



TRANSPLANT NEWS

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THE TRANSPLANT INSTITUTE

July 2009



Chiefs' Corner

Douglas W. Hanto, MD, PhD
Clinical Director

Terry Strom, MD
Scientific Director



There will be some new additions to the Transplant Institute this year. Dr. Amy Evenson will be joining the clinical faculty as a multi-organ transplant surgeon and an Instructor of Surgery at

Harvard Medical School, Dr. Michelle Lai will be joining the hepatology staff as an Instructor of Medicine, Dr. Larry Turka will be joining the research faculty as a Visiting Professor of Medicine and Surgery, and Dr. Todd Valerius will be joining the research faculty as a Visiting Assistant Professor of Surgery.

Dr. Evenson completed her general surgery training at BIDMC in 2007 and her multi-organ transplant fellowship at Northwestern University in Chicago in 2009. She will be involved in all aspects of clinical transplantation, dialysis access, and hepatobiliary surgery. She was one of the most highly regarded residents to finish general surgery at BIDMC over the last decade and received accolades from the Northwestern transplant faculty for her work ethic, technical surgical ability, clinical judgment and compassion.

Dr. Lai completed her internal medicine, gastroenterology, hepatology, and transplant hepatology training at BIDMC. She will be joining the Section of Hepatology in the Division of Gastroenterology and will see patients with liver disease as well as pre- and post-transplant patients, along with developing several clinical research projects. She has been an outstanding resident and fellow and we were lucky to be able to recruit her to stay in Boston.

Dr. Turka joins the Transplant Research Institute as the Co-Scientific Director with Dr. Terry Strom. Dr. Turka is a nephrologist and research investigator and currently the C. Mahlon Kline Professor of Medicine and Professor of

Surgery, Pediatrics, and Pathology and Laboratory Medicine at the University of Pennsylvania. Dr. Turka is an internationally known and respected immunologist who has made seminal contributions to our understanding of the immunobiology of T cells and transplantation. He is currently the Editor-in-Chief of the Journal of Clinical Investigation, one of the most prestigious research journals as well as a member of the Executive Committee of the Immune Tolerance Network. He has been Chief of the Division of Nephrology at the University of Pennsylvania, President of the American Society of Transplantation and has held numerous other leadership positions in transplantation and immunology in the United States and abroad. He will be bringing and recruiting new faculty and post-doctoral fellows that will strengthen and expand the scope of research being done in the Transplant Research Institute.

Dr. Valerius completed his Ph.D. at the University of Cincinnati in Molecular and Developmental Biology and has completed a post-doctoral fellowship in the laboratory of Andy McMahon, Ph.D. at Harvard University where he has been the Project Coordinator studying the molecular determinants of kidney development. In addition to his own laboratory efforts he will collaborate with Dr. Seth Karp in studies of liver development and regeneration.

Also, we have a new Transplant Nephrology Fellow, Mohammed Karim, M.D., who trained at Nassau University Medical Center, and a Transplant Hepatology Fellow, Eric Cohen, M.D., who trained at Northwestern University. In 2010 Kristen Raven, M.D. will start the Transplant Surgery Fellowship after she finishes her chief resident year at BIDMC.

These new additions illustrate our continued commitment to improving and expanding our clinical services, research programs, and educational training of future transplant nephrologists, hepatologists, and surgeons.

Team BIDMC Walks for Kidney Disease

The BIDMC Transplant Institute participated in the National Kidney Foundation's *Kidney Walk* at the Franklin Park Zoo on May 17th, 2009. Shonda Etienne, our fabulous practice assistant, served as the captain and unofficial cheerleader for Team BIDMC. Together, our 19 walkers – staff, patients, and family members – raised \$3,670 for the National Kidney Foundation (NKF). At the same time, we all were able to enjoy the amazing animals at this wonderful zoo.

The NKF is dedicated to preventing kidney and urinary tract diseases, and provides patient services, public and professional education, and patient advocacy. Patient services include local support groups, counseling, financial assistance, public screening clinics for kidney disease, and newsletters. Also, the NKF provides grants to researchers and scientists who are investigating causes of kidney disease, researching the prevention of kidney disease, and improving the quality of life for those with kidney disease.

For more information on the National Kidney Foundation go the web site: www.kidney.org.

