

# Physician Update



Lucile Packard  
Children's Hospital  
at Stanford

A PUBLICATION FOR  
REFERRING PHYSICIANS  
WINTER 2012

## Pain Management Team Expands Services

### COMPREHENSIVE INPATIENT AND OUTPATIENT CARE HELPS RESTORE CHILDREN TO NORMAL LIFE

Pain management has come a long way since the days when physicians mainly used anesthesiology techniques to reduce pain. While many treatments still draw on anesthesiology, the Pain Management Service at Lucile Packard Children's Hospital now incorporates a wide spectrum of approaches, including physical and occupational therapy, psychotherapy, psychiatry, advanced nursing care, massage therapy, education and integrative medicine.

"It's a multidisciplinary program that uses the talents of many specialists to provide comprehensive pain management, symptom management and rehabilitation for children with pain and life-limiting diseases," said Elliot Krane, MD, director of the Pain Management Service at Packard Children's.

The program provides inpatient and outpatient services, including an outpatient intensive rehabilitation program for children with chronic pain. Outpatient rehab services take place at a state-of-the-art clinic, just opened in 2010, that includes new gym equipment and a biofeedback

room. The outpatient pain management clinic will soon move to a larger space near the rehab clinic, and the team is working on expanding inpatient services.

### Around-the-Clock Care

The inpatient pain management service operates 24 hours a day, seven days a week. Usually, the team sees patients with acute pain from surgeries, trauma, or exacerbation of chronic conditions such as cystic fibrosis and cancer. The service also manages detoxification of children who have become physically dependent on sedatives during long stays in the intensive care unit.

The pain management team works closely with the anesthesiologist to plan for postoperative pain control. "We don't wait for the surgery to be over and for the child to develop pain," Krane said. "The planning for the first few days after the surgery really begins before the operation."

Strategies to reduce pain can include conventional analgesic drug management, epidural analgesia and regional nerve blocks, which numb the pain by delivering local anesthetics and other chemicals to specific nerves. The inpatient service also

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offers psychotherapy, massage therapy and integrative medicine techniques such as acupuncture. Carly, a therapy dog, often helps calm or motivate kids.

Many of these treatments are also used to manage pain in infants. The team adjusts the techniques and dosing as needed to account for the baby’s physiological stage and drug metabolism. A nonverbal scoring system is used to evaluate pain, incorporating factors such as blood pressure, heart rate, crying, facial expression and limb position.

### **Comprehensive Care for Chronic Pain**

At the Pain Management Clinic, a multidisciplinary team offers outpatient services to patients with chronic pain. Conditions treated include headache disorders, chronic abdominal pain, fibromyalgia, and chronic pain associated with diseases such as rheumatoid arthritis and cystic fibrosis. Many patients have complex regional pain syndrome (CRPS), which develops when the child’s nervous system overreacts to a minor injury such as stubbing a toe.

Patients receive a two-hour evaluation by a pain physician, a psychotherapist and often a physical therapist. The team then develops a therapy plan, which might include drug management, nerve blocks, psychotherapy, referrals to the rehab center, or hospitalization.

Physical and occupational therapists, based at a new outpatient rehab services clinic at 321 Middlefield Road in Menlo Park, use a variety of techniques to restore function. The team works on improving flexibility, strength, physical endurance, balance and coordination, as well as desensitizing the limb and helping the child to practice everyday tasks. An antigravity treadmill allows kids to walk without bearing their full body weight and helps assuage “the component of fear and anxiety when they start taking those first steps again,” said Leah Wolf, PT, DPT, a physical therapist at Packard Children’s. “It creates a safe environment for them.” The clinic’s biofeedback room has sensors that can show kids information about their heart rate or muscle activity, so they can respond by using breathing techniques or relaxing certain muscles.

Psychotherapy is crucial to helping kids get through the physical and occupational therapy, which can be very painful. “If you’re an adult, you might have the mental strength and drive to soldier through that,” Krane said. “But if you’re a 10-year-old, you don’t.” A psychotherapist provides support by acknowledging that the pain is real and teaching coping strategies, such as self-hypnosis.

Cognitive behavioral therapy can address the anxiety and depression that often come with chronic pain.

