

***Interim Grant Report: One-Year Grant
Eden Health District***

Grantee Organization Name: George Mark Children's House

Program or Project Name: Pediatric Palliative Care for Children with Life-Limiting Illness and their Families from the Eden Health District


Application Number and Grant Amount: Grant No. 16-005; \$20,678

Beginning and Ending Dates of Grant Period: December 1, 2016-November 28, 2017

Organization Contact Person and Phone Number: Ken Sommer, 510-346-1269

Date: June 27, 2017

Signature and title of the person preparing the report:

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Grant Writer/Communications Coordinator

1. Progress in meeting objectives

We are grateful for the financial support of the Eden Health District (EHD) to George Mark Children's House (GMCH) to provide compassionate, holistic care to children and their families from EHD. The goal of GMCH is to provide the highest quality of care to children with life limiting illness and their families by addressing the physical, emotional, spiritual and psychosocial needs of the entire family. In doing so, we strive to achieve the best quality of life possible from the moment of admission onward, through strong collaboration between families and our interdisciplinary team. The objective of this grant is to provide palliative medicine and the full range of supportive services to patients and their families from the EHD. The three main types of care George Mark offers are transitional care, respite care and end of life care.

This report describes our progress in meeting this goal for the first half of the grant period, December 2016-May 2017. **We are pleased to report that we served 6 patients for 62 days of care from the Eden Health District during the grant period, a significant increase over our previous grant period. Additionally, we provided long-term and multi-faceted bereavement support to family members residing in the Eden Health District.**

During the grant period, five patients from EHD received life-affirming respite care including pain and symptom management, palliative aquatic therapy, psychosocial support, and an array of Child Life activities, specifically pet therapy, music therapy, arts and crafts, and sensory experiences. One patient and his family received end of life care, including multi-faceted emotional and practical support prior to and following the death of their child. In total, we provided 62 days of direct patient care.

We'd like to share the story of **Angelina**, our patient who resides in San Leandro to convey the benefits of George Mark care for the whole family – Angelina, her mom, and sister. Angelina has

epilepsy, cerebral palsy, and degenerative disease of the nervous system. Angelina's mom, Robin– who is single – has not been able to find an in-home caregiver she feels confident leaving Angelina with, so works from home, and takes on-line courses. When she needs to take her daughter, Sophia, to school in the rain or bad weather she must bundle up Angelina – in spite of her fragile condition – to make the trip with them.

Angelina's mom, Robin, does, trust George Mark Children's House to care for Angelina. Angelina first came to us for transitional care from Lucille Packard Children's Hospital for seizure and pain control. Since then, Angelina has been admitted for respite care regularly and delights in the attention she receives from both staff and volunteers. She loves being read to and looks intently at each page. Angelina also enjoys music and participates in pet therapy visits which include therapy dogs, zoo visitors, such as chinchillas, turtles, snakes, ferrets, and, chuckwallas.

Angelina's health has slowly declined, which creates much anxiety and sadness for her mother who says that she has tried to prepare herself for daughter's worsening health. Yet, Robin reacts to the painful reality as any mother would, and does what she can to give her daughter the best quality of life for as long as possible. We are grateful that she considers George Mark to be one of the aspects of her daughter's life that enhances its quality and, at the same time, allows Robin a break to help Sophia participate in activities that enhance her quality of life. Angelina's family can rely on the medical expertise of our pediatric palliative care team, to reduce her daughter's discomfort and depend on our caring psychosocial team for Angelina's and her own well-being whatever may come.

2. Meeting grant objectives

We made progress toward meeting grant objectives, and the funds received to date (\$10,339) from Eden Township Healthcare District were fully expended by the care we provided for the patients detailed above.

Although George Mark receives reimbursement from the Regional Center for the respite care – the level of reimbursement is far lower than the cost of the services, and EHD funds were instrumental in bridging the funding gap. As noted above, the care we provided for the 6 patients from EHD allowed us to fully expend the grant.

With support from EHD, we were also able to serve 38 families with bereavement services which include: telephone calls, cards to remember their child on their date of birth and cards to honor their memory on their anniversary of their death. Bereaved families visit George Mark and our Social Worker provides emotional support and memory making activities for family members, including brothers and sisters. Families are invited to decorate a tile remembering their child at George Mark on a quarterly basis. The tiles are installed and become a permanent feature

of a wall located in the George Mark garden. Families may visit their tile and George Mark anytime they like. Our bereavement services are funded entirely through philanthropy.

Bereaved families and those active on our Respite list which include 17 patients and family members from EHD are also invited for our Spring Picnic, and for Pumpkin Day in the Fall. We have reinstated our Spring Prom at GMCH for all patients 12 or older and their families to enjoy the decorations, music, fun, and thoughtful touches of an event that they never imagined their child and they would experience.

3. Timeline

The timeline is consistent with the plan we laid out in the proposal.

4. Meeting measurable outcomes

We projected that we would achieve the following measurable goals by the end of the grant period.

We are on track to meet these goals, however, as noted above, and are on track to fully expend the grant funds. We anticipate serving additional respite patients from EHD over the remainder of the grant period.

In 16/17 George Mark expects to meet or exceed the following goals and objectives:

- Provide critical medical care and support services to 100 severely ill children **(10-14 of whom are expected to be from EHD)**: *To date (our Fiscal Year ends June 30), we have served 87 patients overall. In the six month grant period, we have served 6 patients from EHD so are on track to meet our annual goal.*
- Provide education and psychosocial support services to a minimum of 300 family members **(50-65 of whom are expected to be from EHD)**: *We have served 42 family members as of May 31 from EHD.*
- Maintain a 90% or greater Patient Family Satisfaction rating: *We are on target to achieve by the end of FY 16/17.*
- Maintain an average annual daily census of four patients for a total of 1,460 patient care days: *We have already met this annual goal by May 31, one month prior to the end of FY 16/17.*
- Provide education in the practice and application of pediatric palliative care to 300 physicians and medical and nursing students: *We are on target to achieve by the end of FY 16/17.*
- Engage 150 individuals in meaningful volunteer service: *We are on target to achieve by the end of FY 16/17.*
- Obtain a minimum of 20-25% of operating income from insurance, Managed Medi-Cal, and Medi-Cal reimbursements: *We are on target to achieve by the end of FY 16/17.*

5. Unexpected events

We are pleased to report that we have been able to serve additional patients in need of our services this fiscal year, including an increase in patients from EHD. Factors that have contributed to the increase include: a) instituting a new staffing model that allows us to admit more patients at one time and b) growing visibility among our primary referring partners, including Regional Centers, UCSF Benioff Children's Hospital Oakland, Kaiser Permanente, and other area hospitals. In January 2016, we hired our Physician Liaison on a full-time basis to market our services and to serve as the face of GMCH with physicians, case managers, and hospital and insurance administrators. The two-pronged approach is resulting in an increase in patient census and, in particular, a growing capacity to serve the EHD community, and we will be looking to build upon our efforts in the coming six months.

6. Additional items

We appreciate your support and look forward to the possibility of a continued partnership with the of the Eden Health District in support of better health and well-being outcomes for children with life-limiting illness and their families.