



Children's Hospital Los Angeles  
International Leader in Pediatrics

# imagine

CHILDRENS HOSPITAL LOS ANGELES  
summer 2006





## our mission

To make a world of difference in the lives of children, adolescents and their families by integrating medical care, education and research to provide the highest quality care and service to our diverse community.

## our history

Founded in 1901, Childrens Hospital Los Angeles has been treating the most seriously ill and injured children in Los Angeles and beyond for more than a century, and it is acknowledged throughout the United States and around the world for its leadership in pediatric and adolescent health. Childrens Hospital is one of America's premier teaching hospitals, through its 74-year association with the Keck School of Medicine of the University of Southern California. The Saban Research Institute of Childrens Hospital Los Angeles is a national leader in pediatric research.

Since 1990, *U.S. News & World Report's* panel of board-certified pediatricians has named Childrens Hospital Los Angeles one of the top pediatric facilities in the nation. *Child* magazine has ranked Childrens Hospital Los Angeles among the Top Ten children's hospitals in America.



*Childrens Hospital Los Angeles currently is building a landmark inpatient facility. Stories about the New Hospital Building carry this icon.*



on the cover:  
Atreyu Stuart, born with sickle cell anemia, is Living Proof that Childrens Hospital Los Angeles is Making a World of Difference. (See page 4.)



**Stuart E. Siegel, MD**

Director of the Childrens Center for Cancer and Blood Diseases  
Professor and Vice Chair of Pediatrics at the Keck School of Medicine of the University of Southern California

Whether a family needs our specialized services only once or must come here for years or over a lifetime, we want each child and family member to feel cared for at every moment. This issue of *Imagine* explores some of the ways Childrens Hospital Los Angeles becomes a home away from home for so many families.

When the New Hospital Building opens in 2009, it will be a sophisticated fusion of healing and high-tech wonders, combining the best in family-centered care with the most advanced medical technology. This state-of-the-art facility is closer to reality thanks to our many dedicated supporters.

Your involvement in *Living Proof: The Campaign for Childrens Hospital Los Angeles* is crucial to our efforts to create one of the nation's foremost children's health centers. Please help us today, so the New Hospital Building can take shape to serve the needs of children in our community — and the world. •

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lauren gregorio age 6



*We must care for children everywhere through research to find cures, develop new treatments and prevent disease.*

imaginediscovery



## each **step** of the way

Five-year-old Atreyu Stuart spent a recent afternoon playing with his friends at a local carnival near his Sherman Oaks home. By the time he was ready for bed that evening, the lymph nodes on the left side of his neck had swollen to the size of a ping pong ball, and Atreyu had a fever of 103 degrees. The Stuart family's familiar trip to Childrens Hospital Los Angeles was about to begin again.

Atreyu was born with sickle cell anemia, an inherited red blood cell disorder. He has been coming to the pediatric medical facility since he was six weeks old. Sickle cell disease (the term for the disorder and its complications) causes red blood cells, normally disc-shaped, to become hard, sticky and distorted into a crescent or sickle shape. These hard, pointed red cells clog the normal blood flow, blocking small blood vessels, damaging tissues and causing severe, debilitating pain. For children with this chronic illness, a common viral or bacterial infection can quickly turn into a serious illness such as lung failure.

The Stuarts represent the many families who rely on Childrens Hospital for long-term care. For these families, the medical facility becomes a second home and the primary physicians and

nurses their confidantes and collaborators, offering expert medical treatment, support and hope.

Atreyu, a typically rambunctious preschooler who loves to play with his Hot Wheels and Rescue Heroes, has had pneumonia three times, endured two blood transfusions and has been hospitalized seven times, the longest stay lasting 14 days. Additionally, he comes to Childrens Hospital for monthly check-ups. "We have a great sense of comfort here because we see so many friendly faces," says Kim Stuart, Atreyu's mother. "It's great knowing that no matter what's going on, we will see the same doctors who have treated Atreyu since he was a baby."

When their first-born child was born with sickle cell anemia, Kim and Eric Morgan Stuart were devastated. Sickle cell conditions are inherited from parents who both carry the trait. The disorder mostly affects people of African ancestry, but occurs in other ethnic groups, including people of Latino, Mediterranean and Middle Eastern descent. In the United States, about two million people carry the sickle cell trait and 70,000 have the disorder. "I felt I had let my child down because he inherited this from me," recalls Atreyu's father. "We cried a lot and we prayed a lot."

by elena epstein

FAMILIES WHOSE CHILDREN HAVE SICKLE CELL DISEASE TURN TO THE CHILDRENS CENTER FOR CANCER AND BLOOD DISEASES FOR TREATMENT, EDUCATION AND HOPE.



