

Our Mission

We create hope and build healthier futures

Our History

Founded in 1901, Children's Hospital Los Angeles is one of the nation's leading children's hospitals and is acknowledged worldwide for its leadership in pediatric and adolescent health. CHLA is one of only 12 children's hospitals in the nation—and the only one in California—to be named to the prestigious U.S. News & World Report Honor Roll for 2015-16.

A vital part of CHLA's achievements over the years has been The Saban Research Institute, which comprises the basic, translational and clinical research efforts of the hospital. Established in 1992, it is one of the few freestanding pediatric research institutes where scientific inquiry is combined with clinical care devoted exclusively to children. The Institute's investigators hold faculty appointments at the Keck School of Medicine of the University of Southern California (USC), and the hospital is a member of the Southern California Clinical and Translational Science Institute, an academic-clinical-community consortium.

Children's Hospital Los Angeles is a premier teaching hospital and has been affiliated with the Keck School of Medicine of LISC since 1932



Welcome

You may have noticed that there is a new name and face welcoming you to this annual report. I'm Paul Viviano, and I'm four months into my tenure as president and CEO of Children's Hospital Los Angeles. My first impression: Children's Hospital Los Angeles is a very high-performing pediatric academic medical center, and I could not be more proud to be part of the executive leadership and Board.

I've long been attracted to the mission of CHLA, and words cannot express how pleased and honored I am to serve one of the top children's hospitals in the country. It's been a personal goal of mine, and I'm thrilled to finally be a part of this outstanding institution. I'm looking forward to working with our Board of Trustees and hospital leadership to implement CHLA's strategic plan, and to carry out our mission to create hope and build healthier futures. From my perspective, it looks to be an incredibly bright future indeed.

While settling in, I've been impressed beyond measure with the people I've met at CHLA. From our Board to our senior leaders, our clinical and research faculty, medical staff, nursing workforce, Patient Care Services team, administrative support staff and more, everyone I've encountered has been a cut above—exactly what you would expect of the staff at the top-ranked children's hospital in California.

I invite you to read through Imagine, our annual report, and learn about the literally countless great things happening at CHLA. From providing world-class clinical care on a large-scale basis, to advancing knowledge through our extensive translational research capabilities, to preparing future generations of pediatric physicians and scientists, Children's Hospital Los Angeles continues to reflect the vision and values that are sacred to our commitment to protect our most precious resource—the children entrusted to our care.

I'm so privileged to be here, and honored that you've chosen to join us in fulfilling our mission as well. Thank you very much for your support.

Warmest regards,

Paul S. Viviano

President and Chief Executive Officer Children's Hospital Los Angeles















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Year in Review



Ranked among the top 10 pediatric hospitals in the nation for seven years in a row, Children's Hospital Los Angeles was once again named to the prestigious Honor Roll in the U.S. News & World Report survey of the best children's hospitals. CHLA was the only California pediatric medical center selected for the Honor Roll distinction.



Teaming up with Disney's Marvel, CHLA patients were treated to a special screening of "Guardians of the Galaxy" in the Marion and John E. Anderson Pavilion's fourth floor family lounge. Kids and parents gathered in the dimly lit room—only to be surprised by the movie's star, Chris Pratt, joining them in person for the screening.



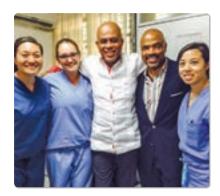
More than 5,000 athletes got up early to participate in the 29th annual Nautica Malibu Triathlon presented by Equinox. Together they raised more than \$1.31 million for CHLA's Pediatric Cancer Research Program.



CHLA Trustee Kathleen McCarthy Kostlan and The Thomas and Dorothy Leavey Foundation donated \$5.5 million to CHLA to establish The Thomas and Dorothy Leavey Foundation Interfaith Center. The gift is the largest ever made to CHLA in support of Spiritual Care Services.



Researchers led by Bradley S.
Peterson, MD, director of the Institute for the Developing Mind, found a powerful relationship between prenatal exposure to common air pollutants and cognitive and behavioral impairment in children.
Neurotoxic PAH (polycyclic aromatic hydrocarbons) are ubiquitous and can readily cross the placenta to affect an unborn child's brain.



