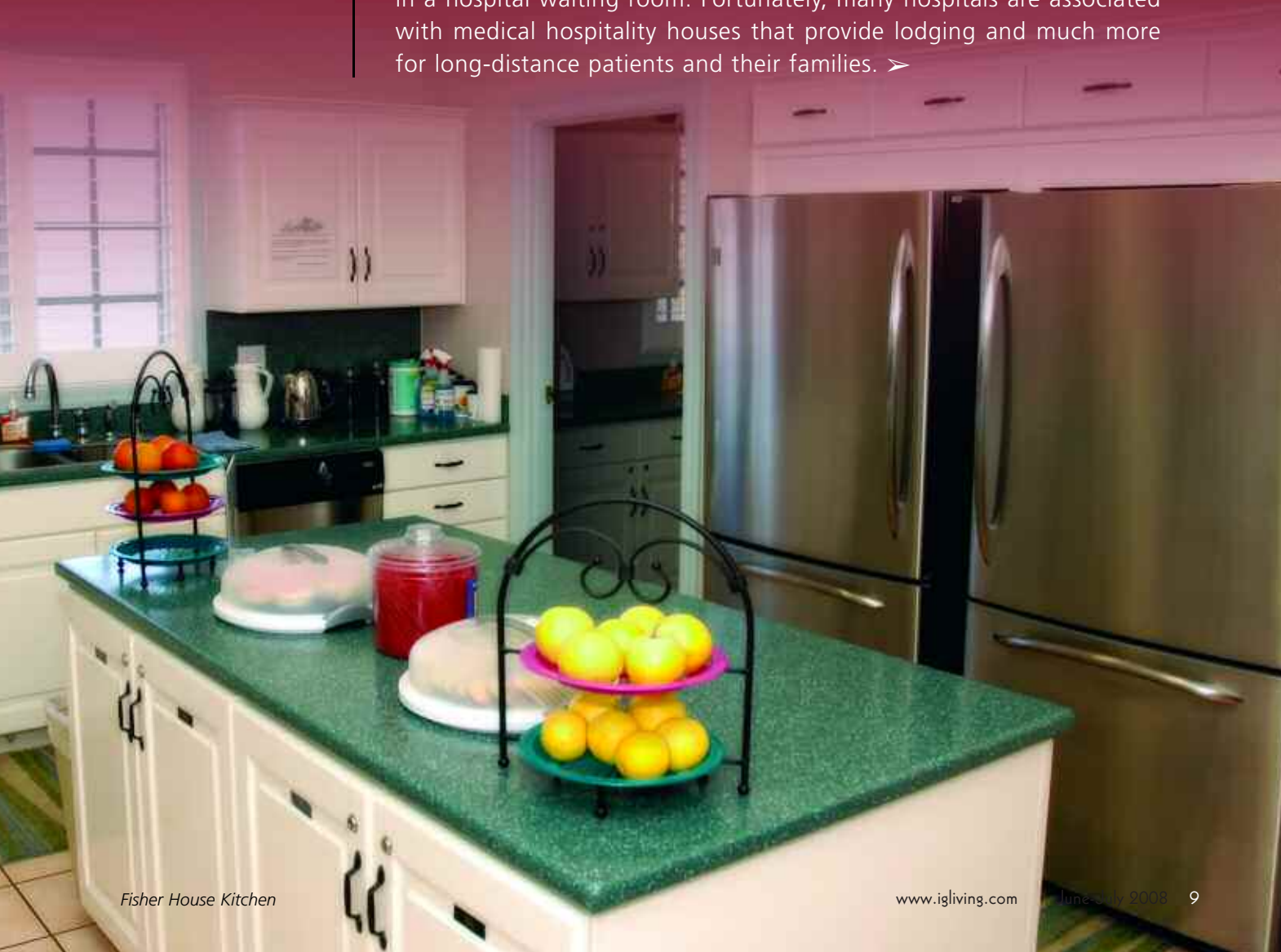


HOME AWAY FROM HOME

By Lauren Gerstmann, MPH

still where the heart is

Hospitality houses are like friends who'll take you in when you need to travel for medical care. It is easy to move heaven and earth to care for a sick loved one, but it is not as easy to move them or yourself. Hotel bills rack up quickly, and you can only spend so many nights on a chair in a hospital waiting room. Fortunately, many hospitals are associated with medical hospitality houses that provide lodging and much more for long-distance patients and their families. ➤



Hospitality houses can be located through the National Association of Hospital Hospitality Houses (NAHHH). More than 150 hospitality houses in the United States are affiliated with NAHHH. Each NAHHH house “assures that a homelike environment is provided to persons who must travel to be with a patient or to receive necessary outpatient care.”¹ Just as helpful, NAHHH keeps a comprehensive database of all the U.S. medical hospitality houses—even those that aren’t affiliated with the association. To view their listings online, visit www.nahhh.org. You can search by state or by house name.

