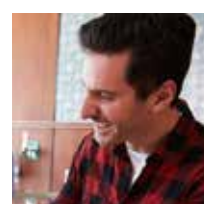





Lighting the Way



Impact Report





Mission 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. The goal is to light the way for children and their families coping with this difficult, life-altering experience.

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

Reach and Impact In a time when collaboration is more important than ever, PPCC expanded its reach not only across the state and nation, but around the world. Through our website, educational programming, advocacy efforts and virtual webinar series, PPCC extends resources and support to families and medical professionals far and wide.

Guided by the voices of the community members, parents and professionals who comprise our dedicated board of directors and membership, PPCC is growing its impact while keeping the needs of children and families at the heart of everything we do.

What is Pediatric Palliative Care?

It is estimated each year that more than 500,000 children and their families in the United States cope with a life-limiting illness or condition. Pediatric palliative care is specialized medical care for children with serious medical 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, among others. For patients, parents and families, pediatric palliative care may make an immense difference by providing extra 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 and/or faith. Above all, pediatric palliative care is family-centered and aims to improve the quality of life and well-being for children and their entire families.

Lighting the Way

By impacting pediatric palliative care.

PPCC is a statewide volunteer group of clinicians, healthcare professionals, social workers, parents and community members with the guidance of an Executive Director 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 and partner with professionals and the community to provide information and resources for families of children with chronic and life-limiting conditions.



Brief History

■ 2008

Through the efforts of the Pittsburgh Pediatric Palliative Care Coalition, Liam's Foundation for Pediatric Palliative Care and Helping Hands-Healing Hearts, the PA Dept of Public Welfare convenes the Pediatric Palliative and Hospice Care Task Force. One of the Task Force recommendations is to establish a statewide coalition.

■ 2009

Stakeholder groups from across PA combine efforts to form PPCC with Betsy Hawley named Executive Director.

■ 2015

PPCC hosts its first statewide conference in Harrisburg, with 150+ healthcare and pediatric palliative care professionals in attendance.

■ 2017

PPCC becomes an independent 501(c)(3) organization.

■ 2018-2021

Through generous grant funding, PPCC launches a new website, toolkits, the Lightning Bug app and the Pediatric Palliative Care Webinar Series, extending its reach to a national level.

■ 2022

PPCC embarks on a capacity-building campaign to grow our organizational staff, financial resources and member engagement in order to provide enhanced resources and support for children, families and providers.



A Message From
Carol May
President of the
Board of Directors

Dear Friends of PPCC:

While I had the privilege of becoming president of the Pediatric Palliative Care Coalition Board of Directors in 2017, I am humbled to have been part of PPCC since the beginning in 2003. Today, two decades later, I am so proud that PPCC is a leading voice for accessible and equitable palliative care for children with life-limiting conditions on a statewide and national scale.

The staff, board and volunteers of PPCC inspire me with their commitment, especially during the COVID-19 pandemic. In 2020, things that were once routine — going to work and school, comforting loved ones who are ill — were suddenly restricted. Meanwhile, the necessity for that comfort and connection only grew. During this uncertain time, PPCC found new and impactful ways to touch the lives of our families and providers.

We served our resilient, forward-thinking caregivers and families through Firefly Chats, the Webinar Series and Virtual Townhalls. Virtual communication also led to two other exciting milestones: the founding of the Clinical Advisory Committee and the Parent Advisory Committee. These groups gain critical insights from the lived experiences of clinicians and parents across the state, thanks to the ability to meet and collaborate virtually.

There are still myriad opportunities for us to be stronger advocates for children, families and providers. We will expand our impact by bolstering three strategic pillars: Sustainability, Collaboration and Advocacy. Our website will be updated into a more comprehensive resource for those we serve. We hope to help establish permanency in how concurrent care is provided in the Commonwealth of Pennsylvania. There is much work to be done, but I could not be more grateful for the people — staff, board, donors, volunteers, parents, providers and advocates — who make this work possible.

Thank you for helping us Light the Way to a brighter future for pediatric palliative care.

Carol May

Carol May
President, Board of Directors
Pediatric Palliative Care Coalition



Lighting the Way **By connecting caregivers to resources.**

The resources PPCC provides to families are thoughtfully selected by professionals and volunteers who know firsthand what it is like to care for children with complex and life-limiting illnesses. Drawing from their personal experience and expertise enables PPCC to curate and recommend literature, webinars, medical professionals, emotional support groups and other resources that uplift families on each step of their journey.

Here are just a few of the many resources available through PPCC that make a difference for children, siblings, caregivers and parents:



Lightning Bug App



We introduce every single family we serve to the Lightning Bug app. Families love the GPS feature that pings you when you arrive at your doctor's office, reminding you to log any information you receive that day. Another great feature is that you can print specific sections of the app to make hospital visits easier. When you take your child for a procedure, for example, you answer the same questions repeatedly for intake nurses, residents, doctors... it can be exhausting. But with the Lightning Bug app, you can print copies of your answers in advance, and simply share a copy with each clinician who needs one.



— Becky Oakley, FNP-C, RN, Executive Director,
Brades' Place



Toolkit: Sibling Support



As a parent of one child with cancer and three healthy siblings, it was hard to know what to do and the right things to say when our sons had questions about their brother's illness. Working on the PPCC Sibling Support Toolkit was so rewarding for me, because I was able to contribute insights from our family's experience, compile information, and identify resources and books to help parents and caregivers work with siblings of children with medical complexities. I particularly like the activities in the toolkit because they engage the entire family and caregiving team in fun and creative ways. And the "What is Important to Me?" document in the toolkit opens the door to honest, interactive conversations with siblings about how they want to be treated and included as families meet the daily challenges of living with children with medical complexities.