Surgeon-in-Chief Henri Ford, MD, MHA, led an 18-member team from CHLA and the Keck School of Medicine of the University of Southern California (USC) on a mission to Haiti to perform a delicate, seven-hour surgery that successfully separated 6-month-old conjoined twins. "We anticipate Marian and Michelle will recover fully and go on to lead healthy and happy lives," says Ford.



Johanna Olson, MD, medical director of the Center for Transyouth Health and Development at CHLA, was featured as an expert during Diane Sawyer's "20/20" interview of Caitlyn Jenner, which attracted 17 million viewers. Olson shared her insights about working with transgender youth and the importance of timely and appropriate care.



Pasadena Magazine's eighth annual Top Doctors issue recognized more than 80 physicians with privileges to practice at CHLA. Many of these physicians are members of the Children's Hospital Los Angeles Medical Group and are academically affiliated with the Keck School of Medicine of USC.



In the largest study of its kind, a team of investigators from nine universities across the country—including Elizabeth Sowell, PhD, director of the Developmental Cognitive Neuroimaging Laboratory at The Saban Research Institute of Children's Hospital Los Angeles—found correlations between parents' income and education level and the brain structures of their children. The results were published in the journal Nature Neuroscience.

Financial Summary

Balance Sheet

As of June 30, 2015 and 2014

(in thousands)

Total Liabilities and Net Assets	\$1,784,878	\$1,714,349
Total Net Assets	1,135,601	1,107,612
Restricted	295,999	299,387
Unrestricted	839,602	808,225
NET ASSETS		
Total Liabilities	649,277	606,737
Other noncurrent liabilities	40,546	38,102
Long-term debt, net of current portion	471,896	479,709
Total Current Liabilities	136,835	88,926
Other current liabilities	73,083	49,122
Accounts payable and accrued expenses	\$63,752	\$39,804
LIABILITIES AND NET ASSETS Current Liabilities		
Total Assets	\$1,784,878	\$1,714,349
Property, plant and equipment, net	920,108	916,773
Other assets	25,847	25,224
Pledges receivable, net of current portion	46,762	64,269
Assets limited as to use, net of current portion	510,422	540,029
Total Current Assets	281,739	168,054
Other current assets	132,698	50,900
Accounts receivable, net	130,293	112,166
Cash and cash equivalents	\$18,748	\$4,988
Current Assets		
ASSETS	2015	2014

Financial Summary

Income Statement

For the years ended June 30, 2015 and 2014

(in thousands)

OPERATING REVENUE	2015	2014
Total Net Patient Revenue	\$829,344	\$577,720
All Other Operating Revenue	223,673	225,595
Total Operating Revenue	\$1,053,01 <i>7</i>	\$803,315
OPERATING EXPENSES		
Salaries and Benefits	468,225	434,647
Professional Fees	107,132	92,269
Supplies	128,291	114,302
Purchased Services	80,165	68,900
Other Expenses	144,533	<i>7</i> 3,819
Total Operating Expenses	\$928,346	\$783,964
EBIDA	\$124,671	\$19,351
EBIDA %	11.8%	2.4%
Depreciation and Interest Expenses	80,242	<i>7</i> 5,812
Operating Gain (Loss)	\$44,429	\$(56,461)
Investment Earnings, Net of Endowment Distribution	\$(17,310)	\$26,269
Net Gain (Loss)	\$27,119	(\$30,192)

Statistical Report

For the fiscal year ended June 30, 2015

KEY STATISTICS	2015
Number of licensed beds	495
Discharges	15,685
Patient days	106,372
Average length of stay (days)	6.8
Outpatient visits ¹	348,440
Emergency Department visits	77,673
Traumas treated	707
Medical transports	2,338
Surgeries	16,262
Active medical staff	802
Employees	5,506
Total National Institutes of Health funding	\$32.2 million
Total research funding	\$74.8 million
Total number of active patents	214

CHARITY CARE AND OTHER COMMUNITY BENEFITS

Charity care ²	\$4.5 million
Unreimbursed costs of medical services for government-sponsored programs ³	\$161.1 million
Research activities	\$29.9 million
Health professions education	\$25.6 million
Subsidized health services	\$7.2 million
Community health improvement services and other community benefits	\$4.3 million

TOTAL COMMUNITY BENEFIT⁴

\$232.6 MILLION

¹ Includes outpatient and lab visits.

