

# Waiting For A Ray Of Hope

FOR FAMILIES LIKE GABY STEELE'S, SUNSHINE HOUSE WILL OFFER A WELCOME RESPITE

By ALIX BOYLE  
Special to The Courant

**E**ight-year-old Gabrielle Steele and her family are eagerly awaiting the opening of Sunshine House, a home-away-from-home for seriously ill children and their families. Gaby, who has congenital muscular dystrophy, is wheelchair-bound and requires round-the-clock nursing care, said her mother, Jacquelyn Steele.

Although the family has night nurses four nights a week, Jacquelyn Steele and her husband, Joe, take turns the other three nights,

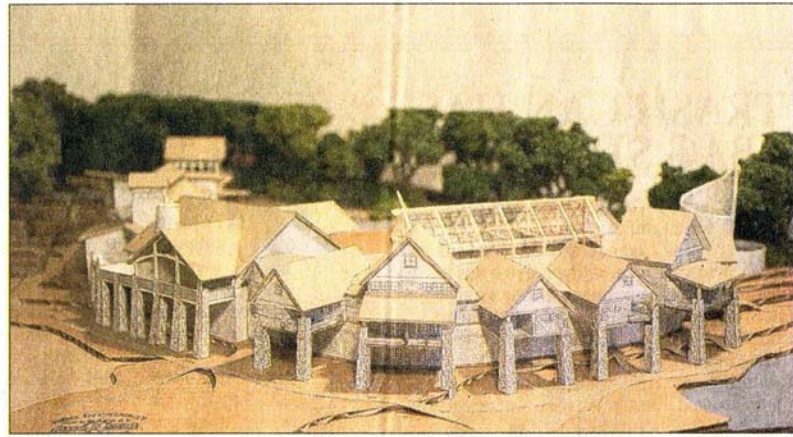
checking on Gaby and repositioning her. It can be exhausting. Gaby needs nine medications and nebulizer treatments, has a permanent tracheotomy and uses a ventilator to breathe.

"Our house is like a mini intensive care unit," Jacquelyn Steele said. "It interrupts family life to have nurses and therapists around all the time. People don't recognize how limited our family is."

The Steeles, who have three other children, wish to have a place to go with the whole family to get a break from the constant role of caregiver, but have some semblance of normal family life. And although Gaby has a host of physical problems, she is cognitively normal and wants and needs stimulating experiences and the company of other children.

"I don't like the fact that Gaby lives in an adult world. She's a second-grader, but can never go out to recess," Jacquelyn Steele said. "Gaby has never met another child in a wheelchair. At a place like Sunshine House, she would see other children like her. And it would be a respite for the whole family. One of the nurses could take care of Gaby, and Joe and I would get to sleep."

Until recently, Gaby attended public school in Prospect, but she developed asthma and her parents decided to home-school her. She cannot



Above photo: DUO DICKINSON / Bottom left: photo courtesy of the Steele family

**SUNSHINE HOUSE**, shown in the rendering above, will provide services to ailing children and their families. At left, Gaby Steele, center, with siblings Katelyn, Kristyn (holding Gaby) and Joey, will benefit from the house.

speak, but communicates with her eyes. She loves being read to and receiving e-mailed greeting cards and videos.

## Porches And Light

The idea of Sunshine House is to provide a

RESPITE, H4



## Respite Homes Designed To Fit Ill Child, Parents, Siblings

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brief respite of a few days to a few weeks for children with life-limiting conditions and their families. The center also would provide end-of-life care.

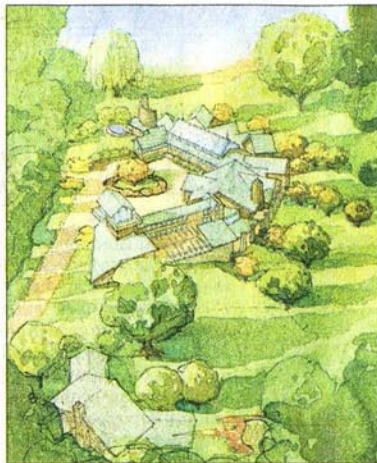
It's now one step closer to becoming a reality. After a long search, Sunshine House recently closed on a peaceful, 8-acre parcel adjacent to a farm on the Boston Post Road in Madison. The town planning and zoning commission approved Sunshine House's proposal to build a village that would contain eight townhouse-style residences, recreation facilities, a theater, an indoor butterfly garden, a chapel and even room for pets, said Amy S. Kuhner, Sunshine House chief executive officer, who also lives in Madison. Doctors and nurses will be available 24 hours a day to provide pain relief and symptom management.