“We provide skills to increase the patient’s ability to take ownership and control over their pain,” said Rashmi Bhandari, PhD, a pediatric pain psychologist at Packard Children’s.

### **Intensive Rehabilitation**

One of the most unique components of the pain management service is the Packard Pediatric Pain Rehabilitation Center (PPPRC), an intensive outpatient program that usually lasts about four to eight weeks. Each day, patients receive four hours of physical and occupational therapy, an hour of psychotherapy, and two hours of school. The program includes weekly family psychotherapy and debriefing sessions to discuss the child’s progress.

The program was launched in 2010 to more effectively help patients, particularly kids with CRPS, return to normal activities. In the past, these children usually had to be hospitalized. “We’re trying to normalize lives,” Krane said. “And when you’re in the hospital, it’s a very abnormal environment.”

Part of that normalization happens during the school sessions, where kids learn in a small classroom alongside other children with medical conditions. The school is a “halfway house” where kids can start regaining their social skills, Krane said. The teacher coordinates with the patient’s regular school, and kids can receive course credit. Together, the teacher and psychotherapist can help children overcome anxiety about returning to school.

The program is one of only about five of its kind in the country. Patients are usually at least 12 years old, although Krane said the program would probably start taking younger kids this summer.

### **Expanding Services**

Other improvements are in store as well. This summer, the outpatient pain management clinic will move to expanded facilities in the same building as the rehab clinic, allowing more frequent team meetings and evaluations of rehab patients. The team also plans to establish an inpatient pain rehab program, which will offer services similar to the PPPRC for children who are too impaired to enter an outpatient program....

Many kids who come through the pain management program return to their regular activities, such as dancing and Little League. Sarah Willhalm, MS OTR/L, an occupational therapist at Packard Children’s, recalls one nine-year-old girl with CRPS who completed the intensive outpatient rehab program and is now swimming competitively. “She was fully restored back to her life,” Willhalm said.

For more information about the Pain Management Service at Packard Children’s, visit <http://pain.lpch.org> or call **(650) 497-8977**. To refer a patient, call **(800) 995-LPCH (5724)**.

# Conjoined Twins Separated in Complex Surgery at Packard Children's

## TWO-YEAR-OLD GIRLS MAKE FASTER-THAN-EXPECTED RECOVERY

A pair of twins born conjoined at the chest and abdomen were successfully separated November 1 in a 10-hour surgery at Lucile Packard Children's Hospital. The operation on two-year-olds Angelica and Angelina Sabuco was the culmination of several months of complex planning involving specialists from nearly every part of the hospital.

"This is a dream come true," said the twins' mother, Ginady Sabuco, speaking through tears at a news conference shortly after the surgery.

"We're very pleased," said lead surgeon Gary Hartman, MD. "Things basically could not have gone better."

The surgery was the second separation of conjoined twins performed at Packard Children's. The first pair was separated in 2007 by a team that Hartman led. The Sabucos' operation was less complex because they shared fewer organs.

"I want them to live normally, like other children," said Ginady. In addition to the obvious psychosocial difficulties, remaining conjoined carried risks for the twins' physical health, such as muscular and skeletal deformities that would have worsened with time.

"Already there are changes in their musculoskeletal systems," Hartman said just after the surgery. The reconstructive surgery that the twins received to their chests immediately began to alleviate abnormalities in the curvature of their chests and spines.

To prepare for the surgery, the radiology team performed extensive imaging. "CT scans showed that the girls had separate hearts; their livers were tightly fused together; and their intestines touched, but their digestive systems functioned separately," said radiologist Frandics Chan, MD. "Their sternums were joined together; their ribs were separate."

The next step in the twins' preparation, performed in July, was insertion under the skin of tissue expanders, small balloons gradually inflated with liquid to prompt growth of extra skin for repair of the separation.

Hartman, Chan, anesthesiologist Gail Boltz, MD, and plastic surgeon Peter Lorenz, MD, devised a detailed plan for the surgery, which involved about 20 physicians and 15 to 20 operating



Angelina with mom, Ginady.



Ginady, holding Angelica.

room staff. The twins arrived in the operating room at 6:30 a.m. November 1. Hartman separated the girls' diaphragms, livers, and bowels, and shortly after noon, he cut the last bit of skin that joined the sisters. One sister was moved with her team to an adjacent operating room for reconstructive surgery—the first time in their lives that the girls were in different rooms.

