Caring for the By Joan Tharp. Community

Campaign Helps Bring Packard's Family-Centered Care to All

nthony Hollingsworth came to
Packard four years ago, a 14-yearold with a heart severely damaged
from a rare cardiomyopathy
(inflammation of the heart muscle). He needed a
heart transplant, and fast.

Anthony's parents needed some immediate attention, too. They were heartsick, struggling to understand that their gregarious and active boy was gravely ill, and there wasn't much time left.

Just as Anthony's heart ended up in good hands with Packard's skilled transplant team, his parents were comforted and supported by an array of family services from the moment they rushed their son through the doors of the Hospital right through Anthony's successful surgery and recovery.

Anthony and his family are not alone. At Packard, healing goes far beyond medical technique to embrace the broader needs of patients and their families. Packard's care also extends outside the hospital walls to reach families without insurance, or those who may not easily have access to quality health care.

Nurturing Packard's unique brand of care and its mission to serve any local child in need is at the heart of the Campaign for Lucile Packard Children's Hospital – a goal that has been enthusiastically supported by many of the Campaign's donors.



Packard social worker Mary Burge, LCSW (right), became an invaluable resource to heart transplant patient Anthony Hollingsworth, his mother Sonja (left), and the rest of his family by assisting them with housing, transportation, counseling, and other needs.

Repairing the Safety Net

One of the Campaign's most important contributions has been to support Packard's policy of providing care to any child in the community, regardless of a family's ability to pay.

Rising medical costs and the state's budget difficulties are taking a toll on community health organizations locally and throughout California at the very time that demand for services is increasing. In addition, more and more families and individuals can not afford medical coverage or have jobs that don't provide health insurance.

Caring for the Community

"Our mission is to be here for the local community, especially for those who otherwise would be unable to get care," explains Packard Chief of Staff Harvey Cohen, M.D., Ph.D. "Through the Campaign, we can preserve and expand our services to become the full-service hospital for the community that we want to be."

More than 25 percent of the children who come to Packard are from families who rely on Medi-Cal and other government-funded programs, which do not fully cover the cost of treatment. Donations to the Hospital weave strength back into this social safety net. In particular, long-time support from the Hospital's seven auxiliaries and annual donations to the Lucile Packard Children's Fund help make up the difference. Last year alone, Packard provided \$40 million in charity and other un-reimbursed care to families in the community.

Healing the Whole Child and Family

The Campaign also translates into support for a wide array of services that lighten a family's emotional and spiritual loads. Through the eyes of a child, medical treatment is scary, often painful, and very hard to understand. Though parents' eyes, having a desperately sick child is an endless replay of the classic nightmare in which disaster looms and you can't run.

Child-life therapists use play to help children understand and cope with the hospital experience, such as practicing lying still on a table, as a child must do when receiving radiation treatment. A visit to the Forever Young Zone recreation room or fun time with a therapist is often the bright spot in a day for a child who has spent days or even weeks in the hospital. Support for these valuable services has expanded during the Campaign, thanks to increased donations and newly established endowments such as the Mary Zelencik Endowment for Recreation Therapy.

Families in need of spiritual support can turn to Packard's chaplaincy service, which is under the direction of The Reverend Wilma J. Reichard, the first holder of the Charles L. Dostal, Jr. Chaplaincy.

"The crisis of a child in trauma or illness is a strengthening of faith for some families. For others, it brings about incredible doubts. And for others it is the first

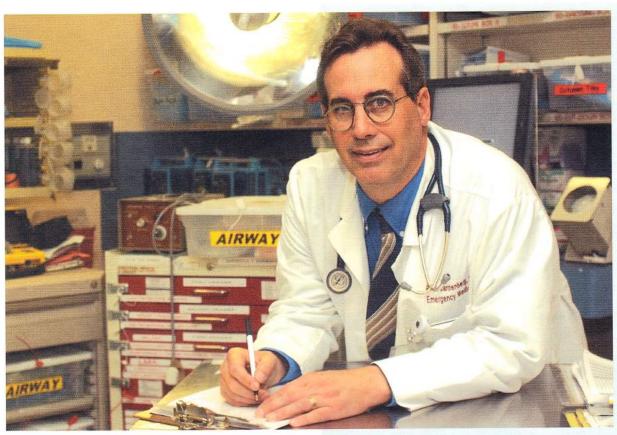
time that faith has been a part of their lives. In each situation, spiritual care is a key part of healing for children and their families," she says.

Chaplain Reichard works closely with psychologist Barbara Sourkes, Ph.D., who was recruited from Montreal Children's Hospital in 2001 to head Packard's new Palliative Care Program. The program addresses the psychological, social, and spiritual needs of children facing life-limiting illnesses and extends to their families as well. A gift from John A. Kriewall and Elizabeth A. Haehl created an endowment for Sourkes' position. The couple also created a matching fund as an incentive for others to support the program.