 $^{^{2}}$ Includes cost of care provided to uninsured and/or underinsured patients.

³ The Medi-Cal program partially offsets these losses through the Disproportionate Share Hospital Program, designed to support "safety net" hospitals, such as Children's Hospital Los Angeles. The Hospital received \$47.7 million in Disproportionate Share Hospital Funding in FY 2015.

⁴ In January 2010, the State of California enacted legislation that provides for supplemental payments to certain hospitals funded by a quality assurance fee paid by participating hospitals as well as matching federal funds (the "Hospital Fee Program"). Supplemental payments and fees related to the Hospital Fee Program produced a net benefit of \$167.1 million to Children's Hospital Los Angeles in the fiscal year ended June 30, 2015.



The Patient Care Services staff at Children's Hospital Los Angeles make an indelible impact on patients and their families, providing care for seriously sick and critically injured children and offering support during a very challenging time in their lives.

In recognition of their important role, the hospital is launching a pioneering institute that will tap into the talent and expertise of these dedicated professionals—who represent nearly 40 percent of CHLA's workforce—to enhance care and bring new innovations to improve patient outcomes.

The Institute for Nursing and Interprofessional Research will support nurses and clinical experts in carrying out research and employing evidence-based practices. The Institute's goals are unique: to explore novel questions and conduct studies with interprofessional teams; to develop a more effective clinical care workforce through research opportunities, education and professional development; and to create a model for pediatric clinical research that puts Children's Hospital at the forefront of the field.



To create and sustain the Institute, the hospital recently kicked off a \$10 million fundraising campaign, which includes a \$5 million endowed chair for the director of the Institute and a \$5 million Nursing and Interprofessional Research Endowment to fuel research across many areas.

The endowment will harness gifts from grateful patients and families, current and former hospital leadership and staff members, and friends of the hospital who care about children's health. Both the endowed chair and program endowment will exist in perpetuity and provide a consistent and dependable source of funding.

"We believe the Institute is the first of its kind because of its large endowment and interprofessional focus," says Mary Dee Hacker, MBA, RN, NEA-BC, FAAN, vice president of Patient Care Services and chief nursing officer at Children's Hospital, who has been named the Institute's inaugural chair holder. "This Institute is a real statement of Children's Hospital Los Angeles blazing into the future."

The Institute will support research on the effectiveness of current practices and the building of better methods and models of care; ways to help patients heal and rehabilitate more quickly and completely; and factors that reduce developmental, social and physical delays that can result from hospital stays.



CHLA President and CEO Paul S. Viviano (left) and inaugural Chair of the Institute for Nursing and Interprofessional Research Mary Dee Hacker, MBA, RN, NEA-BC, FAAN

"We believe the future is about working in partnership and collaboration rather than in silos," says Hacker. "It's not just nurses, physical therapists, social workers and others doing research, but everyone coming together to ask questions, challenging the status quo and engaging in research to advance new knowledge.

"The Institute will help us address questions to ensure we continue to be innovative and groundbreaking in improving the health of children and families we serve," she adds.

Hacker to Lead New Institute

As Children's Hospital Los Angeles set out to create a \$5 million endowed chair for the director of the Institute for Nursing and Interprofessional Research, it didn't have to look far to find the Institute's inaugural chair holder.

The clear choice was Vice President of Patient Care Services and Chief Nursing Officer Mary Dee Hacker, MBA, RN, NEA-BC, FAAN.

The recipient of numerous awards and accolades, Hacker is known for her tireless work and commitment to the hospital. She also has a proven track record in launching new initiatives that are often replicated at other institutions, including the Versant™ RN Residency in Pediatrics, which has become a national model for new graduate nurse residency programs in the U.S.