Lorenz and plastic surgeon Rohit Khosla, MD, rebuilt the girls' chest and abdominal walls. They implanted a thick, custom-made dissolving plate in each girl's chest where the sternum should be, and grafted bone pieces removed during the separation onto the plates. The operation was complete at about 4:30 p.m.

The girls were hospitalized for two weeks, returning home to mom Ginady, dad Fidel and big brother Vincent in San Jose, California, on November 15. With the help of physical and occupational therapy, they were soon walking forward, a skill that replaced the sideways walk they learned together.

"They look fantastic," Hartman said in early December. "The recovery went faster than we were expecting. They are not only walking, they're running." The girls had also recovered from their initial post-surgery shyness with each other to become good buddies. "They like to go shopping," Hartman said with a laugh. "They are back to normal, beyond normal. We see a very bright future ahead for them."

Please visit <http://conjoinedtwins.lpch.org> for additional information, artwork, photos and video of Angelica and Angelina. For more information about pediatric general surgery at Packard Children's, visit <http://surgery.lpch.org>.

# Symposium Will Provide Latest Information on Autism Spectrum Disorders

## **AUTISM CENTER OFFERS COMMUNITY OUTREACH, CUTTING-EDGE TREATMENT, SUPPORT FOR RESEARCH**

Leading experts will gather at Stanford University on May 12 to provide up-to-date information on autism spectrum disorders for parents, caregivers and educators.

The 5th Annual Autism Spectrum Disorders Update, a one-day conference, will cover the latest scientific advances and practical tips for parents. Speakers will discuss treatments, diagnostic tests, legal issues, the transition to adulthood, and common problems faced by patients and families.

The symposium, organized by the Stanford Autism Center at Packard Children's Hospital, is a key part of one of the center's missions: providing community service and outreach for families and care providers. Parents are often bombarded with information, and sifting the good from the bad can be a challenge.

"There are all kinds of information and misinformation," said Carl Feinstein, MD, director of the center. "Parents have a million questions."

Plenary speakers will address two key issues. Anna Penn, MD, PhD, a neonatologist at Lucile Packard Children's Hospital, will discuss how a child's environment before birth may play a role in these disorders—a hot topic since Stanford researchers reported last year that environmental factors are more important than previously thought. The center is also bringing in Peter Gerhardt, EdD, an educator at the McCarton School in New York City, who specializes in helping autistic teenagers adapt their behavior to different social situations.

Breakout sessions with experts will cover a wide range of topics, including the value of genetic testing, whether brain imaging can aid diagnosis, and the status of oxytocin as a treatment. Common problems such as sleep, feeding and digestion, difficult behaviors, and motor coordination will also be addressed. Stanford Law

School attorneys will discuss legal rights and how parents can work effectively with schools to get proper services for their child.

The symposium is just one of many outreach services that the Autism Center provides. The center offers three educational series for parents per year, a parent support group, and classes for Spanish speakers. Waiting lists are coordinated with the Children's Health Council, a nonprofit children's health and educational organization, so that patients can be evaluated as soon as possible.

The center offers diagnosis and treatment for autism spectrum disorders, including autism, Asperger's disorder, and pervasive developmental disorder, not otherwise specified (PDD-NOS). One treatment being piloted is pivotal response therapy, which targets a major developmental issue and actively involves the parents in behavioral treatment. Another clinical trial is testing strategies to improve reciprocal social communication, such as looking other people in the eye.

The center supports cutting-edge research by Stanford scientists, who are investigating everything from the brain structure of autistic children to the contributions of genetics and the environment. Stanford neurobiologist Ricardo Dolmetsch, PhD, and his colleagues are taking skin cells from people with Timothy syndrome—a disorder often associated with autism—and growing stem cells that can be turned into neurons. The work could help scientists determine how the neurons of autistic people are different and test treatments on those cells.

Finally, the center is increasing outreach to the pediatric community. Pediatricians who want to perform early screening for autism are welcome to contact the center for help. "I can't tell you how important early diagnosis is," Feinstein said.