Packard's program was one of the first pediatric palliative care programs in the country, and goes beyond clinical care to address education, research, and advocacy issues as well.



A play session with a child-life therapist can make children more at ease in the hospital and help them recover faster.



Easing Emergencies

Helping families cope can be especially critical during a trip to the emergency room – a stressful event for even the most self-assured adult, let alone for a child in pain sitting in a room full of strangers who are not having their best day. So why not bring the Packard

"As a parent, you want to know that you're taking your child to a place that provides the best possible care."

Bernard Dannenberg, M.D., Davies Family Director for Pediatric Emergency Medicine "brand of care" to the emergency room as well, to make it a little less scary?

Through the efforts of the Campaign, Packard is introducing childfriendly pediatric emergency services within Stanford Hospital's emergency

room, the highest level acuity emergency room serving the local community. Nearly 11,000 children come through Stanford's emergency room each year, a figure that is expected to climb significantly in the future.

Bernard Dannenberg, M.D., was recruited to Packard to develop emergency services for children within Stanford's emergency department.

In January, Bernard Dannenberg, M.D., arrived at Packard as the first Davies Family Director for Pediatric Emergency Medicine. He says a pediatric ER is an essential service to the community. "Emergency medicine is all about serving local children.

"As a parent, you want to be assured that your child is at a place that provides the best possible care," he says. "Addressing the concern of both the child – will it hurt? – and that of the parent – why is there a fever? – is essential to building trust.

A Community Effort

he idea of a pediatric emergency department sparked the imagination of more than 40 Campaign donors over the past several years, beginning with a gift from Pilar and Lew Davies that established the Davies Family Endowed Director of Pediatric Emergency Medicine.

In less than three years, \$11 million was raised to support pediatric emergency services including a \$1 million gift from Packard Hospital Board Chair John Freidenrich and his wife, Jill. The gift pushed Campaign totals over the \$500 million mark.

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A dedicated and trained pediatric ER team can catch the nuances of a child's needs that someone who primarily deals with adults might misread. Little things like taking off your white coat or distracting the child during an exam make a trip to a pediatric ER less traumatic," he adds. In addition to medical staff, the Stanford/Packard pediatric emergency team will include a child-life therapist to help children cope with anxiety or frightening procedures.

In partnership with Packard, Stanford Medical Center will be one of only two Bay Area hospitals offering dedicated pediatric emergency services. (The other is Children's Hospital of Oakland.) Among the child-friendly aspects of the ER will be a separate waiting area for children, filled with games, toys, videos, and Internet access; and exam rooms decorated to cheer up children.

Filling a Growing Need

Just as emergency room visits have increased, so have Packard's outpatient clinic visits, which number more than 100,000 a year. Demand for these services has grown sharply over the last decade, reflecting both California's population growth and an increase in referrals from other doctors, thanks to Packard's reputation. In fact, the hospital was originally built to accommodate only 30,000 clinic visits.

In response to this growing need, the Mary L. Johnson Center for Ambulatory Care opened this fall in a brightly remodeled building across the street

Packard's busy outpatient clinics now have more space and state-of-the-art facilities in the new Mary L. Johnson Center for Ambulatory Care.



from the Hospital. The 31,000-square-foot facility, complete with updated technologies and family friendly touches, now houses six main outpatient clinics, which previously had been scattered in the main Hospital and along Welch Road.

The new Center is home to two of Packard's busiest clinics: Acute Care and General Pediatrics. Families also can find the specialized pediatric services that Packard is known for and that are difficult to come by elsewhere, such as specialists in childhood asthma and rheumatology.

Kids don't much mind spending time in the Center's new waiting rooms, which are equipped with toys, games, computers, and wireless access to the Internet. Eventually, patients and their families will be outfitted with pagers that signal when the doctor is ready so kids can walk around or even play outside while they wait.

The new facility is a gift from Charles and Ann Johnson, and is named in memory of their daughter, Mary. Another recent gift, from the Adalyn Jay Foundation, funded a respiratory clinic at the new Center. Naming gifts for the remaining five clinics still are available for interested donors.

Reaching Out

Packard's family-centered care also extends into the community through a variety of programs and partnerships that have received Campaign contributions. To support these efforts, a number of generous donors have created endowments, including the Mary Stuart Rogers Foundation, Beth and Russ Siegelman, and others.

One of Packard's most recent partnership is with the Ravenswood Family Health Center in East Palo Alto, where the Hospital has supplied a number of medical staff and implemented pediatric programs funded, in part, by donors to the Lucile Packard Children's Fund.

