



HHF Founder Denise Redeker finishing her first 5K with her new heart

Case for Support in 2024

Summary

Heartfelt Help Foundation is a nonprofit that helps financially-challenged heart transplant recipients in Northern California pay medically-required transplant-related expenses when their insurance won't and they can't. HHF is funded entirely by donations.

Need for Change / Opportunity for Social Impact

Heartfelt Help Foundation (HHF) was formed in 2020 by Denise Redeker following her struggles to locate, afford, and retain required near-hospital recovery housing after her heart transplant in 2018. She later heard a conversation between a nurse and a hospital social worker about postponing a heart transplant until the candidate bolstered their personal finances to pay for required after-transplant recovery housing near the hospital that insurance wouldn't cover.¹ Another person told Denise that his daughter recovered from her heart transplant while living in their car because the hospital offered no housing assistance other than a referral to a homeless shelter. Denise committed her second chance at life to bridging these gaps.

According to the US Centers for Disease Control and Prevention (CDC), the relationship between income and health is well established. Lower socioeconomic status is associated with higher risk of developing and dying from cardiovascular disease. Heart transplant is a potential treatment (not a cure) for end-stage heart disease or sudden heart failure, and the procedure saves thousands of lives each year. The number of people who have received a heart transplant with its intense surgery and recovery processes has consistently increased. Ongoing improvement of the science indicates the number will continue to rise. What's not commonly known is that a medically required core component of after-hospital recovery is temporary housing near the hospital until the recipient is stable enough to return home.² Frequently, this cost is not covered by private, public, or government insurance.³ This uninsured expense can be a great hardship, unattainably costly, or adversely impactful on recovery for people who simultaneously suffer financial distress *and* end-stage heart disease or heart failure. Some people don't have the means to pay for both their home and temporary residences along with the many other uninsured transplant-related expenses.

¹ KFF Health News reported a similar situation then added, "It happens every day," said Arthur Caplan, a bioethicist at the New York University Langone Medical Center. "You get what I call a 'wallet biopsy.'" <https://kffhealthnews.org/news/no-cash-no-heart-transplant-centers-require-proof-of-payment/>

² Stanford Hospital's Heart Transplant Program says "After your heart transplant, we ask you to stay within a 30-minute drive of Stanford for three months for your follow-up care." Actual stays depend on recovery progress.

<https://stanfordhealthcare.org/medical-clinics/heart-transplant-program.html>

³ Insurance covers nearly all *medical* services and products associated with the transplant, but this housing is a hotel or apartment, not a medical rehabilitation facility. Milliman Research estimated that for year 2020, the billed medical charges for a heart transplant would be \$1,664,800. <https://www.milliman.com/-/media/milliman/pdfs/articles/2020-us-organ-tissue-transplants.ashx>

Denise was deeply moved by the conversation because the person was an inpatient with little way to raise the money personally, and certainly not quickly. She later learned he was a 40-year-old widower with three dependent children, only modest resources, and no family or friends able to support him. Denise soon held a fundraiser at her home which raised \$12,000 so he and a second patient would have the ability to pay for good quality recovery housing.

The months immediately following a transplant are fragile for recipients.⁴ As such, doctors require them to relocate and live within a few minutes of their transplant hospital for follow up care and emergencies for at least one and often several months. Doctors rarely can forecast one's hospital discharge more than a day or two in advance and they can't predict much in advance the discharge to go home (the lodging duration), because both depend on recovery progress. These unknowns prevent people from securing favorable housing types, locations, and rates on their own. Doctors require recovery to a higher level of stability when people live afar or have a complicated condition.

RC lived in Hawaii and needed a new heart but there is no transplant hospital there. Because home was too far away to arrive in time when "the call" came, he had to relocate to San Francisco while waiting. A family member was able to host him for those several months but had moved away while he was in the hospital. He was a modest wage earner who had been unable to work as his heart deteriorated. After discharge, his doctors required him to remain nearby until he was especially stable because transplant-specific care wasn't available at home. HHF paid for the 6.5 months of recovery housing he needed.

The San Francisco Bay Area hospitals that refer patients to HHF are among the best in the nation and people come from all over the country to receive "the gift of life." However, after discharge, they must be housed in some of the highest cost-of-living regions in the country.⁵ Lodging is charged on a daily basis, so a longer recovery has a larger total cost. Large uninsured expenses can exhaust people's resources from availability for other requirements and needs. Some people don't have the funds to even begin paying the expenses.

⁴ The fragility results from a combination of the heart acclimating in its new home, the large chest incision and separated sternum are early in their healing, deep immunosuppression that creates high risk of infection from touching, breathing, or consuming contaminants, dysfunction of other organs, side effects of the many new medications, mobility limitations and imbalance, and post-traumatic stress.

⁵ The hospital-sponsored Stanford Guest House hotel advertises "below-market rates" and charges recovering patients \$229 per night (no kitchen). Heartfelt Help Foundation does not refer people there.

