

Mayo Clinic William J. von Liebig

Transplant Center

A two-year anniversary update from the director

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Director, Mayo Clinic Transplant Center

The patient comes first

Two years ago, we opened the William J. von Liebig Transplant Center, more commonly known as the Mayo Clinic Transplant Center. We created the center because we are serious about Mayo Clinic's primary value: "the needs of the patient come first."



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Making you the center of care

The word, center, is the key to our approach — making you the center of your care and centering it in one location. There are many areas of transplantation care that are common to all programs. Whether you need blood and marrow, heart, lung, kidney, pancreas or liver transplantation, you need evaluations by an anesthesiologist, dermatologist, endocrinologist, hypertension specialist, infectious disease consultant, psychiatrist, social worker, dietitian and a business office representative. You have many of the same extensive tests. And after surgery, there are frequent outpatient visits and laboratory tests to look for signs of rejection and adverse reactions to medications.

Instead of dealing with the confusion and inconvenience of visiting several different departments across the medical center, you come to a single setting and the necessary specialists come to you.

In addition, our center is connected to operating rooms and an intensive care unit that are dedicated to abdominal solid organ and blood and bone marrow transplantation at Rochester Methodist Hospital. And as Mayo Clinic's current building projects are completed, we will extend our connections to diagnostic and inpatient areas in the Mayo and Eisenberg Buildings.

This integrated, multidisciplinary approach also facilitates collaboration between the various transplant specialists and researchers.

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A two-year anniversary update from the director *The Patient Comes First (Continued)*

Two Innovative Programs

This fall, we expect to begin performing pancreatic islet transplantation for the treatment of patients with advanced diabetes mellitus. In this procedure, islets are isolated from pancreatic tissue and injected directly into the liver. Using this method, some patients can avoid kidney and pancreas

transplantation and the need for high dose immunosuppression.

In June 2000, we began offering living-donor liver transplants. The procedure allows earlier transplantation, thus avoiding worsening complications from liver disease. Ten patients have opted for this treatment since the program began.

I am proud to be the Director of Mayo Clinic's William J. von Liebig Transplant Center. Both Mayo Clinic in Scottsdale and Mayo Clinic in Jacksonville have rapidly growing and successful transplant programs. The combination of all three programs makes Mayo Foundation one of the largest and most successful transplant programs in the United States.

Heart Transplant Caregivers Study to Begin this Summer

On July 1, Mayo Clinic begins a study to learn more about the stressors and quality of life changes experienced by caregivers of heart transplant recipients.

A caregiver is defined as a family member or person living with an actual or potential heart transplant recipient who is related by blood, marriage or adoption, or who is living with and has a long-term commitment with the recipient.

The study requires the completion of four questionnaires. Two will be sent after your significant other is placed on the waiting list — after three months,

and again after 12 months. And two will be sent following transplantation also after three months, and again after 12 months.

If you are a caregiver who meets our definition and our time frames, you can expect the first questionnaire to be sent to you in July. Information that you provide in the questionnaires is completely confidential. Your participation is voluntary and greatly appreciated.

Transplant Center Newsletter

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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.



Research opportunities in kidney transplantation

We are currently enrolling patients who meet the specific criteria in a Calcineurin Inhibitor Free Study. The study compares two different immunosuppression medications to see which medication is more effective in the long term. The medications that will be compared are Prograf® (Tacrolimus), Prednisone®, and Cellcept® vs. Rapamycin® (Sirolimus), Prednisone®, and Cellcept®. All of these medications are drugs approved by the FDA and have been used in transplantation for several years.

When patients come for a pre-transplant evaluation, an overview of the study will be presented. Patients returning for transplant, who meet the criteria of the study, will be asked to participate by one of the transplant team members.

Question and Answer

What should I do while I am waiting for a transplant?

Try to stay as healthy as possible. Do not visit people while they are ill. If someone in your home is ill make sure to use good handwashing after coming into contact with the person.

Visit your local doctor routinely to help ensure that your health is the best it can be prior to transplant.