*Atreyu Stuart, age five, has been coming to Childrens Hospital Los Angeles since he was six weeks old.*

The young parents' quest to find the best care for their son brought them to the renowned Childrens Center for Cancer and Blood Diseases, one of the nation's largest pediatric hematology/oncology programs, which annually treats more than 350 children and adolescents with sickle cell disease. The Sickle Cell Program, the largest in Southern California, works in collaboration with the Keck School of Medicine of the University of Southern California and is one of 10 Comprehensive Sickle Cell Centers funded by the National Institutes of Health.

"Sickle cell disease is a particularly devastating disorder with serious complications that start in childhood and become crippling in adults," says Thomas D. Coates, MD, section head of hematology at the Childrens Center for Cancer and Blood Diseases and director of the Red Cell Defects Program. "Our goal is not only to keep these kids alive, but healthy, with a good quality of life and to make complications much less damaging."

From the start, Atreyu's primary physician has been Thomas C. Hofstra, MD, clinical director of hematology and assistant professor of clinical pediatrics at the Keck School of Medicine.

The Stuarts have developed close relationships with the entire team of specialized nurses and support staff. Their second child, 18-month-old Shiyanne, who did not inherit the disorder, is so comfortable at the hospital, she runs straight for her favorite toy phone in a Chase Place playroom during each visit.

### Extended family

The hospital's care team also has become an extended family for 26-year-old Jenny Gonzalez. Since being diagnosed with sickle cell anemia at age seven, she has had numerous life-threatening complications, including severe pain, a seizure, multiple blood transfusions and joint damage that might require hip-replacement surgery.

"Sickle cell is a complicated disease to manage," notes Dr. Hofstra. It can cause damage to most organs, including the spleen, kidneys and liver. Blocked blood vessels can cause acute, painful episodes referred to as a "sickle cell crisis," which can last for hours or days and require hospitalization.

"Dr. Hofstra is like my second father. I talk to him about everything," says Jenny, who lives with her parents and younger sister in Montebello. A talented artist with a passion for Japanese Anime, she reached her dream of attending The Art Institute of California in Santa Monica in 2001, but was forced to take a break because of hospitalization. "Dr. Hofstra tells me to not give up — that I'm going to get better and go back to art school," she continues. Despite debilitating joint pain, she is taking art and Japanese classes at East Los Angeles College.

### A cure ahead?

With no readily available cure, proper health maintenance is a priority. Patients and their families learn to recognize the early signs of complications and seek treatment. "Significant advances have been made in clinical management," says Dr. Coates, who is a professor of pediatrics and pathology at the Keck School of Medicine. "The promise of gene therapy puts a cure on the horizon."

To work toward that cure, Childrens Hospital is engaged in an active program of basic and clinical research. One example is a groundbreaking study led by physician-scientist Punam Malik, MD, into acute chest syndrome. This serious complication — responsible for 25 percent of deaths from sickle cell disease — develops without warning, causing severe chest pain, coughing, fever and difficulty breathing. Dr. Malik, an associate professor of pediatrics and pathology at the Keck School of Medicine, is investigating a protein in red blood cells that may be an indicator for this deadly syndrome. "My hope is one day we will have an antibody to block its devastating effects," she says.

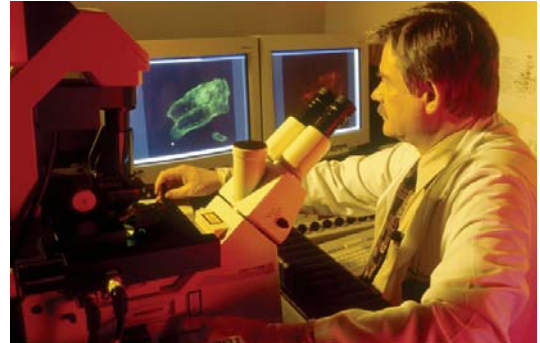
In the meantime, the sickle cell team provides families with information on nutrition, pain management and community resources.

"We want to empower each family with knowledge and give these kids tools to improve their lives," says Debbie Harris, RN, MN, PNP. "Our families are not alone — we are with them every step of the way." •

*You can make a difference in the lives of kids with sickle cell disease and help us find a cure. Please contact Terry Green, vice president of Development, at 323-669-5675 or tgreen@chla.usc.edu.*

“THE PROMISE OF GENE THERAPY PUTS A CURE  
(FOR SICKLE CELL DISEASE) ON THE HORIZON.”

