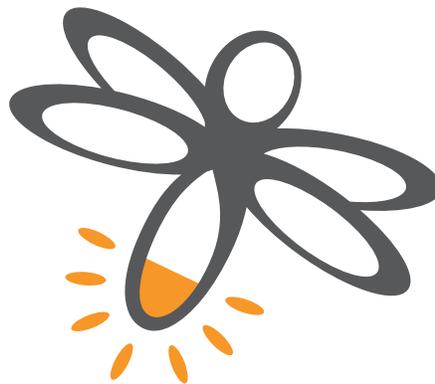
PPCC's impact is far-reaching and the number of children, families and professionals affected is immeasurable. Through the website, educational programming, newsletters and advocacy efforts, PPCC is able to extend its message across the state and country.

The Board of Directors, as well as the membership, includes committed clinicians and community members from across the state. PPCC's collaborative efforts with key stakeholders in the hospice and palliative care community in Pennsylvania and across the country continues to broaden their reach and impact, for pediatric palliative care.



■ Vision

PPCC has a vision of a future where all children diagnosed with life-limiting conditions in Pennsylvania will have access to world-class palliative, hospice and end-of-life care, while their families receive much-needed support.



■ What is Pediatric Palliative Care?

It's estimated each year that more than 500,000 children and their families in the United States cope with a life-threatening illness or condition. Pediatric palliative care is specialized medical care for children with such serious conditions. It focuses on providing relief from many physical and emotional symptoms, including pain, fatigue and the chronic stress of serious illness, which may include genetic disorders, cancer, prematurity, neurologic disorders, heart and lung conditions and others. For patients, parents and families, pediatric palliative care may make an immense difference by providing an extra layer of support at each stage of the journey. It provides connections to medical professionals and therapists who take the time to truly know patients and their families, and understand their wishes, concerns, fears, values or faith. Above all, pediatric palliative care is family-centered and aims to improve the quality of life and well-being for both the child and their entire family.

■ Lighting the Way:

By impacting pediatric palliative care.

PPCC is a statewide volunteer group of clinicians, healthcare professionals, social workers, parents and community members who are committed to improving access to quality pediatric palliative and hospice care for children and families throughout Pennsylvania. PPCC does not provide direct clinical care, but coordinates the collaborative educational and advocacy projects of existing and developing pediatric palliative care and hospice programs. PPCC works with its members to educate, advocate for and partner with healthcare professionals and the community to provide information, resources and education for families that have children with chronic and life-threatening conditions.

☀ 2003

The congregation of Fox Chapel Presbyterian Church in Fox Chapel, PA raises \$50,000 to support a new initiative, Helping Hands-Healing Hearts with the mission of improving the quality of life for children coping with terminal illness.

☀ 2004

The Pittsburgh Pediatric Palliative Care Coalition (PPPCC) is formed under the leadership of Meghan O'Donnell, a bereaved mom and hospice social worker.

☀ 2006

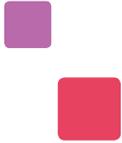
As a result of the efforts of PPPCC and Liam's Foundation for Pediatric Palliative Care, the Pennsylvania Department of Public Welfare convenes a Task Force to study Pediatric Palliative Care and Hospice.

☀ 2008

The Task Force report is published and one of the recommendations is to establish a statewide coalition.

☀ 2009

Helping Hands-Healing Hearts and stakeholders from Liam's Foundation, PPPCC, and Pennsylvania Children's Hospice and Palliative Care Coalition, unite to form the Pediatric Palliative Care Coalition (PPCC). Betsy Hawley is named Executive Director, and a Steering Committee including healthcare providers and parents from across the state assembles.



■ Message from
Executive Director,
Betsy Hawley



The important work of the Pediatric Palliative Care Coalition has been ongoing for more than 14 years. The initial outreach and support began by a compassionate Mission Committee at Fox Chapel Presbyterian Church. Combined with the efforts of the Pittsburgh Pediatric Palliative Care Coalition and Liam's Foundation for Pediatric Palliative Care, it has evolved into a statewide coalition of dedicated volunteers who are committed to expanding the impact and reach of pediatric palliative care.

As the Executive Director, it has been humbling and incredibly rewarding to watch PPCC become a leading voice for accessible and equitable pediatric palliative care in Pennsylvania and nationally. Our work ensures that the smallest voices are not only heard, but attended to. Through our advocacy efforts, members of the Pennsylvania legislature and Congress know that children are an important component of the hospice and palliative care community. We take pride in the support and resources we provide to help make the path easier for medical professionals and families doing this difficult but important work.

