

A Home Away From Home for Dying Children

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By LAURA NOVAK

AN LEANDRO, Calif. — If the house were a hard sell, the pitch might go like this: Hamptons-style estate on five gated acres above San Francisco Bay. Classic clapboard exterior; gabled roof with large stone chimneys. An open floor plan of 15,000 square feet. Eight-burner Wolf range. Great rooms, music, computer and TV rooms. Two guest suites, meditation sanctuary, pet kennels, rose garden and waterfall.

But the house, with its eight bedrooms and private bathrooms, has one final feature that distinguishes it from any other home: the temperature-controlled wake room for families who need several days to say goodbye to the child they have brought here to die.

When it opens its doors to the first pediatric patients and their families in March, the George Mark Children's House will become the only independent site in the country to provide medical child care and end-of-life management for children.

"For Americans, death is a taboo," said Dr. Kathy Hull, a psychologist in pediatric oncology who helped start the home named for her brothers. One died at 16 in a car accident; the other died at 30 from cancer. "I think we're the only society in the world where everybody thinks they're getting out alive somehow. And for children, it's much worse, and not because it doesn't happen but because it's a topic people are not comfortable with."

The George Mark Children's House was created to provide the missing link in two critical components of caring for children with life-threatening illnesses.

The first is hospice care, which focuses on pain management for dying children as

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well as guidance and bereavement care for their families. Currently in the United States there are two options for families in these situations: children can die at home with hospice services, which are not always readily available, or they can die in the hospital. Though some hospitals have tried models similar to those of birthing units, with nicer wallpaper and furniture, some families still cannot escape the feeling of a hospital setting.

"It's still this family coming to the place where their child has received treatment, where they have all these memories of what has gone on previously," said Dr. Barbara Beach, a pediatric oncologist, co-founder and medical director of the George Mark Children's House. "And many families don't want their child to die at home. They feel that they will forever have difficulty being in that space wherever the room is where the child died."

The second goal for Dr. Hull and Dr. Beach was to offer a form of respite care for families. With a full-time staff, the house will serve as the middle point between home and hospital for children whose families may not have had a break in months or years.

"Because in some cases it does not exist, families cannot get respite at home and are on occasion forced to admit their child to the hospital, even though it is not absolutely medically necessary, because they have no one else to care for their child," Dr. Beach said.

Dr. Barbara Sourkes, director of the pediatric palliative care program at Lucile Packard Children's Hospital at Stanford University, says the George Mark house will address America's "invisible families."

"These are families who have a child with a neurodegenerative disease from birth and who live well into their teens," Dr. Sourkes said. "They need total physical care. And many families are dealing with years and years and years with no break at home."

If one of the goals for the house was to offer a middle ground for the patients, it was equally important for Dr. Hull and Dr. Beach to put boundaries around illness and death for the siblings.

"If we take on the medical piece as much as the family wants us to, that then frees up the family to deal with the emotional needs of each other, of the child who's dying

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and of a sibling," Dr. Beach said.

Dr. John Saroyan, a fellow in pediatric pain management and palliative care at the College of Physicians and Surgeons at Columbia University, has been studying the George Mark Children's House since it broke ground in 1999.

"I see the opening of George Mark as a symbol that it's time we make this part of our standard of care for pain and symptom management," Dr. Saroyan said, "as well as psychosocial and spiritual care for children with life threatening conditions."

Christy Torkildson, a pediatric palliative care nurse who is the house director of programs and services, said the first referrals would come from Bay Area pediatric hospitals: Children's Hospital and Research Center at Oakland, Lucile Packard Children's Hospital and the University of California, San Francisco, Children's Hospital.

Children who are not expected to live beyond 19 are eligible for the house. A bed there will cost \$1,400 per day. Families will pay on a sliding scale based on their finances. Ms. Torkildson said the children's house was hoping for Medicaid and MediCal reimbursements. At this point, there is not even a code for such a program on any insurance plan, so the house will have to rely on raising private money. The program cost estimates, based on similar homes overseas and adjusted for labor costs in the United States, are about \$3.5 million a year.

The goal is to keep at least two bedrooms available at all times for plan-ahead respite care for families to use up to four weeks a year.

End-of-life care will always take precedence over respite care, Dr. Beach said.

And then there is the blending of these two components. Over time, families seeking respite care may bond with staff members and perhaps find a favorite bedroom. They can then choose to return to familiar surroundings when their respite needs give over to the final days of their child's life.

"This is going to be a refuge for families who are confronting what I think is one of life's most difficult moments," Dr. Hull said. "And there is going to be a wonderful trained staff of people, sensitive to the needs of the family and responsive to cultural traditions. I mean, really, the safe harbor in the storm."