—THOMAS COATES, MD



## Cancer Center to expand

The Childrens Center for Cancer and Blood Diseases is the nation's largest pediatric hematology/oncology program and one of the two largest pediatric cancer centers in America.

When the New Hospital Building opens in 2009, the Center will occupy the fourth and fifth floors, more than doubling its current space to improve patient and family care. The Center will grow from 44 beds and only five private rooms to 64 beds and 48 spacious private rooms, giving families much-needed privacy at a stressful time. It also will gain additional isolation rooms for patients with infectious diseases. The Bone Marrow Transplant Unit will expand from its current 11 beds to 14, including two new isolation beds to accommodate children who develop an infection. •

*Above, top photo, Dr. Thomas Coates, one of Atreyu Stuart's doctors. Bottom photo: Eric Morgan Stuart and Kim Stuart with their son, Atreyu, and daughter, Shiyanne.*



# more like home



Left: Mary Dee Hacker, RN, MBA.  
Right: Anne Marie Dazé Floyd, RN, MSN.



What does it take to build a hospital where the sickest, most seriously injured kids and their families feel cared for at every step? The 460,000 square-foot New Hospital Building scheduled to open in 2009 at Childrens Hospital Los Angeles must balance state-of-the-art technology and child-friendly design, extreme durability and comfort. Talking about these issues are Mary Dee Hacker, RN, MBA, vice president of Patient Care Services and chief nursing officer, and Anne Marie Dazé Floyd, RN, MSN, director of transition and occupancy.

by candace pearson

## How has Childrens Hospital Los Angeles' philosophy of family-centered care inspired the New Hospital Building?

**HACKER:** In every way. For us, family-centered care means putting yourself in the shoes of a family and asking what you would need to be more comfortable and ready to take on challenges. It's such a tumultuous time that often the family — parents, siblings, grandparents — is the only stable element in a child's life.

**FLOYD:** Our core philosophy says parents know their children best and children should be with the people they trust most. That way they have a better chance of recovering.

## How do you begin to design a hospital where kids and families come first?

**FLOYD:** We started by listening to parents and family members. They are part of the health-care team, so we've involved them in the design of patient rooms and more.

**HACKER:** Patients and family members visited the mock-up patient rooms we created and suggested changes. It has been an interactive process from the beginning.

## So many different families come here. How do you plan for diversity?

**FLOYD:** Our families come from different cultures and financial backgrounds, but we all share the same

basic human needs: sleep, food and a way to keep clean. By meeting these needs, we'll have the greatest impact.

**HACKER:** We addressed the things that interfere most with a family's ability to participate in their children's care. Our families are clear about what they need to get through this crisis. One problem they mention most often is the lack of sleep.

## How are you responding to that need?

**HACKER:** We've created a family zone in each patient room, which feels more like home than the patient or clinical zone, with its medical equipment. The new patient rooms are more spacious than our current rooms.

**FLOYD:** We tested many styles of daybeds. In addition to finding the best bed for family members — wide enough and comfortable enough — we will add a privacy curtain around the daybed and a storage area. Patient rooms also have showers.

## What food services are planned?

**FLOYD:** We already make food trays available in the rooms for families. In the New Hospital Building, there will be a kitchen or nourishment area in each unit for families to store and warm food from home, so they can bring their favorites. We're creating a 24-hour convenience store, the Family

Pantry, along with a new cafeteria, the Hollywood Café, which includes the Ralph M. Parsons Foundation Outdoor Dining Terrace.

Each year, the hospital has 285,000 patient visits and 11,000 admissions and treats more than 58,000 additional patients in the Emergency Department. How does that affect planning?

**FLOYD:** The challenge is selecting attractive materials that hold up to constant use and cleaning so that we provide a pleasing environment which also meets our infection control standards.

#### Where will families go to unwind?

**HACKER:** On every floor, there will be family lounges with floor-to-ceiling windows, seating areas and computers with Internet access. At the end of each hallway will be a built-in alcove with a window. We also will have two gardens — The Joyce and Stanley Black and Family Healing and Meditation Garden and The Jane Vruwink Palmer Healing and Play Garden. (See page 23.)

