



**Lucile Packard  
Children's Hospital  
at Stanford**  
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 **Lucile Packard  
Children's Hospital  
at Stanford**

# A Leader in Transplantation

COMPREHENSIVE CARE FOR CHILDREN

LUCILE PACKARD CHILDREN'S HOSPITAL, A LEADER IN TRANSPLANT MEDICINE

## COMPREHENSIVE CARE FOR CHILDREN

Lucile Packard Children's Hospital at Stanford is a world-class hospital for pediatric transplantation. With transplant subspecialties in kidney, liver, intestine, heart and lung, as well as combined transplants across these disciplines, Packard Children's transplant programs provide a complete set of services in an exclusively child- and family-centered setting. Our transplant teams specialize in treating high-risk patients and complex cases, including liver tumors, rare genetic disorders and combined transplants,

as well as some of the smallest, youngest and sickest patients. In spite of how fragile our patients may be, our outcomes consistently remain among the best in the nation. Research and innovation keep us on the leading edge of transplant medicine through our affiliation with Stanford University School of Medicine and Stanford Hospitals & Clinics. Our transplant specialists are also specialists in the care of children, making Packard Children's the best choice for kids and parents alike.



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# A Legacy of Innovation & Achievement

Patients at Lucile Packard Children's Hospital benefit significantly from the long history of transplant research conducted at Packard Children's in partnership with the Stanford University School of Medicine.

Our physicians performed the first successful heart, lung and heart-lung transplants in children, and continue to advance these and other transplant treatments through research and innovation. In kidney, liver and intestinal transplant, Packard Children's doctors have led the way to improved procedures, such as transplanting adult kidneys into infants, utilizing split liver donors, pioneering intestinal lengthening procedures, and performing transplantation in the very youngest children.

## AT THE FOREFRONT OF CLINICAL RESEARCH

Our groundbreaking studies have led to reduced organ rejection and improved organ function, while also liberating eligible patients from undesirable side effects. The results have improved surgical outcomes and have made life as a young transplant recipient easier to manage. Ongoing research has brought transplant science

into the new millennium by optimizing the potential of genetic signatures to establish which patients are best suited to decreased medication, and which ones might thrive without immunosuppressive medication altogether.

## COMMITTED TO EXCELLENCE

Many factors contribute to Packard Children's highly successful and innovative transplantation programs. Our surgeons, physicians, researchers, nurse practitioners, nurses, social workers, transplant coordinators, physician assistants and child life specialists all aspire to a standard of excellence in pediatric care and are committed to meeting each child's unique needs before, during and after surgery. In addition, care at Packard Children's Hospital is provided by multidisciplinary teams. Transplant surgeons and physicians collaborate with in-house pediatric specialists—neonatologists, anesthesiologists, cardiologists, radiologists

and pathologists—and partner with referring physicians to provide the best diagnosis and ongoing treatment. After transplant, patients are cared for in one of the nation's largest and best-equipped Pediatric Intensive Care Units. The unit's highly experienced critical care staff is specially trained in the care of transplant patients and works closely with the transplant team on daily rounds.

## DEDICATED TO PEDIATRICS

At Packard Children's, our entire medical staff is specially trained in the unique needs of medically fragile children. From the smallest medical equipment designed for the tiniest patients, to empathetic bedside care tailored to meet the unique ways that children experience medical treatment and a medical environment, everything at Lucile Packard Children's Hospital is designed for the infant, child or adolescent in our care.



## PIONEERS IN TRANSPLANT HISTORY

- Stanford surgeons perform nation's first heart transplant and first heart-lung transplant
- Development of steroid-free kidney transplant
- The largest pediatric liver transplant series for malignancy in the nation
- The first pediatric intestinal transplant in Northern California
- The first ever randomized study, in children or adults, for treating highly sensitized recipients for kidney transplantation
- Longest-surviving pediatric heart and heart-lung transplant patients
- The first to use genetic profiling to determine a child's inherited likelihood of organ rejection and to tailor post-transplant medications
- The first pediatric heterotopic heart transplant in California
- Successful transplantation of adult-size kidneys into small children
- The first hospital on the West Coast to use a Berlin heart pump as a bridge to transplant for a child



# Kidney Transplantation

## NOTABLE ACHIEVEMENTS

Since its inception in 1995, Packard Children's Kidney Transplant Program has grown to be recognized as a world leader based on outstanding results, innovative research, acclaimed faculty and exceptional clinical staff. Our team has performed more than 300 pediatric kidney transplants at Packard Children's and maintains one of the highest success rates in the country. Success at this level depends on a constellation of experts whose dedication to research, discovery and outstanding care marks every step of treatment.

Packard Children's Kidney Transplant Program has achieved one of the highest success rates in the United States and the world. All 50 children who received a living-donor transplant at our hospital between January 1, 2001, and June 30, 2003, had a functioning kidney three years later. This rate of 100 percent graft survival is 10 percent higher than statistical expectations. In addition, all children who underwent a kidney transplant in the 18 months prior to June 30, 2007, had graft survival after one year. Only three other high-volume (more than 20 per year during the 18-month reporting period) transplant centers in the United States achieved 100 percent survival

and, of those, Packard had performed the most transplants. Nearly one quarter of Packard's patients were infants and small children less than five years of age, underscoring the exceptional quality of the work and outcomes even more.

Behind these excellent results are years of dedication to innovation and superb patient care. Transplant surgeons, nephrologists, anesthesiologists and nephrology nurse clinicians work closely with intensive care physicians and nurses, who play an essential role in every successful transplant by providing painstaking care in the critical hours and days after surgery. Additional support from the renal program manager, transplant coordinators, social workers, child life specialists and recreation therapists, pediatric peritoneal dialysis coordinators, renal nutritionists, research coordinators, financial counselors, and administrative and support staff cover the full spectrum of patients' and families' needs. Attention to every detail by every member of the team adds up to excellent outcomes for our young patients. And those young patients and their families, who put their trust in our team, are themselves pioneers of new treatments that have the potential to benefit other patients across the country and the world.

Our program's excellence in research and treatment is underscored by referrals of patients from other leading academic hospitals. To date, patients from more than 20 states and seven countries outside the United States have been referred to the program. Many of these cases come to Packard Children's because they pose challenges few other medical centers can meet. These patients include newborns with kidney failure from birth, infants with kidney failure caused by structural abnormalities of the bladder and urinary tract present at birth, and mothers carrying unborn children with major kidney defects.