Visit your dentist at least once a year. Have your dentist write and send a letter to your transplant coordinator, stating that they have seen you and your dental health is good. This is important to prevent any dental infections that could cause problems for you after your transplant.

A letter to Mayo Clinic from a living donor

I write this in hopes it will help someone decide to donate an organ. How I came to be a donor is very interesting. A friend of mine, Mary, introduced me to a man named Michael and we became friends. Mary, Michael and I would often get together for lunch. In December 2000, Michael went into end stage renal failure and asked me if I could take him to and from the hospital for dialysis. I saw with my own eyes how Michael's health became worse day after day. He went to dialysis three times a week while waiting to find a match from a living donor. No one in Michael's family could donate for him, and neither could Mary. Whenever I picked Michael up for dialysis, he had no energy and was pale in color.

About the first month into treatment, Michael told me he wished he could get someone to donate a kidney for him. I asked what was involved in a donation. I had my own blood typed and crossmatched and was able to meet the most critical of the factors. I went through two days of extensive testing at the hospital, where they assessed my general health, my heart, lungs, blood and kidneys.

The transplant was done on June 13th. Michael and I had to be at the hospital at 5:45 a.m. At my pre-op, my blood pressure was monitored, an IV was put in and I changed into the usual hospital gown. At no time did I have second thoughts.

The surgery was done laparoscopically, using television cameras to aid the surgeons in seeing during surgery. An incision of two and a half inches was made just below the navel for the surgeon's hand. Previously, surgeries were done by removing the kidney through the back or side. In these cases, a rib was removed and recovery time was longer. When my surgery was done, my abdomen was inflated with carbon dioxide, the abdominal muscles were pulled gently apart and held aside while the surgery was performed. This made recovery time minimal. Following surgery, I felt only some discomfort from the use of carbon dioxide, which lasted less than 36 hours. I left the hospital a day and a half later and was feeling nearly 100 percent after five days.

Four weeks after surgery, I was working again. Michael was in the hospital only five days. He has recovered wonderfully. His color has come back and he feels stronger each day. The kidney I donated to him is working to perfection. It is truly miraculous to see how easy this was on me and how quickly we both recovered. I hope this encourages others to give the gift of life.

- Larry Klemmer

What do I do if I need surgery while I am waiting?

Contact your transplant nurse coordinator before having the procedure done. Depending on the type of procedure, you may need to be placed on an inactive status waiting list. Your transplant coordinator will be able to assess the need to be placed on this list. What this means is that while you are

recovering from your surgery, you will not be offered an organ. It would not be to your benefit to have a transplant when you are weak and trying to recover from a previous surgery. In the inactive status, you will still be able to gain time on the waiting list up to 30 days.

Living-donor liver transplantation

Giving a loved one a gift of life

The Mayo Clinic Liver Transplant Program performed its first living donor liver transplantation in June 2000. Our success is comparable to that of our traditional program — 92 percent survival after one-year; 89 percent after three years.

Sixteen of seventeen recipients of living donor transplants are alive and doing well. One required retransplantation. More than 12 potential donors are currently undergoing evaluation.

The risk of graft failure is reduced in living donor transplantation because the time between removal of the liver from the donor and transplant into the recipient, is much shorter than with a cadaver donor. The procedure is also becoming more common because the patient does not have to contend with lengthy waiting times. More than 500 adult-to-adult procedures have been performed in the U.S., and more than 1,000 worldwide.

Who can benefit?

- Patients with symptomatic liver disease and low MELD score, liver and bile duct tumors, familial amyloidosis, pulmonary hypertension or hepatopulmonary syndrome
- Foreign nationals — limited by UNOS
- Children — adult-to-child transplantation is safe and effective