"It's a very exciting time as we capture the capability of our talent at the hospital to make a tremendous impact on the lives of children and their families," says Hacker, who will be leaving her position as chief nursing officer, which she has held since 1993, to oversee the Institute and serve as a consultant to the Children's Hospital Los Angeles Center for Global Health. "I've never been in a role or institution where the future is so rich with opportunity; we are positioned so extraordinarily well.

"To have been part of that culture for 40 years is unbelievable," she adds. "I believe the work we do is sacred. Families welcome us when they're the most scared and overwhelmed, and look to us to say, 'Please help us.' And we do."

Children's Hospital Los Angeles Welcomes Arnie Kleiner and Lynda Boone Fetter as Co-chairs of the Board of Trustees



Arnold "Arnie" Kleiner and Lynda Boone Fetter were elected co-chairs of the Board of Trustees of Children's Hospital Los Angeles in July 2015, succeeding outgoing Board Co-chairs Cathy Siegel Weiss and Theodore "Ted" Samuels.

"Since joining CHLA, I have had many opportunities to benefit from the leadership of Arnie Kleiner and Lynda Boone Fetter," says Paul Viviano, who began his tenure as CHLA president and CEO in August 2015. "They are committed to CHLA's mission and to the work ahead to expand CHLA's leadership in health care for children in Southern California."

"In partnership, Arnie and I will work to build on the quality and excellent reputation of CHLA in a time when the health care industry is facing comprehensive change," says Boone Fetter. Kleiner says both he and Boone Fetter "are honored to serve as co-chairs during the hospital's next stage of advancement. The quality of our staff is incomparable. Combined with the enthusiasm, diversity and skill of the Board of Trustees, our team will make Children's Hospital Los Angeles a better place for the children of Los Angeles, California and the world."

A member of the Board of Trustees since 2004, Boone Fetter has served on and chaired numerous Board committees, and she was integral to the creation of the Boone Fetter Clinic, which is housed within the Institute for the Developing Mind and provides innovative and comprehensive care for thousands of children facing autism and other neurodevelopmental disorders. She is currently a principal/manager of Boone Fetter LLC and principal of Samuelson & Fetter LLC, a premier development firm in

Los Angeles. For more than 30 years, she and her husband, Blaine, have founded several private real estate and development firms.

Kleiner has spent more than three decades advancing the missions of children's hospitals across the nation. A member of the CHLA Board of Trustees since 2002, Kleiner previously served as the Board's vice chair. He is a longstanding CHLA benefactor, most notably in support of the annual broadcast of the Emmy Award-winning ABC7 television special "Imagine: A Celebration of Children's Hospital Los Angeles."

Kleiner's career in broadcast media has spanned more than 45 years. He was most recently president and general manager of KABC-TV, a position he took over in 1996. He steered the station to its current topranked status in the ultra-competitive Los Angeles television news market.



On June 1, Children's Hospital Los Angeles opened its new pediatric care center in Encino. The new facility, Children's Hospital Los Angeles – Encino, is staffed by Board-certified CHLA Medical Group physicians in a range of specialties and subspecialties, including hematology-oncology, nephrology, neurology, orthopaedics, pediatric surgery and urology.

This marks the fifth outpatient care center that CHLA has opened since 2010, preceded by centers in Arcadia, Valencia, South Bay and Santa Monica.

"Patients from the San Fernando Valley and immediate neighboring communities will now have access to some of the nation's top pediatric doctors," says Robert Adler, MD, chief medical officer of the CHLA Pediatric Network.

For additional information about CHLA – Encino, including address and work hours, go to **CHLA.org/ENCINO**.

Children's Hospital physicians are also staffing the general pediatric, pediatric intensive care and neonatal intensive care units at Providence Tarzana Medical Center. CHLA's hospitalists, intensivists and neonatologists—physicians charged with overseeing hospitalized and critically ill patients—are on the units 24 hours a day.