For more information about the Stanford Autism Center at Packard Children's Hospital, visit <http://autism.lpch.org> or call (650) 721-6327. To register for the symposium, visit <http://childpsychiatry.stanford.edu>.



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# NASA Guests Visit Packard Children's Simulation Center

## LEARNING FROM SPACEFLIGHT SIMULATION TO ENHANCE MEDICAL SAFETY

NASA's astronauts learn how to fly by simulating the real thing. Over and over, they practice the maneuvers of spaceflight in simulators so true-to-life that astronaut crews can pilot real spacecraft perfectly on the first try.

Now, the experts who run NASA's training programs are extending the knowledge gained from decades of spaceflight simulation to another high-risk enterprise: saving the lives of critically ill children and expectant mothers. Two professionals from the NASA contractor United Space Alliance visited Lucile Packard Children's Hospital on November 17 and 18 to share their expertise at the hospital's Center for Advanced Pediatric & Perinatal Education (CAPE), an international leader in simulation-based training of physicians, nurses and other health care professionals.

"We began exploring ways to deliver safer, more effective, more efficient care by learning from their extensive experience in simulating spaceflight, one of the most high-risk activities human beings can undertake," said Packard Children's neonatologist Louis Halamek, MD, who directs CAPE.

Halamek hopes the visit will be the beginning of an extended collaboration between those with expertise in spaceflight and the health care industry. "Simulation is an integral part of everything they do at NASA, and their model is one that those of us in health care should emulate," he said.

At CAPE, health care professionals learn how to manage difficult clinical situations during simulations that are highly realistic but do not put real patients at risk. CAPE's resources include working medical equipment, patient simulators capable of generating realistic anatomic and physiologic cues, video cameras to record all of the activity for use during debriefing sessions that follow each simulation, and a control room where instructors sit behind a one-way mirror to ensure that the patient simulator responds to the actions of the trainees in a realistic fashion. CAPE has provided training and expertise to health care professionals from 45 U.S. states and 45 foreign countries.

The guests from United Space Alliance, Darrel McGregor and Michael Sterling, work at NASA's Johnson Space Center in Houston and have extensive experience in the training of astronauts, flight controllers and their instructors. They have supervised thousands of hours of spaceflight simulation and develop spaceflight training standards. Their trip to Packard Children's follows a visit that Halamek made to the Johnson Space Center in early 2011 under a grant from the Center for Aviation Safety and Research at the Parks College of Engineering, Aviation and Technology at St. Louis University.



**“Our colleagues at NASA have a wealth of knowledge about the effective use of simulation to enhance safety.”**

During their visit, McGregor and Sterling shared their insights into how simulation enhances safety with CAPE's simulation instructor team. They observed and provided feedback on a hospital-wide disaster drill and a series of simulations in Packard Children's labor and delivery unit, and met several Packard Children's leaders to share ideas for potential future collaboration between NASA and the health-care industry as a whole.

Halamek hopes the collaboration will enable the health care industry to learn from NASA's decades of experience in using simulation to teach people how to respond to challenging situations. "Our colleagues at NASA have a wealth of knowledge about the effective use of simulation to enhance safety," Halamek said. "Our hope is that our collaboration will result in better outcomes for both industries."

For more information about the Center for Advanced Pediatric & Perinatal Education (CAPE) at Packard Children's, including classes offered, FAQs and registration, please visit <http://cape.lpch.org>. Programs are offered to physicians, nurses and allied health professionals. Participants in CAPE training are eligible to receive CEU credit, NRP accreditation and certificates of completion. All classes are held on the second floor of 700 Welch Road.

## PHYSICIAN PARTNER RELATIONS UPDATE

### Packard Pass Photo Badges Debut at Packard Children's

A new ID badge system, Packard Pass, now provides a temporary photo badge to visitors who enter Lucile Packard Children's Hospital's main hospital facility at 725 Welch Road. The Packard Pass system, which was introduced to improve patient safety and hospital security, replaces the handwritten badges that have been issued to hospital visitors in the past.

As of February 8, all outpatients, family members and visitors are required to obtain a Packard Pass each day when they arrive and wear it so that it can be seen while they're in the hospital. Inpatients are still being identified with medical ID bracelets, and children under age 14 who are not inpatients receive a badge with the name and photo of the adult accompanying them. All children under 14 must be accompanied by

an adult to enter the facility. Physicians and hospital employees who do not have their permanent badge must obtain and wear a Packard Pass for the day.

