



Complex Child E-Magazine

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Support Award

George Mark Children's House

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Relight a Beacon of Support

Pediatric Hospice Programs are an essential source of support for so many families for whom all other treatments have failed or have been deemed too dangerous to try. However, they are not typically recognized as essential, possibly because of difficulty imagining that children, who are assumed to have relatively more resilient and youthful bodies, will lose their fight against disease. The result of this denial is the sad reality that when children's bodies cannot fight any longer, there is limited support available. In many cases, families rely on palliative care from Pediatric Hospice Programs, like George Mark Children's House, which is often not covered by insurance programs and thus desperately needs financial support.

We first learned about the pediatric palliative care system after our daughter suffered sudden birth trauma that resulted in brain injury and multi-organ failure. As a newborn, she was given the best opportunity to survive by a dedicated team of doctors. However, at six weeks old, an MRI revealed the unexpected severity of her birth trauma and brain injury. The doctors who were treating her chronic kidney failure with dialysis removed her from the kidney transplant list. We were devastated because we knew without a transplant her failing kidneys were ultimately going to end her life.

Extreme sadness was coupled with a fear of the unknown until we learned about a Home Hospice program, which included a hospice nurse who would check in with us once a week and be available to answer questions to help maintain our daughter's comfort and quality of life in the days that followed. Our daughter's bridge to a transplant, her dialysis, was stopped and we brought her home on this Home Hospice program. Thankfully, off dialysis her kidney function improved enough to allow her to be taken off hospice at six months old. Although we have been blessed with an additional four years with her, we still are very aware of the fact that at some point her damaged kidneys will no longer be able to support her and a hospice program will once again be required.

Recently, I learned from a friend that there was a non-profit residential pediatric hospice, George Mark Children's House, the **only** facility in the United States that can provide support **and** accommodations for the entire family. My friend's infant son had experienced a similarly devastating brain injury at birth and she had stayed at George Mark Children's House with her whole family, enjoying some respite time while her son received necessary medical attention. Sadly, they returned again a few weeks later not for respite, but because her infant son was losing his fight against respiratory illness.

Because our experience compelled me to support her, I visited her family at George Mark Children's House expecting in the very least a somber and sobering time. I was pleasantly surprised to find a sunny home-like setting tucked away in gorgeous foothills. As I walked down the hall to the nurses' station, I smiled when, through the windows, I saw a child-friendly play structure on a grassy knoll. The bright atmosphere was also skillfully enhanced by cheery décor, which included a mural of a soothing nursery tale on the wall of my friend's son's room. She received visitors while her three older sons played elsewhere with volunteers. A nurse and another volunteer came in periodically to check on her infant son while he slept in this calming environment with oxygen administered through tubes placed in his nose. He slept peacefully and when the light from the windows glowed on his porcelain skin, it calmed his visitors and mobilized us to support his family with comforting exchanges. On my way out again I was further comforted by passing a cafeteria buzzing with conversation and a room equipped with mats and mirrors, likely for a child's sensory exploration.

In comparison, the fragile-as-an-eggshell atmosphere we experienced when we brought our daughter home on home hospice was not at all apparent. Specifically, the first six months off dialysis and on Home Hospice before my daughter stabilized were the most emotionally and medically confusing months of our lives. Emotionally, our friends and family did their best to support us, but having never experienced this extreme situation they were not entirely sure what they could say or do to help us. Medically, although the weekly nursing visit and on-call support from both the Hospice Nurse and our Pediatrician were helpful, for the most part we were on our own at home worrying that every new symptom was a sign that she was in pain or that she was losing her fight.

Surprisingly, although faced with similar uncertainty on hospice, my friend seemed much less anxious, calmed by trust that the medical staff at George Mark Children's House could attend to her son's needs appropriately. She spoke of feeling thankful that the volunteers were providing her older children much needed individual attention during a very confusing time. My friend also shared that George Mark Children's House has a community of families who help support each other and provide much needed comfort, understanding, and words of wisdom that individuals who are not experiencing life with a terminally ill child cannot provide. Finally, my friend said that she was trying to obtain insurance coverage but she was told that George Mark Children's House relies on donations so that services can ultimately be provided at no cost to the families.

I came back to George Mark Children's House to support my friend after her son had passed away. Positive impressions from my first visit definitely made it easier to return.

My friend explained how helpful the staff at George Mark Children's House had been guiding them through the most difficult parts of their journey with a terminally ill child, such as making arrangements for his memorial. Many of the details were taken care of so that they could reflect on time with their son and the rest of the family without worrying about painful planning. I was not able to stay for his Memorial later in the day, but I was taken aback when she said I could still visit with her son because George Mark Children's House had made arrangements so that family and friends could spend as much time as they needed to appropriately say goodbye to a loved one before the typical preparations occurred. I was led to a more serene room with an alcove that housed the viewing area filled with mementos made by loved ones who cherished her son. Although I had only known the family for four months, I did not feel out of place because the warmth was inherently welcoming to anyone who recognizes the worth of sweet innocents and ultimately supported my need to grieve along with the family.

We have been managing my daughter's terminal illness for four years now but my heart still aches both when I remember both how close I've already come to losing her and that she will pass away. Because the emotions associated with our daughter's time on Home Hospice are still powerful, George Mark Children's House has calmed lingering fears about what would happen once our daughter's kidneys could no longer support her. With medical staff close by we would not need to worry either that an important symptom was missed, causing our daughter undue suffering or that help would not arrive in time when it was needed. There would also be less concern that our constant focus on and worry about our seriously ill daughter would frighten or alienate her very observant siblings. The volunteer staff at George Mark Children's House could help reduce or even avoid additional emotional distress associated with the loss of a sibling, such as feeling left out, feeling afraid of upsetting adults or feeling afraid of getting sick themselves if they did not understand that not all children become seriously ill or die young. Indeed, witnessing firsthand the effects of being gently and warmly guided through an otherwise dark, cold and seemingly endless tunnel made the day when we would need to say good bye to our daughter a little less daunting. Furthermore, our experiences solidified a desire to draw on George Mark Children's House's support both for possible respite care for our medically complex daughter and for palliative care during her final days, if the circumstances allowed.

Knowing this, I felt great sadness when I learned recently that George Mark Children's House is suffering severe financial difficulties as a result of the failing economy. I initially felt selfish sadness because it may mean that our family will lose a much-anticipated source of support. However, I also felt universal sadness because it also means so many other families will suffer additional stress during their child's final days. My heart aches for families who already rely on George Mark Children's House's services in order to maintain their children's quality of life because they will now be faced with significantly less support. Without George Mark Children's House families would face a dark, overwhelming and confusing journey, relying on either limited outpatient hospice programs or multiple hospitalizations for symptom management.

It is no surprise that in troubled economic times, the most vulnerable are the ones who fall through the cracks and get lost in the dark. Therefore, I find myself hoping that a spark from somewhere will relight George Mark Children's House's beacon so it can remain an essential source of support for these families in their time of need. Typically, financial sponsorship is reserved for curative treatments, ground-breaking treatments aimed at preventing illnesses from taking so many innocent lives. Sponsors, however, are also needed to help this non-profit residential pediatric hospice break a different kind of ground for the innocent terminally ill children and their families.

George Mark Children's House lights the path traveled less often by giving these families much needed knowledgeable support and a chance to walk in warmth and comfort until it is time for the child to move on. For this reason, it goes without saying that we must find a way to **relight this beacon of support.**