

Changing the World of *Pediatric Palliative Care*

What is happening in Pasadena, Texas is changing the pediatric palliative care world for the better.

Long-recognized as a leader in service, support and compassion for medically fragile children and their families, Project Joy & Hope developed in 2014 a concept for Phase II of its Tulip Project.

Phase I included three duplexes to provide family-based housing. Phase II will add three more duplexes and a Palliative Care Center. Funding for the duplexes has already been committed through generous contributions, and the focus turns to funding the Center.

The Center will house administrative offices for PJH and the Texas Pediatric Palliative Care Consortium that was established by PJH in 2007. It will also include: art therapy and activity room for kids; career and business center, and exercise area for parents; end-of-life care planning programs; public and private meeting spaces for individuals and families, as well as for organizations to provide continuing education training; and, a volunteer work room.

Project Joy & Hope Capital Campaign

The completion of Phase II will immediately affect those in need and the pediatric palliative care community. By doubling the number of housing units to 12, these spacious, comfortable duplex homes will provide additional short-term or transitional housing.

The creation of the Palliative Care Center will enable PJH to continue serving the few while helping prepare the many.

Please make a contribution of cash, in-kind services, planned gift or publicly traded stock to this important effort that truly touches the world of pediatric palliative care.

According to an American Academy of Hospice and Palliative Medicine 2013 report, there is only one palliative care doctor for every 1300 patients, and the gap is growing because of changes in the scope of work of palliative care professionals. Amidst this field, the pediatric specialty stands separately with uniquely different needs and issues for children and their families.

>> Since 2000, Project Joy and Hope (PJH) in Pasadena, Texas has served medically fragile children and their families in myriad ways. PJH founded the Texas Pediatric Palliative Care Consortium (TPPCC) to help organizations statewide with training and collaboration opportunities.

>> PJH's cornerstone project is The Tulip Project, which helps keep families together when their children are waiting for a bone marrow or major organ transplant, undergoing treatments/therapies for initial disease, experiencing recurrent disease, or utilizing palliative care services.



The center will include: expressive therapy and activity room for kids; career and business center, and exercise area for parents; end-of-life-care planning programs; public and private meeting spaces for individuals and families, as well as for organizations to provide continuing education training; and, a volunteer work room. Pediatric palliative care professionals describe expressive therapies as those that focus on the process rather than the product to address psychosocial, emotional, physical, cognitive, communicative and developmental needs. Specialists promote effective coping through play, preparation, education and self-expression activities. At the Center, children will benefit from such therapies, and caregivers will learn how to utilize them.

Each room provides a naming opportunity to honor or memorialize a loved one, or to add your name to those who love and care for others in need.



What makes Project Joy & Hope unique?



"PJH does not just look at what the seriously ill child needs, but what the family may need too. Whatever that need may be, the staff looks for solutions and involves their volunteers in helping meet the challenge. It may be groceries, gas for trips to the medical center, money for parking or even a birthday party for a sibling. The message is that there can always be joy and hope."

Susanne Dullack
PJH Volunteer since 2006



"Our family is blessed to have found Project Joy and Hope during the toughest time in our lives. Dealing with your child having to go through bone marrow transplant is a very scary thing. Add to that the stress of being away from home, and not knowing where we would stay for the duration of the process. Being able to simply have a home-cooked meal after months in the hospital means the world to us. Project Joy and Hope provided that and so much more. They have provided a home away from home."

The Perez Family



"The Palliative Care Center will provide a space for education related to the caring for these fragile children, their siblings and families. Many caregivers have not had the education or training and are not aware of how best to care for these children. They often do not know what they do not know and do not often understand the unique challenges and needs these children have. This lack of education compromises care, referral to resources and overall support."

Gina Leigh Jones, RN, CPLC Children's Memorial Hermann Hospital

Impact of the campaign

The Project Joy & Hope Capital Campaign will complete the second half of Phase II of The Tulip Project to provide the opportunity to serve more children and their families with housing and many other needs that are addressed with palliative care. It also extends its reach through programming and connections that will occur in the Palliative Care Center. The Center will enable and empower the organization to project joy and hope to families, community members, palliative care providers and many more. The impact of the PJH concept and team has already affected the field of pediatric palliative care nationally. With the successful completion of the Campaign, thousands of people affected by palliative care situations will be better prepared and comforted for life and living.

The Center will serve as the administrative offices for PJH and will become home of Texas Pediatric Palliative Care Consortium. The creation of the Center will enable PJH to continue serving the few while helping prepare the many.

Children and their families will use the facility for a variety of services and programs that are needed by the medically fragile children, as well as their siblings and parents. Within the building will be opportunities for normalcy during difficult times, with space for art, exercise, conducting business, counseling and important, personal conversations. Space will be also be dedicated for continuing education that will help train professionals and providers in the field, as well as for educational programs for families seeking information about legal, emotional and financial guidance. The multi-purpose center will be unique to Texas and a role model for communities around the country.

Project Joy and Hope has served hundreds of people with specialized needs through direct services, outreach, training and more. PJH will continue to expand its reach, transform perspectives, and enhance the development of pediatric palliative care support thanks to outside contributions for its vision. With the new housing elements already funded, we now focus on making the Pediatric Palliative Care Center a reality.

Thanks to a challenge grant from the Mabee Foundation of Tulsa, Oklahoma, timeliness is of the essence. At least \$650,000 must be raised by June 2017 to garner their generous grant. This will complete the Campaign.



The Tulip Project - a place of hope and healing





























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www.joyandhope.org

Our mission is to promote physical and psychological well-being of children with life-limiting conditions and their families, through community awareness, education, and supportive care programs.

Project Joy & Hope is a 501c3 nonprofit organization.