Some of the best-known programs, the Ronald McDonald House Charities and Fisher Houses, are not affiliated with NAHHH. Though these organizations’ houses are listed on the NAHHH website, more extensive information can be obtained by contacting the specific organization or an individual house. Ronald McDonald Houses serve families traveling for medical care for their children, whereas Fisher Houses serve military families.

The Ronald McDonald House Story

The first Ronald McDonald House was founded in Philadelphia in 1974 by Philadelphia Eagles player Fred Hill and Dr. Audrey Evans, a pediatric oncologist and philanthropist. Hill, whose daughter had won her battle against leukemia, wanted to help the hospital that saved her life. Ten years later, the house had made so much of an impact that a larger charity was formed to create similar hospitality homes near other children’s hospitals. The charity was established “in memory of McDonald’s founder and children’s advocate, Ray Kroc ... to help seriously ill children and their families and to continue the success of the first Ronald McDonald House.”² The organization is decentralized, with each house operating independently but following guidelines and standards set by a global headquarters financed by the McDonald’s corporation. Headquarters provide general advertising and fundraising assistance, but each house is a separate entity with its own board of trustees.

The McDonald’s standards ensure that Ronald McDonald Houses, which host families from all over the world, are cheerful spaces. Patients and their siblings have bountiful play space, and guests can share meals and company in

beautiful common rooms. Patients can stay there when they leave the hospital, and families can stay there during their children’s hospital stay. Each Ronald McDonald House is just minutes away from doctors and emergency facilities. The houses are designed with large kitchens that have multiple cooking stations. Since the Boston Ronald McDonald House pioneered bone marrow/stem cell transplant suites in 1985, many of the houses now include special accommodations for the most vulnerable patients and their families. Volunteers bring food and entertainment to the guests. At the Ronald McDonald House in Washington state, volunteers donated so much time that in 2006 their hours totaled the equivalent of 11 full-time employees.³

In Cincinnati, the Ronald McDonald House is within walking distance to the Children’s Hospital and the zoo. On some evenings, zoo staff bring animals to visit families. Jennifer Goodin⁴, executive director of the Ronald McDonald House in Cincinnati, sees the house as a place where she “hopes [guests] would feel as comfortable as they do in their own home,” and that they would “allow staff and volunteers and the whole community to take care of them at this difficult time and that they would find strength in the other families that are going through the exact same thing ... that they will find hope.”

In addition to amenities such as Internet connections, playrooms and communal areas, the emphasis is on creating a safe sense of community. Jennifer successfully campaigned to shut down a dangerous bar across the street. “The police had all these statistics, and there was something like 600 police calls to that site each year; something was going on every day,” including drug deals and gang activities.



Jennifer Goodin plays with Ronald McDonald House children

¹ www.nahhh.org.

² www.rmhc.org/about/history-of-ronald-mcdonald-house-charities.

³ www.rmhcseattle.org/news/house_facts.php.

⁴ Interviewed on 1/31/08.



Fisher House living room, bedroom and common area

Due to her petitioning, the state board of liquor control refused to renew the bar's liquor license.

Emotion is audible in Jennifer's voice when she talks about the house and its occupants. Next to the birth of her own children, the most memorable day in Jennifer's life was the day she helped deliver a baby boy on the lobby sofa. A woman from Indiana with a high-risk pregnancy was staying in the house so that as soon as she gave birth, her son could be taken for heart surgery. The woman went into labor so quickly that she couldn't make it to the hospital next door. The whole staff supported the birth, wiping her forehead, coaching her breathing and calling paramedics to take the baby to the hospital right away. Years later, Jennifer still keeps in touch with the family,

The Cincinnati house, which doesn't have a particular emphasis, works closely with the entire children's hospital next door. The hospital draws patients from all over the globe, and the physicians know that it is critical that their families have a safe and affordable place to stay near the hospital. When Marc Leavitt, a renowned surgeon, was recruited to Cincinnati Children's Hospital, he visited the

Ronald McDonald House before making his decision to join the surgical team.