## ADVANCING MEDICAL FRONTIERS

Physicians and surgeons at Packard Children's have led the way in successful transplantation in children who are very young and very small, pioneering such innovations as the transplantation of adult-sized kidneys into infants, steroid-free suppression of organ rejection, desensitization for patients who have a very low likelihood of finding a compatible kidney, and the use of genetic profiling to determine a child's inherited likelihood of organ rejection and to tailor post-transplant medications. In addition to Packard Children's novel techniques in transplantation, our specialists have also

pioneered the optimal management of severe congenital abnormalities in children whose abnormal urinary tract led to renal failure and transplantation.

## STATE-OF-THE-ART CHILDREN'S DIALYSIS CENTER CONVENIENTLY LOCATED INSIDE PACKARD CHILDREN'S HOSPITAL

At Lucile Packard Children's Hospital, we recognize the critical role of dialysis in a state-of-the-art pediatric kidney transplant program. More than three-quarters of children who come to Packard Children's for kidney transplantation do so while receiving maintenance dialysis. We believe optimal dialysis is a key contributor to the excellent outcomes our kidney transplant program provides.

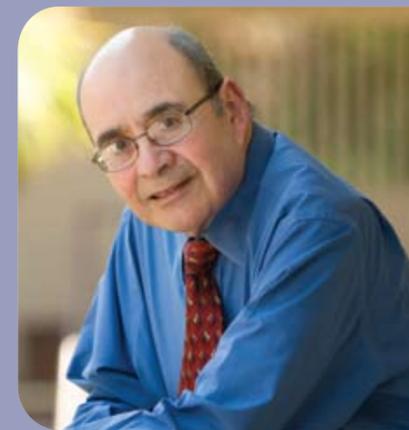
Lucile Packard Children's Hospital's 3,000 square-foot dialysis center houses six state-of-the-art dialysis machines plus a training annex where parents can learn how to care for their children on dialysis at home. Because the Dialysis Center is located inside the hospital, patients can be seen by the medical team frequently during dialysis to monitor care and respond to problems. Packard Children's also provides the most advanced dialysis water purification technology available anywhere; only at Packard can children receive treatment using ultra-pure dialysis water.

Children receive highly specialized nursing care and attention from a multi-disciplinary team in a cheerful and stimulating setting. This is especially important to those

children with families who come to Packard for kidney transplantation from outside the Bay Area. The expertise of the dialysis team keeps patients awaiting kidney transplants in optimal physical condition, while the Center's fun and creative activities boost patient morale. Children can access the Internet, play video games, watch movies, spend time with child life therapists and even do homework in an area overlooking a sunny, landscaped courtyard.

“It has been a remarkable 15 years since Packard Children's opened its Pediatric Kidney Transplant Program, and the overall performance of the program through that period of time has been unsurpassed, both clinically and with its complementary clinical and basic science research. The program has been a world leader in patient and graft survival outcomes since its inception, despite the fact that it has had a larger percentage of infants receiving transplants as well as children with congenital urologic abnormalities. But this has been the strength of the program—its pursuit of absolute clinical excellence and its

genuine commitment to address the issues in a pediatric kidney transplant program through a major clinical and basic science research effort that leads the field in the number of yearly medical publications and presentations at national and international meetings. The program thus continues on its quest towards a perfect transplant for each and every child it manages with end-stage kidney failure. That this is all possible can be gleaned from its record of accomplishments and from the makeup and dedication of Packard Children's pediatric kidney transplant team, including its transplant surgeons, nephrologists, nurses, social workers, research personnel and other staff members.”



Oscar Salvatierra, MD  
Active Emeritus  
Advising Dean, School of Medicine  
Past Director, Pediatric Kidney Transplantation  
Lucile Packard Children's Hospital



# PROFILE

## Ka'apeha Kanae: *Once in a Lifetime*

Ka'apeha was just 6 weeks old when his doctors in Hawaii diagnosed him with a form of "biliary atresia." His bile ducts, which carry bile from the liver to the intestine, were flowing in the wrong direction, leaving his liver in bad shape. He was referred to Lucile Packard Children's Hospital, where he received months of care and blood transfusions. But, at 9 months old, his liver failed. Packard's team transplanted a donor liver, but his body soon began to reject it. Knowing that a very sick liver can sometimes be worse than no liver at all, experts at Packard suggested a novel treatment. A new method of "liver assistance," known as CVVH (continuous venovenous hemofiltration) had been used in a handful of cases to sustain patients with no liver while they awaited a donor for transplant. His parents agreed it was his best chance.

The team removed Ka'apeha's failing liver and placed him on CVVH. He got far worse before he got better, but ultimately the CVVH machine, blood pressure medicines and mechanical ventilation gradually helped Ka'apeha recover. As he improved, a donor liver match became available. This time Ka'apeha's new liver transplant was a success.

With constant attention and expert management by his team of caregivers, Ka'apeha had survived for more than 80 hours, longer than any child at the time had ever lived without a liver. "Our faith was really tested," said his mother, Averi, "and really strengthened."

Today Ka'apeha is a happy 11-year-old. Innovations in anti-rejection therapy developed at Packard Children's have helped reduce his ongoing medication to a once-a-day pill, while also ensuring his good health.



# Liver Transplantation

**INTERNATIONALLY RECOGNIZED**  
Launched in 1995, the internationally recognized Pediatric Liver Transplant Program at Lucile Packard Children's Hospital is one of the largest and most experienced in the world and has performed over 400 pediatric liver transplants. Our experienced staff, quality facilities and team approach to health care have earned the program a premier reputation in liver transplantation. As one of the largest referral centers for children with liver disease in the Bay Area, our core team of transplant surgeons and hepatologists has been together for 20 years. Packard Children's pediatric liver transplant team performs an average of 30 liver transplants per year, making us one of the highest-volume centers in the country. Our team's success rates are exceptional compared with other high-volume centers because two-thirds of our patients are under 2 years

of age and many weigh less than 6 kilograms. Furthermore, many of our patients require transplantation for liver cancer (hepatoblastoma) or combined organ transplantation such as liver and kidney, liver and intestine, and liver and heart. Packard Children's is committed to accepting the most challenging cases, including children other hospitals consider too young or too sick to transplant. We perform pediatric liver transplants using full-size livers, split-liver and reduced-size donor organs and perform many combined transplants. This broad range of transplant options and use of novel techniques to increase the donor pool allow us to minimize wait times and provide children with better chances for a successful transplant. We also have an active living donor transplant program and expertise in complex liver surgery such as hepatobiliary surgery and surgery for portal hypertension.