We hope to see everyone at next year's *Kidney Walk* to help support the NKF and the 26 million Americans with kidney disease!!!

Transplant Orientation

The **liver transplant** orientation class is held on the second Thursday of each month from 3 to 5 pm. Every patient being considered for liver transplantation must attend one class with a family member or support person. Topics include:

- Caring for yourself while waiting for transplant
- Understanding your MELD score
- Symptoms of liver disease and their management
- Medications and side-effects
- Nutritional issues and concerns
- Transplant hospitalization and aftercare
- Financial and insurance issues

The remaining **kidney transplant** orientation classes for 2009 will be held on:

- September 9, 2009, 9:00 – 10:30 a.m.
- November 19, 2009, 9:30 – 11:00 a.m.

Topics include dialysis, benefits of transplantation, and live donor kidney transplantation. Call The Transplant Institute at (617) 632-9700 to sign up for the class.



Kirsys Capellan, Frank Rogers (2004 kidney transplant recipient), and Noelle Dimitri at the *Kidney Walk*

People in the News...

Michael Curry, MD was appointed to the United Network for Organ Sharing Liver and Intestine Transplantation Committee.

Erica Gemellaro, RN received the Certified Clinical Transplant Nurse credential from the American Board of Transplant Certification.

Douglas Hanto, MD, PhD was elected as a Director of the American Board of Surgery.

Scott Johnson, MD was appointed Director of the Surgery Residency Training Program at BIDMC.

Didier Mandelbrot, MD was appointed Chair of the Healthy Donor Website Workgroup of the American Society of Transplantation.

Martha Pavlakis, MD was promoted to the rank of Associate Professor in the Harvard Medical School's Department of Medicine.

Jim Rodrigue, PhD was appointed to the Ethics Committee of the American Society of Transplant Surgeons.

Christin Rogers, PharmD was appointed Chair of the Community of Practice for Transplant Pharmacists of the American Society of Transplantation.

Erin Sexton RN, received the Certified Clinical Transplant Coordinator credential from the American Board for Transplant Certification.

Kim Sullivan, RN received the Edward and Marilyn Schwarz Patient Education Award.

Lauren Wedge, RN received the Certified Clinical Transplant Coordinator credential from the American Board for Transplant Certification.

Transplant Pharmacy News



by *Christin Rogers, PharmD, BCPS*
Clinical Pharmacy Coordinator – Transplant Services

Generic anti-rejection medications are now available and you should have received some information from the Transplant Institute about this. Your pharmacy may start to provide you with generic formulations of Cellcept® or Prograf®. Cellcept® is the manufacturer's name for mycophenolate mofetil and Prograf® is the manufacturer's name for tacrolimus. There are currently 7 different makers of generic Cellcept. Generic formulations of Prograf® are not yet available however, it is expected that they may be available some time after June of 2009.

Generic medications contain the same active ingredients as brand name medications. Some states (e.g. MA) require a generic formulation to be dispensed if it is available. Depending on your state and/or insurance company's rules, you may begin receiving a generic formulation of Cellcept® or Prograf® without being informed. It is important to know that generic medications are tested in healthy adults and are not tested in transplant patients before they are approved by the FDA. For this reason, your transplant team may need to monitor you closely after switching to a generic anti-rejection medication.

Your transplant team has decided that it is ok for you to take generic medications as long as you notify your transplant coordinator of the change. **It is important to note that a change to the generic formulation of Prograf® may change your drug levels.** For this reason, we are requiring that if you change to a generic formulation of Prograf® that you notify your transplant coordinator so they can schedule additional lab tests. We are requiring that you have weekly Prograf® levels (12 hour trough) for a minimum of two weeks to ensure you levels remain stable. If you prefer to stay on brand name Prograf® or Cellcept® you may be required to pay higher co-pay. If you wish to continue on the brand name product you must notify your transplant coordinator so they can write your prescription correctly. If your prescription is not written with the statement "No substitutions or Brand Name Medically Necessary" you will receive a generic product.

Please contact your Transplant Coordinator if you:

- Notice any differences in the appearance of your medication
- Begin taking a generic mycophenolate mofetil or tacrolimus
- Receive a generic mycophenolate mofetil or tacrolimus that looks different from the generic product you may already be taking.

If you notice any differences in your health while taking the generic medication, please contact your Transplant Coordinator immediately.