Making the Decision

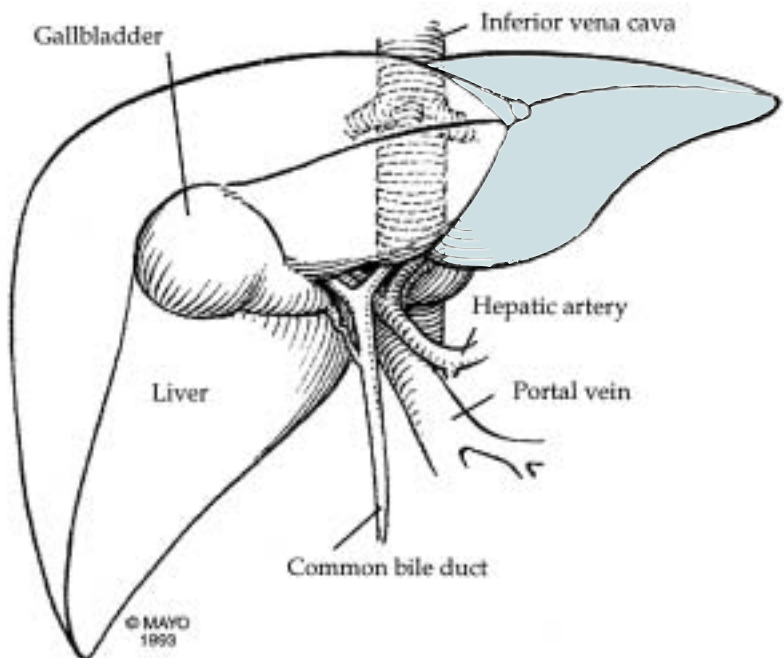
Making the decision

We will encourage you to consider living donor transplantation if we conclude you have a condition likely to benefit from it. Potential donors can contact the living donor nurse coordinator for a preliminary survey. A more extensive evaluation follows if donor suitability is determined.

The procedure

In living donor liver transplantation, a part of the liver is transplanted from a healthy person to the recipient. During the donor operation, the surgeon removes the liver section with the veins and bile ducts that lead to it, and attaches it to the recipient structures.

The right liver is made up of half the eight liver segments. It accounts for 60 percent of the total liver and is an excellent fit for most adults. The left lateral liver, comprised of two segments is much smaller and ideal for babies and small children.



Living donor liver transplantation

Giving a loved one a gift of life (continued)

What donors should know

We have the highest respect for potential donors and never coerce them to proceed. We treat medical and personal matters, and issues concerning the decision whether or not to proceed with the donation, with the utmost confidentiality.

Here are some other facts potential donors should consider before making their decision.

A donor:

- Receives counseling and support from identification through recovery
- Undergoes an extensive medical evaluation to ensure optimal health
- Must have a blood type compatible with, but not necessarily identical to the recipient's
- Must have a compatible liver size — small enough left lateral for a child or large enough right liver for an adult
- May have anatomical variations in blood vessels and bile ducts that influence suitability
- Will regenerate a complete and appropriately-sized liver within a few weeks
- Can expect some post-operative discomfort and to remain in hospital for one week after the operation
- Has an estimated risk of death between 0.5 and one percent in our program — temporary risks include incision problems, bile leaks and blood clots
- Only occasionally requires blood transfusion
- Has no long-term health risks following recovery

The majority of donors recover completely within a few months of the operation. All report deep satisfaction that they have been able to give the “gift of life.”



Donor organ shortage is critical

- More than 17,000 patients are registered on the United Network for Organ Sharing (UNOS) liver transplant waiting list
- About 4,500 cadaver donor livers are available annually
- Waiting time increased from one month in 1988 to more than a year in 2000
- Over one-third of patients wait more than two years

Liver transplant support group

Please join us at the Family Waiting Room, Station 10-2, from 1:30 p.m. to 2:30 p.m., for the following Liver Transplant Support Group meetings. Meetings are held most Tuesdays and Fridays and patients and their families are welcome.

