

One Place Like *Home*

For children fighting frightening illnesses, Adopt A Room and its remarkable volunteers have created a healing home away from home.

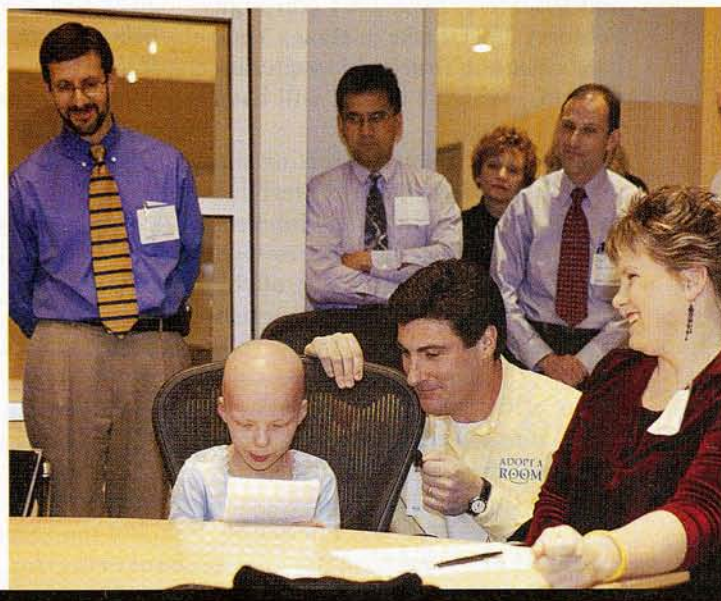
By Julia Nissim | Photography by Craig Bares

Born years and miles apart, two beautiful baby girls, one with deep brunette locks and a smile that lit up the room, the other with rosy cheeks, soulful hazel eyes, and sandy blond peach fuzz, fought—with high spirits and grace—for every day of the far too few they spent on Earth.

For eleven years, leukemia ravaged the body, but not the mind, of one of the little girls. As she shed her curls in chemotherapy, she collected several flashy wigs to match her vibrant, healthy attitude. The other, at the tender age of six months, was diagnosed with spinal muscular atrophy, which prevented her body from developing muscle. Despite a severely curved spine and limited mobility, she learned, with intuition and extreme determination, to bite her finger in order to turn her head so she could playfully interact with her brother and sister.

The two girls' spirits never wavered, yet their bodies were weak and badly scarred. Katelyn Schepperle, age eleven, and Madison Millington, age two, died within thirteen months of each other. From the legacy of the two precious little girls and their unforgettable spirits, one pioneering Twin Cities organization aims to comfort many seriously ill children just like them.

Adopt A Room, founded by Brian Schepperle and Dave Millington in honor of their daughters, is the first nonprofit organization of its kind in the country to renovate children's hospital rooms through corporate and private sponsorship. Seriously ill children and their families spend days, weeks, and months at a time in the hospital battling disease, but oftentimes their surroundings, not to mention their situation, are less than comfortable. AAR's philosophy is that in the face of illnesses that are virtually uncontrollable, parents and children can and should have the power to control their environment. Based in White Bear Lake, the organization works to create



Schepperle passionately explained, the disease was out of



At a focus group, Eric Ruegsegger (above) had lots of great ideas, including adding Playstation and other fun things to do. Brianna Hestekin, left, told the group how much she loved gym, Christmas, her family, and her second family—her doctors and nurses. “I tell the nurses my feelings,” she said.

what it calls a win-win-win situation for children, their families, and the hospital staff—a room that, despite being in a hospital, is similar to the one a child has at home. John Schreiber, MD, head of pediatrics at the University of Minnesota Children’s Hospital, Fairview, serves on the organization’s patient-care advisory board and has worked with Schepperle, Millington, and AAR from its inception. “I met a group of businessmen who had been distressed by the infrastructure of standard hospitals, particularly how it affects children. Their idea was that parents really lose control when a child’s ill. Why couldn’t it be that at least in the room where they stayed, they could have control? The environment, the lighting—the child and parents can really regulate the environment of the room.”