Transplant Support Groups

From learning about your illness to long-term recovery, transplantation can be a complex and an emotionally challenging process. For many patients, support groups are a way to meet others who are going through the same challenges and to learn from those who have already faced them.

At BIDMC, we offer a Liver Transplant Support Group for patients who are listed for and who have had a liver transplant. The meeting is held in the solarium on Farr 10, the dedicated inpatient transplant unit, every Wednesday from 12 noon to 12:50 p.m. and is co-led by Amanda Reed, LICSW, liver transplant social worker, and Maureen Doherty, LICSW, Farr 10 social worker.

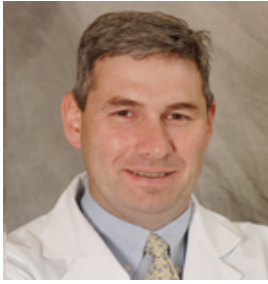
The BIDMC Liver Center also has a support group for adults with Hepatitis C infection. It meets the second Wednesday of each month from 6 to 7 p.m. on the 8th Floor of the Lowry Medical Office Building (one floor above The Transplant Institute). If interested in attending this group, please contact Tiffany Taskaya at (617) 632-1072 for more information.

Patients also can attend the STATS group, which is co-led by a BIDMC liver transplant recipient. STATS, or Second Time Around Transplant Support, is open to transplant patients, donors, and family members. The group meets the second Tuesday of every month from 7 to 9 p.m. in the Strazi Conference Room at Jordan Hospital in Plymouth. Call (774) 269-1283 or email statssupport@gmail.com for more information.

If you need help finding other support groups, contact your transplant social worker or nurse coordinator.

Staff Profile

Michael Curry, M.D., Medical Director of Liver Transplantation



Dr. Curry has served as Medical Director of liver transplantation at BIDMC since 2003. He is a highly regarded leader in the evaluation and management of liver disease, as well as in the field of transplantation. He has served on many regional and national committees and advisory boards, and he is highly sought as a speaker throughout the country. He has published numerous scientific articles and book chapters, and has given many lectures and presentations at professional meetings.

Dr. Curry has cared for hundreds of patients with hepatitis C virus infection, cirrhosis, hepatocellular carcinoma, and other types of liver disease. His patients know him as someone who provides very high quality medical care in a compassionate and sensitive manner. “Dr. Curry is always on top of his game and knows what’s going on,” says Thomas, one Dr. Curry’s many grateful liver transplant recipients. “I trust him and have the utmost respect for him. He is a very knowledgeable and compassionate man.”

“A couple of years ago, I was told I needed a liver transplant. I never really thought the day would come when I would actually have the transplant, but it did. I am very, very fortunate that Dr. Michael Curry and his staff have been with me throughout the entire process — every step of the way. Dr. Curry has a calm and reassuring way about him that gave me confidence that everything would be OK. I believe I would not have survived the process without him.”

Joseph F., 2008 liver transplant recipient

Training the next generation of leaders in the management of patients with liver disease and transplantation is also a part of Dr. Curry’s dedication to the field. He finds this part of his job to be very rewarding. Of course, his trainees have benefited greatly from his mentorship as well. “While Dr. Curry is known for his vast fund of knowledge, I have also learned that his decisions are always guided by his conscience and his words by his compassion,” said Dr. Michelle Lai, who recently completed her hepatology fellowship and has joined the Transplant Institute faculty. “I knew since medical school that I wanted to be a hepatologist. It was not until I worked with Dr. Curry that I realized that I wanted to be a hepatologist like Dr. Curry.”

Waiting for a liver transplant is a time of great challenge and uncertainty for most of his patients. He considers this the most difficult part of his job because he knows that he cannot fully understand the burden that patients with liver disease and their families experience every day. “Every patient’s experience with liver disease is different,” he says. “But I know that waiting for a transplant is filled with anxiety and worry for everyone. I wish I could do more to make this part of the transplant process easier. This is one of the reasons why we place such emphasis on the support system – to help patients cope with transplant waiting and with recovery after transplant.”

