Safe and Sound
Team Approach Transforms Surgical Care for Kids
Dear Friends,

At Lucile Packard Children’s Hospital, delivering exceptional care is a team effort. Our caregivers marshal the talent, resources, and support of the entire Packard community to help patients grow and thrive.

As a result, we’re making lasting contributions to pediatric and obstetric medicine and bringing Packard-quality care to children and expectant mothers across the western United States. In this issue of Packard Children’s News, we’re pleased to share exciting developments in surgical services, and the ways in which these advances meet the needs of families in our community and beyond.

Packard’s team-centered approach to surgical care is at the forefront of each of these stories. Coordination among caregivers, families, and other hospitals and clinics has fueled a range of achievements—from breakthroughs in organ transplantation, to novel approaches in anesthesia and pain management, to a rapidly expanding surgical outreach network. Thanks to these collaborations, we’re able to provide a more successful, comfortable, and restorative surgical experience to patients and their families.

Fostering key relationships within our community is instrumental to our success. Among all of our connections, our most rewarding continues to be our partnership with you, our supporters. None of our advances would be possible without your generosity and dedication. Please join us in celebrating our Hospital by participating in the second annual Packard Summer Scamper on June 23. More information about this exciting event is available at SummerScamper.org. Side by side, we can bring a healthy future to children and families everywhere.

Thank you for your continued dedication and generosity.

Sincerely yours,

David Alexander, MD
President and Chief Executive Officer
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You may not hear the ocean’s roar when you walk into an operating room at Lucile Packard Children’s Hospital, but there is a sea change in surgery under way nonetheless. Day and night, weekdays and holidays, highly skilled surgeons and scientists are developing, refining, and teaching procedures designed to make surgery safer, more effective, and less traumatic for children and families.

“Pediatric surgery is evolving to keep up with the needs of our patients,” says Thomas Krummel, MD, the Susan B. Ford Surgeon in Chief at Packard Children’s and the Emile Holman Professor and Chair of Surgery at Stanford School of Medicine. “All the new procedures and therapies—in almost all surgical subspecialties—are developed and organized around ways that are less invasive. It makes a big improvement for a child’s care.”

Packard surgeons are skilled in a full range of specialties unavailable at most children’s hospitals, from repairing congenital heart abnormalities in a newborn—complex surgeries involving experts across multiple disciplines—to more common outpatient procedures. Teams of surgeons, anesthesiologists, nurses, hospitalists, and other specialists conducted more than 5,200 procedures last year, developing expertise that enables them to apply and hone their skills in both routine and challenging practices.

“Everybody prioritizes the good of the child,” says Krummel. “No problem is too big, and no problem is too small. That same mentality pervades outpatient procedures as well as the most complex challenges.”

Newly recruited specialists have brought unique skills to the mix. And state-of-the-art facilities dedicated to the care of children, such as the Ford Family Surgery Center, allow surgeons to operate with unprecedented safety, precision, and effectiveness. As Packard Children’s refines its plans for expansion, its new operating rooms will streamline services for young patients, with integrated surgical, imaging, pre-op, and recovery suites to provide a seamless transition of care.

In recognition of its strengths in coordinating complex care, Packard Children’s recently was accredited by the American College of Surgeons as a Level II pediatric trauma center. Trauma—a bicycle accident, a fall from a
swing, a sports injury—is the leading cause of death in children older than 6 months. “If you care about children, a commitment to trauma care is essential,” says Krummel. “And good trauma care requires a carefully choreographed multidisciplinary team.”

Winning Teams

Packard’s pursuit of surgical innovation benefits from its proximity to Stanford University and to the Stanford School of Medicine, which encourages communication among specialists in fields that might not normally interact. This close alignment between lab and practice promotes unique approaches to making surgery less invasive and encouraging faster recovery. Whether it’s bioscientists developing instruments sized especially for children, or stem cell researchers exploring strategies to prevent scarring or regrow malfunctioning organs, physician-scientists collaborate closely to apply research breakthroughs from the bench to the bedside.

“All our research starts with a fundamental question: What is the critical unmet need?” says Michael Longaker, MD, FACS, director of the Hagey Laboratory for Pediatric Regenerative Medicine and the Deane P. and Louise Mitchell Professor. “From stem cell biology to tissue engineering to photonics, a deep commitment to biomedical research has encouraged advances.”

Close ties with Silicon Valley entrepreneurs in biotechnology, robotics, and high-tech enterprises also further the work, Longaker says. “There’s a mindset of collaboration and of innovation in this area, and Packard benefits from that culture: People are willing to take a risk to make a major impact. The key is how to make those advances widely available.”

This collaborative approach promotes the multidisciplinary teamwork and thoughtful integration of technology that keeps Packard surgeons at the forefront of change.

“We have the facilities in place, and we have some of the finest specialists in the country, with vast and diverse experience and a willingness to embrace innovation,” says Craig Albanese, MD, the John A. and Cynthia Fry Gunn Endowed Director of Pediatric Surgical Services. “We have a special opportunity here to take pediatric surgery to a whole new level. There will be tremendous changes ahead that will benefit children and families in our care.”

No Problem Too Big, No Problem Too Small

By Ruth Schechter

Making Pediatric Surgery Safer, Seamless, and More Precise
Jeremiah Kwakye of San Jose was just 15 months old when his parents brought him to Lucile Packard Children’s Hospital for a life-saving liver transplant.

“I handed my son to the surgical team and said, ‘This is the only child I have, so I need you to take really good care of him,’” recalls Andrea Kwakye, Jeremiah’s mother. “That’s when I lost it. I still get all teary-eyed just thinking about that day.”
When Jeremiah awoke after five hours in surgery, his condition had already improved dramatically. “The first thing I noticed was his beautiful white eyes,” Andrea says. “It was shocking, because they had been yellow since the day he was born.”