#### How will families access information to make decisions for their children?

**FLOYD:** The Bill and Helen Close Family Resource Center will include a library and computers, as well as a small classroom. Parents with laptops



*The Lund Family demonstrates the versatility of an acute care room planned for the New Hospital Building. By the window are Kenny Lund with Elizabeth, age three, left, and Clare, age seven. At the desk, center, is Katherine, age six. Posing as patient is Megan, age four, with mom, Mary.*

will be able to access the Internet from their child's room, enabling them to work remotely or stay connected with friends and family via email.

#### How will you help families find their way around?

**FLOYD:** People are so stressed, they can literally get tunnel vision and easily get lost. Each floor will have distinctive color coding and visual themes to guide families and visitors.

#### Ultimately, what will the New Hospital Building mean for kids?

**HACKER:** We celebrate the lives and spirits of kids. We are doing whatever

we can to ensure that more kids have healthy futures. Our goal is to help each family get through this process and become confident and capable of mastering this crisis. The New Hospital Building will enable us to do just that. •

*To help us build our children's future, please contact Melissa DoVale, associate vice president of Major and Planned Gifts, at 323-671-1706 or [mdovale@chla.usc.edu](mailto:mdovale@chla.usc.edu).*



healing



*Melissa Reider-Demer, RN, MSN, CPNP, a certified pediatric nurse practitioner in the Childrens Brain Center, with Damian Arroyo, age eight.*

THE RELATIONSHIPS THAT NURSES AT CHILDRENS HOSPITAL LOS ANGELES FORM WITH PATIENTS' FAMILIES PLAY A KEY ROLE IN A CHILD'S HEALING.

## watching **Over**

The first time Melissa Reider-Demer, RN, MSN, CPNP, met Damian Arroyo, he was screaming. The six-year-old boy thrashed violently around on the exam table in the Neurology Clinic at Childrens Hospital Los Angeles. He was so unruly, it was impossible to put his socks on, let alone examine him.

That was two years ago. Today, Damian can sit still and follow simple directions. He lets Ms. Reider-Demer examine him from head to toe. At his last appointment, he did something he's never done before. He gave her a hug.

"I was amazed," she says. "His behavior has improved so much, he's a different kid."

Seeing that kind of progress makes Ms. Reider-Demer's job as a neurology nurse practitioner at Childrens Hospital so rewarding. Much like other nurses and nurse practitioners, her job goes beyond medical care. Over time, she develops relationships with her patients' families, offering them care, support and education in this home away from home.

"Pediatric nurses don't just take care of the child, they take care of the family,"

explains Mary Dee Hacker, RN, MBA, vice president of Patient Care Services and chief nursing officer. "Our job is to come alongside family members to help them care for their children during a time of enormous concern, tragedy or fear."

### Same language

The Neurology Clinic at Childrens Hospital is part of the Childrens Brain Center, an interdisciplinary alliance that includes physicians and scientists with world-class expertise in pediatric neurology, neuropsychology, neurosurgery, neuroimaging, neuroophthalmology, neuropathology, rehabilitation, developmental linguistics, genetics and neuropsychiatry. Many of the Center's patients have severe neurological and behavioral disorders, including epilepsy, learning disorders, mental retardation, neurogenetic conditions, head injuries and cerebral palsy.

Damian is one of those complex cases. He was born with static encephalopathy, a condition where the brain doesn't function normally. He has been diagnosed with severe mental retardation, global develop-

by katie sweeney

mental delays, a generalized seizure disorder and multiple behavioral problems. He is undergoing evaluation for autistic tendencies.

His biological mother, who used cocaine and heroin during her pregnancy, lost custody of Damian when he was a baby. He was placed in a foster home, but was difficult to care for. At the age of 15 months, he came to live with new foster parents, Lupe and Juvenal Arroyo, in Palmdale. The Arroyos, who adopted Damian in 2005, have been taking him to Childrens Hospital for the past seven years.

For the last two years, he's been cared for by Ms. Reider-Demer, who holds a master's degree in nursing. As a certified pediatric nurse practitioner (CPNP), she collaborates with doctors in the Childrens Brain Center. Nurse practitioners diagnose and medically manage patients, prescribe medications and perform therapeutic treatments — just one example of the responsible roles nurses assume hospital-wide.

From their first meeting, Ms. Reider-Demer was impressed with the Arroyos' dedication. "Just spending 15 minutes with Damian at that time was exhausting," she

says. "Here was this family who wanted to adopt him. They're extremely devoted parents."

Lupe Arroyo says she appreciated how Ms. Reider-Demer patiently explained medication options and potential side effects. When she found out Ms. Reider-Demer was the stepmother of two children with autism, she felt a bond. In particular, Ms. Reider-Demer understood the difficulty the Arroyos had in securing certain state-funded resources for Damian.

