

A drawing of the proposed Sunshine House hospice facility in Madison.

Contributed photo



Waiting on a dream

Hospice center for children
still on drawing board,
13 years
after
nonprofit
agency
formed

By Amanda Pinto
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MADISON — When Amy Kuhner walks across the wooded 8-acre parcel on Barberry Hill Farm, slated to one day become home to the Sunshine House, it's clear she's taken the walk countless times.

She doesn't seem to need the stakes — marking spots in a facility that will provide respite care for families with children with limited life expectancy, and end-of-life care for the children — to guide her.

Kuhner, president and CEO of Sunshine House Inc., can tell when a tree branch has fallen since her last visit. She looks at a sprawling field of leaves and bramble and points out where a handicapped-accessible footpath will be. Kuhner knows every detail and nuance of the Fort Path Road site, of funding goals and project plans.

The public knows very little.

Kuhner has been developing the idea for Sunshine House, and founded the nonprofit agency to create it, in 1996. She has declined to specify a timeline or an estimated total cost.

That lack of information, said Duo Dickinson, the local architect who designed the complex at no charge, comes from the desire to build a facility that is one-of-a-kind; there is no model from which to base estimates.

The facility will contain eight town-house style suites for children and their families, a separate cottage for bereavement care, a path through the sprawling 25-acre farm, a butterfly house and a "Starshine" room where parents can be with their children after the child dies.

It will also have around-the-clock nursing staff and a community living area including a dining room, library, home theater and music room.

Everything will be free of charge.

Kuhner's methods are atypical, Dickinson said.

Kuhner, a Yale Divinity School graduate, conducted an extensive site search, and her "ideal site characteristics" checklist included not only physical aspects of prospective properties, but

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Among those involved with the proposed Sunshine House hospice in Madison are, from left, family representative Bob Franchini of Branford, CEO Amy Kuhner of Madison, holding a model of the planned facility, treasurer Camille Murphy of Guilford and architect Duo Dickinson of Madison.

Sunshine: Proposed hospice center for children needs \$1.3 million

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also stipulated that the chosen site should have a "healing quality to land, good energy in general area."

The land Sunshine House Inc. purchased was not for sale, Kuhner said.

"I knew the land we were looking for would not be on the market. It had to be special," she said, adding that an intuition — one could call it providence, God, or the universe, she said — has guided all aspects of the process. It has taken her to England, where she visited children's hospices and Winston's Churchill's birthplace, where she was inspired to create the butterfly garden.

It is a reason, Dickinson said, this project has moved more slowly than others he has worked on.

"Time isn't of the essence," he said. "Being right is of the essence."

What's being done?

The project has come a long

way since Kuhner financed an initial feasibility study with student loans, she said.

Sunshine House, Inc., which is registered as a charity in the state Attorney General's Office, received \$850,000 in federal funding for the project in 2001. Kuhner said the organization has so far raised \$1.2 million — and that money has been used for feasibility studies and other project expenses.

"It's a unique building; the funding has really come from the parents of children who have gone through this nightmare scenario (of illness)," Dickinson said.

Dickinson has donated his time; Kuhner is the only salaried employee of Sunshine House, Inc., Sunshine House, Inc. Treasurer Camille Murphy said.

Her 2009 base salary is \$97,000 — with living expenses included, she is due to be paid \$100,600 — but she has not collected a salary this year because of lack of funds, Murphy said.

From inception to date, Kuh-

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Bob Franchini

ner has been paid about \$62,000 annually, Murphy said.

The 8.1-acre site was purchased from Kingsley Goddard for \$850,000, not using the federal funding, Murphy said. Although the nonprofit gained approval from the Planning and Zoning Commission to build on the site in August 2007, the land deal did not close until October 2008, Murphy said. Dickinson said the P&Z permitting will likely have to be renewed.

Kuhner also said the non-profit agency has secured status as a pilot children's comfort care center, and has brought on Perkins Eastman, and architecture and design firm experienced in both building for medically fragile children, and constructing the butterfly conservatory at the

American Museum of National History, to augment Dickinson's designs.

To pay Perkins Eastman, and greater define the interiors of the facility; Kuhner said \$1.3 million is needed for the next phase. She said she is working on establishing a public fundraiser for soliciting donations. Perkins Eastman has not yet provided a cost estimate, Kuhner said.

Once shovels are in the ground, construction will take about two years, Dickinson said.

WHO WILL BENEFIT?

Dr. Eileen Gillan, a pediatric hematologist and oncologist at Connecticut Children's Medical center, who has signed on as medical director at Sunshine

House, said when Kuhner first described the facility it was like a "dream I've had for my patients."

Gillan, who has been with Sunshine House since 1998, has cared for 150 children who have died, and seen her share of "horror stories."

One child's parents, unable to cope with the loss of their child, simply dropped the youngster off at a hospital to die, Gillan said. Another child, sent home with morphine to control the pain as the youngster was dying, was deprived of the medication. The child's parents took the morphine to get high, Gillan said.

At Sunshine House, children wouldn't have to die at home or in a hospital facility, they could be among peers, a butterfly garden and nature, Gillan said.

"What this is about is helping these families live and live quality existences, so we don't focus on the illness, we focus on living," said Bob Franchini, of

Branford.

Franchini's son, Paulie, died when he was 9 years old in 1997; Paulie could not walk or talk, and required constant care, because he was born with an umbilical cord wrapped around his neck.

Franchini said his family could have benefited from the Sunshine House; they could have taken vacations to the facility with Paulie, and utilized respite care.

Franchini said he is grateful to Kuhner, and proud to be a part of the Sunshine House project — an effort he said Paulie led him to.

"He smiled every day of (his life) and the things he taught us we would never have learned otherwise: tolerance, patience, how to do hard things," Franchini said. "Blessings still come based on his existence."

The Sunshine House Web site is sunshinehouse.org.

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