Jeremiah’s jaundiced eyes were caused by an extremely rare inherited liver disease called Crigler-Najjar syndrome, a condition that affects fewer than one in a million newborns. The disease is caused by a genetic defect in the liver that prevents the breakdown of bilirubin, a yellowish pigment that’s a byproduct of discarded red blood cells. Over time, the accumulation of excess bilirubin in the bloodstream can result in brain damage.

Packard surgeon Carlos Esquivel, MD, PhD, and his colleagues in the children’s liver transplant program recommended replacing Jeremiah’s liver with a healthy organ capable of producing a bilirubin-busting enzyme.

“Twenty-five years ago, a child under age 2 like Jeremiah was not given the opportunity to have a liver transplant, because the mortality was so high,” says Esquivel, the Arnold and Barbara Silverman Professor in Pediatric Transplantation. “In our program today, the survival rate for children of all ages is close to 100 percent.”

Jeremiah, now 7, is one of those success stories. “He’s doing phenomenally well,” Andrea says. “He does what a typical first-grader does—plays, runs, and drives his parents crazy. He eats a lot, he’s growing, and he’s smart as a whip.”
Andrea credits her son’s remarkable turnaround to the extraordinary care provided by a dedicated team of surgeons, nurses, hepatologists, gastroenterologists, anesthesiologists, physician assistants, transplant coordinators, social workers, developmental specialists, dieticians, and pharmacists.

“We had such an awesome transplant team, Jeremiah couldn’t help but do well. They want your child to be well and to grow up healthy.”

— Andrea Kwakye

Jeremiah Kwakye of San Jose was just 15 months old when he received a liver transplant to treat a life-threatening genetic disorder called Crigler-Najjar syndrome. Now thriving at age 7, Jeremiah is a Packard success story.

Transplant Leader

The pediatric transplant team at Packard Children’s performs nearly 70 liver and kidney transplants a year, many in high-risk infants and newborns. “Small livers have very small blood vessels,” says Esquivel, chief of the division of transplantation at the Stanford School of Medicine. “If the vessels clot, the liver will do poorly. You have to use very fine sutures, ones that you can’t even see with the naked eye.”

Since 2006, Packard has consistently ranked among the top three pediatric liver and kidney transplant centers in the United States in terms of number of transplants, successful patient outcome, and graft survival, according to the U.S. Department of Health & Human Services.
“We’re one of the few places that also performs multi-organ transplants,” Esquivel adds. “We’ve done combined liver-kidney, liver-heart, liver-intestine, and the first pediatric liver-double lung transplant. One advantage of being treated here is that we have so many transplant specialists on site.”

Esquivel helped pioneer several innovative surgical techniques now used at pediatric hospitals worldwide. “Because of the chronic shortage of organ donors, we’ve had to be creative,” he explains. “For example, we figured out how to take a liver from a deceased adult donor and trim it down to a size that would fit a small child. In Jeremiah’s transplant, I only used about 40 percent of the donor liver. We were also among the first to transplant part of a liver from a living adult to a child. The transplanted portion grows to normal size, and the donor’s liver also grows back.”

Today, the transplant team at Packard treats more children with liver cancer than any other U.S. hospital. “About 80 percent of our liver transplant patients have no recurrence of their cancer,” says Kenneth Cox, MD, chief of pediatric gastroenterology, hepatology, and nutrition. “We also see children with rare metabolic diseases that can damage the brain, kidney, heart, and other organs. Our goal is to transplant the liver before that damage occurs.”

Packard’s emergence as a national transplant leader is due in large part to an unrivaled patient outreach service. A network of outreach clinics spans across the western United States, with locations in California, Hawaii, Nevada, New Mexico, Oregon, and Washington. Packard physicians and transplant coordinators make on-site evaluations and referrals, and provide ongoing post-transplant care in close coordination with families and their local pediatricians.

Studies show that Packard’s outreach clinics have achieved a remarkably high success rate in isolated areas across the rural West. “That’s because we integrate children back into their community, and educate the community on how to care for them,” says Cox. “It’s a unique model, and it’s the way health care should be practiced.”

**Lifelong Care**

“One thing the transplant team teaches you is that the surgery is not the final component of treatment,” notes Andrea Kwakye. “This is a lifelong process for your child.”

Her son, Jeremiah, continues making regular visits to Packard to fine-tune his immunosuppression medication so that his body won’t reject the transplanted liver. It’s a delicate balancing act, because too much immunosuppression could trigger a deadly infection of Epstein-Barr virus, or EBV, which can then lead to cancer.

“EBV infection is one of the highest-risk complications in pediatric transplantation,” says Cox. “Packard has been a leader in studying how to prevent EBV from forming cancers in kids. We used to see about a 6 percent risk of young transplant patients getting cancer, now it’s dropped to 1 percent. We hope to eliminate that risk entirely in the very near future.”

Packard physician-scientists are also looking for ways to minimize the use of immunosuppressive drugs. “We’re doing quite a bit of research to better understand the mechanisms of organ rejection,” says Esquivel. “It’s sophisticated work involving molecular biology and genetic studies.”

It is estimated that as many as 25 percent of children who undergo liver transplants might
Karla Corona spent 14 months on the national kidney waiting list before a donor organ finally became available. Today, the 19-year-old from South San Francisco is back in college and looking ahead to a bright future.
not need immunosuppressants. “The problem is that we don’t yet have a test to identify which children are prone to rejection and which are not,” says Esquivel. “We were the first to report that young children may develop tolerance—in other words, their immune system might eventually learn to tolerate the graft. But we don’t have a good way of knowing when it’s safe to stop giving medication. Right now it’s just a matter of trial and error.”