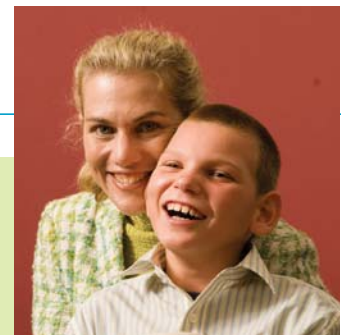
"With Melissa, I feel we speak the same language," Mrs. Arroyo explains. "She's living it herself, so she understands. It makes you feel you're not alone."

### Educating parents

Last year, the Arroyos were able to secure several state services, including behavior therapy, speech therapy and respite care. Since then, Damian has made immense strides. Now eight, he's talking for the first time and can say a handful of words.

Ms. Reider-Demer enjoys teaching families about available resources and how to navigate the inevitable red tape. "It's a complicated process, and many parents don't know what to do," she says. "I try to help because these resources can often make a big difference for their child's health."

Mrs. Arroyo has been sharing her knowledge with other parents as well. For her family, Ms. Reider-Demer has become an invaluable resource. "I know I can talk to her, and she listens," she says. "That's what I love about Childrens Hospital. It feels like a real family." •



### In the zone

Patient rooms in the New Hospital Building will be private and more spacious than current hospital rooms. Each is being designed with three distinct areas: the clinical zone, just inside, where doctors and nurses will monitor patients; the patient zone, with soothing, colorful ceiling murals; and the family zone, featuring a large window. Here, family members will be able to sleep on a pull-out bed, or work and stay connected to friends and family using a nearby telephone and computer dataport. •

helping children to walk, run and grow

## the associates

Melissa Gomez enjoys playing hide-and-seek and putting on costume plays with her sisters and cousins. Not unusual pursuits for a 10-year-old, but before coming to Childrens Hospital Los Angeles, Melissa could walk only on her tiptoes and needed a walker. “Now, she has both feet on the ground,” says her mother, Ana Gomez.

Melissa, who has cerebral palsy, is a beneficiary of motion analysis, which employs specialized cameras and computers to study a child’s joints and muscles in action and plan appropriate treatment. Following her assessment in the hospital’s John C. Wilson, Jr. Motion Analysis Laboratory, the orthopaedic surgeons were able to combine eight procedures in a single operation, including tendon lengthening, tendon transfers and re-alignment of her calf and thigh bones.

“We have faith she will walk on her own one day,” says Mrs. Gomez.

A lot of people Melissa has never met are rooting for her.

The Associates, the 25 volunteer fund-raising groups that support Childrens Hospital, have made a commitment to raise \$5 million for The Associates Endowments for Pediatric Spine Disorders and Motion Analysis

Research, and the New Hospital Building Physical and Occupational Therapy Facility and Hydrotherapy Room.

Their gift will further the investigations of Tishya Wren, PhD, director of research in the Wilson Motion Analysis Laboratory, and assistant professor of research in orthopaedics and radiology at the Keck School of Medicine and in biomedical engineering at the Viterbi School of Engineering of the University of Southern California.

“We focus on some of the most vulnerable children, for whom funding resources are often scarce. We’re very grateful to the Associates,” says Dr. Wren. “If we can demonstrate a positive impact of motion analysis on surgical outcomes, more children will benefit.”

The Associates also are supporting an Endowment in Pediatric Spine Disorders for David L. Skaggs, MD, vice chair of the Division of Orthopaedic Surgery at Childrens Hospital, and the first orthopaedic surgeon in California to implant a life-saving titanium “rib” in a child with severe chest and spine deformities. The result of this groundbreaking procedure is a straighter spine and wider chest cavity, with more room for growing lungs to develop.



*Members of the Board of the Men's Guild, one of the newest Associate groups. Above, center: John Winnick, founder and president, with Chris Angelica, left, and Anthony Mansour, Jr., right, charter members.*

“With the Associates’ generous commitment, we’ll be able to recruit and retain top faculty and continue this important research,” says Dr. Skaggs, an associate professor of orthopaedic surgery at the Keck School of Medicine.

Also, as a component of this three-part project, the Associates are funding a Physical and Occupational Therapy Facility and Hydrotherapy Room in the New Hospital Building. When open, it will expand significantly the current therapy space for patients working to build motor skills and muscle coordination.

“The Associates have always supported the most forward-looking projects, such as these,” notes Bonnie McClure, chairman of the Associates and Affiliates and a hospital trustee. “Helping children to walk, run and grow is critically important.”