In 2018 and beyond, we will continue to focus on the pillars of our mission. We will provide cutting-edge education, invaluable information and resources, along with robust volunteer programs. Some of our key goals include: recruiting new stakeholders and volunteers to support PPCC's mission, developing family support programming, expanding our staff capacity and growing our annual statewide conference. Additionally, we plan to increase regional educational events, re-envision our website and build upon our current advocacy efforts. In order to sustain this level of activity, we will diversify and expand our funding through our membership program and an annual fundraising campaign.

These are ambitious goals. To meet them, we are counting on your support. Through increased advocacy, volunteer efforts and financial donations, we will make a greater impact by expanding our outreach, thus improving the quality of life for more children and their families.

Thank you for helping to Light the Way for the future of pediatric palliative care.

Betsy

■ **Lighting the Way:**
By sharing hope.

PPCC provides comprehensive, current information and resources on pediatric palliative care and hospice options, and offers children and families educational, emotional and social support. PPCC also strives for a more connected community by introducing families and medical professionals to other support organizations and self-help groups in Pennsylvania and across the country.

The following resources are available on the PPCC website:

- PA Resource Map and Links
- Care Plan Book
- Videos, Publications and Articles
- Family Stories/Testimonials

■ **Lighting the Way:**
By providing outreach and education.

PPCC provides regional education and networking programs across the state. The Annual Conference provides an opportunity for education, networking and inspiration as clinicians from across the state come together to learn and grow. Smaller regional programming is held throughout the state to reach those in more rural areas. Additionally, webinars are planned to allow for greater flexibility for busy clinicians and families. PPCC supports ongoing education through regular e-newsletters featuring articles on topics such as care coordination, transitioning care or pain management. PPCC's website serves as a clearinghouse for events and news on pediatric palliative care across the state and country.

Annual Statewide Conference
 2015 Harrisburg
 2016 Pittsburgh
 2017 Philadelphia
 2018 Harrisburg

2018 Goals:



Build State-of-the-Art Resources



Heighten Awareness of Pediatric Palliative Care



Continue to Develop Innovative Educational Programs



Implement Family Support Program

☀ **2010**

The leadership and volunteer network of PPCC expands, to include families, concerned citizens and medical professionals from hospitals, home health care agencies and hospices across the state.

☀ **2010-15**

PPCC continues to build awareness and advocacy, while making an impact across the state with educational programming expanding to include Erie, the Lehigh Valley, and several rural communities.

☀ **2011**

PPCC increases its information, resources, marketing and outreach initiatives with a more interactive and robust website.

☀ **2012**

Advocacy efforts continue as PPCC members meet with Congressional leaders in Harrisburg.

☀ **2014**

PPCC continues to expand its reach and resources with an electronic newsletter and the publication of the Care Plan Book, available to families free of charge on the PPCC website, in hard copy or on flash drive. PPCC collaborates with other statewide groups to increase advocacy efforts.

Care and support of families is at the heart of PPCC's work. Elisabeth McNulty and her son, Case, are an ideal example of PPCC's support in action.

In December 2010, Liz gave birth to her fourth child and only son, Case Daniel. Liz knew throughout her pregnancy that Case would be fighting a tough battle. Sonograms showed that Case's limbs were 11 weeks behind in growth, his heart was defective, his kidney was covered in cysts, along with other birth defects and congenital anomalies. His diagnosis was grim. Liz and her family knew they had to take it day by day.



Case spent the first six weeks of his life in Children's Hospital of Pittsburgh of UPMC. Through 22 surgeries, hundreds of stays in the hospital, and dozens of procedures, he is still going strong. At six years old, Case has had to fight more than many people will ever endure. He has a growth disorder called Russell-Silver Syndrome, a stomach which requires a feeding tube and IV nutrition, one kidney and many ongoing medical battles. Since many of his chronic health issues remain unknown, his family has no clue what to expect next...only that they are blessed and thankful to have Case in their lives.

■ **Lighting the Way:**
**By sharing stories
of care and support.**

Liz connected with PPCC three years after Case's birth. PPCC continues to support Liz and her family in many ways. Liz's career as a Family Support Specialist at Bayada Home Health Care means that PPCC can support her both personally and professionally. Through her career in health care, Liz knows how helpful it is to share with families the many ways the PPCC network can support them, too. Whether families are looking to modify their home or are trying to find the right care for their children, PPCC's network and resources can help their children to live more fully.

And as a mother, Liz appreciates how helpful and easy it is to find many resources thanks to PPCC. Most importantly, Liz is grateful for the emotional support and personal connections that PPCC provides. "They are a soft place to fall," Liz said. "It's wonderful to know that there is an organization that is there for support at any phase. They are there to hold your hand and walk you through it."