Packard Children's provides a Teen Clinic (detailed on page 17) designed especially to meet the unique needs of adolescents after transplant and helps them in their transition to adult services.

Packard Children's liver transplant team takes pride in fostering collaboration with our referring physicians through our extensive outreach programs. The transplant team makes regular visits to various outreach sites in California, Oregon, Washington, New Mexico and Hawaii to perform on-site pre-transplant evaluations and to continue to monitor the patients after the transplant along with the local health care team. This allows for an easy transition for the child back to the community and provides optimal continuity of care.



“We are recognized as the leader in transplant research, immunosuppression management and overall patient care. Our patients are like our extended family.”

Waldo Concepcion, MD  
Pediatric Transplant Surgeon  
Director, Pediatric Kidney Transplantation  
Lucile Packard Children's Hospital



## PROFILE

### Ricardo Martinez: *Parents on Care Teams Make the Difference*

Ricardo Martinez was born eight weeks early with an undetected intestinal torsion, or twisting. Plagued by infections and a belly swelled to 45 centimeters, Ricky needed several surgeries at his hospital in Madera, California. There, doctors discovered and repaired his torsion and removed several perforated sections of his intestine. With only a fraction of his intestine left, Ricky had to be fed by total parenteral nutrition, which gradually devastated his liver. A few months later, he hemorrhaged during a liver biopsy. He was rushed to Lucile Packard Children's Hospital, where he was treated and evaluated for a combined liver and intestinal transplant.

Less than a month later, Dr. Carlos Esquivel, and his surgical team at Packard successfully replaced Ricky's liver and small intestine. He recovered well until his breathing tube was removed. His mother, Lilia, noticed that he seemed short of breath.

Doctors took her concern seriously and called in a team to examine him. Within minutes, he was prepared for another surgery that remedied the problem. "That day they gained my complete trust," Lilia said. "I liked that they took my opinion seriously. What I said mattered." These days, Ricardo lives and eats like any other healthy two-year-old. His smile sparkles, and so does his future.

Including parents as members of the care team is an essential aspect to expert medicine. Parents know their children's signs and subtle changes better than anyone. Packard Children's Family-Centered Care program was developed by transplant experts, and has now grown to encompass every specialty at the hospital. Because no one knows a child better than their parents.



“They took my opinion seriously. What I said mattered.”

**Lilia Martinez**  
Mother of Ricardo Martinez

## Intestine Transplantation

### INTESTINAL REHABILITATION PROGRAM

For decades, total parenteral nutrition (TPN) was the only therapeutic option for children with inadequate bowel function, or short bowel syndrome. But the severe and often life-threatening side effects of TPN, including line sepsis, liver failure and ultimately the need for transplant, make it a complicated and limited option. Innovative care through Packard Children's Intestinal Rehabilitation Program encourages early referral and care planning with referring physicians to dramatically improve outcomes for children who might otherwise require TPN or transplant. Following children early in treatment allows for cooperative support of each patient and the best timing of care. Our highly skilled group

of gastroenterologists and allied health care professionals work with surgeons to optimize intestinal function in children to avoid a liver or intestinal transplant. The program includes creative nutrition and the use of novel surgical approaches such as the Serial Transverse Enteroplasty Procedure (STEP), which is used to lengthen and taper the bowel and may improve overall bowel function and nutrient absorption.

### LIFE-SAVING INTESTINAL THERAPY

When transplant becomes necessary, the team at Lucile Packard Children's Hospital is able to provide the best intestinal or combined liver and intestinal transplant possible. Packard Children's has helped intestinal transplantation progress from

an experimental procedure to a life-saving therapy. As a leader in transplant surgery and research, Lucile Packard Children's Hospital's contributions to major advances in surgical techniques, immunosuppressive medications, infection prevention and treatment, patient selection and timely placement on the transplant waiting list have helped improve success rates. Packard Children's Intestinal Transplantation Program, founded in 2001, has performed more than 40 intestinal transplants. After transplantation, children no longer need total parenteral nutrition. Longer-term transplant recipients eat normally and no longer require catheters, gastrostomy tubes or ileostomies. Best of all, these children are living a better life than thought possible only a short time ago.



“The LPCH transplant team is compassionate, devoted to the care and comfort of their patients and their families and fully committed to excellence.”

**Carlos Esquivel, MD, PhD**  
Chief, Division of Transplantation  
Lucile Packard Children's Hospital



## PROFILE

### Elizabeth Craze: *Surviving—and Thriving*

Before heart transplants were a medical possibility, Susan and Charlie Craze lost three of their five children to heart disease before they had reached age 3. When the youngest of their surviving children, two-year-old Lizzy, suffered heart failure in 1984, the Craze family traveled from their home in Cleveland, Ohio, to Stanford Hospital in California, where Lizzy would become the youngest child in the world at the time to undergo a heart transplant.

The family moved to the Bay Area to make the best follow-up care easier to obtain, and then followed Lizzy’s care team down the hall to Packard Children’s when it opened in 1991. “Packard was magnificent,” recalls Susan. “Everything was state-of-the-art; so much better for nurses and families.”

Lizzy needed a kidney transplant when she was 16 years old. Afterwards, Packard’s nurses helped her take responsibility for her own care. “They walked me through all my pills and every detail about how to take care of myself,” says Lizzy. As one of the longest-surviving pediatric heart transplant recipients, Lizzy has transitioned to adult care at Stanford with an excellent prognosis and a full and happy life. She still follows much of the good advice given to her at Packard Children’s. “I exercise regularly and take good care of my heart—I guess everyone should.”

Today, thanks to Lizzy’s history-making surgery and the data that have accumulated from other pediatric transplant cases, surgeons at Packard Children’s Hospital are performing some 15 pediatric heart transplants each year. At a time when there are about 325 such surgeries nationwide, Daniel Bernstein, MD, chief of pediatric cardiology, says that makes Packard “one of the top three or four transplant centers” in the country.