Cox and his colleagues are developing innovative therapies that could prevent the need for transplants in certain diseases. “In 1993, I discovered that a rare liver and colon disease called primary sclerosing cholangitis (PSC) can be treated with the oral antibiotic vancomycin,” says Cox. “I had been using vancomycin to treat a child with PSC for a separate bacterial infection, and noticed that the PSC had also disappeared. At the time, the primary treatment for PSC was a liver transplant, but with vancomycin, the transplant was avoided. We’re still trying to better understand how the drug makes this disease go away. At Stanford you can do that kind of research, because you have top scientists from many disciplines to collaborate with.”

Recently, surgeon Stephan Busque, MD, of Packard’s kidney transplant program demonstrated that adult patients could be weaned off anti-rejection medication by suppressing their immune system with radiation, then infusing their thymus with immune cells from the donor. This groundbreaking therapy may soon be tested in younger patients.

“Our obligation is to care for children,” says Packard gastroenterologist William Berquist, MD. “That’s the responsibility we have, and one that we gladly welcome. When you take care of a little baby and then you see her graduate from high school, that’s tremendously gratifying.”

Organ Shortage

One of the biggest problems in transplant medicine is the nationwide shortage of donor organs. “There is a tremendous amount of anxiety for families in the waiting period,” says Debra Strichartz, RN, the liver and intestinal transplant program manager. “Occasionally there are patients who don’t get an organ in time.”

Karla Corona of South San Francisco, then 18, was placed on the national kidney waiting list in 2010 after doctors at Packard Children’s discovered that her kidneys were too small to function properly. Fourteen months later, she finally received a call that a donor kidney was available.

“I was nervous,” Karla says. “When they told me they’d found a donor, all the emotions really came to me. But when I arrived at Packard everyone made me feel so comfortable.”

Karla’s transplant began at midnight and ended around 4 in the morning. Surgeon Waldo Concepcion, MD, opted to keep Karla’s kidneys intact, so now she has three—two small kidneys and a normal-size adult one.

“Our passion is children,” says Concepcion, chief of pediatric kidney transplantation. “They depend on us to provide life for them. So if there’s a transplant at midnight or five transplants in two days, they’re all going to be done, because you don’t know when the next organ will be available.”

A large percentage of kidney transplant patients at Packard are under 2 years old. Many of these small children receive organs from adult donors, a technique pioneered by Oscar Salvatierra, MD, professor emeritus of surgery and of pediatrics.

“One advantage of an adult-size kidney is that the blood vessels are larger and don’t clot,” says Concepcion, professor of surgery at Stanford. “The donors are primarily parents—the best of the best donors—so there is also an immunologic advantage in early infants.”
For decades, steroids were a cornerstone of post-transplant therapy. But in the 1990s, Salvatierra introduced steroid-free immunosuppression, now the standard of care for kidney transplants. “A child from the old era of transplantation often battles deformities produced by steroids—hip dysplasia that eventually requires surgery, weak bones that form arthritis at the joints, as well as diabetes, infections, and metabolic problems,” Concepcion explains. “We have to do more than just give them life from transplantation. We also have to give them a successful life, and that includes taking steroids out of the picture. That has been done.”

**Future Directions**

In 2007, Packard opened a state-of-the-art dialysis unit for kidney patients awaiting donor organs. But for kids awaiting a liver transplant, dialysis is not an option. To address that challenge, Esquivel and Olivia Martinez, PhD, professor of surgery, are exploring the use of stem cells as a possible bridge to transplantation. For children like Jeremiah, stem cells might eventually be used to replace the damaged gene that prevents the breakdown of bilirubin in the blood. “Right now, if one gene is defective we have to replace the entire liver, which seems like overkill,” Esquivel says. “So the potential of stem cell research is huge.”

As associate director of the Stanford Institute for Immunity, Transplantation, and Infection (ITI), Esquivel is working with other researchers to develop a better understanding of the immune system to design targeted therapies that prevent organ rejection and treat a broad range of immunological diseases.

Concepcion, a research associate at ITI, is developing a multidisciplinary consortium of researchers from different specialties to find new treatments for individual transplant patients. “Right now we have a cookie-cutter approach that fits everybody,” he says. “We want to have individualized care to prevent viral infection and rejection, and to create the longest graft life a patient can have.”

For Karla, now 19, the prognosis is very good. She’s in college, has a boyfriend, and is careful about taking her immunosuppression drugs. “I was told that my kidney might last 50 years,” she says. “It depends on me and the way I take care of it.”
Comfort Always
Helping Young Patients Manage Pain
By Theresa Johnston
When 2-year-old Lexsea Morgan of Ben Lomond was scheduled for surgery at Lucile Packard Children’s Hospital last February to fix a congenital kidney problem, her mother had an unusual request: Would it be okay if she remained at her daughter’s bedside while the little girl was anesthetized? “I remember when I handed off my oldest daughter for surgery years ago I was just a nervous wreck,” Jennifer Morgan recalls, “so this time I asked if there was any possibility of my being able to come into the operating room with Lexsea and stay with her until she was out.”

