

Mayo Clinic William J. von Liebig

# Transplant Center

## Gift of Life Transplant House: A TLC community

For 18 years, Gift of Life Transplant House has been home away from home for patients and their families waiting for, and recovering from transplant surgery, as well as those returning for checkups or treatment. The house is beautiful — a restored Georgian Colonial brick home with a modern addition — but its true beauty lies in the rich web of tender, loving

care woven by the community of guests, staff and volunteers.

“Our guests have so many difficult challenges,” says Sr. Margeen Hoffmann, Executive Director of Gift of Life Transplant House. “We ease their journey by providing an affordable, homelike environment that fosters mutual support, fellowship and hope.”

## Mother and son: caregiver and heart recipient

There is sound reason for the Gift of Life policy that requires a companion to stay with each patient. Besides helping with physical needs, the companion's close relationship with the transplant recipient becomes the center of the TLC web. Bob Christianson, age 53, and his mother, Clara Christianson, age 84, were Gift of Life guests for two months last summer following Bob's heart transplant. “Mom never bargained for raising me twice,” quips Bob,

a high school woodworking instructor whose optimism and sense of humor no doubt helped in his recovery. Sr. Margeen knows that the support companion is often in greater need of emotional care than the patient.

“For the first few critical days, the patient is often unconscious — and they need lots of sleep after discharge from hospital,” explains Sr. Margeen.

*Continued  
on page 2.*

### On the inside...

#### **“Gift of Life Transplant House”**

– pg. 2

#### **“Annual Transplant Picnic Recap”**

– pgs. 3 & 4

#### **“Transplant Center Nurse Receives Transplant from Co-worker”**

– pg. 5



Bob and Clara Christianson spent two months at the Gift of Life Transplant House following Bob's heart transplant in 2002



## ***Mother and son: caregiver and heart recipient***

*– Continued from page 1.*

“That leaves the caregiver to face the challenges alone for much of the time.”

Clara agrees.

“I never could have done it if

we had been holed up in some hotel room,” she says. “I like my peace and quiet, but it makes you feel better to get out and talk to other people.”

There are 48 guest bedrooms at Gift of Life. That means there are about 100 people going through the transplant journey together. As they share their concerns in one of the many cozy nooks scattered throughout the house and garden, enjoy a game of billiards, prepare a meal, or participate in one of the many other communal activities offered, their web of support grows and strengthens. In many cases,

lifelong friendships are made. Sr. Margeen, a social worker by profession, understands that to support the house’s mission, she needs to maintain an exceptional staff of employees and volunteers.

“I look for generous, compassionate people who have had a life experience that has left them with a special ability to be sensitive to the needs of our guests,” she explains. “Our staff is

very special. They generate the goodness that makes our house feel like a home. Lots of people do little things that count — like baking goodies, sewing homemade quilts, installing a fan or offering rides to guests.”

“There’s often a birthday party or a spontaneous celebration,” says Bob. “We had fun. Someone even brought in an angel food cake and other goodies for Angel Day.”

### ***Transplant Center Newsletter***

**Mark Stegall, M.D.**  
*Medical Consultant*

**Jennifer Goodman**  
*Communications Consultant*

**Yvonne Hubmayr**  
*Freelance Writer*

**Monica Young**  
*Graphic Designer*

Editorial Board:  
**Charise Bauer, Ellen Case, Joan Meyer,  
Jayne Oles, Kathy Schwab, Sandy  
Schwartz, Michelle Skaar**

Mayo Clinic has offered transplantation as a treatment option for adult and pediatric patients since 1963. Mayo organ transplant programs have earned worldwide recognition for their expertise and success. In 1998 the separate organ and tissue transplant efforts united under the umbrella of the Mayo Transplant Center. This cooperation enhances the ability of Mayo physicians and scientists to share expertise and resources, offer comprehensive integrated transplant services, and to conduct innovative research in transplantation.

## ***All the touches of home***

For a fraction of hotel costs, guests get a room with a private bath, telephone and Internet access, linens and space in a pantry, fridge and freezer. In addition, they

have access to fully equipped kitchens, coin-operated washers and dryers, several dining areas, reading and reflection rooms, and television, playroom, exercise and recreation areas. A shuttle service takes them to Mayo Clinic, the hospitals, grocery and department stores.

## ***A healthful environment***

Gift of Life is licensed by the State of Minnesota and Olmsted County Public Health Department. To ensure meticulous cleanliness and a healthy environment for immune-suppressed transplant

patients, housekeeping staff use commercial equipment and products. Guests are not permitted to smoke or use alcohol or other recreational drugs.