The house always has a waiting list of about four to five days. Given that families cannot make a reservation in advance of their visit to Cincinnati, most find other accommodations for at least part of their stay. This, however, is about to change. With the support and endorsement of the hospital, a much-needed expansion is about to break ground. The Cincinnati house is adding 30 rooms (bringing the total to 78) with a targeted completion of February 2009. Fifteen of the new rooms will be transplant suites. The goal is that it will still feel like one house: The existing kitchens and dining rooms will expand, maintaining the social heart of the house. The expansion should reduce the waiting list from about 25 to 30 families per night to five to 10.

The support families feel in the Ronald McDonald House cannot be overestimated. One mother says, "From day to day, I did not know whether my 2-year-old son would need more surgery or be able to go home. We were separated from his father and his brother, but he was happy in ➤

the house. Six months later, he asks me when he can return to the 'old McDonald House' to see his friends and ride the elevator!" She continues: "It was incredibly moving and inspiring to meet other families at the house and to experience the caring of staff and volunteers. One Friday night, after we learned we would soon go home, we wanted to express our gratitude with Shabbat candles, wine, and challah [ceremonial bread]. All of our new friends joined us—Christian, Jewish, Muslim. We put our arms around each other and broke bread in honor of our children."

The Fisher House Story

Active-duty military personnel are often on the move. Serving all over the world, some must travel great distances for specialized medical care. To assist military personnel and their families, the Fisher House program was developed in 1990.⁵ Partnering with private philanthropists, Zachary and Elizabeth Fisher originally endowed the organization. Each major military medical center has at least one Fisher House. Designed in a similar fashion, the houses meet the Fishers' standards; most importantly, each feels like a home.

Propelled in part by the increased number of combat casualties in Iraq, the program is now expanding. But, the program is not only for injured military personnel.

A significant portion of military families who use the Fisher House are traveling for treatment of a civilian family member.

As director of the Fisher House as well as of Morale, Welfare and Recreation (MWR), Tim Scully wears two hats. The two programs at the Naval Medical Center in San Diego offer support and respite, with Fisher House guests able to use the workout facilities at MWR to relieve stress.

The Fisher House provides housing that is almost "like grandma's house or a bed and breakfast." Guests have their own rooms, but share a kitchen, living room and dining room. Amenities such as common rooms, secluded areas, televisions, Internet and workout facilities are available. Tim's goal is to "make sure that the [high] standards of the Fisher House are met ... We are not trying to provide something that is basic housing. We are trying to provide the best housing—the most comfortable environment with the most compassion." He continues: "Our role really is to make sure that the families staying here have every care taken care of. If we don't provide it, we find it for them."

The San Diego house follows Navy guidelines, which give priority to active duty soldiers and their dependents. But retired military personnel are also eligible. Although

this house gives priority to family members of combat victims, guests are just as likely to be visiting an ill patient as a wounded patient. According to Tim, the houses were built long before the war started, and will be here long after this war. The house is almost always full.

Despite the high occupancy rates, families are rarely turned away. If they cannot be accommodated at the house, the house will work with other organizations (including the Fisher House Foundation) to make sure that their hotel expenses are paid. But the demand keeps growing. Fortunately, more houses are in the works. Right now, there are 38 houses and five more are under construction. At the San Diego Naval Base, a second Fisher



A Fisher House

⁵ www.fisherhouse.org/aboutUs/aboutUs.shtml.

House is being built next to the first. They will be close enough together to share their outdoor spaces. The new house will add 11 rooms with slightly bigger rooms and kitchens. It was scheduled to be finished just in time for Memorial Day.

Fisher Houses were originally designed to offer short-term respite for acute medical events. In San Diego, the average stay is 12 days. When the program started, families made other arrangements if they needed housing for more than 30 days. According to Tim, this requirement is no longer enforced. Much is based on the needs of the guests and the needs of the patients. At an Army Fisher House in Washington, D.C., some guests stay for years (see Nick's story).