Children's Hospital Los Angeles – Encino

Kirk and Anne Douglas Purchase da Vinci Robot for CHLA

Last March, actor Kirk Douglas and his wife, Anne, donated \$2.3 million to Children's Hospital Los Angeles for the purchase of a da Vinci robot for the Division of Pediatric Urology in the Department of Surgery.

The \$2.3 million gift also supports the training of physicians in the use of the device, which can help surgically correct urological problems in children and infants.

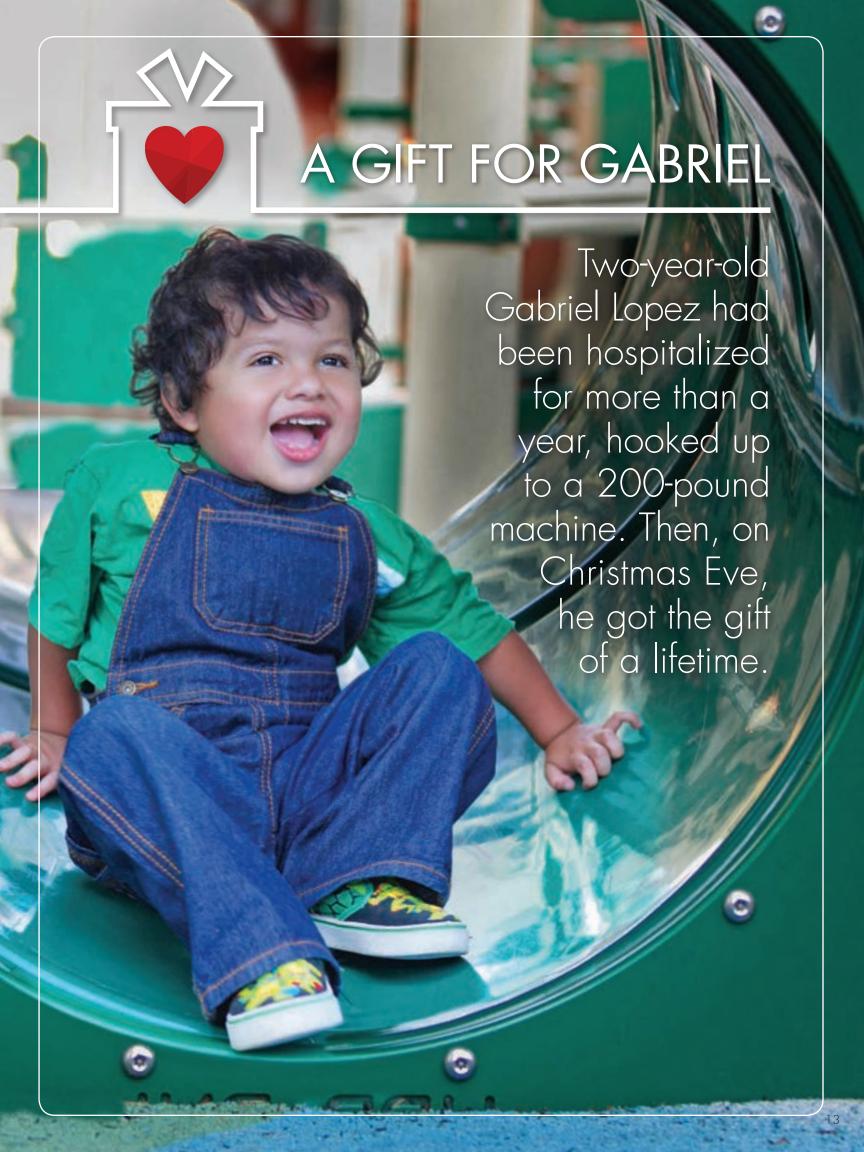
"The new robot will expand the hospital's capacity to perform major surgery on infants and children using technology that permits faster inpatient and at-home recoveries," says Division Chief Roger E. De Filippo, MD, noting the smaller incisions and magnified 3-D imagery enabled by the device. "It is an incredible gift."



The Douglases have supported CHLA for 15 years. The da Vinci robot, which has been given the name Spartacus (a nod to the 1960 movie in which Kirk starred), was one of three wish-list items the hospital submitted to them.