Having mom or dad present during anesthesia induction isn’t always appropriate, particularly if the parent is squeamish or the procedure is complicated. In Lexsea’s case, though, doctors were receptive. After making sure Jennifer was properly suited, they allowed her to sit on the toddler’s gurney and even to hold the anesthesia mask gently over her daughter’s face. “I waited until she was not fully sedated but pretty out of it—to the point she wouldn’t notice that I wasn’t there—and then they took over and did their thing and it was a very successful operation,” Morgan says. “Having a chance to visualize what was going on gave me a lot of peace of mind.”
While parent-present induction remains rare in the operating rooms, in other parts of the Hospital it’s almost routine, says anesthesiologist Rebecca Claure, MD. Parents are often present for procedures ranging from MRIs and radiation treatments to colonoscopies and catheterizations. “A lot of the time we need to use ‘giggle juice’ [short-acting valium] to calm down the smaller kids, but if you have a parent there you often don’t need any,” Claure notes. “I’ve had parents say they don’t want to see their child that way, and we don’t want them to feel guilty about that choice. But for those parents who are interested, we talk through what they can expect to see, and we reassure them.”

Mobile Medicine

Family-friendly induction isn’t the only thing that people appreciate about the anesthesiology service at Packard Children’s. Unlike adult anesthesiologists, who spend most of their time in the operating room, Packard anesthesiologists are constantly on call, working their bedside magic on kids in widespread units throughout the Hospital. More than half of the 12,000 anesthetic procedures they do each year—from regional blocks and light sedation to general anesthesia—are performed outside the OR, in places like imaging suites, the Cardiac Intensive Care Unit, the Neonatal Intensive Care Unit, and the Bass Center for Childhood Cancer and Blood Diseases.

Why the traveling roadshow? For one thing, children feel pain more acutely than grownups. They’re also a lot squirmier—particularly when facing strangers armed with needles. As service chief Anita Honkanen, MD, explains, “Adults can typically endure a lumbar puncture without anesthesia, but it’s frightening and they have to hold still. With the aid of an anesthetic, we can get kids to sleep in their parent’s arms in the procedure room, and often they don’t even know that the parent ever left.”

A U.S. Army veteran and mother of five, Honkanen came to Packard Children’s nine years ago, when there were 15 anesthesiologists on the payroll. Today she oversees 30 staff physicians plus residents and half a dozen hand-picked fellows. Many of them work in teams focusing on complex sub-specialties, such as transplant anesthesia, cardiac anesthesia, neuroanesthesia, and pain management.

As the anesthesiology staff has evolved over the years, so has the technology. R.J. Ramamurthi, MD, clinical director of operating room management, is especially grateful for four new SonoSite ultrasound machines that assist with placing intravenous lines and nerve
blocks. “Before we got them,” he says, “people were using anatomical landmarks and it was a hit-or-miss thing. With ultrasound you actually see the nerves and other structures, so there’s no guesswork involved. Essentially it improves patient safety, with less poking.”

Another useful new tool is SimBaby, a high-tech mannequin that can mimic breathing, crying, vital signs, and signals of distress. Following scripted scenarios, Packard anesthesiologists wheel the lifelike doll and its attached laptop computer all over the hospital, acting out emergency situations and complex surgeries with their colleagues. “Anesthesia is like flying an airplane,” Ramamurthi explains. “You have a takeoff (induction), maintenance, and landing (waking up at the end). So we simulate events just as a pilot would, to get the feel for situations before we’re faced with them in real life. That’s a big thing that we are proud of, because we are the first children’s hospital on the West Coast to do it.”

**Furry Friend**

On a warm spring afternoon, a mellow golden retriever named Carly is walking her daily rounds on the first floor at Packard Children’s. The certified therapy dog and her owner, clinical nurse specialist Sandy Sentivany-Collins, RN, are relaxed and playful, but their mission is serious: To get children’s minds off their pain and their bodies moving again. “We get a lot of requests for Carly to come visit; she has a very positive influence on the children’s mood,” says anesthesiologist Elliot Krane, MD, director of Packard’s Pain Management Service.

“We need a multidisciplinary approach because pain is multidisciplinary. It affects not just one part of the body but the entire well being of a child.”

— Elliot Krane, MD
Canine therapy is one of several approaches that Krane and his team use to help children deal with post-operative pain, or the pain of injury and disease. Many youngsters benefit from medications like anti-inflammatories, opioids, and nerve blocks. Others find it helpful to talk with a clinical psychologist. Still others find relief in hypnosis, biofeedback, acupuncture, or physical therapy. Sometimes family counseling is necessary as well, to teach parents how to help their children without coddling them.

Most cases require a combination of tactics. “We need a multidisciplinary approach because pain is multidisciplinary,” Krane says. “It affects not just one part of the body but the entire well being of a child, including their mood. And then the mood, in turn, affects how much pain they feel.”

Over the course of a typical day, Krane and his team of physicians, psychologists, and nurses will evaluate and treat around 25 patients—a five-fold increase from when he arrived at Packard in 1994. He particularly remembers 14-year-old Bailey Deacon, of Los Gatos, who spent six weeks in the Hospital last year suffering from intense burning pain in her feet. The cause was erythromelalgia, a rare, possibly genetic nerve disorder exacerbated by heat and stress. By the time her father carried her into Krane’s office, the girl had lost 35 pounds and was a sleepless wreck.

Packard offers unique therapies to lift the spirits of children in pain, including visits from a golden retriever named Carly. The certified therapy dog and her owner, clinical nurse specialist Sandy Sentivany-Collins, RN, make daily rounds providing “Carly consults” across Packard Children’s.
Bailey Deacon of Los Gatos suffered from a rare nerve disorder called erythromelalgia, which caused her such intense, burning pain that her father had to carry her into Packard Children’s. Pain management doctors developed a multi-tiered treatment plan to get the 14-year-old back on her feet, pain-free and eager to return to school.
“When Dr. Krane saw what kind of distress she was in, he put in an epidural so she could finally rest. That was huge,” her grateful father, Troy, recalls. Krane also treated Bailey’s feet with a solution of capsaicin—the same substance that makes peppers hot—to desensitize her nerve endings. Anti-seizure pills also helped to slow her pain response, as did some time with a clinical psychologist, advancing her recovery still further.