Photo courtesy of Steve Fisch Photography

“They walked me through all my pills and every detail about how to take care of myself.”

**Elizabeth Craze**  
Heart and Kidney Transplant Patient

## Heart Transplantation

### PIONEERS OF INNOVATION

Packard Children’s transplantation team performed the world’s first successful pediatric heart transplant in 1984 and continues to play a pivotal role in on-going innovations. Recent accomplishments include reducing and preventing heart transplant coronary artery disease, understanding how viral infections affect the transplanted organ, and using molecular testing to noninvasively determine a patient’s risk for rejections. At Packard’s Pediatric Advanced Cardiac Therapies Clinic, our doctors are testing a new generation of drug treatments that can help avoid the need for a transplant in children with heart failure.

### COLLABORATIVE EXPERTISE

Packard Children’s Heart Transplant Program is one of the preeminent children’s heart transplant centers in the world. Because we integrate the clinical, administrative and academic functions

of pediatric cardiology into a single unit, our patients benefit from a breadth of medical expertise. Packard Children’s team has performed more than 200 pediatric heart transplants. Although we specialize in complicated cases—such as severe congenital heart disease and pulmonary hypertension—we have the largest number of long-term survivors in the world and among the best one and five-year survival rates.

Unparalleled surgical outcomes are the direct result of the innovation and teamwork of our physicians, nurses and allied health care professionals. Our program’s overall non-risk-adjusted survival rate is among the very best in the country, even more remarkable given the high-complexity and high-risk patients referred to Lucile Packard Children’s Heart Center from around the world.

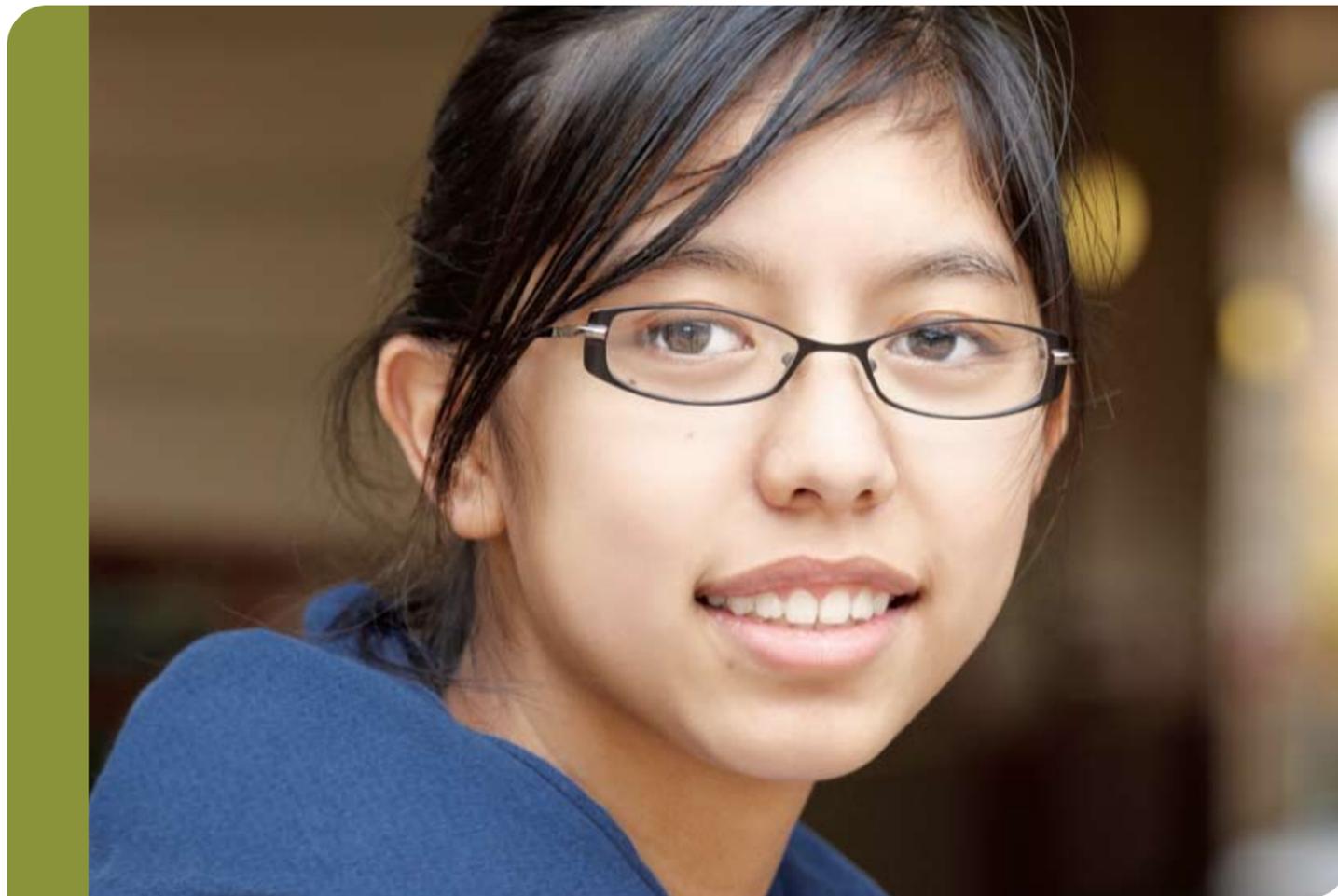
### BRIDGE TO TRANSPLANT

For patients who urgently need a transplant weeks or months before a donor organ becomes available, Packard Children’s goes above and beyond to provide the world’s most advanced cardiac support. Our physicians were among the very first to petition the FDA for unique use of the Berlin Heart external pump device to support patients awaiting transplant, and Packard holds the record for longest pediatric heart-assist in North America, at 234 days. The Children’s Heart Center at Lucile Packard Children’s Hospital also routinely provides advanced cardiac support, including extracorporeal membrane oxygenation (ECMO) and external right and/or left ventricular assist device (RVAD/LVAD) support for younger children, as well as totally implantable LVAD support for older patients.



“Mrs. Packard believed that all children equally deserve the best care available. Her philosophy lives on today within every LPCH family-centered transplant program. Although our primary goal is outstanding patient outcomes, we never lose sight that the patient is a person and a child.”