SM was age 22 when she finally received simultaneous transplants of her heart and liver at a SF Bay Area hospital. At birth, doctors found she had only half a working heart. Throughout her life, she endured multiple procedures, heart surgeries, complications, and many sets of multiple months in hospitals. Treatments for her heart damaged her liver. She lived in Nevada where there are no transplant facilities. When transplants were the only realistic treatment remaining, her condition was so uniquely complicated that two transplant hospitals in other states would not accept her. She spent a year and a half as an inpatient waiting for and recovering from the transplants. Charges for her recent medical care totaled over \$7 million. Her parents traveled between the hospital and home to monitor, comfort, and advocate for her, to care for her twin sister at home, and for one parent to continue working to maintain their health insurance. They depleted their resources during years of unreimbursed medical-related expenses and travel. After the transplants, HHF helped them pay for two months of recovery lodging which their insurance wouldn't pay.

People enter the heart transplant process from all walks of life. Some enter in financial distress due to one or more of the many possible and realistic no-fault factors.⁶ Fortunately, the life-saving surgery is extended to more than just those who can afford the uninsured expenses, but some people need financial help as they begin their second chance at life.

TW is the single parent of an infant daughter who needed a new heart at nine months old. She left her modest-wage job to be with her daughter for the 341 days they spent together in the hospital before and after surgery until discharge to nearby recovery housing. While in the hospital, TW continued studying toward becoming a nurse. Temporary lodging was not covered by their Medi-Cal insurance, and it was unaffordable for them. HHF paid for 2.5 months of lodging near the hospital tailored to their needs.

⁶ The many situations include low wage employment, unemployment from disability as their hearts declined, forfeited employment to care for a child with a fatal heart condition, modest and dwindling savings, debt from medical care in the months or years before the transplant, large copayments and deductibles, costs for treatment or pharmaceuticals that exceeded insurance coverage, costs for medical-related travel, costs for medical equipment or supplies, and family and friends unable to provide support.

Organizational Overview

HHF is a 501(c)(3) nonprofit, public benefit, direct service organization which helps heart transplant recipients from the SF Bay Area hospitals pay for their required post-transplant housing when their insurance doesn't cover it and they themselves lack the means to afford it. No one else in Northern California helps heart transplant patients the way we do.

HHF partners with the hospitals' social workers who independently and knowledgeably determine people's financial need for HHF's services. HHF fosters relationships with near-hospital lodging providers to identify suitable sites that accommodate our beneficiaries' unique needs, have availability for short notice reservations, and allow flexible length stays. HHF negotiates reduced rates to most efficiently and effectively use the funds donated to us.

In addition, from her first-hand experience, Denise mentors transplant patients through the stresses of their situations and helps them make the best of the life changes that come with being a heart transplant recipient. She also educates the public about organ donation and transplant.

The outcome is that people in financial need receive essential help, promptly when and where necessary to best recover. HHF helps position people to have close access to follow-up or emergency medical care. HHF enables people to begin their second chance at life in a place that facilitates steady and reliable recovery,⁷ of the same quality used by people with larger resources. With HHF support, transplant recipients are not forced by their financial weakness to stay in substandard accommodations which could risk, impede, or reverse their recovery while they are fragile.⁸ People return home with a new lease on life from the surgery, and, following HHF support, can become as strong physically, financially, and emotionally as possible since the initial recovery was not inhibited by their financial limits. They are better prepared to serve their families, communities, employers, and peers as Transplant Thrivers, not mere survivors.

JJ received a new heart at age 18 after receiving a new kidney and a new liver in previous years. His mother, a single parent and modest wage earner, had medical insurance but it didn't cover non-medical expenses like

⁷ Temporary housing facilitates recovery when it is clean, safe, private, individualized for the patient's condition, and able to accommodate mobility restrictions, the mandatory caregiver (who might be other than the recipient's partner) and sibling(s) if the recipient is a child. Additionally, it should include a kitchen (to minimize exposure to a possibly contagious public, control meal costs, and enable cooking of healthy meals in a confirmed clean environment), and also allows flexible duration for changes in the recovery period.

⁸ HHF support means people don't have to spend their month(s) of early recover in a basic bed-and-chair motel room, a series of low-end room rentals as available, an unsafely distant location, a unit lacking disability accommodations, someplace shared with other people, a homeless shelter, or a vehicle.

recovery housing, even though his doctors required it. She depleted her resources around the prior transplants. HHF paid for the three months of recovery housing JJ needed.

Suite-type hotels currently are the only realistic option for post-hospital recovery because they offer a reasonable combination of quality, availability, flexibility, and price. We pre-screen hotels to best serve our beneficiaries, and we negotiate price reductions to responsibly use donated funds. Payments go directly to the lodging providers on behalf of transplant recipients, not to patients.

HHF is fully inclusive and enthusiastically serves a broadly diverse population where financial ability and medical requirements collide. We help adults as well as families of pediatric patients. Our only qualifier is financial need verified by a transplant team social worker, consistent with the spirit of donations made to us. We charge no fee to anyone for anything. No one at HHF takes any kind of pay, salary, or stipend. Everyone volunteers. We carefully control our few and small expenses for fundraising and administration. Our main constraint is having sufficient funds to support the number of referrals we receive and the extent of help each person needs.