Tim talks about camaraderie at the house, and says it is inherent in the way the homes are designed. "Anytime I go over there, I tend to see at least two families together ... [The design] promotes that, and encourages people to eat together—fairly large kitchen ... incredible yard, gazebo ... areas where people can congregate, share stories, vent—whatever the case may be." It is no accident. From the beginning, Fisher Houses were deliberately designed to be more like private homes than hotels. They offer spaces for seclusion, and places to gather.

Tim's motivation is, in part, personal. He knows firsthand how important it is to have a place to rest and refresh when a loved one is hospitalized. In 1990, Tim's mother passed away from cancer three weeks after he learned of her diagnosis. "I was lucky enough to see her in the hospital before she passed away [but I] slept in the waiting room for a few days." He says that being able to rest, restore, and spend time with his brothers and sisters at a comfortable place would have been invaluable. Offering this type of respite to the Fisher House guests is his passion.

Occasionally, Tim becomes personally involved. "I do photography, so sometimes I offer my photography to them," Tim says. A beautiful photograph can create a special memory even of the most difficult times. "I am very proud to be a part of [this]," says Tim.

One house guest, Misty,⁶ stayed at the San Diego house while her husband had knee surgery. Caught up in the stress, Misty had not thought about where to stay while her husband recovered. His surgeon made arrangements for Misty at the Fisher House. The house was "really homey, I liked it a lot," says Misty. "I was really thankful to have a place to go where I could take a shower; I could rest



Fisher House dining room

if I needed to." It is a beautiful facility with comfortable furnishings, high-quality appliances, and all the current technology. Internet access at the house was a big comfort to Misty, because it meant she could keep in touch with her family. "It was kind of like a home away from home, because you could do your laundry there, and you could cook, and you could relax ... It was really nice."

Fisher Houses are financed through private funding and donations. Volunteers also donate their time. Volunteers at the San Diego house relandscaped the grounds. In Washington, D.C., a volunteer is building new cabinets. Most volunteers have an emotional connection to the houses or the military. But awareness is also increasing among high-profile celebrities and politicians. Larry King and Denzel Washington are major contributors, and California Gov. Arnold Schwarzenegger has visited.

The Ronald McDonald House and Fisher House programs are two examples of places to stay when traveling for medical care. Many other wonderful housing programs are out there that are dedicated to providing the comforts of home. They are easy to locate online through the National Association of Hospital Hospitality Houses, or by talking to a doctor or care coordinator at a hospital. Medical travel is inherently stressful, but small supports can make a big difference. ➤

⁶ Interviewed on 2/24/08.

Radel's Experience at the Ronald McDonald House

George and Corinne Brewer first met Radel Vasquez a few years ago when he came to the United States from the Dominican Republic for orthopedic surgery. The Brewers volunteered for Healing the Children,⁷ an organization that sponsors doctors and volunteers to travel around the world to provide medical care. The organization also sponsors children who cannot find care in their own country, making it possible for them to travel to the United States for medical care. For the past 25 years, the Brewers have hosted children who need acute care. After Radel's surgery, the Brewers thought they might never see him again. But as soon as he returned home, Radel developed signs of Fanconi anemia, a genetic disease that causes problems with a patient's stem cells and eventually leads to leukemia. Radel was accepted into a research study at Cincinnati Children's Hospital. Despite that the Brewers live in New Jersey, they once again stepped in to help. George had recently retired, so they felt that they could provide 8-year-old Radel with the time and intensive support that he needed. George says, "Normally we had kids come for a couple of weeks, a couple of months ... it was in our

home, and they were like one of our children. Going to Cincinnati was a big project."

In 2007, the Brewers and Radel spent 10 months at the Ronald McDonald House in Cincinnati. "That place is wonderful ... It was clean, friendly, [everyone was] reaching out," comments George. He felt strong support from the staff and volunteers. "There was a different meal, and a different cook, and a different provider [every night]." The Brewers felt supported not only by the house, but also by the whole community in Cincinnati. Their stay in Cincinnati soon lengthened from an expected 100 days to 250, but the house made it feasible. Radel even thinks of it as a positive experience. He told me, "It was good. [I liked] the people and all," and he enjoyed playing with the kids and toys there. George says that the staff and volunteers made his family feel at home. Radel would often sit behind the registration desk and pal around with the staff.