**Clifford Chin, MD**  
Director, Pediatric Heart Transplant Program  
Lucile Packard Children’s Hospital



“Packard Children’s is an amazing place. We have the highest of standards for patient safety and care. We provide a pleasant atmosphere and an environment where the depth of knowledge, experience and information is complemented by state-of-the-art equipment. It helps to ensure the best possible outcome for our little patients.”

**Carol K. Conrad, MD**  
 Director, Pediatric Lung and Heart-Lung Transplant Program  
 Lucile Packard Children’s Hospital

## Lung Transplantation

### COMPREHENSIVE TREATMENT

With one of the best post-operative outcomes for adolescents in the world, the lung transplant team at Stanford University has performed more than 25 pediatric double lung transplants since 1989. Our team works closely with experts from Packard Children’s Center for Cystic Fibrosis and Pulmonary Diseases. Together, we provide treatment for the full range of chronic diseases that may require lung transplantation—from cystic fibrosis, bronchopulmonary dysplasia, surfactant protein deficiency and interstitial lung disease to genetic defects. Lung transplantation is a highly specialized and generally rare option for treatment for children with end-stage lung disease. Lung transplantation offers the promise of treatment for otherwise untreatable lung diseases. Our multidisciplinary care

team evaluates candidates and treats their diseases at every stage, in one location, and attends to all related issues for patients and families. When transplant is necessary, experts in surgery, medicine, pulmonology, nutrition, physical therapy, child psychology and pharmacy, along with clinical nurse specialists trained in the care of transplant patients, offer the very best support to transplant candidates before, during, and after surgery. This comprehensive treatment ensures that every aspect of a child’s life is considered during treatment. Our patients stay at or nearby the hospital for several months after treatment and are followed daily to ensure the best possible outcome.

Packard Children’s is one of 17 hospitals in the United States that participates in the International Pediatric Lung Transplant Collaborative. At each of these centers, only

a few patients undergo transplant annually. We partner closely with them, which allows for in-depth analysis and comparison of the efficacy of treatment regimens across centers and generalization of findings. A common treatment regimen allows participating centers to collect data together to advance knowledge and inform the practice of immunosuppressive treatment for all patients. Through the IPLTC, universal guidelines for immunosuppression have been developed in pediatric lung transplantation. With these established, future research efforts can identify the effect of treatments that improve survival, such as the most effective medical regimens to treat cytomegalovirus and fungal infection that can occur after transplant. Database sharing and other studies are in progress, keeping LPCH at the forefront of innovation and research in transplant medicine.

## Heart-Lung Transplantation

### A LEADER IN TRANSPLANTATION

The world’s first successful combined heart-lung transplant was performed at Stanford Hospital in 1981. Our Pediatric Heart-Lung Transplant Program is staffed by some of the foremost cardiothoracic surgeons and pulmonologists in the field. As a world leader in children’s heart-lung transplant, Lucile Packard Children’s

Hospital is also the only center for this treatment in Northern California. Our team has performed more than 20 pediatric heart-lung transplants since 1986 and has some of the longest-surviving patients.

Our transplant team specializes in complicated cases, such as children with severe congenital heart disease or

pulmonary hypertension, a condition in which the pulmonary arteries supplying blood to the lungs have been damaged irreversibly by high pressure. The collaboration of our surgical experts and multidisciplinary care teams ensures that the patient and family receive the most advanced care available.



## Living Donor Program

FOR MORE THAN 10 YEARS, transplant teams at Lucile Packard Children's Hospital have been performing living donor transplants, for both kidney and liver transplant recipients, with excellent results and no complications among donors. In the first three years following kidney transplantation, half as many living donor recipients experience episodes of acute rejection as compared to deceased donor recipients. Research data indicates that kidney recipients of deceased donor transplants are at greater risk of transplant rejection over the long term than living donor recipients. Because parents or other relatives are often the best candidates for organ donation, a quick recovery time is essential so that donors may be available to care for their children. Packard Children's is a leader in minimal-incision nephrectomy,

which expedites recovery and patient functionality.

The ability to perform living donor liver transplants makes Packard Children's less dependent on the short supply of donor organs. The liver is the only solid organ that can grow and regenerate in both donor and recipient. The advantage of living donor liver transplantation is the ability to schedule the surgery on an elective basis. This allows the transplant team, along with the family, to decide the optimum time for the procedure. Patient survival is over 90 percent for our living donor program, with graft survival of 85 percent. Donors have included parents, grandparents, aunts, uncles and close family friends. All donors to Packard Children's patients are currently alive and well.

# Transition to Adulthood: Packard's Teen Clinic for Liver Transplant Patients

Great advances in the long-term survival of pediatric transplant patients make the move from pediatric to adult care a routine part of growing up. At Lucile Packard Children's Hospital at Stanford, pediatric and adult teams work together to support patients and families during this transition and to ensure that patients get the best care possible as they grow older.



“We have the best chance for success when we bring teens together with their peers to talk about the challenges of living with a transplant and outline concrete, baby steps they can take toward independence. They need to understand that they have to be invested in maintaining the good outcomes they've enjoyed since their transplant.”

**Marcia Castillo, RN**  
Teen Clinic Coordinator  
Lucile Packard Children's Hospital



AFTER YEARS OF CAREFUL management by parents and caregivers, many adolescent patients who have undergone liver transplant may not be independently adherent with their care regimen and are under-prepared to advocate for themselves in the world of adult care. Packard Children's Teen Clinic for liver transplant patients—the first of its kind—tackles these problems head-on. The monthly clinic helps prepare adolescents with liver transplants to assume responsibility for their health as they transition into the world of adult care.

Clinic participants are challenged to reach a number of goals designed to teach them how to care for themselves. Younger patients, for example, are expected to be able to describe their health status and read a thermometer. Older patients are taught the names and purposes of the medical tests, how to call the clinic and make or change their own appointments, and how to call a pharmacy for refills before their regular medication runs out. Young adults are expected to obtain health insurance coverage independent from their parents'.

The Teen Clinic is a multi-disciplinary clinic that includes specialists in hepatology, child psychiatry, social work and transplant coordinator staff. Teen clinics take place once a month during normal clinic hours. This monthly clinic provides time for adolescents to be seen independent of their parents, allows exploration of their own thoughts, and encourages health promotion and opportunities for self-advocacy training.