Today Bailey is back at school, enjoying freshman science and algebra classes at Presentation High School in San Jose. “Every now and then you hit a home run,” Krane acknowledges, smiling. “But we’re still learning, still in the infancy of pain management, compared to what I hope it will be like in 20 years. We’re still using variations on 2,000-year-old drugs. Even NSAIDS [non-steroidal anti-inflammatory drugs] are basically aspirin, and that’s been around since the time of Hippocrates.”

Small Bodies, Small Doses

Perhaps the biggest challenge in pediatric anesthesia is figuring out how much medication small bodies need. Most painkillers, sedatives, and anesthetics were designed and approved for adults, and scaling down their dosages for an infant or child can be tricky, says Gregory Hammer, MD, director of pediatric anesthesia research. That’s why it’s essential to understand the pharmodynamics and pharmokinetics of various drugs: how they affect the body, and how the body distributes, metabolizes, and eliminates them.

One of Hammer’s latest clinical studies is looking at morphine and methadone, to understand how these well-known opioids are metabolized in four age groups: babies, toddlers, school age children, and teens. Hammer and his team at Packard Children’s are also investigating etomidate, used for the induction of anesthesia in children with heart failure. “We like to use etomidate on children with heart failure because it doesn’t tend to lower blood pressure,” Hammer says. “We’re also looking at promising newer drugs, such as dexmedetomidine, a novel sedative that doesn’t cause respiratory depression.” It’s also less likely to cause delirium, an upsetting side effect that can hamper a child’s recovery.

Still another research project—one that should be of special interest to parents—involves the long-term effects of anesthesia on the developing brain. Studies in animals suggest that exposure to anesthesia at a very young age might be associated with lower performance on tests of memory, attention, and learning. So cardiac anesthesiologist Lisa Faberowski, MD, is reviewing longitudinal studies to see if there might be similar effects in children.

In the meantime, service chief Honkanen tells families, “One of the critical things to remember is that you don’t do a surgical procedure on a child unless you really need to. You have to weigh the risks—a very small chance of a subtle change later on—versus a very real problem at the present moment.”

Back in Ben Lomond, little Lexsea Morgan is feeling much better now. Free of her chronic urinary tract infections, the brown-eyed toddler is running all over the house, stopping just long enough to catch up on her favorite television show, Dora the Explorer.

Looking back, her mother is profoundly grateful for the peace that surrounded them both on the day of surgery. “I was surprised because I kept telling everybody that I was going to completely lose it. But by knowing where Lexsea was, and the people who were with her, and the room that she was in, I barely cried,” Jennifer Morgan marvels. “If this were a normal hospital, that opportunity would have been unlikely, but because it’s Packard, they really were geared to making us comfortable.”

And her Packard Children’s anesthesiologists couldn’t be more pleased to hear it. As R.J. Ramamurthi likes to say, “Creating a feeling of calm for the family is not just a science, it’s an art.”
In Good Hands
Packard Develops Outreach Network of Pediatric Surgical Care

By Ruth Schechter
When it comes to pediatric surgical care, Lucile Packard Children's Hospital has turned the traditional model on its head. Through a network of outreach clinics spanning the western United States, Packard now brings its world-class surgeons to the patients, rather than the other way around.

“We’ve really focused on a new approach, where our surgical team reaches out to hospitals that don’t have the expertise we do to perform pediatric procedures in their communities,” says Frank Hanley, MD, executive director of the Children’s Heart Center at Packard Children’s and the Lawrence Crowley Professor in Child Health.

As pediatric surgery becomes more complex and specialized, many regional hospitals face the daunting task of providing highly specialized care for children with rare diagnoses, an issue compounded by limited staff and declining budgets.

In response, Packard Children’s has established a network that now encompasses strategic partnerships as far afield as Tacoma, Albuquerque, Honolulu, and Billings, Mont. Outreach clinics provide services in many pediatric surgical specialties, including organ transplantation, cardiovascular surgery, orthopedics, and urology. Packard experts offer a full range of surgical skills, from diagnosis to follow-up care and ongoing rehabilitation.

“Children and their families benefit, as do the hospitals in the network, which can perform more effectively,” says Craig Albanese, MD, the John A. and Cynthia Fry Gunn Endowed Director of Pediatric Surgical Services. “The partnerships we’ve established offer a full spectrum of care that serves the needs of different communities. Instead of a hospital referring children to us, we send our experts to them.”

Taking a Flexible Approach

Packard Children’s has developed several different models—tailored to specific facilities and needs—that help bring surgeons to outlying communities. These models range from “borrowing” space for monthly clinics to embedding a Packard surgical team on site that is fully integrated with the host hospital’s staff.

The working model at Good Samaritan Hospital in San Jose, for example, was established five years ago in collaboration with Packard’s pediatric surgery service. With no children’s hospital in the South Bay, Packard opened an outpatient clinic in Los Gatos. In a short time the small, stand-alone facility began offering urology, pulmonary, gastroenterology, and general surgery clinics several days a week. Today, a pediatric general surgery team works alongside Good Samaritan pediatric anesthesiologists, nurses, and staff to provide full-time, inpatient care.

“We saw a real need to reach out to this area because so many of our patients live down here,” says Gary Hartman, MD, director of regional pediatric surgery services at Packard Children’s and chief of pediatric general surgery at Good Samaritan. “We did a careful survey of the community physicians, and they identified the biggest demands.”