— Joan McConahy, Website Administrator and Newsletter
Editor, PPCC



Toolkit: Creative Expressions



I've seen the profound impact of the Creative Expressions Toolkit as both a parent and an educator. When my son, Jack, was receiving treatment at UPMC Children's, he was able to create beautiful pieces of artwork with the help of Child Life specialists — and I was able to create right along with him. There's a special connection that happens when you and your child are hand-in-hand, creating something together. It brings you closer, and the artwork you take away from that experience is a priceless memory.



— Cassie Grassmyer, Field Experience Coordinator,
Instructor and Student Teaching Supervisor, Saint Francis
University



At PPCC, empathy is the foundation of advocacy. Many of our board, staff and volunteers know firsthand what it is like to care for a child with life-limiting illness, and to embark on a healing journey after losing a child. This journey is one that loving mother Joan McConahy is all too familiar with. In 2002, Joan's second son, Sam, lost a brave battle with pediatric cancer. Today, Joan puts her whole heart into her work with PPCC, lighting the way for families like her own, and for children like Sam.

Lighting the Way By sharing stories of care and support.

Born in 1995, Sam was a fun and feisty child with a big personality. Thus, it wasn't hard for his family to tell when something was amiss. "When he was 4, he complained that his head hurt," Joan recalled, "and he wasn't his normal self. Then he lost his appetite, got sick... so we took him to the Children's Hospital Emergency Department."

Sam's admission to the ED was the start of a courageous battle with stage 4 glioblastoma. Two-and-a-half years into the fight, the cancer spread to his spine. Knowing there was nothing more to be done, Sam's oncologist, Dr. Regina Jakacki, advocated that the best thing for Sam was to be surrounded by the comfort and normalcy of his home, with his family.



"Palliative care wasn't even a term I'd heard at the time," Joan said, "but Dr. Jakacki was very forward-thinking. Her guidance led us to Forbes Hospice, and Sam began hospice care on Christmas Eve, 2001. He had a wonderful nurse who came to our home. She even brought him little things he liked to make him happy, like Juicy Fruit gum and toy trains," she remembered. "He was home more often than not, but when we were at Children's, there were so many services that helped our family there, too. Pastoral care, sibling support, child life... they all made a difference."

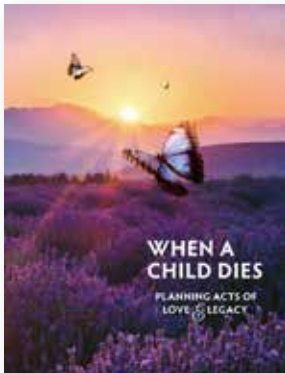
Sam passed away on March 10, 2002, in the comfort of his home, with his family by his side. But his spirit and legacy would live on yet. In 2004, Joan connected with the founders of Helping Hands-Healing Hearts. "They were looking for volunteers," she said, "and I didn't hesitate at all. I couldn't think of a better way to honor Sam."



Almost 20 years later, Joan continues to give Sam's life new meaning through her work with PPCC. She serves as website administrator, newsletter editor and is a vocal advocate for parents. "We've made amazing advancements, and I'm inspired by the palliative care professionals I meet who are passionate about wanting to do better," she said. "If we keep finding innovative ways to deliver information, resources and support to families and caregivers, so many lives will be changed for the better."

Joan's story exemplifies the compassion and care that drive PPCC's mission each and every day. With strong advocates who understand the difficult journey, PPCC will continue to support and uplift families every step of the way.





Lighting the Way

By helping families say goodbye.

Nothing can prepare a family for the pain that comes with losing a child. To help families navigate the difficult journey of saying goodbye, PPCC embarked on a four-year collaboration with the Funeral Service Foundation, the National Funeral Directors Association, and the Greater

Illinois Pediatric Palliative Care Coalition to develop “When a Child Dies: Planning Acts of Love & Legacy.” This free guidebook provides inspiration and guidance to families for every aspect of planning a child’s funeral — from selecting a funeral home, to writing an obituary, to finding personal and meaningful ways of celebrating their child’s life and legacy. In the most confusing, isolating, unbearable time, this resource is helping families take those first few steps on the path to healing.

“Losing a child is unimaginable. It leaves bereaved families feeling alone and isolated. ‘When a Child Dies’ is a beacon in the darkness. Hearing the words of families and grief professionals who understand their pain shines a light in a very dark time.”

— Betsy Hawley, Executive Director, PPCC

“What a beautiful and caring publication. Sending heartfelt gratitude to all involved in its creation. I know the book will ease the unthinkable journey through the loss of a child.”

— Dr. Kimberly Bower, Rady Children’s Hospital San Diego

“This booklet is beautiful, and I’m so happy to hear it has already been put to great use. Resources like this and the people who create them make this world a brighter place.”

— Buffy Peters, Director, Hamilton’s Academy of Grief & Loss

Current Goals:



Advocacy

Catalyze positive change among pediatric palliative care and hospice providers, and amplify the voices of families and caregivers so their firsthand experiences can help other families along their own journeys



Sustainability

Embark upon a capacity-building campaign that will enable PPCC to build out a robust development program, increasing our impact and cultivating even greater involvement from those we serve



Collaboration

Strengthen our existing collaborations statewide and nationally, and cultivate new partnerships that will advance the ability of health care providers to meet the needs of children with chronic complex illnesses



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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.

Lighting the Way:

By leading the way.

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