Radel was discharged from the hospital within a month of getting a curative bone marrow transplant. At the Ronald McDonald House, Radel was able to play with other children between his frequent hospital visits. He

Fisher House Facts

- Serving military families traveling to visit hospitalized relatives
- Whether patients stay in the house varies from house to house
- More than 10,000 military personnel and their families have been served annually since 1990
- All funding is raised privately; houses may not actively solicit donations
- Families do not pay for their stay
- Every major military hospital and many VA centers have houses
- 38 houses currently exist, five more are under construction

For more information or to make a donation, see: www.fisherhouse.org.

To learn about the San Diego Fisher House, see: www.nmcsd.med.navy.mil/service/services_view.cfm?csid=88 or call 619-532-9055. To learn about the Washington, D.C., Fisher Houses, see: www.wrampc.army.mil/visitors/visitservice/meals/fisher/Pages/default.aspx or call 202-545-3218.

Ronald McDonald House Facts

- Serving seriously ill children and their families who are traveling to children's hospitals for medical care
- Children may be traveling for inpatient or outpatient care
- More than 10 million children and their families have been served
- As long as the stay is medically necessary, there is no limit on length of stay
- Houses are not medical facilities, although patients may receive home healthcare services
- Houses are financed by private donations
- Families are asked to pay between \$5 and \$25 per night, but this fee is waived in cases of financial hardship
- 271 houses in 30 countries

For more information or to make a donation, see: www.rmhc.org.

For more information or to donate to the Cincinnati Ronald McDonald House, see: www.rmhcincinnati.org/home or call 513-636-7642.

⁷ For more on Healing the Children, please see www.healingthechildren.org or call 800-992-0324 or 509-327-4281.



Radel Vasquez

wore a mask to protect his recovering immune system, but many of the children in the house wear masks, so his illness did not set him apart or isolate him. The Brewers kept Radel occupied without jeopardizing his health. They took him on outdoor activities—to baseball games and to the zoo—and the Ronald McDonald House helped arrange tickets for everything. The entire time, Radel was in touch with his family back home. His mother has sole care of his siblings and is the only financial support that the family has, but she was able to travel to America to support Radel around the time of his transplant, and the Ronald McDonald House welcomed her as well.

“The people in the house were extremely good to him, and to us as well,” says George. They became close with staff and volunteers. When the Brewers returned to Cincinnati with Radel for a three-month follow-up, they went to dinner with one of the front-desk volunteers and her family. George still speaks with amazement about their experience in Cincinnati. “There is a waiting list for groups to provide meals [to the houseguests].”

Nick's Experience at the Fisher House

Just over a year ago, Nick lost his leg in the war in Iraq. Originally based out of North Carolina, Nick was shipped to the Walter Reed Army Medical Center in Washington, D.C., for medical care. When first out of the hospital, Nick stayed at the Malogne House on base. But the cramped quarters didn't have cooking facilities, and Nick wanted to be somewhere that would help him learn to be back in the “real world.”

The Fisher House was a great improvement. Nick has his own room and bathroom, as well as areas to cook, eat and socialize. Being around other veterans has been invaluable. “It really helps being surrounded by guys who are going through the exact same thing that I have.”

For Nick, the best thing about the Fisher House is that it is a community. The house in Washington, D.C., is small enough that Nick has gotten to know everyone there. Houses vary in character, and the manager of the house in Washington, D.C., discourages personal relationships between staff and guests. Even so, the staff has been warm. Everyone will “bend over backwards to help you.” Nick speaks particularly fondly of one man who “cares about the people here, and he doesn't mind showing it.” Right after Nick's surgery, he would run errands for Nick, knowing that Nick couldn't drive.

For Nick, the Fisher House is home. When he first arrived, his wife, Krystal, was on bed rest while pregnant with their first child, so his mother cared for him. Now his wife is with him. It isn't easy; their two children are staying with Krystal's mother in North Carolina—one is 15 months old and the other (their “happy accident”) is only 3 months old. But Nick is just out of surgery and is not far enough along to have the kids around. Hopefully, they will be able to join them soon. It will be a year before Nick is ready to leave his doctors and the Fisher House. In the meantime, the Fisher House is providing him with a place to create a new community and to reunite with his family while he heals.

Other Housing Options

If a hospitality house is not an option, alternatives exist. Some hospitals work with local hotels, apartment managers and corporate housing offices to provide significantly discounted short- or long-term lodging. A care coordinator can provide details about options. Also, those affiliated with a religious group should check if local resources can provide food, lodging or support. ■