"The new Packard Pass system will help us protect our patients, families and everyone in the organization," said project manager Jennifer Jiao, RN. "For instance, if we have a disaster, we will quickly be able to run reports to list everyone in the facility."

Upon entering the hospital, visitors will be asked to swipe their driver's license or government-issued ID card and have a photo taken. Those without a government ID can have their information entered manually. They will be asked what part of the hospital they are visiting and answer brief questions about their recent health before having the badge printed. The whole process takes about a minute. Badges expire at midnight on the day they



are issued.

The new system will make it easier for Packard Children's employees to help enforce the hospital's current visitor policy.

"Packard Pass supports existing hospital safety

measures, improves communication and identification, and helps us to know the names and faces of those who are most important to the mothers and children in our care," said Jill Sullivan, Packard Children's vice president of transformation and the executive sponsor of the new system.

For more information about Packard Pass, visit [www.visitors.lpch.org](http://www.visitors.lpch.org) and click "Visitor Badges—Packard Pass," or contact Aaron Salazar, director of security and parking services, at (650) 723-0595.

## Packard Children's Hosts Event on Eating Disorders and the Brain

### It's Time to Talk About It: The Brain and Eating Disorders

February 28  
7–8:30 pm

Packard Children's  
Auditorium

725 Welch Road  
Palo Alto, CA

#### EXPERT PANEL WILL DISCUSS HOW EATING DISORDERS AFFECT BRAIN STRUCTURE AND FUNCTION

Eating disorders cause more than just weight loss—they can also change the structure and function of the brain. As part of National Eating Disorders Awareness Week, Lucile Packard Children's Hospital will hold a panel discussion and Q&A on February 28 called "It's Time to Talk About It: The Brain and Eating Disorders."

Adolescent health experts will discuss what happens to the brain when it's malnourished, including the effect on endocrinology, brain structure and cognitive processing. Attendees will also learn about the Comprehensive Eating Disorders Program at Packard Children's and what can be done to help people with these disorders adopt a healthier thinking style. After a one-hour panel discussion, audience members will have half an hour to ask questions.

The speakers, all from Packard Children's, are Cynthia Kapphahn, MD, MPH, medical director of the Comprehensive Care Unit; Neville Golden, MD, chief of adolescent medicine; Kathleen Kara Fitzpatrick, PhD, instructor of psychiatry; and Jim Lock, MD, PhD, psychiatric director of the Comprehensive Eating Disorders Program.

This free community symposium will be held from 7 pm to 8:30 pm in the Packard Children's Auditorium at 725 Welch Road in Palo Alto. Free parking is available across the street at 730 Welch Road; parking at 725 Welch Road is also available for a fee.

To register for the event, visit <http://calendar.lpch.org> or call (650) 724-4601. For more information about the Comprehensive Eating Disorders Program at Packard Children's, visit <http://eatingdisorders.lpch.org>.



**Ken Cox, MD**, chief medical officer, chief of pediatric gastroenterology and nutrition, and director of the Center for Transplantation at Lucile Packard Children's Hospital, will be the recipient of the American Liver Foundation's "Salute to Excellence" Award. The award will be presented in March at the 12th Annual Salute to Excellence Awards Gala in San Francisco. The annual event honors those who have made an outstanding contribution to biotechnology and medical innovation, and to date it has raised more than \$4.5 million.

**Deborah Franzon, MD**, was appointed medical director of the Pediatric Intensive Care Unit at Packard Children's on November 1. Franzon joined the faculty in Pediatric Critical Care Medicine in the Department of Pediatrics at Stanford in 2007. Since then, she has worked to improve many aspects of care across the hospital, including medical transports, hand-offs and use of the electronic medical record to optimize care delivery.

**Karl Sylvester, MD**, mentored a research project by two high school students who were finalists in the prestigious national Siemens Competition in Math, Science & Technology. The students, Jeffrey Ling of Palo Alto Senior High School and Helen Jiang of Henry M. Gunn High School, were awarded \$10,000 on November 29 for their project to develop a system that uses demographic, clinical and molecular data to predict which premature infants with necrotizing enterocolitis will progress to severe disease.