Melissa Gomez would agree. •

*To support the Associates Project, please contact Bonnie McClure at 323-669-5431, or [bmcclure@chla.usc.edu](mailto:bmcclure@chla.usc.edu) or Leslie Nafie, assistant vice president of Major and Planned Gifts, at 323-669-4146 or [lnafie@chla.usc.edu](mailto:lnafie@chla.usc.edu).*

by candace pearson



# family care

Until age seven, Tyson Montgomery was perfectly healthy. When he started experiencing frequent urination, his parents worried about a urinary infection or even diabetes. A biopsy told the chilling news: Tyson had pelvic rhabdomyosarcoma, a malignant tumor of the muscle tissue.

Soon, an ambulance rushed him to Childrens Hospital Los Angeles. “Suddenly you’re drafted into a world you didn’t even know existed,” says his mother, Kelly Montgomery. “When you see so many children with cancer in one place, it’s shocking. It feels surreal, as if you want to say, ‘Please wake me up.’”

There was no waking up, however. Like so many other families, Kelly and Rick Montgomery — along with Tyson and his older brother, Cole — were immersed in a new reality. They were grateful to be in a hospital for children. “From the moment you walk in to Childrens Hospital, you’re loved, supported and treated with respect and dignity,” she says.

Today, Tyson, 16, returns to the hospital for check-ups, having lost his bladder to cancer. He also skateboards, drums and plays tennis and basketball. “There’s no keeping him down,” says his mom.

by candace pearson

## Always there

For Beth Huston, her son Will’s official diagnosis of cystic fibrosis (CF) at five months of age only confirmed her worst suspicions. She and her husband, Bob, knew early on something was amiss. Between two and four months, Will only gained four ounces, yet he was bloated.

The first year was the toughest, getting Will to gain weight and learning how to care for him at home. Staff members in Childrens Hospital’s Cystic Fibrosis Center reassured the family they were there to help at every corner. “I hung onto that,” says Mrs. Huston.

She immediately started researching the inherited disease that causes damage to the lungs and pancreatic ducts. Now, she tries to focus on the day-to-day moments with her son, an active eight-year-old who plays soccer and baseball. “I know the doctors at Childrens Hospital are on top of every advancement.” The hospital’s leadership in research to find a cure for CF has received generous support from another patient family, Lewis and Dorothy Webb, whose granddaughter, Nicole, is a former patient.

## The best chance

Michael and Emilie Hill met in college while pursuing chemistry majors. Educating themselves about their six-year-old daughter’s pancreatic cancer has helped offset a feeling of “being out of control,” he says.

Elizabeth never even had typical childhood ear infections. Sudden, recurring bouts of diarrhea at age four led to tests by a pediatric gastroenterologist, revealing a tumor in Elizabeth’s pancreas. Surgeons at another hospital operated to remove her pancreas, spleen, duodenum and gall bladder, and Elizabeth had four months of chemotherapy. After a short respite, the cancer attacked her liver. In March 2005, the doctors advised against further treatment.



In the New Hospital Building, set to open in 2009, families will be able to relax and relieve some of the stress of being in the hospital in special Family Lounges on each floor. Each will feature comfortable seating, computers with Internet access and floor-to-ceiling windows.

THREE FAMILIES SHARE THEIR EXPERIENCES AT CHILDRENS HOSPITAL LOS ANGELES,  
A PLACE THEY SAY WELCOMES AND WATCHES OVER THEM AT EVERY STEP.

The Michael Hoefflin Foundation for Children’s Cancer told the Hills about Childrens Hospital Los Angeles. “At our first meeting, we knew we had found the place and the doctors who would give Elizabeth the best chance,” says her father.

Elizabeth had surgery on her liver at Childrens Hospital. Recently, new tests have detected cancer cells in her lungs, and she is undergoing more chemotherapy. For the most part, she has been able to use the services of the Day Hospital in the Childrens Center for Cancer and Blood Diseases. “That makes it possible for us to go in for treatment and go home at night, which is wonderful,” says Mr. Hill.

On Elizabeth’s long outpatient days, her brothers — Mike, Matthew and Danny — are kept happily occupied by child life specialists in Chase Place playrooms. The specialists also told the Hills that children often talk with their parents about their illness at unexpected times. “It’s true,” says her dad. “One minute, Elizabeth will ask a serious question about her tumors, then the next minute, she’s talking about princesses again.”

