

# 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. 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

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.



## ● 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 that have children with chronic and life-limiting conditions.

☀ 2003

The congregation of Fox Chapel Presbyterian Church 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 and Hospice Care.

☀ 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), with Betsy Hawley named Executive Director.



• Message from  
Executive Director,  
Betsy Hawley

The important work of the Pediatric Palliative Care Coalition has been ongoing for more than 15 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 not only in Pennsylvania, but nationally. Our advocacy work ensures that the palliative and hospice needs of children are heard and recognized by local, state, and federal legislators. 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.

During the unprecedented COVID-19 pandemic, PPCC has remained steadfast in its efforts to support our families and medical professionals. With the development of Firefly Chats for families and virtual town hall gatherings for medical professionals, PPCC has found new ways to serve the needs of those who care for children with medically complexities. It has been an honor to witness the resilience and tenacity of all of our caregivers during this difficult time.

As we move forward, we will continue to focus on the pillars of our mission by providing an array of educational offerings in a variety of formats, more online Toolkits, and resources for use by families and increased advocacy efforts. Having launched collaborative partnerships across the state and nationally, we will continue to extend our reach and expand our capacity.

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.

A handwritten signature in black ink that reads "Betsy".

Betsy Hawley  
Executive Director  
Pediatric Palliative Care Coalition

## ● 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:

- Lightning Bug App
- Publications, Articles, Videos
- Webinars
- Toolkits:
  - Care Plan Book
  - Creative Expressions: Art, Music, Play
  - Caring Conversations

### 2021 Goals:



**Enhance  
Lightning  
Bug App**



**Expand awareness  
of pediatric  
palliative care**



**Develop innovative  
educational programs  
and partnerships**



**Update and  
develop Toolkits  
for family  
support programs**

## ● 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 pediatric palliative care professionals from across the state to come together to learn and grow. Smaller regional programs are held throughout the state to reach those in rural areas. Additionally, webinars are planned to allow for greater flexibility for busy clinicians and families. PPCC supports ongoing education 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.

## 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.

## 2011

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.

## 2012

PPCC increases information, resources, marketing and outreach initiatives with an enhanced website.

## 2013

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

## 2014

PPCC expands reach and resources with an electronic newsletter and the publication of the Care Plan Book. PPCC collaborates with other statewide groups to increase advocacy efforts.

## 2015

PPCC hosts first statewide conference in Harrisburg, PA, with over 150 healthcare and pediatric palliative care professionals in attendance. PPCC joins the Patient Quality of Life Coalition (PQLC), a national advocacy group.



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, 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:

- inform 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 conferences
- volunteer, mentorship and new family support programs

### PPCC Fundraising Focus:



Expand participation



Increase PPCC membership



Increase attendance and sponsorship of the PPC Webinar Series



Expand grant opportunities through foundation partnerships

## 2016

PPCC hosts 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.

## 2017

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

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

## 2018

PPCC receives large grant from the Women's Board of Pittsburgh, enabling an expansion of resources for families.

PPCC launches a re-envisioned website with Toolkits for families and providers.

## 2019

Lightning Bug App becomes available for families to use.

Webinar series is introduced as a collaborative partnership.

## 2020

Firefly Chats series is launched to virtually support and connect families.

COVID 19 Virtual Town Hall series supports medical professionals during the pandemic.



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## ● Lighting the Way: By leading the way.

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