# W All are Welcome...

*Gift of Life is open to everyone regardless of financial condition, race, or nationality.*

"Illness does not discriminate and emotional need is much greater than financial need," says Sr. Margeen. "Many of our past guests who could afford to pay more make generous donations out of goodness and gratitude for the service that we

provide."

Financial support also comes from grants, memorials, and fundraisers, such as an annual golf tournament and silent auction, and the sale of note cards, logo-embroidered clothing, and cookbooks.

## Taking the final step to recovery



Clara is now back in her own home and, though she enjoys her own bed, she misses the Gift of Life community.

"The house is all about hope," says Clara. "It's just not possible for people going through the transplant process to be in a better place — you won't find another group like it."

---

*"The house is all about hope," says Clara.*

---

Bob is back in his home, too, and looking forward to teaching again. For a brief moment, he gets uncharacteristically serious to acknowledge the depth of his gratitude.

"I've died once — almost twice," he says. "The Gift of Life means what it says."



## 250 Enjoy 15th Annual Transplant Picnic

Lively conversation and laughter punctuated the festive atmosphere at Essex Park in Rochester last July when more than 250 people gathered to savor the success of transplantation. It was perfect picnic weather; sunny skies and not too hot. There was a delicious lunch, fun games for the kids, Jason the Juggler for entertainment — and lots of support for the transplant community.

### **A popular pilgrimage**

The idea of having an annual picnic developed from an exuberant group of liver transplant recipients and their families and friends, back in 1987. In conjunction with the annual golf tournament, more and more transplant recipients made an annual pilgrimage to Rochester to support the Gift of Life Transplant House, and meet up with old friends at the picnic. By the 1990s, word had spread throughout the transplant community and heart and lung, blood and marrow, and kidney and

pancreas transplant recipients joined in the festivities.

### **They came from near and far**

Many people traveled great distances to attend the picnic. Sara Penaloza de Jesus, a liver recipient from June 2000, came from Mexico City. There were 42 liver recipients from 10 states, 26 kidney and pancreas recipients from four states, 10 heart and lung recipients from three states, and 10 blood and marrow transplant patients from three states. And several living

*Continued on page 4*

kidney and liver donors were also present with their recipients. Attendees heard an invocation by Syl Hengsteg and then enjoyed a delicious lunch.

Afterwards Chris Arnold, who had a liver transplant in November 2000, shared his personal experience of receiving the gift of life.

Drs. Charles Rosen, M.D. and Mark Litzow, M.D. provided an update on the Transplant Center, and the blood and marrow transplantation (BMT) and liver transplant programs. They discussed new Transplant Center initiatives such as the increasing success of BMT, laparoscopic donor nephrectomy, kidney transplantation for sensitized patients, upcoming islet cell transplantation, and living donor liver transplantation.



Chris Arnold and his wife attended the transplant picnic. Arnold, who had a liver transplant in November 2000, shared his personal transplant experiences with other attendees.

## Deserving *thanks...*

The Transplant Center Coordinating Committee:

**Bev Taylor** (*social work*)  
**Deb Dicke-Henslin** (*kidney/pancreas*)  
**Kay Kosberg** (*kidney/pancreas*)  
**Kristin Eggebraaten** (*liver*)  
**Lenora Smith** (*Charlton Transplant Clinic*)  
**Jan Larson** (*Gift of Life Transplant House*)  
**Terece Abad** (*Gift of Life Transplant House*)

This committee has worked hard to make the picnic a success. They received valuable support from the Gift of Life Transplant House Board, staff, and volunteers.

## Mark Your *calendar*

The annual  
**“Celebration of  
 Life Picnic”**

will be held on  
**July 12, 2003**  
 at Essex Park.

For more information,  
 including times and  
 directions, please contact your  
 nurse coordinator.



# Transplant Center Nurse Receives Transplant From Co-worker



**Michele Lee (left) received a kidney transplant in September 2001, when fellow transplant nurse Jane Boots (right) donated a kidney to her friend. Mikel Prieto, M.D., (center) was a member of the transplant team that performed the transplant. (Submitted photo)**

Last year, Jane Boots and Michele Lee, two registered nurses in Mayo Clinic Rochester's Transplant Center, became patients in their own unit when Boots donated one of her healthy kidneys after Lee's kidney began to fail. Their personal experience has given them a unique perspective in their professional lives.

## Sharing the story with patients

Lee and Boots do not discuss their experience with every patient. But they don't hesitate if they think it will help their patients.

"If there's someone who's having a hard time, I might tell them I've had a kidney transplant," Lee said. "Most react in amazement — especially when I tell them I was back at work just six weeks after the surgery. I think it can give them the confidence that they will be back to regular activities in a short time."