"We picked the most complicated and the most expensive one, and we gave extra money for the doctors to make themselves familiar with the machine," Kirk told The Hollywood Reporter. "I never saw it until I Googled it, and I can't tell you how impressed I was by what we were giving."





Monica Horn, RN, CCRN, CCTC, was tired.

That wasn't surprising, considering it was the middle of the night, and Horn had been working since that afternoon. Fortunately, as a veteran transplant coordinator at Children's Hospital Los Angeles, she was used to long nights. And on this particular night, there was extra excitement in the air.

After all, it was Christmas Eve. And the little boy on the operating table was getting the best Christmas present she could think of: a new heart.

Horn, like many of the doctors, nurses and support staff working that night, knew the boy well. In fact, she'd seen him almost daily for more than a year. She even knew his favorite song: Elvis Presley's "Love Me Tender."

As she worked through the night, one image in her mind eased any fatigue and renewed her energy.

"I can't wait," she thought, "to see him run down the hallway."

Failing heart

When Ivonne Moreno and Robert Lopez welcomed their son, Gabriel Lopez, into the world in June 2012, he seemed like a healthy baby. But after six months, everything changed.

"He started being really fussy all the time," his mom says. "I was always taking him to the doctor, and they would say, 'Oh, he has an ear infection.' But he wasn't getting better."

One night, with Gabriel breathing hard and vomiting, his parents brought him to a local emergency room. The next thing they knew, an ambulance was rushing Gabriel to Children's Hospital, where he was admitted to the Cardiothoracic Intensive Care Unit (CTICU).

"Everything happened at once," Moreno recalls. "When I saw him in the hospital bed, with all the tubes and wires coming out of him, I started freaking out."

It was a scary scene, but Gabriel was in good hands. The Heart Institute at CHLA is one of the largest and busiest pediatric cardiac programs in the country, treating



Monica Horn, RN, CCRN, CCTC, transplant coordinator

nearly 8,000 children a year and providing the most advanced, lifesaving treatments available for virtually every heart disorder and defect seen in children.

Gabriel's diagnosis was dilated cardiomyopathy, a disease where the heart becomes weak and enlarged and is unable to pump blood like a healthy heart.

On that first trip to CHLA, medications stabilized him, and he went home soon



A Child Life specialist distracts Gabriel with an iPad during a site dressing change for the cannulas connecting him to the Berlin Heart device.

"The Berlin Heart has changed the face of heart transplant for pediatric patients. It's been a godsend. Not only are kids able to survive long enough to get a transplant, but their organs are better supported. It puts them in a much better physiologic place when transplant occurs."

-Cynthia Herrington, MD

afterward. But over the next several months, his disease progressed rapidly, and he was put on the waiting list for a heart transplant.

By October 2013, after catching a cold, his condition deteriorated. Once again his parents brought him to Children's Hospital, and Gabriel was admitted to the CTICU. But even after a month in intensive care, on the strongest possible doses of intravenous heart medications, his heart continued to fail.

"The blood flow to his body was so poor, we had to put him on a ventilator," says Jondavid Menteer, MD, medical director of the Cardiac Transplant Program and the Mechanical Cardiac Support Program. "Even breathing was getting to be exercise for him."

A 'bridge' from Berlin

If Gabriel had been born a decade ago, he would have almost certainly died.

"That was the story of probably a third of the babies we listed for heart transplant," Menteer says. "Older children were faring better, but a third of the babies were dying. They couldn't live long enough to get a heart."

Then, the Berlin Heart came along.

The Berlin Heart is a type of ventricular assist device (VAD), a mechanical pump that takes over the work of one chamber of the heart and pumps blood to the body and vital organs.



Cynthia Herrington, MD, program director, Heart Transplant Program



Gabriel during his yearlong stay at CHLA, connected to the Berlin Heart

Ventricular assist devices have been used in adults since the late 1980s, but adult-sized devices pump too much blood to be used in babies and small children.

The Berlin Heart was the first "miniature" VAD designed specifically for these young patients, providing them a desperately needed "bridge" to a transplant. First used in Europe (the manufacturer is based in Berlin), it's the only VAD approved for children by the U.S. Food and Drug Administration.