Another is Packard's mobile health clinic for teens. The Teen Van visits schools, community centers, shelters, and other sites throughout the region to provide free, comprehensive health care to homeless and



A Little Help Makes All the Difference

eventeen-year-old Evelin Rosario of San Jose says she stopped sliding downhill in school and turned into a straight-A student thanks to the Teen Van – and all because she received a pair of eyeglasses.

Evelin's family had no health insurance when she first came to the Teen Van. When she revealed to the van's medical director, Seth Ammerman, M.D., that she had to sit in the front row of class to see what the teacher was doing, he gave her a certificate for a free eye exam and glasses.

Now the world looks a lot better to Evelin. "I feel a lot more confident now," she says. "I can write stuff down in class, and I never used to because I couldn't see."

uninsured teens and young adults. The service, now in its ninth year, receives close to 1,000 visits from teens each year, and is one of the only mobile health clinics of its kind in the country. More than 60 percent of patients return to the van for follow-up care – a remarkable measure of just how effective and trusted the service is.

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"The average teen comes to us when he or she is sick, or has to do something like get a physical to play sports," says Seth Ammerman, M.D., medical director of the Teen Van. "Teens have so many other things going on that we always try to do a comprehensive evaluation on the first visit – to see if they are caught up on immunizations, to see about their nutrition, and to see what other concerns they might have.

"We focus on prevention and early intervention among at-risk youth. These are the ones with the least access to healthcare, and they are the most underserved. And these are our kids – they're from our neighborhoods," he adds.

Tackling Trends

Packard now has some of the best minds addressing access to health care and other key children's health issues, thanks to Campaign support and the Hospital's strong ties to Stanford University.

Thomas Robinson, M.D., M.P.H., an associate professor of pediatrics and medicine at Stanford, is leading Packard's new Center for Healthy Weight. Robinson, who is a faculty member at the Stanford Prevention Research Center, has launched innovative research into community-based programs to prevent childhood obesity – a health problem that has been characterized as the most severe childhood epidemic facing the country.

"The obesity epidemic is caused by a toxic environment, one in which calories are plentiful, inexpensive, and highly promoted; and where we have engineered physical activity out of our lives," Robinson says.

Paul Wise, M.D., M.P.H., a newly recruited pediatrician and health policy researcher, has found that advances in children's health frequently are unavailable to the children who need them the most.

Robinson teams up with families, schools, community organizations, and local policy makers in Bay Area communities to make neighborhoods safer and more accessible for playing outdoors, provide physically active after-school activities such as hip hop dance classes, and offer more healthful nutrition.

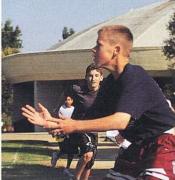
"We are developing comprehensive clinical programs at LPCH to meet the needs of overweight children, but this epidemic can only be addressed effectively through primary prevention," he says. "To do that we need to reach out to where kids and families spend their time. We can't just wait for

Eleven-year-old Sterling North participated in a six-month program to help children manage healthy eating habits and active lifestyles. The community-based program was

developed by Thomas Robinson, M.D., M.P.H., director of Packard's Center for Healthy Weight.







them to come see us after they become worried about their weight, because by then it is already too late to prevent the problem."

Another expert supported through the Campaign is pediatrician and health policy researcher Paul Wise, M.D., M.P.H., who is exploring the inequity in healthcare among different populations, particularly access to the latest medical techniques and procedures. Wise was recently recruited from Boston University and Brigham and Women's Hospital in Boston where he was vice-chief of Social Medicine and Health Inequalities. He is leading the Center for Health Policy, Outcomes, and Prevention at Packard. Wise explains that breakthroughs in children's health frequently are not available in equal measure across society, for reasons ranging from differences in what health insurers will cover to differences in the capacity for communities to get the word out to families about new medical treatments.

"Here we are, located in the middle of one of the world's greatest engines of technical innovation – Silicon Valley. And yet, despite the great strides we make in interventions, the kids who could most benefit aren't always getting help," says Wise. "My job is to make sure the fruits of innovation get to every child in need."

Getting a Chance

Anthony Hollingsworth knows first hand what technology and innovation can do to save a life, but he also knows that the Packard brand of care means much more. A year after his heart transplant, Anthony decided he didn't need to stick to his strict regime of anti-rejection medications. He wound up back at Packard, and nearly died. He lay unconscious, under heavy sedation, for a month as medical staff fought to stabilize his condition.

When he awoke, the first people he confessed to about his actions were Chaplain Wilma J. Reichard and his heart transplant social worker, Mary Burge, L.C.S.W., two people who have supported his family throughout his treatment.

Today, Anthony is a robust 18-year-old who does his own brand of service to the community when he comes back to the Hospital for checkups. "I've known kids in the Hospital who died because they didn't get the chance I got to save myself," he says. "Whenever I come to the hospital, I try to talk to kids, to tell them not to take life for granted. It can change at any moment."