Each parent says sharing with other families has brought them comfort in the darkest times. So has the commitment of hospital staff. “I tell everyone, ‘If your child has any health issues, get him or her to Childrens Hospital,’” says Beth Huston, whose family includes daughters C.J. and Cassie.

“There’s a continuous caring,” adds Kelly Montgomery.

Michael Hill agrees. Over the past year, his family has spent more than 100 days in the hospital. “It feels very welcoming — from the admitting process on. Childrens Hospital knows how to care for children and for their families.” •



Top photo: Michael and Emilie Hill with Mike, far left, Danny, Elizabeth and Matthew. Bottom: Beth and Bob Huston, with Cassie, C.J. and Will.



 profile

# natasha shows [backyard queen]

*Natasha Shows reigns over her Moreno Valley backyard from her own palace: a two-story, full-sized dollhouse built by her grandfather, Isao Takahashi. When the seven-year-old isn't pretend-cooking in its kitchen, she might be commanding two of her subjects — a golden retriever and German shepherd.*

*She races around her kingdom, despite having Peter's Anomaly, a rare congenital disorder in which the cornea of the eye may be scarred, and cataracts and glaucoma can develop.*

*In their research, her parents, Dorian and Hiromi Shows, kept running across the name of one leading specialist: Jonathan Song, MD, director of the Cornea Institute, part of the Vision Center at Childrens Hospital Los Angeles, and assistant professor of clinical ophthalmology and pediatrics at the Keck School of Medicine of the University of Southern California. Six years ago, Natasha became Dr. Song's patient. Since then, she's had four corneal transplants to maximize vision in her right eye, among other procedures. With no chance for vision, her left eye has been replaced with a prosthetic eye. It doesn't seem to slow her down.*

*Natasha plays tetherball with her sisters, Chanel, 13, and Tiffany, nine; speaks fluent Japanese; and is learning Braille with the help of her grandmother, Kazue. "As a parent, you want to provide the best care for your kid," says Mr. Shows. "I can't speak highly enough about how Childrens Hospital and Dr. Song have taken care of our entire family. Five stars." •*



AT CHILDRENS HOSPITAL LOS ANGELES,  
SOCIAL WORKERS SUPPORT FAMILIES IN CRISIS, USING  
THE UNIVERSAL LANGUAGE OF COMPASSION.

# human resource

If it “takes a village” to raise a healthy child, what extra support is needed for families whose children are seriously ill or injured? At Childrens Hospital Los Angeles, some of that “extra” comes from 50 skilled social workers who work in every inpatient unit and outpatient clinic.

Tammy and Kris Massman know what it means to get that assistance. Halfway through their pregnancy, a routine ultrasound revealed possible problems with their baby’s heart. Three weeks later, a more sophisticated scan led to the diagnosis of hypoplastic left heart syndrome, a severe congenital heart defect. Two of their son’s four heart chambers were extremely small and would be unable to function properly.

Then the Massmans met Mark Sklansky, MD, director of Fetal Cardiology at the Heart Institute of Childrens Hospital and associate professor of pediatrics and obstetrics/gynecology at the Keck School of Medicine of the University of Southern California. “Dr. Sklansky studied the monitor, watching Michael’s heart, for a long time,” says Mrs. Massman. “He didn’t sugarcoat anything, but he gave us an action plan and a reason to hope.”

*continued on p. 20*





*Above: Social Worker Scott Ferguson, LCSW, talks with Tammy and Kris Massman. Top: Tammy and Kris with their son, Michael. Top right: Michael has had two successful heart surgeries so far.*



## The Bill and Helen Close Family Resource Center

Families need accurate, up-to-the-minute information to make decisions about their children's care. It will be even easier to get that when the New Hospital Building is completed in 2009. Just off the Marion and John E. Anderson Building's John Stauffer Lobby will be the entrance to the New Hospital Building and the Bill and Helen Close Family Resource Center. It will offer Internet access, multilingual print and video reference materials, referrals to community groups and workshops to teach home care skills. "Young children can't decide about their medical care," says Anne Marie Dazé Floyd, RN, MSN, director of transition and occupancy. "Their parents must decide for them. This up-to-date knowledge will help them do just that." •



**“I KNOW IT WAS THE DOCTORS AND NURSES WHO SAVED MICHAEL. BUT IT WAS SCOTT AND LISA WHO SAVED ME.”**

**—TAMMY MASSMAN**

Just hours after he was born in August 2005, Michael Robert Massman II (named after his grandfather, a Marine who died in Beirut in 1983) was transferred to the hospital’s Cardiothoracic Intensive Care Unit (CTICU) before undergoing the first of three corrective surgeries.

