

15-004

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**Interim Grant Report: One-Year Grant
Eden Township Healthcare 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 Township Healthcare District
Application Number and Grant Amount: Grant No. 15-005; \$15,000
Beginning and Ending Dates of Grant Period: December 1, 2015-November 28, 2016
Organization Contact Person and Phone Number: Ken Sommer, 510-346-1269
Date: June 14, 2016
Signature and title of the person preparing the report:

Alice Bruff, Grant Writer

1. Progress in meeting objectives

We are grateful for the financial support of the Eden Township Healthcare District (ETHD) to George Mark Children's House (GMCH) to provide compassionate, holistic care to children and their families from ETHD. 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 ETHD. 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 2015-May 2016. Aaron is a 12 year old boy from a bilingual Spanish speaking family who resides in Hayward. Diagnosed with epilepsy, quadriplegia, cognitive delay, and cerebral palsy, Aaron has an array of special needs and is medically fragile. He is one of 5 siblings who live with their mother and father in a blended family in a small second floor apartment. Aaron came to GMCH in March for a 7 day stay and is scheduled to return for another stay of 7 days this month. Aaron's medical condition is considered acute and so he requires a medically safe environment where he will be closely tended, and so is perfectly matched with George Mark.

Aaron's mother, Lucia, who has worked as a social worker in the past but is unable to do so because of Aaron's medical and care needs, sees Respite Care at George Mark as a life-saver for her family. Lucia is diabetic and has been prescribed diabetic boots to help her feet heal. As Aaron has grown, she finds it more difficult to move him and so can't wear the boots because they throw off her balance when she is lifting him. Additionally, because of the difficulty of moving Aaron from the second story apartment to their car, Aaron's brothers and sisters don't have the opportunity to go out and visit parks, pools, and zoos. Lucia describes their everyday life as largely confined to the apartment. Lucia, her husband and children will use Aaron's Respite

Care to help Lucia convalesce and for their children to get outside, explore, and enjoy the activities most children take for granted.

At George Mark for Respite Care, Aaron has had an opportunity to spread his wings and experience a new and medically secure environment staffed with nurses and physicians trained in Pediatric Palliative Care. Aaron has enjoyed our Child Life Specialist, Social Worker, and the caring, committed trained volunteers who are on-hand to wheel him around the grounds, and play his favorite music and videos. He also benefited from visiting with our gentle pet therapy dogs who come to George Mark with their owners weekly. Other activities include a sensory room with special ADA accessible toys and equipment, and palliative aquatic therapy overseen by an RN who specializes in helping patients like Aaron who are stiff and have trouble breathing relax and breath more deeply in the water. Aquatic therapy results in deeper relaxation and can reduce the incidence of seizures. Aaron's parents, and siblings got a much needed break to rest and recharge and Aaron had a special experience in a safe therapeutic environment he will be able to enjoy upon his return.

2. Meeting grant objectives

We made progress toward meeting grant objectives, and the funds received to date (\$7,500) from Eden Township Healthcare District were fully expended by Respite Care provided for Aaron and his family described in #1 above. Although Aaron's stay was partially paid for by the Regional Center, their reimbursement did not cover the full cost of his stay, and ETHD funds were instrumental in bridging the funding gap. We were also able to serve 5 families from ETHD with bereavement services which include: ongoing 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 remember their child anytime they like.

A series of workshops for bereaved families from GMCH was offered January 12, February 2, March 8, and April 12 by our Social Worker and Clinical Psychology Intern. Families appreciated the opportunity to share their experience with others in a facilitated group and found the sessions supportive during a difficult time. An online support group is currently under development to respond to requests by the many parents who want to participate in a group but have difficulty traveling to GMCH. While we didn't have any ETHD families elect to participate in the onsite workshops, we will invite all bereaved families who have used our services to participate in the online forum.

Bereaved families and those active on our Respite list which include 42 patients and family members from ETHD are also invited for our Spring Picnic, and for Pumpkin Day in the Fall. We recently 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, while the number of ETHD patients and family members has been less than projected, we are on track to fully expend the grant funds. We anticipate serving additional Respite patients from ETHD over the remainder of the grant period.

In 15/16 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 ETHD**): *To date, we have served 74 patients overall, and 1 patient from ETHD. We expect to serve additional patients from ETHD during the grant period.*
- Provide education and psychosocial support services to a minimum of 300 family members (**50-65 of whom are expected to be from ETHD**): *We have served 42 family members to date from ETHD.*
- Maintain a 90% or greater Patient Family Satisfaction rating: *We are on target to achieve by the end of FY 15/16.*
- Maintain an average annual daily census of four patients for a total of 1,460 patient care days: *We are on target to achieve by the end of FY 15/16.*
- 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 15/16.*
- Engage 150 individuals in meaningful volunteer service: *We are on target to achieve by the end of FY 15/16.*
- Obtain a minimum of 20-25% of operating incPome from insurance, Managed Medi-Cal, and Medi-Cal reimbursements: *We are on target to achieve by the end of FY 15/16.*

5. Unexpected events

The only unexpected outcome was that the number of patients from ETHD admitted during the first half of the grant period was lower than projected. We anticipate serving more patients from ETHD during the remainder of the grant period. We have hired a Physician Liaison on a part-time basis to increase our visibility and to serve as the face of GMCH with physicians, case

managers, and hospital and insurance administrators. We expect with more regular communication between GMCH and our referral partners that we will increase our patient census from ETHD, as well as other areas. We are continuing to build our referral relationships with County Health Departments, UCSF Benioff Children's Hospital Oakland, Kaiser Oakland, and other area hospitals, along with health insurers and anticipate receiving additional referrals from ETHD residents.

6. Additional items

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

George Mark Children's House
Eden Township Grant Tracker YR 15-16

Eden Township Patients

Funder	Date	Patient Name	Type of Insurance	Type of Patient	Dates of Stay	Amount Used	Amount Added	Running Balance	Released	Date
Eden Township	3/21/2016	I. Arias	RCEB	Respite	3/30/16-4/6/16	7,500.00	7,500.00	7,500.00	7,500.00	3/31/2016
Total						7500	7500			

Balance Check 0

937.5