Date	Subject	Presenter
Friday, June 21	Nursing Goals & Concerns	Kaye Lundberg
Tuesday, June 25	Stress Management	Jackie Johnson, LICSW
Friday, June 28	Normal Liver Functions	Hepatologist
Tuesday, July 2	Positive Self-Esteem	Jayne Oles, LSW
Friday, July 5	Infection Control & the Immunosuppressed Patient	Robin Patel, M.D. (Infectious Disease)
Tuesday, July 9	Faith Systems & Critical Care	Chaplain Syl Hengesteg
Friday, July 12	Post Hospital Management	Kevin Gaustad
Tuesday, July 16	Relaxation Techniques	Jackie Johnson, LICSW
Friday, July 19	Liver Transplant Surgery	Michael Ishitani, M.D. (Transplant surgeon)
Tuesday, July 23	Quality of Life	Jayne Oles, LSW

Cardiothoracic transplant support group

Please join us at 4 Mary Brigh Conference Room 510 in Saint Marys Hospital, from 4 p.m. to 5 p.m., for the following Cardiothoracic Transplant Support Group meetings. Meetings are held most Mondays and patients and their families are welcome.

July		August	
Date	Subject/Presenter	Date	Subject/Presenter
July 1	Open Group	August 5	Open Group
July 8	Pharmacy	August 12	Cardiologist
July 15	Open Group	August 19	Open Group
July 22	LifeSource		
July 29	Open Group		

Upcoming events

Mayo Clinic's annual "Celebration of Life Picnic" will be held Sat. July 13, 2002 at Essex Park from 11 a.m. to 3 p.m. If you haven't already registered, you may still return your registration form or contact your nurse coordinator. Desserts, lawn chairs and outdoor games are welcome. In case of rain, tune your radio to KNXR 97.5 or KROC 106.9 for an alternate location. Cost is \$7 per person (children six and under free) for food catered by the Canadian Honker.



For More Information...

For more information on Mayo Clinic's William J. von Liebig Transplant Center, visit us on line at: www.mayo.edu:80/tranplant-rst



Blood and marrow transplantation

An overview from Mark Litzow, M.D.

Mayo Clinic blood and marrow transplantation program director

Blood and marrow transplantation (BMT) is life-saving treatment for many cancers, genetic disorders and other diseases affecting the blood and marrow. There have been many improvements made in the 30 years since the first BMT was performed. And there are encouraging new developments. But it remains an intense and difficult process with the potential for many complications. You will need the support of friends and family to help you through it.

What is the HLA System?

The human leukocyte antigen (HLA) system is a series of proteins on most cells in your body. The proteins allow your immune system to differentiate your own cells from foreign ones such as microorganisms and donor cells. That way it can destroy the invaders without damaging your own cells.

In the early 1970s, physicians learned how to identify different HLA systems. This discovery led to the first successful BMT because it meant being able to match siblings and patients, preventing the body from rejecting transplanted cells.

Types of blood and marrow transplantation

Physicians name blood and marrow transplantations according to the relation of the donor to the recipient, and whether the transplanted stem cells come from bone marrow, blood or the umbilical cord.

Stem cells produce all the different types of cells and tissues that make up your body. They also copy themselves. There are many types of stem cells. You need the type of stem cells that allow blood counts to recover more rapidly and

lower the risk of infection and bleeding after your transplant.

- **Allogeneic** — means that the stem cells are donated by someone other than the patient. The term, syngeneic, is a special term for transplantation when the donor is an identical twin. An allogeneic donor can be related or unrelated. Unrelated donor transplants are possible because individuals of similar racial and ethnic background can share the same HLA type. Lists of HLA typed individuals are available in computer registries throughout the world but the procedure is riskier than donor-related BMTs.
- **Autologous** — means that the stem cells are collected from the patient before chemotherapy or radiation treatments and reinfused after completion of treatments.
- **Bone marrow** — bone marrow cells are collected by needle aspiration from the pelvic bones under general anesthesia.
- **Peripheral blood** — blood stem cell donors are treated with Neupogen® and/or Leukine® to encourage stem cells to migrate from the bone marrow into the blood where they can be collected.
- **Umbilical cord blood** — a rich source of bone marrow-type stem cells mostly used for children because of the limited number of stem cells obtainable.

The Process

Approval for BMT must be obtained from your insurance company or third party payer beforehand. You will then have a series of tests to help us assess the status of your disease and to make sure you are physically and emotionally healthy enough to withstand BMT.