Our visions are:

- Our top priority is achieving consistent, stable, and sufficient funding so we can reliably support every qualified heart recipient who social workers refer to us, without exhausting our resources and having to decline someone who needs help.
- Next, we aim to help heart recipients who are unable to pay travel costs for return trips to their transplant medical team for routine but specialized checkups or for necessarily expert procedures after they've returned home far away.⁹
- Eventually, we want to support parents who are unable to afford lodging near their inpatient child who is awaiting or after transplant, and transplant candidates who cannot afford near-hospital housing that's medically required because home is too far away to arrive within the required few hours when a matching organ becomes available, but their insurance doesn't cover the cost.
- Our longest-term vision is to support medically-required, uninsured costs for financially at-risk people who need or received a life-saving transplant of any organ.

⁹ Funding travel expenses for people unable to afford a long drive and overnight stay, on top of possibly unpaid time off work, is not merely financial support, it is life support because a transplant specialist's examination and aftercare are more likely to detect organ rejection and other life-threatening situations early enough to implement a successful action plan.

Each form of support is important because transplant patients with financial inabilities can lack equity in and access to the healthcare they need. The United Network for Organ Sharing, who maintains the nationwide organ transplant list, says, *“There are multiple non-medical costs that you should account for when planning for your organ transplant surgery. The cost for housing prior to and after your organ transplant can be one of the most expensive non-medical costs you encounter. If you don’t live close to your transplant center, lodging can be essential to access your medical care.”* Medical insurance is not likely to expand to more often cover housing, since it is a non-medical cost. Therefore, HHF made housing its first step.

Financial Summary

Since inception in 2020, HHF has helped 26 heart transplant recipients pay for over 1,100 total days of temporary recovery housing, cumulatively about \$148,000, and averaging about \$5,700 per person. Support payments have trended upward, with the recent half averaging about \$7,300 per person. The trend is from two main factors: hospitals referring people needing longer recoveries, and higher lodging rates following the low Covid-era pricing we obtained in our early period. Two beneficiaries’ housing totaled over \$17,000 each, one was over \$11,000, three were over \$9,000 each, and six were \$1,500 or less each because of assistance from the hospital or insurer. Two people needed support for over 3 months each and one person for over 6 months. The current average recovery housing period is 1.5 months. We’ve supported the parent(s) of 12 children who received new hearts (44% of all our beneficiaries), including ones 8 and 19 months old. Our average support for each of these parents has been about \$8,200. Thus far, 73% of HHF’s beneficiaries live in Northern California.

We project the future volume of financially in need heart recipients referred to us will rise from our long-term average of about 1.0 per month to soon average 1.5 - 2.0 people per month, recently experienced, as more local heart transplant social workers learn about us. We expect the average outlay per person will continue to increase as the social workers refer patients, especially children, with more difficult recoveries.

To provide adequate financial support to our beneficiaries, aggregate contributions must be substantial and must increase every year. A prediction based on our history indicates near-future annual funding needs of \$70,000 - \$170,000 for our existing scope of service. The wide range results from using low and high estimates for referral volume and recovery duration. More would be needed to implement one or more of our extended visions.

To supply our funding needs, HHF markets and solicits through a website, subscription newsletters, social media, podcast appearances, speaking engagements, in-person and virtual fundraising events, applications for grants, sponsorships, and partnerships, and donation requests to curated individuals.

Grants, gifts, awards, and investor participation in large and recurring sums are crucial to help satisfy the needs of the heart transplant community's most vulnerable members.

2024 Program Goals and Evaluation

HHF will measure its success across ten key dimensions:

- Raise and maintain sufficient funds to meet the financial needs of heart recipients who lack insurance to pay for medically-required post-transplant housing and are unable to afford it themselves
- Disburse funds for the highest possible benefit to qualified heart transplant recipients
- Receive six new grants, gifts, or awards of \$5,000 - \$15,000, and through them develop relationships toward renewing those funds each year
- Secure strategic partnerships with 10 - 20 new individuals or businesses committed to donating \$1,000 - \$4,000 per quarter
- Arrange in-person events in six Northern California areas to increase community awareness of heart transplant successes and challenges, and gather donations of \$2,500 per event, or \$15,000 total from one or more virtual events
- Increase the total donations received from non-grant, non-event sources by 20%
- Expand and strengthen our partnership network of lodging providers and achieve 15% rate reduction overall from rates paid in 2023
- Mentor transplant candidates and recipients, documenting situations and benefits
- Educate the public about organ donation and transplant, documenting the events
- Increase the number of volunteer Directors and volunteer staff to match the growth in responsibilities for fundraising, administration, and serving beneficiaries

Heartfelt Help Foundation thanks you for your time and consideration.

For more information contact

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Contributions are fully tax deductible when nothing of value is received in exchange.

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