Since 2008, CHLA has implanted 17 Berlin Hearts; nearly all patients have made it to transplant.

"The Berlin Heart has changed the face of heart transplant for pediatric patients," says Cynthia Herrington, MD, program director of the Heart Transplant Program. "It's been a godsend. Not only are kids able to survive long enough to get a transplant, but their



The Berlin Heart, Gabriel's lifeline, kept him tethered to a 200-pound machine.

organs are better supported. It puts them in a much better physiologic place when transplant occurs."

Herrington implanted Gabriel's Berlin Heart on Dec. 5, 2013. With the device now taking over his heart's toughest task—pumping blood to the body—Gabriel improved significantly. The catch? His mechanical heart pump was tethered to a 200-pound machine. He would have to stay in the hospital until a heart was available.

His parents and family at his side, Gabriel did his best to resume the business of being a toddler, even with the awkward tubes that dangled from his body and kept him from running free. He grew taller. He learned to walk. He played with his toy cars and watched his favorite cartoons.

Most of all, he loved music, especially Elvis Presley songs. Music therapists in the Mark Taper-Johnny Mercer Artists Program at CHLA not only helped Gabriel with his speech, but also distracted and calmed him during medical procedures and hours-long dressing changes.

Meanwhile, Gabriel's doctors and nurses provided the complex, collaborative and highly specialized care that's critical for Berlin Heart patients, working together in seamless fashion to prevent complications such as bleeding, stroke and infection.

Still, the months dragged on.

"When the year mark came, it started hitting me a lot," says Moreno. "I wanted to see him with other kids, running around. I wanted him to come home. I was praying every hour that he would get a heart."

'He's finally got it'

At 2:15 p.m. on Dec. 23, 2014, Monica Horn's smartphone dinged. A possible donor heart was available for Gabriel.

After 21 years as a transplant coordinator at CHLA, Horn has learned not to get her hopes up when such calls come in. Many times, the heart turns out to not be a good fit—either for size reasons or because it's not truly healthy.

But this time, she couldn't contain her excitement. Yessss! she thought. He's finally got it.

The donor heart, it turned out, was in excellent shape. Transplant surgeon Ram Kumar Subramanyan, MD, PhD, got the call to perform the surgery.

Subramanyan knew Gabriel well and had assisted in implanting his Berlin Heart. At CHLA, two Board-certified heart surgeons participate in every open-heart surgery.

"What I love about this program is our team mentality," he says. "It's a dream job. Gabriel isn't 'my' patient or another person's patient. He's everyone's patient."

At midnight on Dec. 24, Gabriel was wheeled into the operating room. Over the



Ram Kumar Subramanyan, MD, PhD, transplant surgeon

"It's one of the greatest things we do. In someone else's loss, a new life is created. It's an unbelievable feeling."

-Ram Kumar Subramanyan, MD, PhD

next six hours, Subramanyan and the surgical team carefully removed his swollen, atrophied heart, along with the Berlin Heart that had sustained his life for 384 days—the longest period a CHLA patient has spent on the device.

In their place, Subramanyan deftly sewed in the strong, healthy donor heart, and watched it beat in Gabriel's chest.

"It's one of the greatest things we do," he says. "In someone else's loss, a new life is created. It's an unbelievable feeling."

Heartfelt thanks

After 15 months at Children's Hospital, Gabriel went home Jan. 22, 2015. With a healthy heart, he's no longer "leashed" to the Berlin Heart machinery. Gabriel is making up for lost time.

"Every morning, he wakes up so happy," says his mom. "He's constantly playing. He doesn't want to take naps; he doesn't want to miss one second of the day. He just loves life.

"I'm so thankful for Children's Hospital," she adds. "The people there, they became our family. If it wasn't for them, I wouldn't still have my son."

Gabriel, now 3, is also grateful. When he returns to CHLA for checkups, he happily greets his doctors and nurses. Although he has some developmental delays, he's catching up and making strides in his speech and physical development.

And yes, Horn did get to see him run down that hallway.