One of the world’s most respected pediatric centers, the Heart Institute performs more than 900 cardiothoracic surgeries and 550 cardio catheterizations annually, making this the largest pediatric cardiovascular center in the western United States. The Heart Institute will occupy an entire floor in the New Hospital Building when it opens in 2009, and its CTICU will expand from 11 to 14 beds.

Shortly after Michael was admitted, Scott Ferguson, LCSW, entered his family’s life. As a social worker primarily assigned to the CTICU, his immediate goal with all families is to ensure they have resources to sustain them through the crisis. He helps them identify relatives and friends they can count on, and encourages them to seek support. In addition, as a licensed clinical social worker, he can provide crisis intervention and short-term counseling to families who need and want it.

“I also serve as a bridge between families and medical staff,” he says. “Our doctors are world-class innovators, and they sometimes speak in the abbreviations of sophisticated medical

culture.” Because parents rarely know that language, Mr. Ferguson helps them formulate questions and get information to better understand their child’s condition. That can be challenging when parents are exhausted and worried. “When I met Scott, I hadn’t slept in over 24 hours,” recalls Kris Massman. “When he asked if I had questions, I probably did, but I couldn’t think what they were at that moment.”

So the social worker maintains long-range vision. Sometimes his first gesture is as simple as encouraging parents to take care of themselves during the crisis of hospitalization. As trust grows, he can do more: refer them to support groups in their area, recommend state-funded programs that will provide in-home therapy after their child is discharged, suggest counseling centers or explain the logistics of applying for extended family medical leave.

Time off from work was certainly an issue for Mr. Massman. His employer sent him the necessary paperwork. “Under the circumstances, I couldn’t deal with it,” he says. “I asked Scott if he could help and the next thing I knew, it was done. I could focus on what really mattered to me — my son.”

Now an active toddler, Michael has had two successful surgeries and will have one more in 2008. These days, when the family visits the hospital, they skip the CTICU and head for the Cardiology Clinic, where they work primarily with Social Worker Lisa Hornak, MSW.

“For many families, we become like a second home,” she says, “because they’re connected to us for so long and come in so often.” She sees a lot of happy endings in her job. “I have patients who are now all grown up, and doing just great.”

With its world-renowned medical staff, the Heart Institute at Childrens Hospital accomplishes amazing feats. Working in collaboration, its social workers contribute to that achievement. “I know it was the doctors and nurses who saved Michael,” says his mom. “But it was Scott and Lisa who saved me.” •



michael may age 6

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*There may be no more important gift than providing for the health of our society's children, for they are the future.*

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# room to **play** and reflect



*Alexa Lass, age five, plays in the hospital's John Stauffer Lobby, above left. Above, top right, Rocio Alcaraz and her son, Austin, study the interactive P-LA-Y Tower, while Natalia Lira and volunteer Cindy Weaver share a good book in The Saban Story Corner, bottom right. Facing page: In The Joyce and Stanley Black and Family Healing and Meditation Garden, Lauren Gregorio shows off her drawing skills. Ann Wakulich, RN, takes a break from work in the Childrens Orthopaedic Center to enjoy the roses. Bottom right: Andy Andrade spins through on wheels.*



Surrounded by roses, a young mother shares a picnic with her daughter in The Joyce and Stanley Black and Family Healing and Meditation Garden — the girl’s intravenous pole plugged into an outdoor power source installed for just that purpose. Inside Childrens Hospital Los Angeles’ John Stauffer Lobby, a father stops at the Aromas Coffee Cart before watching his son command a computer screen on the P-LA-Y Tower.

Together, these colorful, child-friendly spaces offer a respite from the

stresses of hospitalization. When the New Hospital Building opens in 2009, families and visitors will enjoy another green scene: The Jane Vruwink Palmer Healing and Play Garden. It will feature a play structure designed and donated by Shane’s Inspiration, a non-profit organization that builds universally accessible playgrounds that allow children of all abilities to play side by side and become friends.

The future garden will carry the name of its prime benefactor. “I love flowers and gardens for the happiness

they bring to everyone,” says Mrs. Vruwink Palmer, a longtime hospital supporter. “As the garden thrives, it will help the children who use it to thrive as well.” •

*To help us create much-needed family spaces in the New Hospital Building, please contact Melissa DoVale, associate vice president of Major and Planned Gifts, at 323-671-1706 or [mdovale@chla.usc.edu](mailto:mdovale@chla.usc.edu).*

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