Caring for a child with a serious or life-threatening illness is incredibly scary. Doctors do not always have the time to give the support that families need through this difficult journey. With education, resources and personal touches, PPCC serves as a much-needed bridge between impacted families and the medical side of palliative care.

■ **Lighting the Way:**
By working for positive change.

Through legislative action and advocacy work, PPCC continues to be a leading voice for accessible and equitable pediatric palliative care by playing a key role in initiating and implementing positive change locally, statewide and nationally.

To accomplish this work, PPCC staff and members:

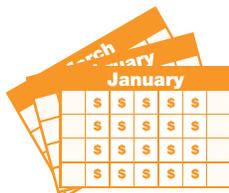
- educate Pennsylvania legislators about the importance of availability, education, and funding for palliative and hospice services for children
- attend congressional advocacy meetings on Capitol Hill
- serve as a national voice and expert resource for pediatric palliative care
- support the education and training of healthcare professionals addressing end-of-life patient concerns through The Palliative Care and Hospice Education and Training Act
- participate as a member of the Patient Quality of Life Coalition

■ **Lighting the Way:**
By increasing support for more opportunities.

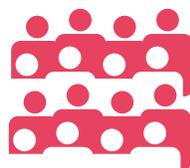
PPCC seeks to increase and diversify its funding opportunities to further the growth of PPCC's outreach, educational and advocacy efforts through:

- meetings, seminars and annual statewide conference
- volunteer, mentorship and new family support programs
- increased advocacy

PPCC will focus on the following fundraising efforts:



Rolling out an annual campaign increasing individual, corporate and foundation donations



Strengthening the PPCC Membership Campaign



Increasing attendance and sponsorships at the statewide conference, and developing additional for-profit educational programs



Expanding focus on grant opportunities

☀ **2015**

PPCC joins the Patient Quality of Life Coalition (PQLC), a national advocacy group. PPCC hosts its first statewide annual conference in Harrisburg, PA. More than 150 healthcare and pediatric palliative care professionals attend.

☀ **2015-16**

PPCC hosts its second annual statewide conference in Pittsburgh, PA, with increased financial support, attendees, presenters, sponsors, and exhibitors.

PPCC becomes a national voice for pediatric palliative care with increased state and federal advocacy efforts. PPCC launches its first membership campaign to diversify and expand funding opportunities.

☀ **2016-17**

PPCC becomes a 501(c) (3) organization.

The third annual conference is held in the Philadelphia region with more than 100 participants.

PPCC is chosen for the Steel City CodeFest and awarded a Forbes Foundation grant to develop the Family Caregiver app.

■ Lighting the Way: By leading the way.

Board of Directors

Betsy Hawley, MA

Executive Director
Pediatric Palliative Care Coalition

Dana Dombrowski, MSW, LSW

Social Worker and Psychosocial Program Coordinator
Pediatric Advanced Care Team
The Children's Hospital of Philadelphia

Nicole Hahnlen, RN, CHPPN

Clinical Nurse Coordinator
Hummingbird Program
Penn State Hershey Children's Hospital

Susanna Hegnes, MEd

Certified School Psychologist
Pittsburgh, PA

James Joyce, MBA, MHA

Manager, Hospice and Palliative Care
Excela Health
Greensburg, PA

Gwenn LaRagione, RN, BSN, CCM, CHPPN

Clinical Nurse Coordinator
Pediatric Advanced Care Team
The Children's Hospital of Philadelphia

Carol May, RN, MSN, MBA, CHPPN

Manager of Supportive Care Department
Children's Hospital of Pittsburgh of UPMC
Pittsburgh, PA

Donna Salovay, Esq.

Registrar
Western Pennsylvania School for Blind Children
Pittsburgh, PA

Jeanne Vogt, RN, CHPN

Hospice Director
Lehigh Valley Hospice
Allentown, PA

Bobbi Zimmaro, RN, MSN, CRNP, CHPN, HTP

Pediatric Palliative/Hospice Consultant
Healing Touch Practitioner
Lansdale, PA



pediatric palliative
care coalition

384 Fox Chapel Road,
Pittsburgh, PA 15238
412.963.8243
ppcc-pa.org

©2017 Pediatric Palliative Care Coalition

PPCC is not a health care provider and does not give medical advice or treatment. PPCC does not endorse or recommend any listed facilities, service providers, or support groups herein. PPCC offers the list and information as a resource only. PPCC does not pre-screen or pre-evaluate the facilities or providers in any way; nor does PPCC pre-screen, pre-evaluate, or consider the Medicare/Medicaid status of the providers.

PPCC is a 501(c) (3) organization.