His unwavering dedication to improving the lives of his patients is impressive. It also is why he has received both the Best Doctors in America Award and the Patients’ Choice Award. “The most rewarding thing is to see my patients and their family get back to a better life than the one that they had with end stage liver disease. It’s the primary thing that motivates me to come to work every day,” he says. Indeed, Dr. Curry has seen the benefits of liver transplantation. “Liver transplantation can lead to substantial changes in quality of life,” he says. “It’s truly one of the most rewarding things to see a patient years after transplant, who is physically healthy and able to live life to the fullest.”

With Dr. Curry’s dedicated and compassionate approach to medical care, many more BIDMC patients will experience these same benefits from liver transplantation.

Giving the Gift of Life

An interview with Raja, a living kidney donor

Donating a kidney to a person in need – be it a loved one, friend, or stranger – is a wonderful and courageous gift. Each year in the U.S., over 6,000 adults willingly give this gift of life. In December 2008, Raja gave her husband an early holiday gift – her left kidney.

Describe why you decided to become a living donor.

When my husband was hospitalized for renal failure, I knew there was a minimum 3-year wait for him to receive a deceased donor kidney. Being a healthy person, I wanted to be his first choice for a living donor.

What information was most helpful to you?

When I went through the testing, it was very helpful to know that the donor does not need to be a family member. I had visited many websites to learn more about kidney failure, dialysis, transplantation, and living donation.

What surprised you most about the donation experience?

I was under the impression that just wanting to be a donor was enough for the transplant to move ahead. Since I was overweight, I had to lose 40 pounds to be a kidney donor. Though I was mentally ready to be a donor, losing weight was not easy. I pushed myself very hard for almost 8 months. The fact that I was doing this for my husband helped me achieve the weight loss.

What was the biggest challenge after surgery?

I wanted to recover from the surgery quickly and move on with our lives. Although I was comfortable, there was a small fear that I shouldn't pick up any other physical problem.

What is most satisfying about being a donor?

Giving my husband a second chance to live his life. Many of us take our body for granted, but this experience has made me realize how important my body is and I will continue to keep it healthy.

What recommendations do you have for others who are thinking about becoming a living donor?

It is the most wonderful experience of my life. There are no words to express the feeling you have when you give life to someone else. This really is the “gift of life.” You can live a normal life with one kidney.

Other thoughts?

I would like to thank the entire transplant team for giving us new life and for being there to support us through the donation and transplant experience.

Receiving the Gift of Life

An interview with Raj, a kidney transplant recipient

Receiving a kidney transplant can positively transform one's physical health and quality of life. A kidney from a living donor can last twice as long as one from a deceased donor. In December 2008, Raj received a kidney from his wife.

Describe your quality of life before transplantation.

I was on dialysis and I felt very tired and lethargic. I was in no mood to do anything other than stay home and vegetate. I took medications that affected every part and function of my body. I could not take my kids out for an outing. Overall I kept asking myself, “Why me?”

Why did you pursue a live donor kidney transplant, rather than wait on the list for a deceased donor kidney?

Watching me struggle had negative impacts on my family. I knew that the longer I was on dialysis the more damage it would cause my body. I wanted to get back to work and take care of the family. Most of all, I have a wife who loves me and wanted us to grow old together.

What thoughts or feelings did you have about asking someone to donate a kidney to you?

I had reservations because she was my wife and I often wondered what would happen if things went wrong. Who would take care of our children?

What is the biggest challenge since your transplant?

Adjusting to normal life. I have the urge to just go out and be free but I know that I have limitations and to hold back is the most difficult thing. The medications and their timing were challenging. I had to set alarms to make sure that my meds were taken at the same time everyday.

Describe what the transplant has allowed you to do that you couldn't do before.

The transplant has done remarkable things to my body. I have never felt this energized. I play tennis with my son for two hours, which I could not do before my transplant. It has given me the freedom to be a good father, son, and husband to my family. It has allowed me to realize how precious life is and how it must be enjoyed.

What are your future goals?

I am studying now to be a medical professional. My ultimate goal is to be an anesthesiologist assistant and to work on transplant cases.