Participating teens are assigned to one of four groups: early adolescence (ages 12 to 14); mid-adolescence (ages 15 and 16); late adolescence (age 17); and young adulthood (ages 18 to 21). After their standard clinic checkup, teen transplant patients gather in another room with a child psychiatrist to discuss anything that may be on their minds. Topics for discussion are provided by the psychiatrist, and may include medication adherence, body image, sex and sexuality.

On the same day, a separate support group is held for parents and facilitated by Packard Children's transplant social workers. Here, families learn to support their child's transition process and understand their own transition away from their child's care. Many patients report that just meeting and getting to know other transplant teens is the most useful aspect of the program. Parents, in turn, report relief that their children are becoming more autonomous. While parents understand that, for transplant patients, following a doctor's instructions is a matter of life and death, many teens do not. Helping teens have a realistic understanding of their health is a key objective of the program, as is shifting the primary interest in and management of the patient's health from the parent to the patient.

Our specialized Teen Clinic is the building block for our successful transitioning program. This purposeful, planned movement of adolescents and young adults to adult care is a unique aspect at Lucile Packard Children's Hospital and the hallmark of a successful transplant program.

## A HOSPITAL FOR CHILDREN

From the sunny hallways filled with children's artwork to the model train, from the bright and inviting waiting rooms to pet therapy, everything at Lucile Packard Children's Hospital is geared toward making children feel welcome and safe. Built in a circular design around a central courtyard, the hospital has 27 gardens and outdoor play areas. Half-moon cut-outs along the nurses' stations let growing kids see right through the counter. The Forever Young Zone recreational therapy room provides a "medical-free" place where patients and siblings can play with toys, work on arts and crafts projects, enjoy monitored and secure Internet access, or interact with other patients and siblings. Packard Children's also provides a complete spectrum of family support services, including a fully accredited

school program for inpatients and siblings, personalized housing assistance, interpreters, social workers, psychologists and an in-hospital chapel and chaplaincy program. Additional programs, such as our week-long summer camp exclusively for transplant recipients, help foster community among kids with transplant experience in common. Before they even arrive at the hospital, kids can get an inside look online, through Packard Kids Connection at <http://kids.lpch.org>. Our playful, child-driven Web site offers games, videos, and step-by-step demonstrations of tests and treatments to help kids feel more confident and in control when they come to the hospital. In these and so many other ways, Packard's staff, design and programs are devoted to the care of infants, children, adolescents and their families.



“Packard's Family-Centered Care Program is the feature that sets it above other hospitals. I was allowed to be a part of the decision-making process, allowed to make my voice heard. The doctors would actually thank me for my contributions to the discussion.”

**Liann Seki**, mother of Jackie Seki, one of the first combined intestine and liver transplant recipients.



## Family-Centered Care

PARENTS AND FAMILIES HAVE long recognized and valued the expertise of the health care providers who give them care. Packard Children's transplant teams also recognize that parents and families have their own expertise, and they know their children and family best. The Family-Centered Care Program at Lucile Packard Children's Hospital believes that families and professionals can have a true partnership, where the expertise and opinions of each are valued when making decisions about the health care of children.

Our Family-Centered Care Program involves families as active partners in

every aspect of care—from assisting in the medical management of their child during hospitalization, to sitting on committees that help establish hospital policies. We've found that supported, well-informed families form productive partnerships with their caregivers and are a great resource for future transplant patients and their families. Trained parent mentors, whose children have been through transplantation themselves, volunteer at our hospital, providing practical advice on everything from spirituality and insurance issues to post-surgical compliance.





## Advancing Research

PACKARD CHILDREN'S interdisciplinary transplant teams have forged some of the most significant advances in pediatric transplant medicine. Our innovative breakthroughs in all disciplines of transplantation medicine have dramatically improved survival rates and the ongoing quality of our patients' lives.

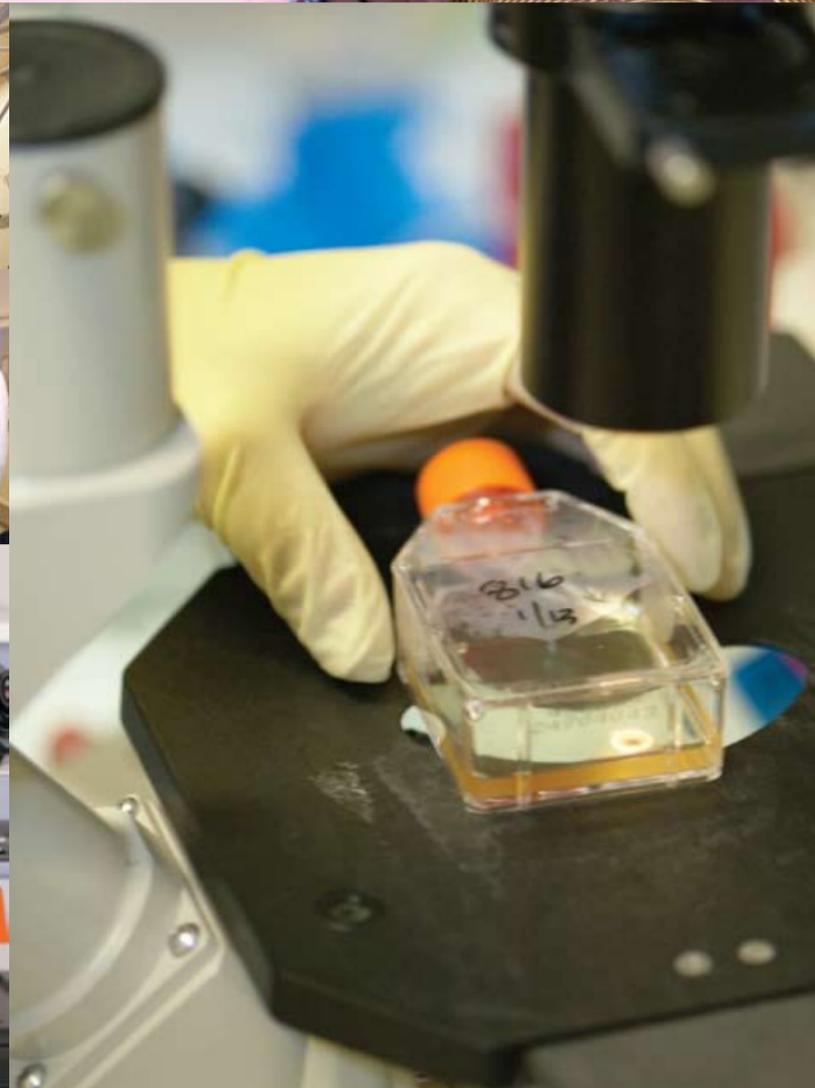
For pediatric kidney transplant recipients already on steroid therapy, researchers on the pediatric nephrology and transplant teams at Packard Children's looked deeper to find the pattern of gene expression that distinguished patients at higher risk of organ rejection from those who might safely benefit from a reduction in all immunosuppressive medication. Customizing immunosuppression helps to lower patient care costs and lowers the risk of malignancies and infections, thus lowering patient morbidity.