Boots sometimes shares the story to help donors confirm that they are doing the right thing. "I think it helps when they hear it

from a nurse who donated a kidney," Boots said. "I'd donate another one if I had three. It seems like a no-brainer to me."

## The first two kidney transplants

It was not Lee's first kidney transplant. At the age of 15, she developed an illness that caused a rare disease in her kidneys. Her mother donated the kidney for her first transplant, but it failed after developing a clot the first day after surgery. That necessitated a second transplant, this time from a cadaver.

For ten years, the cadaver transplant worked well. Lee completed high school and her nursing education, and began working at Mayo Clinic. After that time, antirejection medication side effects began taking a toll on the transplanted kidney.

## A week away from dialysis

The recent transplantation took place in September, 2001 — about a week before Lee would have had to begin regular kidney dialysis.

"We didn't want to see Michele have to go on dialysis," Boots says.

As Lee neared her transplant date, her routine had become fairly simple.

"I was working 12-hour shifts, so I'd spend all of my time at home just resting up to get ready for my next shift," Lee says. "My ankles really swelled up after each shift. That's one of the first things I noticed after this transplant: I have skinny ankles again!"

## Sharing the kidney

Even so, in the months leading up to Lee's transplant, she continually asked Boots if she was sure she wanted to donate a kidney to a co-

worker.

"It just seems like such a big sacrifice for a friend to make," Lee said.

Boots responds, "I have two kidneys, I can live with one, why wouldn't I help?"

Boots' parents were concerned about her decision, knowing that there were risks. But when they saw how much better Lee looked immediately after surgery, they understood their daughter's generosity.

## Advice for others

Boots reminds people to tell their families if they've decided to be an organ donor upon death. Lee advises people not to be afraid to seek family members as donors. Living donor transplants are becoming more common. Last year at Mayo Clinic, 204 of 240 kidney transplants were from living donors — related and unrelated to the recipient.

"Sometimes people are afraid to approach family members, but the process is such that if someone ends up deciding not to go through with it, the reason for it is kept confidential," Lee said.

The donor's surgery is done laparoscopically, meaning the incision is much smaller than with traditional surgery, and normally results in a faster recovery time.

Boots and Lee can now truly empathize with their patients. But the best news is that they both feel good as a result of their experience — Lee because she now has a kidney that works the way it's supposed to — and Boots because she has given the gift of life.

**"What greater gift can you give?"** asks Boots.

# How much will my transplant COST ME?

Most people waiting for transplant are extremely ill. Chances are you don't remember all of the information your transplant financial coordinator gave you at your initial meeting. At the meeting, you probably received a total cost estimate of your transplant surgery that included:

- Initial evaluation
- Donor charges
- Hospitalization period — physician and facility fees, organ procurement charges
- Outpatient follow-up charges for one year
- One year's supply of immunosuppressive drugs.

However, there are many factors that can change the estimate.

"Many of our patients are surprised when they receive a bill for costs not covered by their insurance company," says Dan Owen, a transplant financial coordinator. "My advice is to check with your insurance company before coming to Mayo. We give you a broad cost estimate range for your type of transplant. But, because of the diverse nature of transplant surgery, and unpredictable changes in insurance coverage, it's difficult to give a precise estimate."

## *Additional expenses*

- Travel, food and lodging — rarely covered by insurance companies
- Other medical expenses not related to transplant surgery
- Unpredictable complications — additional or different tests, consultations and treatment
- If the number of donors tested, or the number of stem cell collections for particular types of blood and bone marrow transplant exceeds the standard
- If your employer changes the company's insurance plan, there may be changes in your benefit package.



### **Where can I get help with additional expenses?**

- Your social worker can offer assistance in finding suitable accommodations and will work with you to defray other out-of-pocket expenses.
- If you are no longer able to work you may be eligible for disability benefits.

## *What if I can't pay my monthly bill?*

Communicate any hardship regarding your monthly payment agreement with the billing department. Call the number on your monthly billing statement to make arrangements.

## *What if my insurance*

If there is a change in your insurance plan, it is important to let us know immediately. When an employer chooses a different plan, the whole process must be reevaluated.

## *changes?*

Call the transplant financial coordinator with whom you met.



## *For More Information...*

For more information on Mayo Clinic's William J. von Liebig Transplant Center, visit us online at:

[www.mayoclinic.org/transplantcenter-rst/](http://www.mayoclinic.org/transplantcenter-rst/)



---

200 First Street SW  
Rochester, Minnesota 55905  
[www.mayoclinic.org](http://www.mayoclinic.org)

MC4221-02rev0103