Farr 10 News



Farr 10 is the Transplant Institute's in-patient unit. This acute care unit hosts the kidney, liver, and pancreas transplant patients where our dedicated multidisciplinary team care for complex liver, kidney and pancreas transplant candidates and recipients on a 24/7 basis. This team is a collection of hard-working, knowledgeable, highly skilled and compassionate nurses and other staff. In honor of International Transplant Nurse Day, which was celebrated in April, Erica Gemellaro, Transplant Unit Based Educator and Norma Wells, Transplant Nurse Manager, hosted a number of staff educational opportunities and appreciation festivities. To the left is a picture of some of our staff;

including bedside nurses, transplant coordinators, case managers, nutritionist, manager and educator. This picture was taken following a game of Transplant Jeopardy, an educational and fun team-building event! As nurses on Farr 10, we love the work we do. We take pride and care in our patient population and we look forward to celebrating International Transplant Nurse Day again next year!

New *Donate Life New England* Website Launched

Registering to give the Gift of Life just got a bit easier. In May 2009, with the support of Massachusetts Governor Deval Patrick, a new website was launched that allows New England residents to register online to be an organ and tissue donor at the time of their death. *DonateLifeNewEngland.com* offers residents a way to securely and confidentially register as an organ donor. The registry is a computer data base of individuals who have made the decision to be a donor. It allows organ and tissue donation professionals to determine at the time of death if you had registered to be a donor so that your wish to donate can be fulfilled.

Many transplant recipients and family members ask us how they can “give back” for the gift of life they received. How about promoting the benefits of organ donation? There are many different ways to do this. Volunteer to speak to religious organizations, schools, and civic groups in your community. Add *Donate Life New England* to your Facebook or MySpace page. Use your email address book to send a quick note to family members and friends about how you registered to be an organ donor and someone else’s donation decision benefit you or your loved one.



Gratitude is Good For You

Everyone knows it’s good to be grateful, but did you know being grateful is good for you? Studies show that grateful people benefit from better health, more optimism, less stress and even experience fewer episodes of clinical depression. With this knowledge, BIDMC created Grateful Nation, an interactive community that gives grateful people the opportunity and resources to connect, give back, and be thankful. Hopefully, one thanks will lead to another, and we’ll create an unending positive cycle of gratitude. Visit www.GratefulNation.org for more information on how you can make a difference.

Innovative Liver Research



Innovative research is being done in the BIDMC Transplant Institute and the Harvard Medical School that has great importance for patients with liver disease.

We have known for years that the liver is able to repair itself to some degree. But it has been difficult to pin down exactly how this happens – until now.

“The human liver has an amazing ability to regenerate from as little as 25 percent of its tissue,” says Seth Karp, MD, BIDMC transplant surgeon and assistant professor of surgery in the Harvard Medical School. “Through our research, we have discovered how the liver’s cells behave in repairing itself. The process seems to be much simpler than we previously thought.”

Dr. Karp and his research team are trying to discover new drugs and methods to help the liver do what it already does naturally – repair itself when it’s been damaged by liver disease. “Our studies now center on this novel and modifiable signaling pathway that is so critical for liver repair,” says Dr. Karp. “Drugs that affect this pathway can enhance liver repair, which could potentially affect the lives of millions of people with acute and chronic liver disease.”

For some adults with acute liver injury or cancer, new drugs would help to boost liver repair and facilitate recovery after removing the damaged part of the liver. For adults with chronic liver disease, new pharmacological treatments that help the liver to repair itself will reduce or eliminate symptoms of liver failure, prolong life, and improve quality of life.

The importance of Dr. Karp’s research has been widely recognized by the scientific community. His research is funded by the National Institute of Diabetes and Digestive and Kidney Diseases at the National Institutes of Health. He also receives funding from the American Society of Transplant Surgeons (ASTS), and is the Co-Chair of this organization’s Cell Transplant Committee. Dr. Karp is a past recipient of the ASTS-Astellas Faculty Development Award and the ASTS-Wyeth Collaborative Scientist Award.

“If we can develop effective drugs to help the liver repair itself, some patients may be able to avoid liver transplantation completely,” says Dr. Karp.

Transplant Trivia

In each issue of *TransplantNews* we’ll ask a transplant trivia question. From the correct answers submitted by email, we’ll randomly select a winner to receive a Donate Life gift. Congratulations to Russ M., who correctly answered the trivia question from our last newsletter – the first successful living donor kidney transplant was performed in Boston in 1954. This issue’s question is...

New England’s first successful liver transplant was performed in what hospital and in what year??

Email your answer to jrodrig@bidmc.harvard.edu. The winner will be announced in the next *TransplantNews*.