### STEROID-FREE REVOLUTION FOR KIDNEY TRANSPLANT RECIPIENTS

Some of the most noteworthy achievements in the recent history of kidney transplantation were made at Lucile Packard Children's Hospital. Our physician researchers were the first to remove side-effect-laden steroids from the mix of immunosuppressant medications used to reduce organ rejection in pediatric kidney transplantation. In a study that eventually grew into a multi-center trial, we proved that many patients fare significantly better post-transplant without the steroid therapy that has been the cornerstone of anti-rejection therapy in kidney transplantation since the 1950s. Patients in the initial study grew more and stayed healthier than similar transplant patients who were receiving steroids. Their new organs thrived in the steroid-free environment, performing even better than the kidneys of children receiving steroids. Their blood pressures also remained normal and none developed the unpleasant cosmetic side effects associated with steroids. The multi-center trial has helped to confirm that the absence of steroids enhances kidney function and reduces the chance of acute rejection.

### IMPROVED DIAGNOSIS OF REJECTION

Currently, diagnosis of transplanted organ rejection is performed by a pathologist who examines a biopsy of a troubled graft to distinguish between rejection, infection, drug toxicity or something unexpected. Unfortunately, changes caused by rejection may be subtle and many transplant centers do not have experienced transplant pathologists to provide accurate diagnosis. Packard Children's transplant nephrologists are working to harness the power of computers to read biopsies from transplanted kidneys to more accurately measure the chances of rejection. This would improve diagnosis and choice of treatment in the short term and be a better prediction of what is in store for the child in the future. This technology may someday utilize the Internet to allow Packard Children's expert nephrologists and pathologists to provide cutting-edge diagnosis and management recommendations to assist the local doctors caring for that child, across the country or around the globe.



## Research Pioneers

### INSTITUTE FOR IMMUNITY, TRANSPLANTATION AND INFECTION

The Institute for Immunity, Transplantation and Infection (ITI) at Stanford University represents an ambitious effort to integrate recent advances in our understanding of the immune system response in solid organ transplantation, autoimmune and infectious diseases. While we knew very little about the immune system 50 years ago, there is now a wealth of information about this complex network of cells and molecules that provides our natural defense against many diseases. In the case of organ and bone marrow transplantation, the very drastic treatments used to prevent rejection are often as life threatening as the original disease. There is an urgent need to develop less toxic, immune-system-based therapies which will not leave the patients at risk for infectious diseases or cancer.

An important development of ITI was the creation of the Human Immune Monitoring Center (HIMC), a key component that will perform a wide variety of cutting-edge immune assays (a number of which are only available at Stanford) on clinical samples from patients and will be linked to a state-of-the-art bioinformatics unit that will analyze the data. Stanford's HIMC is the only one of its kind in the world and provides important new information on the immune status of individual patients, resulting in a whole new level of personalized medicine. The HIMC draws together clinicians treating transplant patients and basic scientists to unravel the mystery of the underlying cause of disease and possible treatment options for each patient. This facility addresses a primary need in translational medicine by providing investigators a one-stop laboratory that can apply current and novel immunological assays to analyze clinical trials and provide the highest-quality patient care available.

### NEW APPROACHES TO DIAGNOSE AND TREAT POST-TRANSPLANT CANCER

While new immunosuppressive drugs help restrict the immune system from attacking the new graft, improving graft survival for

transplant patients, they also interfere with the immune system's primary ability to prevent infection. For example, patients receiving immunosuppressive drugs can develop infections associated with the Epstein Barr Virus (EBV). Normally a relatively harmless infection, EBV can cause the development of cancer in transplant



“Testing genes in a blood sample can now individualize immunosuppression for a transplant patient.”

Minnie Sarwal, MD, PhD  
Medical Director, Pediatric Kidney Transplant Program  
Lucile Packard Children's Hospital

patients receiving immunosuppression. In children, whose immune systems are not fully developed, EBV-associated tumors are a leading cause of post-transplant death.

Research by physicians at Packard Children's has led to the development of a quick and simple blood test to measure EBV levels in transplant patients, allowing

doctors to rapidly alter medication to reduce viral levels and avoid development of cancer. This test has since been adapted for use by other transplant centers and is now a routine part of post-transplant care. The same Packard physicians showed, for the first time, that a rapid and highly sensitive blood test can determine the status of the transplant patient's immune system for EBV infection. This test will allow doctors to know before and after transplant which patients are more likely to develop serious EBV infection and allow more customized treatment for patients at risk.

For those patients who do develop EBV-related cancer, there has historically been little to offer in the way of effective treatment. However, new work by Packard Children's physicians has begun to unravel the complex interactions between the virus and the graft recipient's immune system for the first time to better understand how and why cancer can develop. As a consequence of this groundbreaking work, drugs are being developed and tested that show great promise in the treatment of EBV-related tumors. This work has emerged from 15 continuous years of NIH-sponsored laboratory and clinical research in EBV disease at Packard Children's.

### NEW STRATEGIES TO HARNESS IMMUNE RESPONSE AFTER TRANSPLANTATION

One of the most exciting developments in transplant science has been the discovery of unique cell populations in the blood that can help the graft recipient accept their new organ. These cells, called T regulatory cells, are capable of interfering with and preventing the immune attack on the foreign tissue. Packard physicians showed for the first time that pediatric liver recipients carry T regulatory cells in their blood, and that monitoring these cell levels revealed whether graft rejection was occurring or, alternatively, if the patient's immune profile was protective for the graft. Replacing graft biopsy with a simple blood test marked a significant improvement in post-transplant patient care. This study also showed that measuring T regulatory cells

in the blood could help determine which patients can have their immunosuppression reduced without risking organ rejection. These findings also give promise to the idea that, in the future, we will rely less on immunosuppressive medications and instead be able to recruit these cells for the purposes of specifically preventing graft rejection. Along these lines, Packard Children's doctors have initiated studies to grow and expand these T regulatory cells in the laboratory to try and better understand how they may be applied to patient care.