Until just a year and a half ago, Adopt A Room was merely a vision in Schepperle’s mind. Desperate for consolation and searching for someone to whom he could relate, Millington approached Schepperle at the Dellwood Hills Golf Club near their

homes on a night in mid-August 2004. Although it was an ambush of sorts, Schepperle welcomed the opportunity to console a man who was painfully overwhelmed with the anticipated loss of his daughter—Schepperle had been in his shoes just a year earlier. Aware that he could not ease the pain, Schepperle offered up the only other thing he had to give Millington—an idea. Adopt A Room was Schepperle’s vision, but Millington clung to it, believing it was destined to become a reality.

Not more than a week later, their shared vision wound up on the doorstep of the Minneapolis office of Perkins+Will, an architecture firm especially well known for designing facilities in the health care sector. Chuck Knight, office managing director, was working on some initial drawings for a new University of Minnesota Children’s Hospital, Fairview, when Millington, his close friend and next-door neighbor, dropped by to chat about AAR. Knight agreed that the idea was great, but cautioned Millington, “You can’t do a room, you gotta do a floor, but really you can’t do a floor, you gotta do a hospital.”

In September of 2004, AAR met for the first time with the U of M and several doctors—many with whom Schepperle had become personally acquainted during Katelyn’s treatment—and they readily agreed to AAR’s proposal.

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their hands, but the environment was at their fingertips.

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Three existing rooms in the U of M hospital were slated for renovation—and the possibility that AAR's design concept would be implemented in the new children's hospital, scheduled to open in 2010, was promising.

Four months after that late-night, golf-course chat, AAR was an up-and-running nonprofit organization complete with a board of directors from various companies around the Twin Cities, a secured location for renovations, and a world-renowned health care architecture firm designing the state-of-the-art rooms. Finally, AAR could bring into the project the most important group of people—the real experts who have lived in the hospitals with the gray walls, confusing, big machines, and lumpy beds next to stiff plastic chairs—the children.

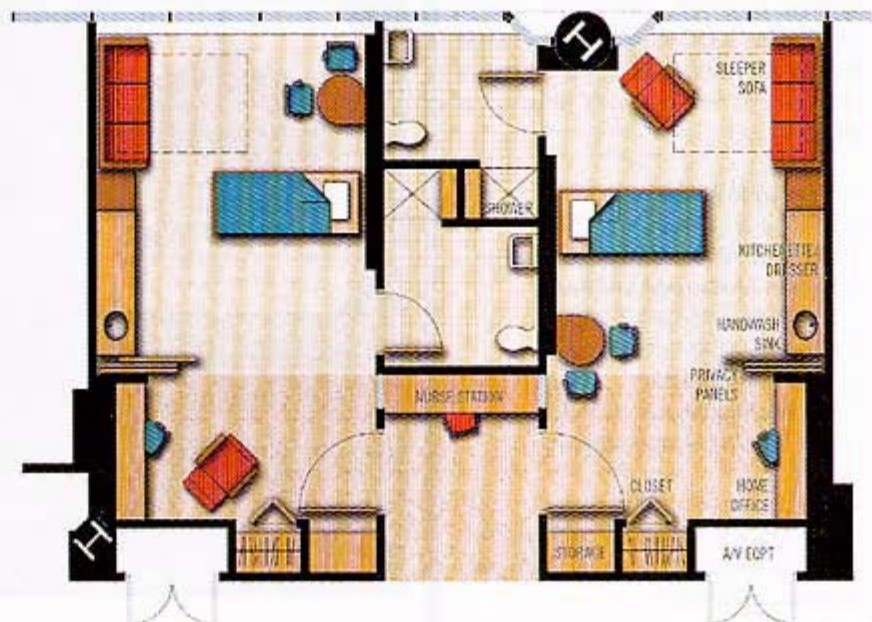
In the downtown Perkins+Will office, many separate but equally important powerhouses—kids, parents, doctors, and architects—gathered on a chilly winter night in December of 2004 to discuss how to transform an average hospital room into a healing haven. Eight-year-old Brianna Hestekin greeted the crowd. In a raspy little girl's voice, with the light creating a soft glow around her bald head, she thanked everyone for coming. Brianna, suffering from Ewing's sarcoma, a

rare form of bone cancer, visited the U of M hospital every three weeks for chemotherapy. She told the room how much she loved the gym, Christmas, her family, and her second family, the nurses and doctors at Fairview. "I tell the nurses my feelings," she said. Following Brianna, Schepperle passionately explained the purpose of the evening to the crowd: The disease was out of their hands, but the environment was at their fingertips. By gathering families and getting patient input to redesign the environment, it could give kids back some control over their lives. His voice wavered for just a moment, as if to overcome a lump in his throat, and he said, "Tonight we begin to create a home away from home."