Hartman and his team treat anything from hernias to appendicitis in Good Samaritan’s Children’s Surgery Center, which features specialized laparoscopic instru-
ments and an adjacent pediatric intensive care unit. Complex surgeries that require more advanced equipment are transferred to Packard’s main hospital.

“Our relationship here represents a strong commitment to the needs of children,” Hartman explains. “It’s a partnership with the pediatricians and the families in the community. But the best benefit is that people don’t have to travel as far to receive the same high standards of care.”

That concern for the patient experience is echoed by William Kennedy, MD, associate chief of pediatric urology, who oversees outpatient surgical services at four partner institutions, including John Muir Hospital in Walnut Creek, Dominican Hospital in Santa Cruz, the Pediatric Group of Monterey, and California Pacific Medical Center in San Francisco. “I don’t mind the travel if it helps make my patients more relaxed and happy. People want to be able to have their care delivered closer to home. Isn’t it better if one person drives so that eight families don’t have to?”

Kennedy remembers one incident in particular: The family lived in the East Bay and had been coming to Packard for follow-up care after a surgical procedure. Kennedy saw the patient about a year later after he was established at John Muir. “I remember the mother looking at me, and saying, ‘Can I level with you? I finally understand what is going on with my child.’ After packing her kids in the car and driving for an hour and a half, she arrived at Packard completely frazzled and tired, so she couldn’t focus properly on the content of the visit. Now she drives to their appointment in five minutes and arrives alert and refreshed. That, in a nutshell, is why outreach is so important.”

“I don’t mind the travel if it helps make my patients more relaxed and happy. People want to be able to have their care delivered closer to home.”

— William Kennedy, MD
Specialty Services

The flexibility of the Packard outreach model enables surgeons in different specialties to tailor their services to patient needs. For example, because most pediatric urology surgeries do not involve life-threatening conditions, the large majority of children Kennedy sees receive outpatient procedures, and about half are one-time services. Patients who require long-term or follow-up care are best off closer to home, where they can be followed by their family pediatrician, Kennedy explains.

“We’ve created our partnerships very carefully so the highest quality of care is maintained,” he says. “We work closely with our colleagues to learn what they need. We maintain an open dialogue at all times. We’re there to help them and work alongside them to provide the best care for the child.”

At Santa Clara Valley Medical Center in San Jose, Julie Fuchs, MD, oversees seven surgeons who provide consultation, inpatient and outpatient surgery, and outpatient clinical care and follow-up. The team provides the same specialized services patients receive at Packard, including treatment of the full range of neonatal congenital problems.

Orthopedic surgeon Lawrence Rinsky, MD, established a pediatric clinic at Santa Clara Valley in 2010. Today, he and his team see between 80 and 100 patients each week for consult, scheduling, and follow-up care. Twice a month they operate on approximately 10 patients, taking care of fractures, hip and foot disorders, and musculoskeletal diseases. Complex spine surgeries are transferred to Packard, which has the specialized technology for such delicate procedures.

Neurosurgery Needs

Children in isolated areas of Lake Tahoe, the eastern Sierra, and northern Nevada—where regional medical institutions lack resources for specialized pediatric neurosurgery—are seen in Packard outreach clinics for diagnostic and ongoing care. Coordinated by neurosurgeon Michael Edwards, MD, the Lucile Packard Children’s Hospital Endowed Professor in Pediatric Neurosurgery and Pediatrics, the clinics are organized according to the needs of the community and the facilities available at each site.

At St. Rose Dominican Hospital in Henderson, Nev., for example, a former Stanford pediatric neurosurgery fellow sees patients daily, making referrals to Packard Children’s that cannot be accommodated on site. Another model, established in Reno, maintains a biweekly diagnostic clinic in association with Sierra Neurosurgery Group, where a Packard caregiver determines the best site for surgery. In the past six months, only a few select patients were transferred to Packard Children’s because of the complexity of the surgery.

“The key is to establish good relationships and good communication. Often these hospitals have limited
resources for complex pediatric neurosurgery,” Edwards says. “They have asked us to step in to help, and we want to work with them. It's a nice opportunity to develop future relationships for referrals and training.”

Enhanced Opportunities for Care

Participating surgeons say they enjoy the challenge of reaching out to new communities of families and developing new clinical programs, while still receiving the support and connection of Packard Children’s.

“I have the opportunity to build something new, and I like the responsibility of treating interesting cases,” says Claudia Mueller, PhD, MD, surgical lead at California Pacific Medical Center (CPMC) in San Francisco. Mueller works full-time at CPMC in a partnership that was launched just last October. In a few short months she has handled more than 100 inpatient and outpatient surgeries, and she serves as the point person for follow-up care.

“It’s a happy marriage: We integrate the best of what Packard has to offer with the best of what CPMC already has in place,” says Mueller, the Tashia and John Morgridge Endowed Faculty Scholar in Pediatric Translational Medicine. “Our patients don’t get just one surgeon—they benefit from the whole Packard team approach. It really is the best of both worlds for all involved.”

Practice Makes Perfect

The benefits of this outreach program go both ways. Packard surgeons are able to practice their craft and hone their skills for caring for children with both routine needs and with rare or unusual conditions.

“We provide outstanding surgical services to families that otherwise might not have access to that level of expertise,” says Hanley, “and we dramatically expand the patient base to allow for robust clinical research that advances the standard of care.”

“Packard has great specialty expertise. But you need complex cases to maintain proficiency,” adds Claire Mailhot, RN, EdD, director of planning for children’s surgical services. “Expertise and experience improve not just the surgery, but the care before and after.

“For example,” she says, “our cardiac teams need a minimum of 250 cases to keep up proficiencies in cardiology, radiology, and related specialties. Pediatric neurosurgery is another area that’s so subspecialized that the procedures are best performed in centers where they are done frequently.”