**Sumit Bhargava, MD**, joined the division of Pediatric Pulmonary Medicine as a clinical associate professor on October 1. Bhargava, who came to Packard Children's from an assistant professor position at the Yale School of Medicine, completed his medical education in India and is board certified in both pediatric pulmonary medicine and sleep medicine.

**David Stevenson, MD**, has received the March of Dimes Foundation's Jonas Salk Award for Leadership in Prematurity Prevention. The award is given for achievement in improving human health through health care leadership, medical practice or scientific discovery. It was awarded October 20 in Washington, DC. Stevenson, the director of the Johnson Center for Pregnancy and Newborn Services at Packard Children's, is also the principal investigator for the March of

Dimes Prematurity Research Center at Stanford University School of Medicine, the nation's first transdisciplinary research center dedicated to identifying the causes of preterm birth. The center brings together specialists in disciplines ranging from neonatology and genetics to computer science and artificial intelligence, the first group of experts from diverse fields to work together so closely to study prematurity.

**Sharon Geaghan, MD**, who holds a joint appointment in the departments of Pediatrics and Pathology, received an Outstanding Speaker of the Year Award from the American Association for Clinical Chemistry, an international society composed of medical professionals with an interest in clinical chemistry, clinical laboratory science and laboratory medicine. This is the second consecutive year that Geaghan has received the award, which was given January 11 in Washington, DC.

On October 19, the St. Baldrick's Foundation, a volunteer-driven charity dedicated to raising money for children's cancer research, awarded research grants to three researchers at Packard Children's and the Stanford University School of Medicine.

**Michael Wei MD, PhD**, and **Yoon-Jae Cho, MD**, both received \$330,000 St. Baldrick's Scholar awards, and **Samuel Cheshier, MD, PhD**, was awarded a \$100,000 Research Grant.

**Jody Winzelberg, AuD**, who directs Audiology and Rehabilitation Services at Packard Children's, received the clinical prize in the Stanford University School of Medicine's 2011 Abuse Awareness Awards October 12. Winzelberg, an original member of the Stanford Domestic Violence Task Force, speaks annually with medical students.

**Lee Sanders, MD**, won the Sabra Woolley Award for Best Oral Presentation at the Health Literacy Annual Research Conference held October 17 and 18 in Chicago. HARC is the only national meeting of the nation's leading scholars in health literacy, including investigators from internal medicine, family medicine, nursing and cognitive neuroscience, and pediatrics. The award, which honors a medical anthropologist who is a leader in health literacy research, was given for Sanders' NICHD-funded work on a low-literacy approach to obesity prevention in the first two years of life.

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**Abdominal wall reconstruction with dual layer cross-linked porcine dermal xenograft: The "Pork Sandwich" herniorrhaphy.** Satterwhite, Miri, Chung, Spain, Lorenz and Lee. *Journal of Plastic, Reconstructive & Aesthetic Surgery*. 2011 Oct 13. [Epub ahead of print]

**Comparison of umbilical venous and intraosseous access during simulated neonatal resuscitation.** Rajani, Chitkara, Oehlert and Halamek. *Pediatrics*. 2011 Oct;128(4):e954-8.

**End-Stage Renal Disease and Cardiomyopathy in Children: Cardiac Effects of Renal Transplantation.** Lal, de Biasi, Alexander, Rosenthal and Sutherland. *Transplantation*. 2012 Jan 27;93(2):182-7.

**Collaborative healthcare immersive learning dynamic: transitioning to simulation-based learning.** Bergero, Hargreaves, and Nichols. *Clinical Nurse Specialist*. 2012 Jan;26(1):42-47.

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**Sociotechnical Challenges of Developing an Interoperable Personal Health Record: Lessons Learned.** Gaskin, Longhurst, Slayton and Das. *Applied Clinical Informatics*. 2011;2(4):406-19.



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## Physician Update

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## UPCOMING CME COURSES

### 20th Annual Pediatric Update & Pre-conference

July 19–21, 2012

Frances C. Arrillaga Alumni Center, Stanford, CA

For complete conference and registration information, call  
**(650) 497-8554**, email **cme@lpch.org** or visit **http://cme.lpch.org**.