That night, the kids and parents separated into two groups while the architects and doctors went back and forth between the two, facilitating discussions, gathering input. A petite mother with wavy light brown hair slightly frazzled from a long day actively contributed

Two rooms at the U of M Children's Hospital, Fairview, will be completed this month. The floor plan (below) and computer rendition (above) were based on ideas from kids and their families.

to the parents' brainstorming session. Kasey Ruegsegger gave several ideas for the room from a parent's perspective, but stressed that there was surely one thing



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that would make a dramatic difference—a better place for parents to rest. In the kids' meeting, her son Eric, who had been in and out of the hospital with alveolar rhabdomyosarcoma since the summer of 2003, was energetically offering up his ideas. He wanted more fun things to do in his hospital room, like play Tiger Woods Golf, a video game that he managed to start up—during the session—on a nearby Perkins+Will TV equipped with Sony Playstation.

The resulting parents' wish list included a more comfortable sleeping



area, a coffeepot and minifridge, more storage for personal items or food, private rooms and bathrooms, and a place where they could try to catch up on work. The kids' wish list, a bit more whimsical, and rightfully so, included lava lamps “with the little kinda goo in it,” a ceiling that changed from day to night, TVs with Internet capability, Playstation, and online movies “like in hotels,” night-lights for nurse check-ups, and privacy signs that read, “Do not disturb—OR ELSE!”

To the combined group, members of the Perkins+Will team read the parents' and children's lists, reminiscent of a five-star hotel listing—bigger, better beds, storage space, Internet capabilities, a high-tech TV system, great lighting, decorations, a fridge, and coffeepot—“so you don't have to go out of the room 10 million times a day like Mom does,” Brianna said.

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rooms was the only matter left to configure. Kraus-Anderson Construction, a local company with a well-documented list of health care clients, stepped into the action in the winter of 2005. Executive vice president Gary Hook personally committed himself and the company to providing AAR with the finest of Kraus-Anderson services indefinitely. Kraus-Anderson also provided resources to

Twin Cities celebrity chefs. Golden Ticket Golfing also marked the beginning phase of construction at the University of Minnesota Children's Hospital, Fairview.

The "showcase rooms," as AAR, Perkins+Will, and Kraus-Anderson refer to them, are three regular rooms that were converted into two more spacious private rooms on the fifth floor of the U of M's East Bank facility. From every angle, every fabric,

clients and their families with everything they need to feel good: State-of-the-art technology includes an oversized sixty-inch plasma screen on a Magicwall system facing the bed; a lighting system equipped with a multitude of different color palettes and designs, even the sky and stars, to decorate the ceiling; and a bedside touch screen to control it all. The room's numerous machines, which were once clearly visible, are hidden in a "headwall," an exclusive wood-

The new rooms are full of magic and a bit of mystery.

help execute AAR's first annual fundraiser, Golden Ticket Golf. With candy-colored decorations and golden-hearted guests, the Willy Wonka-themed event this August raised awareness for the organization—and \$100,000—with an afternoon of golfing, auctions, and dinner cooked by

every storage shelf and shimmering fixture in the two rooms, completed this month, reflects AAR's mission—donor-sponsored hospital rooms that feel like a home away from home for seriously ill children.

The two new rooms are full of magic and a bit of mystery, providing pa-

paneled structure behind the bed. Most important, the comforts of home are everywhere. There's plenty of storage for clothes, food, and personal items. There's a kitchenette in the room and a separate area, with Internet and phone access, where parents can work. Near the bigger,

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For more information on Adopt A Room, donations, or next summer's golf event, write to Adopt A Room at PO Box 10504, White Bear Lake, MN 55110 or visit AAR's website, adoptaroom.org.

family and friends in the face of an uncomfortable, frightening illness.

