

Children’s Hospital New Orleans: Pediatric Palliative Care Program

The “Pelican Krewe” is an interdisciplinary pediatric palliative care (PPC) team of doctors, nurses, social workers, integrative therapists, child life specialists, and spiritual care experts, providing an extra layer of support for children and families living with serious illnesses. PPC starts at any age and at any stage of illness promoting healing, comfort, and optimization of quality of life—*making each day the best day possible*.

Vision

- All children and families in the gulf state region facing serious illness will have access to comprehensive support to prevent, anticipate and mitigate suffering in all its forms throughout the entire duration of serious illness both in the hospital and the home.

Mission

- We will achieve our vision through an interdisciplinary workforce advocating for every child and family to have access to the support necessary to live as well as possible with serious illness.
- Our interdisciplinary workforce will become a Center of Excellence for pediatric palliative care in the Gulf State Region:
 - o Providing quality clinical care including integrative therapies
 - o Collaborating with our Gulf Coast community to advance education
 - o Engaging in advocacy
 - o Providing leadership and expertise in the region
 - o Participating and initiating innovative research and quality improvement



Benefits of Palliative Care: PPC services improve patient and family satisfaction, improve symptom control, increase quality of life and meaningfulness for patients and families, reduce the burden of care felt by parents, decrease health care utilization and lengthen survival.

Palliative care also assists in the following domains:

- Anticipation, Assessment, and Treatment of Symptoms
- Facilitate communication between the family and the primary care team to understand and advocate for goal-concordant care and complex decision-making.
- Optimize quality of life with an emphasis in understanding meaningfulness
- Improve coordination of care across settings from the different inpatient units to outpatient settings even into the home setting
- Peripherally attend to the resiliency needs of hospital staff.
- Through an interdisciplinary lens of social workers, chaplains, nurses, child life, and physicians, we will design a goal-concordant plan that is frequently reassessed through illness trajectories.
- Education outreach to clinicians to improve primary palliative care skills with the goal of institutional integration within the hospital

Our unique pediatric palliative care team is thought to have a sorrowful job as we care for children with serious illness and their families. However, that is not how we see it. We have the honor to bear witness to incredible stories of strength and perseverance; and most importantly, we get to figure out what FUN may look like for each unique family.

Pelican Krewe

Tier 1 0-\$500

- Donate to the Pelican Fund
- Donate to the supplies for the palliative care team
- Birthday party fund for patients
- Resiliency program for pelican krewe
- Educational materials
- Coping kits for children and families
- Books for family for coping with grief and serious illness



Tier 2 \$501-6000

- Educational scholarships for pediatric palliative care (PPC) providers to receive more training in PPC
- Donate to the Pelican Fund
- Bereavement kit funding
- Bereavement program funding
- Integrative therapies supply

Tier 3 \$6001-10,000

- Fundraising event
- Donate to the Pelican Fund
- Program development assistance
- Research assistance for a year
- Yearly Lecture in Donor's Name
- Yearly (small) Conference in Donor's Name

Tier 4 - >\$10,000:

- Position Endowment
- Comfort Suite
- Endowment for the program
- Research staff
- Home visit program
- Outpatient program
- Training support for formal staff
- Physical space acquisition and renovation for patients or the teams
- Supportive services for families—vouchers, gift cards, etc.
- Bereavement Program—funeral expenses, condolence cards, support groups, counseling, memorial services, hiring of SW/psychologist to create a bereavement support group and program
- Providing integrative and complementary services such as massage, aromatherapy, expressive therapy
- Educational initiatives, including fellowship support, graduate medical education initiatives, medical school initiatives, interprofessional educational initiatives
- Operational expenses—office supplies, mileage reimbursements
- PPC video about CHNOLA and LSU pediatric palliative care program
- Holiday dinner for patient families who are admitted being delivered to the hospital
- Yearly Celebration of Life for our Patients who are Living
- Yearly CHNOLA Memorial for bereaved families
- Memorial Garden

Pelican Fund:

The Pelican Fund, which is philanthropically supported, provides us the flexibility for our team to think creatively on how to best support families receiving palliative care.

Bereavement Kit:

When children die, the Pelican Krewe has implemented a program called “bereavement kit.” This program allows bedside nurses and staff to feel empowered to provide the best post-mortem care possible when patients die.

- Composed of thumb print charm, foot and hand prints, and lock of hair in beautiful box

- Heartbeat recordings are also offered to families that can then be printed and put to the family’s favorite song.

Advance Care Planning Documentation:

Documentation such as *5 Wishes*, *My Wishes*, *Voicing My Choices*, which are pamphlets for families to discuss a child, adolescent, or young adult’s wishes. It also allows for legacy-making for families and to talk about difficult topics.

Marketing and Printing:

Pelican Krewe will need extraordinary support from marketing and printing to help with community and hospital education.

Books:

We hope to have a source of books that can facilitate coping, grieving, and support for families who are living with serious illness.

Supplemental Supportive Supplies:

- *Comfort wipes* – Every child and family living with serious illness is offered integrative therapies, which promote aromatherapy. These aromatherapy wipes provide soothing scents that can allow families to comfort themselves and their children in nonpharmacological ways.
- *Dyspnea Fans* – These fans provide comfort at the bedside. Children with dyspnea (or shortness of breath that causes anxiety) are soothed with these fans.
- *Seabands* - <http://www.sea-band.com/> These are helpful for nausea/vomiting.
- *Tissues*: Palliative care should offer high-quality tissues.
- *Coping Kit*- PPC and families can make coping kits together.
- *Soothing music and music player*

Condolence Cards

Condolence cards are sent to every bereaved family following the death of their child.

Resiliency Program

As a part of the day to day experiences in caring for children who are seriously ill, team resiliency is incredibly essential. Importantly, resiliency team-building can take many forms:

- Attending team retreats
- Encouraging team support via counseling
- Team remembrance evenings to help honor patients who have died.
- Team celebrations and meals together

Transport Program

We provide quality of life excursions usually in partnership with a Make-A-Wish. Our transport team accompanies our sickest patients to places like the aquarium or zoo for their final wishes before reaching end of life. Make-A-Wish does not fund the transport team who provides ambulances and a team

We provide end of life transports home as well. This sort of transport is generally for the sickest child who is experiencing end of life and the family hopes for their death to occur at home. We will utilize our transport team and partner with Acadian to accomplish a family's goal.

Memorial Program

Our Children's hospital does not currently have a yearly memorial to honor all of our deceased patients. Yearly memorials is an opportunity for families to return back to the hospital to see that their child is remembered and cherished. It provides legacy building for families. It is also a way for staff to see the families they cared for as well.

Professional Development and Continuing Medical Education

To provide quality PPC, formal team members will require subspecialty training to develop PPC skills and communication techniques. CME recommendations are as follows:

- Medical director to attend Ascend leadership conference by American Academy of Hospice and Palliative Medicine (AAHPM)
- Core team attends Harvard's Palliative Care Education and Practice (PCEP)
- Advance practice nurse and physicians to attend Master Pain Class at Minnesota Children's
- Education on Palliative Care and End of Life Care (EPEC) is a train the trainer conference
- End of Life Nursing Education Consortium (ELNEC) train the trainer for core nursing members of team
- Join Center to Advance Palliative Care (CAPC)
- Yearly societal meetings
- Social Worker for Hospice and Palliative Network (SWHPN) for our social worker to attend yearly
- Vital Talk (train the trainer certification)