Madison architect Duo Dickinson donated his services to design the village and thought long and hard about how to keep it home-like while making the building functional enough to accommodate children in wheelchairs.

"When you think about what makes a building, on the most emotional level, a home, it's scale. And how do you make a 30,000-square-foot building intimate?" Dickinson said.

The townhouses are designed to have light entering the rooms on three sides and porches to look out on the trees and pond on the property. Most hospital rooms have long corridors and flat exterior walls and just one window facing out in one direction.

"It is without question the hardest thing I have ever designed as an architect, and it will be without question the most important thing I do as one," Dickinson said.



DUO DICKINSON

**WHEN DESIGNING SUNSHINE HOUSE**, Duo Dickinson's primary concern was keeping the place homey. "How do you make a 30,000-square-foot building intimate?" Dickinson said.

The tri-level townhouses, entered on the middle level, are designed to be flexible enough to fit the ill child, his parents and siblings: any size or type of family. There will be a communal kitchen with a chef to cook meals, but the kitchen will be open at any time to parents who find cooking relaxing. The plans include a community living room, family room, library and music room. Therapeutic spaces include a pool and a multi-sensory room. There also will be spaces for quiet reflection, including the Starshine room, a retreat for parents whose

child has died.

Outdoors, parents can garden and siblings can explore the woods. The property has a variety of mini-climates: bright sunshine, cool damp shade, a glade of trees. Families can also walk to the farm adjacent to the property, to the beach a mile away or to the town with its bookstore, movie theater, coffee shops and post office.

Families would stay at Sunshine House free of charge; medical insurance may be used to pay for respite care in the future.

## Small-Town Setting

Kuhner searched for years for this small-town setting. She did extensive research in the United Kingdom, where children's hospices and respite care centers are commonplace; more than 30 such centers are in operation, all funded primarily through private donations.

Sunshine House is not licensed as a hospice, although it will provide end-of-life care for children and their families. The Connecticut General Assembly licensed Sunshine House as a "pilot comfort care center" for children in 1999.

There is one children's hospice currently operating in the United States, the George Mark Children's Home in San Leandro, Calif., and another is in the works in Phoenix.

Kuhner, who holds both an MBA from UCLA and a masters of divinity from Yale, has been working with families to find out what they actually need in a place that is part sanctuary, part medical facility and part imaginative play zone.

"Most of the children who will come here have diseases you have never heard of and are expected to die sometime in childhood,"

Kuhner said. "It's a hidden population. They can't go to camp because they are ventilator-dependent, they can't move, but they still have their minds."

Even the most debilitated children will appreciate looking at the butterflies, listening to music or floating in the therapy pool. Many of the children's ailments require round-the-clock care administered by exhausted parents who desperately need a break.

"This is truly designed from a family's point of view," Dickinson said. "It's never been done this way before and it's taking a long time by type-A standards. But if you rush to get it done, you don't get it right."

Kuhner and the Sunshine House board of directors hired Perkins Eastman, a well-known New York architectural firm with experience in pediatric health care facilities, to design the inside of the village. In the coming year, an administrative consultant will come on board to help hire employees and run a capital campaign to raise the millions of dollars needed to complete the project, Dickinson said.

In the meantime, families like the Steeles look forward to the day when they can take a break all together.

For a child like Gaby, who spends much of her time in the hospital or at doctors' and therapy appointments, it's important to be able to share fun times with her family, her mother said.

"Gaby's happy with the little things," Jacquelyn Steele said. "Loud noises and crowds aren't her cup of tea. She'd like a dip in the hot tub or a visit to the butterfly house."

>> For more information:  
[www.thesunshinehouse.org](http://www.thesunshinehouse.org)