The network also creates expanded opportunities for education. “For residents, there’s a larger population to serve and a better chance for follow-through,” says Rinsky. “If a patient needs to come to Packard, there’s also better continuity of care.”

“Thanks to our outreach network,” adds Hartman, “patients can get world-class surgical care closer to home. It’s like having Packard in your own backyard.”

Ana Homonnay
New Members Join Foundation Board

Timothy Brackney, Manuel A. Henriquez, David Lee, and William Sonneborn were recently elected to the board of directors of the Lucile Packard Foundation for Children’s Health.

Brackney is the Northern California regional managing director for Resources Global Professionals, a leading multinational provider of consulting services. Previously, he was senior manager at Price-waterhouseCoopers LLP, working in their audit and then consulting practices. Brackney received a BBA in accountancy from the University of Notre Dame, and an MBA from the Stanford Graduate School of Business. He is a past board member of the Doernbecher Children’s Hospital Foundation, and also served on the board of the Leukemia and Lymphoma Society.

Henriquez is co-founder, chairman, and CEO of Hercules Technology Growth Capital. He is a 25-year veteran of the venture capital and financing community, with previous experience at VantagePoint Venture Partners and Comdisco Ventures. Henriquez received a BS in Business Administration from Northeastern University and is a member of the University’s Board of Directors. He previously served on the board of Charles Armstrong School, an independent elementary and middle school that serves students with language-based learning differences.

Lee is a founder and managing partner of SV Angel, an angel fund with investments in companies such as Twitter, Foursquare, Flipboard, Dropbox, and Airbnb. Prior to SV Angel, Lee was at Baseline Ventures, a leading seed-stage venture firm. He was a founding member of Google’s New Business Development team and led business development at StumbleUpon prior to its sale to eBay. He also was a corporate attorney at leading technology law firms. David has an MS in electrical engineering from Stanford, where he was a National Science Foundation graduate fellow; a JD from NYU; and a BA from Johns Hopkins.

Sonneborn joined Kohlberg Kravis Roberts & Co (KKR) in 2008. He heads KKR Asset Management, and is CEO of KKR Financial Holdings LLC. Previously, he was president of TCW and CEO of The TCW Funds, Inc and served on the board of The TCW Group Inc and Sompo Japan Asset Management in Tokyo. Prior to TCW, Sonneborn spent six years in investment banking at Goldman, Sachs & Co in both New York and Hong Kong. He is a graduate of Georgetown University. He is involved in a variety of non-profit organizations and serves as a trustee of the Saint John’s Health Center Foundation and the Los Angeles Council of the Boy Scouts of America.

Kohl’s Sponsors Child Safety Program

Kohl’s Cares continues its tradition of generously supporting Packard Children’s with a gift of more than $170,000 for the Kohl’s Child Safety and Outreach Program. The program, which is dedicated to preventing injuries in children, educates parents on proper installation of car seats, best practices for keeping children safe while riding in vehicles, and tips for preventing falls. With support from Kohl’s this year, Packard was able to purchase a van that will allow the program’s bilingual technicians to widen their community outreach efforts. The program is active at fairs and community events in the South Bay and Peninsula, providing helmet fittings, equipment inspections, and safety tips for bicyclists and pedestrians.

Since 2005, Kohl’s has donated more than $720,000 to Packard Children’s to help promote the safety and health of local children. The commitment is made possible thanks to the Kohl’s Cares® program, which raises funds through the sale of special $5 plush toys and books. Net profits from sales of these items at stores throughout the Silicon Valley are directed to Packard Children’s.
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HEDCO Funds Imaging Upgrade

The HEDCO Foundation has made a generous grant of $750,000 to help fund the purchase of a new 1.5 Tesla MRI scanner, an important upgrade for the Children’s Imaging Center at Packard.

Under the direction of Radiologist-in-Chief Richard Barth, MD, Packard staff have pioneered advances that are transforming radiology across the spectrum of prenatal care and child and adolescent health. The gift of the new MRI will keep Packard at the forefront of discoveries in pediatric imaging, improving outcomes of care for children with cancer, heart defects, fetal anomalies, neurological conditions, and other disorders.

HEDCO Foundation is a much-appreciated and long-time supporter of Packard Children’s, having also played a vital role in the development of the Cystic Fibrosis Program and the construction of the Pediatric Endosurgery Suites. The private foundation, based in Danville, engages in a wide range of philanthropy spanning medical research and social welfare.

Golf Benefit Supports Teen Van

Packard’s Mobile Adolescent Health Services program, affectionately known as the Teen Van, was the proud beneficiary of $22,500 from the 17th annual Bill Hewlett & Dave Packard Charity Golf Classic, held in September at Boulder Ridge Country Club in San Jose.

The annual tournament is a joint fundraising effort of HP Silicon Valley Golf Club and Agilent Technologies Golf Club. Since 1995, the event has raised nearly $360,000 for various programs at Packard Children’s.

Pizzo Awarded Howland Medal

Philip Pizzo, MD, dean of the Stanford School of Medicine, is the recipient of the 2012 John Howland Medal, the highest honor bestowed by the American Pediatric Society. The medal honors Pizzo for a lifetime of achievement, spanning four decades in research and care for children, as well as his leadership and advocacy in pediatric academic medicine.

Established in 1952, the medal is named for John Howland, MD, an outstanding clinician-scientist who led the first full-time academic pediatrics department at Johns Hopkins Hospital. It is awarded annually to luminaries in the field of pediatrics who have distinguished themselves as scientists, leaders, and teachers.