Writing to Donor Families

Many transplant recipients choose to write a letter of gratitude to their donor’s family. In response, many donor families have said that receiving a personal card or letter from the recipient of their loved one’s organs gives them comfort and consolation.

The decision to write to your donor’s family is a very personal one. If you decide to communicate with your donor’s family, there is a process in place that is designed to respect your privacy and the confidentiality of the donor and his/her family. You should not reveal your full name, mailing address, telephone number, transplant center, or transplant doctor’s name. However, it is okay to talk about yourself, what the transplant means for you and your family, and your gratitude for the gift of life.

Once your letter or greeting card is complete, you should put it in an unsealed envelope. You should then also include on a separate sheet of paper your full name and the date of your transplant. Put these items into another envelope and mail it to your transplant coordinator or you can mail it directly to the New England Organ Bank at One Gateway Center in Newton, MA 02458. A Family Services Representative will review your letter to ensure confidentiality and then tell the donor family that they have received correspondence.

This process can take a few weeks. You may or may not receive a response from your donor’s family, who may still be grieving the loss of a loved one. For more information about communicating with your donor’s family, please talk to your transplant coordinator or social worker.

Reaching Out to Dialysis Clinics

Our kidney transplant team has been “on the road” providing transplant updates and information to dialysis clinics in Massachusetts. Noelle Dimitri, LICSW, Transplant Social Worker, Louise Riemer, APRN, Dialysis Access Coordinator, and Linda Walsh, RN, Transplant Nurse Coordinator, visit dialysis centers for informal lunch meetings to provide staff with updates in the field of kidney transplantation.

The goal of these in-service meetings is to increase the dialysis staff’s knowledge about transplantation. We also use this time to continue the collaborative clinical relationship between the dialysis unit and the Transplant Institute. The in-service meetings are attended by dialysis nurses, patient care technicians, social workers, nutritionist, and administrative support personnel. We discuss the transplant evaluation and testing process, live kidney donation, the different types of kidneys available, the transplant waiting list and its management, post-transplant care, delayed graft function, transplant nutritional issues, and the psychosocial evaluation and services in transplant.

The in-services have been well received and have generated lots of discussion and questions. If dialysis staff want more detailed information about other services or programs in the Transplant Institute, we make arrangements for a follow-up in-service. For instance, one dialysis unit raised questions about racial disparity in transplantation, and so our transplant psychologist, Jim Rodrigue, PhD, presented strategies the Transplant Institute is implementing to reduce racial disparity in kidney transplantation.

Following the in-services, dialysis staff have commented that the transplant process seems less mysterious. They also report feeling better equipped to answer patients’ questions about transplantation. We have also been able to conference more regularly about patient care issues and to keep dialysis staff better informed about a patient’s progress through the transplant process.

If you are interested in one of our services at your dialysis clinic, please contact Noelle, Louise or Linda for more information at (617) 632-9700.

The “Weight” is Over

Join the Transplant Institute’s new weight loss program

Have you been told by your transplant doctor to lose weight? Has it been difficult for you to lose weight? Are you unsure about the most effective strategies to lose weight? Would you like some help from a team of behavioral health and nutritional specialists? Then we have a program for you!

Why is your weight such a big deal? For the general population, obesity increases the risk of hypertension, diabetes, and other health problems. For transplant patients, obesity heightens the risk of surgical complications, delayed graft function, longer hospitalizations, new onset diabetes after transplantation, and cardiovascular problems. Obesity also can affect your rehabilitation potential, your quality of life, and your survival after transplantation.

Our new group-based weight loss program will help you to learn more about proper transplant nutrition, exercise, and effective strategies for changing longstanding habits and attitudes around eating and weight gain. The group is open to all transplant candidates and recipients and will meet every Wednesday, 2 to 3 p.m. in the Transplant Institute conference room (7th Floor, Lowry Building).

The first group meeting will be on August 26th. Please call (617) 632-9700 to reserve a spot in the group.

Just a Click Away

Don’t forget to visit our new website at www.bidmc.org/transplant. You’ll find helpful information about our kidney, liver, and pancreas transplant programs, our comprehensive dialysis access service, our hepatobiliary surgical care, and our internationally recognized research activities. Look for videos of patients who share their personal stories, podcasts on coping with stress, as well as other how-to topics, and illustrations of transplant and living donor surgery.