Two beautiful baby girls inspired two groundbreaking, healing rooms. One Twin Cities organization, created out of the hope that the restoration of a room would renew the fighting spirit of the soul, has changed the entire philosophy behind patient care.

Schepperle notes that Adopt A Room hopes to bring in more corporate and private sponsors for the next wave of renovations soon.

"People want to give back, but they don't know how," says Schepperle. "This has a direct impact—it's one of the few things we can do to make things better. There are millions of dollars in research that may benefit kids in three to ten years. We may lose a lot by then. This is how we enjoy the ride now." ♣

Julia Nissim is a freelance writer living in Chicago and former Mpls.St. Paul Magazine intern.

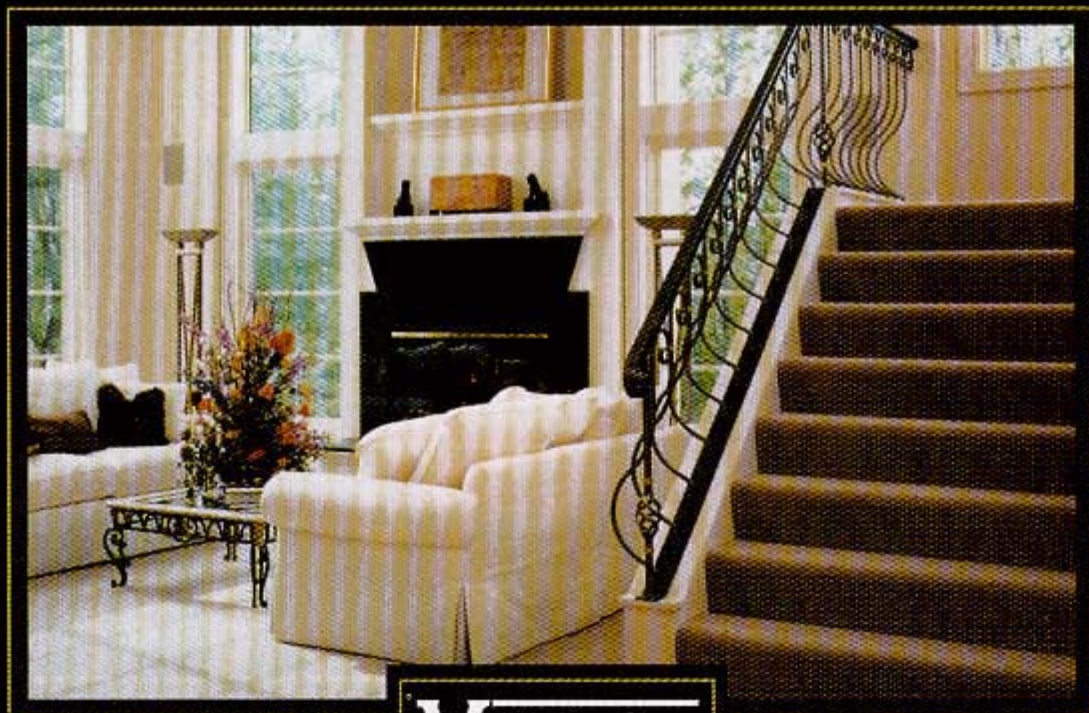
fluffier patient's bed is a custom-made pullout bed for a parent—and centrally located, private bathrooms complete with Hans Grohe "rain" showers and special tiles lining the floor that gently illuminate at night. And these two rooms are only the first of many.

"Our plan is to transport this philosophy to all of the rooms in the new hospital," says Schreiber. "We look at it to distinguish the new Uni-

versity of Minnesota hospital. Minnesota is used to leading, and this again will put us on the map in an area that's very exciting. We're at the forefront for children's hospital design."

Finally, Adopt A Room has made a place in honor of Katelyn and Madison, in honor of Brianna and Eric, who both died during the year, a place where a child can renew his or her sense of wonder, refresh the spirit, and feel comfortable with

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