New Director of the Bass Center

Kathleen Sakamoto, MD, PhD, has been appointed director of the Bass Center for Childhood Cancer and Blood Diseases at Packard Children’s, and chief of the division of hematology, oncology, and stem cell transplantation in the department of pediatrics at the Stanford School of Medicine. Previously, Sakamoto was a professor and chief of the division of hematology-oncology and vice-chair of research at Mattel Children’s Hospital and the David Geffen School of Medicine at UCLA.

Sakamoto studies the molecular regulation and development of blood cells. Her research focus is to understand how aberrancies in blood formation result in diseases, including leukemia, bone marrow failure, and myeloproliferative disease.

PHILIP ZIPPO, MD

KATHLEEN SAKAMOTO, MD, PhD
IN THE 
news

Arvin Elected to American Academy of Arts and Sciences

Ann Arvin, MD, the Lucile Salter Packard Professor of Pediatrics, is among nine Stanford professors who have been named newly elected members of the American Academy of Arts and Sciences (AAAS). Arvin serves as vice provost and dean of research and professor of microbiology and immunology at Stanford School of Medicine.

The academy is one of the nation’s most prestigious honorary societies, and also a leading center for independent policy research. Members contribute to academy publications and studies of science and technology policy, energy and global security, social policy and American institutions, the humanities and culture, and education.

Wang Wins NIH New Innovator Award

Packard pediatrician C. Jason Wang, MD, PhD, received an NIH New Innovator Award in September. The award, which provides $1.5 million in research funds over five years, is designed to support unusually creative investigators at an early stage of their careers. Wang will use his award to study how to motivate patients to follow medical advice more diligently. Each year, millions of patients fail to take their medications, follow diet and exercise advice, or adhere to other recommended treatments. Wang’s team will design a smart phone application that links health behaviors to activities that patients already enjoy.

Kay Recognized for Excellence in Academic Pediatrics

Mark Kay, MD, PhD, has been awarded the Samuel Rosenthal Prize for Excellence in Academic Pediatrics. The prestigious prize comes with a $50,000 grant to be used for two years of research. Kay, a professor of in the departments of pediatrics and genetics at the Stanford School of Medicine and a member of the Child Health Research Institute, Bio-X, and the Cancer Center, plans to use the award as seed money for his research in the mechanisms of gene regulation.

Masimo Foundation Supports Liver Research

The Masimo Foundation for Ethics, Innovation, and Competition in Healthcare has granted $50,000 to support research efforts led by Packard chief medical officer Kenneth Cox, MD. Cox, chief of pediatric gastroenterology, hepatology, and nutrition, is studying a new oral antibiotic to treat primary sclerosing cholangitis (PSC), a chronic liver disease that often leads to liver failure and transplantation. His research may transform care for patients suffering from PSC. Cox also recently received the American Liver Foundation’s 2012 “Salute to Excellence” Award, honoring individuals who have made an outstanding contribution to biotechnology and medical innovation.

The Masimo Foundation supports programs, initiatives, and research designed to improve patient safety and outcomes, promote efficient and cost-effective healthcare delivery, and provide advanced healthcare to people worldwide who may not otherwise have access to lifesaving technologies.
Dylan Pace of Redwood City was 5 years old when doctors at Lucile Packard Children’s Hospital cured him of kidney cancer. Today he’s a healthy eighth-grader, using his passion for sports to give back to other young cancer patients.

Earlier this year, Dylan organized Take a Slice at Cancer, a charity sports tournament that raised over $40,000 for Packard’s Cancer Patient Care Fund. Dylan was eager to direct event proceeds to this important resource for families in need. “It helps sick kids get treated, even if their families can’t afford it,” he explains.

Once he began planning the tournament, Dylan used PackardPages.org to spread the word. “We’re huge fans of Packard Pages,” says his mom, Karen. “There are so many fundraising sites available, but we felt that this was the best. It’s just so powerful to have a fundraising page tied directly to Packard Children’s.”

Dylan agrees. “Using Packard Pages was so easy,” he says. “I could email the link to everybody, and they just had to click. They could even keep their donation anonymous.”

Packard Pages also let Dylan tell supporters about his connection with the Hospital. “I hoped that hearing my story would make people feel like they weren’t only supporting Packard—they were also giving back to what I went through.”

Dylan is still using his Packard Page to inspire friends and family to stay involved with Packard Children’s. Karen says, “A number of his donors told him, ‘I expect you to call me again next year!’”

To see Dylan's personal fundraising page, please visit PackardPages.org and search “Pace”.

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Host Your Own Event Today

Hosting a fundraiser is fun and easy! With the following tips and tools at your disposal, you can make a critical impact on children’s health in just a few steps:

- **Planning tips and checklist** to get you started
- **Event timeline** to keep you on track
- **Ideas, spreadsheets, logos**, and any other guidance you may need along the way
- **Packard Pages** to raise online awareness and support among family, friends, and colleagues

Packard Pages are perfect if you’re throwing a benefit event, gathering donations in lieu of gifts for a birthday or wedding, or honoring someone special. With our simple online fundraising tools, you can create a personal web page, share your story, watch your progress, and send thank you notes to supporters. Visit PackardPages.org to create your page today!

For more information about planning an event to benefit Packard Children’s or the Stanford School of Medicine, please call (650) 498-6328 or email communityevents@lpfch.org.
The Summer Scamper is back! Join us on Saturday, June 23, for the second annual Packard Summer Scamper. All proceeds benefit patients and families at Lucile Packard Children’s Hospital.

The day begins with a 5k run/walk and 10k run on certified courses around the beautiful Stanford campus. It continues with a kids’ fun run for children ages 3-10, and culminates with a post-race expo featuring an awards ceremony, live entertainment, and refreshments.

Sign up today at SummerScamper.org!