We then insert a special

intravenous line, called a central venous catheter, which is used throughout your treatment to make frequent blood tests and intravenous medications and transfusions more comfortable and convenient.

The next step is to collect the stem cells from the source that we determine is optimal for you. Once your source of stem cells is assured, we start you on high dose chemotherapy and/or total body irradiation (TBI) (called the conditioning regimen). The treatment kills cells that are growing and dividing.

The target is cancer cells but it will also severely lower your blood count levels. The conditioning regimen takes one to ten days, depending on the program chosen to best combat your disease.

One to three days after completion of the conditioning regimen, we infuse your reserved stem cells.

Complications of blood and marrow transplantation

It takes the transplanted stem cells 10 to 20 days to produce new blood cells. During that time your low blood counts put you at risk for infection and bleeding. To reduce the risks, we treat you with antibiotics, and red blood cell and platelet transfusions.

You may experience persistent nausea after transplant or develop fever, mouth sores or diarrhea until your blood counts recover. When you can return home after transplant can vary from a few weeks (usually with autologous BMT) to a few months (usually with allogeneic BMT).

It is possible that your disease will recur after transplant. The risk of recurrence depends on the type of transplant and on the state of your disease at the time of transplant.

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Blood and marrow transplantation

An overview from Mark Litzow, M.D.

Mayo Clinic Blood and Marrow Transplantation Program Director (continued)

Graft-versus-host disease

If you have an allogeneic transplantation, you are at risk for graft-versus-host disease (GVHD).

You have probably heard about heart transplant patients rejecting their transplanted heart. That happens when the immune system recognizes the transplanted organ as foreign and attacks it. Rejection is not much of a problem in BMT because we suppress your immune system before transplantation.

However, in allogeneic BMT, you get your donor's white cells along with the stem cells. That means you get their immune system. The immune cells from your donor are called "graft" cells and yours are the "host" cells. In graft-versus-host disease, the graft cells recognize the host cells as foreign and attack them.

We give you drugs to suppress your immune system to reduce the

occurrence or severity of GVHD. These drugs can further increase your risk of infection.

Survival rates

Complications of BMT can result in slow recovery or even premature death. Most Patients undergoing autologous transplant have less than five percent chance of dying from a complication. For allogeneic transplant, the risk is much higher — from 10 to 50 percent, depending on the stage of disease and type of transplant.

A glimmer of hope

If you do develop GVHD, the news is not all bad — it may help fight your underlying disease. BMT physicians noticed that patients who develop GVHD after transplant have a lower risk of leukemia recurrence than those who do not get the complication. Subsequent studies

have shown that the donor's immune system can kill leukemia cells that have survived chemoradiotherapy.

BMT physicians have applied this research and developed a milder form of allogeneic transplant called non-myeloablative or mini-allogeneic transplant.

Patients having a mini-allogeneic transplant receive less intensive chemoradiotherapy. The goal is to lessen the side effects of transplant and use the transplanted immune system to stimulate remission. At Mayo Clinic, we choose mini-allogeneic transplant for some patients who would be otherwise ineligible for conventional BMT. The ability of the immune system to fight a patient's cancer after allogeneic BMT has inspired Mayo Clinic researchers to actively study ways we can stimulate the patient's own immune system to fight their cancer after autologous BMT.

Diseases Treated with BMT

Hematologic Disorders and Malignancies	Solid Tumors	Autoimmune and Congenital Disorders
Acute leukemias Chronic Leukemias Myelodysplastic syndromes Agnogenic myeloid metaplasia Hodgkin's disease Non-Hodgkin's lymphoma Multiple myeloma Amyloidosis	Breast cancer Ovarian cancer Germ cell cancer Sarcoma Brain tumors Neuroblastoma	Aplastic anemia Autoimmune diseases including: • Rheumatoid arthritis • Multiple sclerosis • Systemic lupus erythematosus and others Hemoglobinopathies Immunodeficiency Disorders Lysosomal and Peroxisomal storage diseases



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