### HEART TRANSPLANT RESEARCH

Innovative approaches in the care of pediatric patients before, during and after transplantation continue the longstanding tradition of Stanford University pioneer, Dr. Norman Shumway, who in 1968 performed the first successful heart transplantation in the United States. Current research focuses on the use of medical therapy to avert or avoid transplantation and improve outcomes, for those waiting for transplantation, through pediatric-specific mechanical

assist devices. For those who ultimately require transplantation, investigations have focused on novel therapies to care for the high-risk patient, use of gene testing to noninvasively assess for organ rejection, evaluation of new anti-rejection medications, and methods to reduce complications. Our physicians are recognized leaders in the field with their prime objective of improving the lives of children who need cardiac transplantation.





## TRANSPLANT CAMP



Every summer, Lucile Packard Children's Hospital hosts a weeklong camp for transplant recipients ages 8 to 18 at Camp Meeker on California's beautiful Russian River. The camp has become a treasured tradition for kids who look forward to this event as a rare opportunity to bond with others with whom they can easily identify. Long-term friendships are forged among the children, and

often, at pick-up and drop-off, among parents as well. Camp activities include outdoor activities, arts and crafts, a day at the beach, canoeing, evening events, and a celebration dance and talent show. In addition to the older campers who volunteer as counselors, the camp staff includes five nurses who provide medical supervision, and one Child Life specialist, along with voluntary attendance by Packard Children's doctors, social workers and other staff.

“When I first went to transplant camp in 2001, I was a little scared, but after a few days, it was one big family and none of us wanted to leave.”

**Marina Monica**  
19-year-old kidney transplant recipient, transplant mentor, and camp counselor

## Housing

### RONALD MCDONALD HOUSE

When patients and their families are comfortably and securely accommodated, they are better able to focus their energy on recovery. The Ronald McDonald House at Stanford is a half-mile walk or a regularly scheduled shuttle ride from Packard Children's Hospital. Bright, airy and comfortable rooms provide ample amenities, while a variety of living rooms, entertainment areas and outdoor spaces offer relaxing alternatives. A \$15.9 million renovation was completed in 2002, doubling the facility's nightly capacity to 47 families. Solid organ transplant patients make up almost 30 percent of the guests. Transplant recipients returning for frequent follow-up visits make up an additional 20 percent. The Ronald McDonald House reserves two isolated

wings for immune-suppressed patients and their families: six rooms for children recovering from bone marrow transplants and eight suites for all other transplant recipients.

The Ronald McDonald House requests just a small donation per night from families traveling from more than 50 miles away, but never turns a family away if they are unable to pay. Programs are tailored for longer stays to keep families together during a time of crisis and to encourage socialization and recreation. The staff and volunteers of the Ronald McDonald House at Stanford foster an exceptionally supportive community among patients and families, support that makes treatment more effective and less stressful.

### HOTELS AND HOMES WITH A HEART

Packard Children's Department of Social Services Housing Programs Office is dedicated to accommodating families from out of town, regardless of their ability to pay. Each family's individual needs, including medical, financial, transportation and number of members are taken into consideration. When other accommodations are full, our **Hotels with a Heart** program provides discounted rates at local hotels to parents whose children are undergoing life-saving treatment. In exceptional cases, an alternate program, **Homes with a Heart**, pairs families with local residents who generously open their homes to those in need.

## Outreach Programs

LUCILE PACKARD CHILDREN'S Hospital works with doctors, hospitals, and several clinics in Hawaii, Oregon, New Mexico and California to provide outreach services. Outreach services include on-site evaluations, consultations for disease

and complications and preliminary follow-up visits for recent transplant recipients. These comprehensive visits maintain an essential relationship between Packard Children's staff, referring physicians, the patient and their family.



# A Special Place for Healing and Hope

RANKED ANNUALLY AS ONE of the nation's top pediatric hospitals by *U.S. News & World Report*, Lucile Packard Children's Hospital at Stanford is devoted to the care of children and expectant

mothers. Providing pediatric and obstetric medical and surgical services and associated with the Stanford School of Medicine, Packard Children's offers patients locally, regionally and nationally the full range of

health care programs and services—from preventive and routine care to the diagnosis and treatment of serious illness and injury.

For more information, visit [www.lpch.org](http://www.lpch.org).



## ONLINE ACCESS AND SUPPORT



Lucile Packard Children's Hospital's award-winning MD Portal Web site, available at <http://mdportal.lpch.org>, allows doctors to refer patients online, track referrals and view patient's clinical information including lab results, appointment history, medication, radiology, pathology and microbiology reports, clinical notes and fact sheets. Our MD Portal Web site also gives users the ability to view and register for continuing medical education courses, read Packard Children's news and view or print information about diseases that can be distributed to patients' families. Up-to-the-minute access to a referred patient's health record is a critical aspect of Packard's goal in partnering closely with referring physicians to provide successful transplants.

### TO REFER A PATIENT OR SCHEDULE AN APPOINTMENT

<b>Kidney Transplant Program</b>	T (650) 498-5480	F (650) 497-5557	<a href="http://kidneytransplant.lpch.org">http://kidneytransplant.lpch.org</a>
<b>Liver Transplant Program</b>	T (650) 725-8771	F (650) 736-7857	<a href="http://livertransplant.lpch.org">http://livertransplant.lpch.org</a>
<b>Intestinal Transplant Program</b>	T (650) 725-8771	F (650) 736-7857	<a href="http://intestinaltransplant.lpch.org">http://intestinaltransplant.lpch.org</a>
<b>Heart Transplant Program</b>	T (650) 721-2598	F (650) 736-8912	<a href="http://hearttransplant.lpch.org">http://hearttransplant.lpch.org</a>
<b>Lung and Heart-Lung Transplant Program</b>	T (650) 721-2598	F (650) 736-8912	<a href="http://lungtransplant.lpch.org">http://lungtransplant.lpch.org</a>