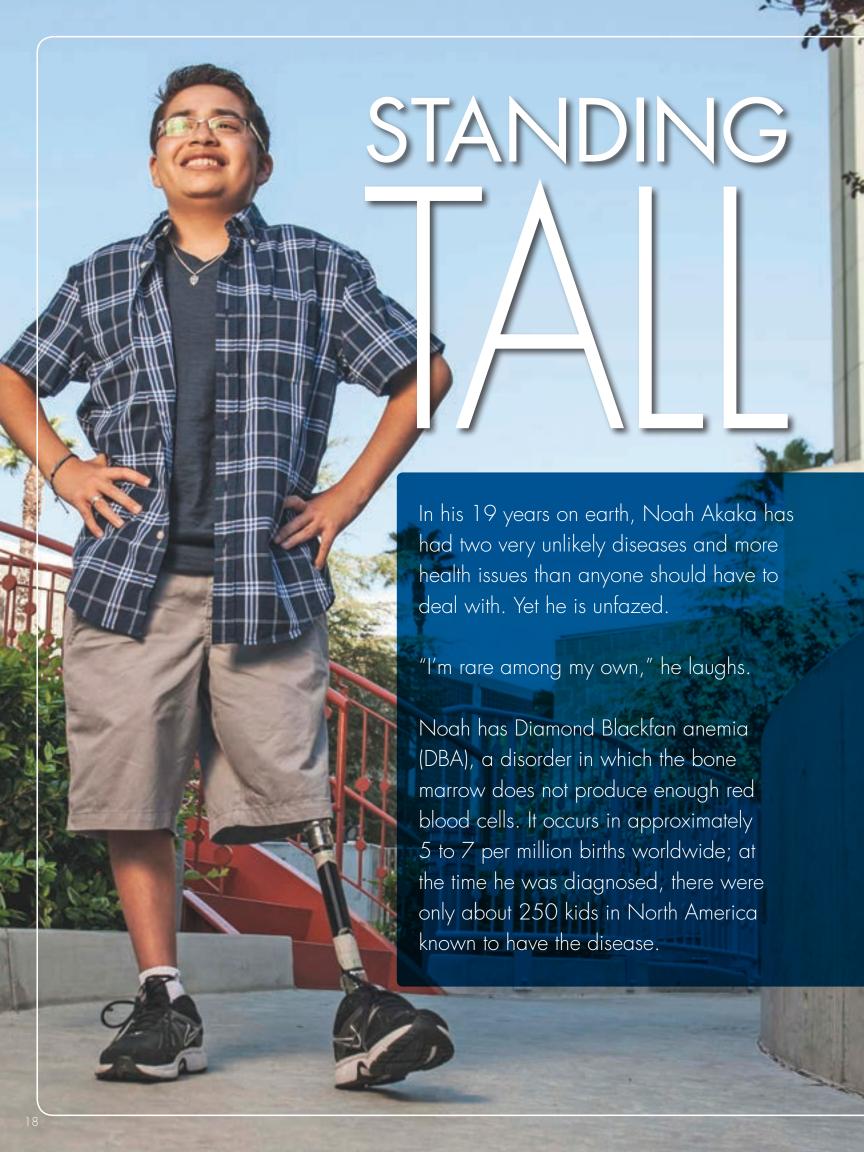
In fact, when Gabriel saw her at an outpatient clinic several weeks after his transplant, he not only ran to her—he threw his arms around her in a hug.

She couldn't have imagined a better reward. 🦫



Monica Horn and Gabriel, reunited







Noah gets a checkup from his oncologist, Leo Mascarenhas, MD.

It was Easter Sunday when his mom, Regina Delgado, realized her newborn baby was really sick. The next day, Noah's pediatrician sent him straight to a local hospital. There his hemoglobin count was found to be 2.3; normal for an infant is 9.5 or above. Noah and his mom were rushed to Children's Hospital Los Angeles by ambulance. After numerous tests, Delgado was finally given an answer: "He has Diamond Blackfan anemia," she remembers the doctor telling her.

The rare disease came with difficult complications. Noah had to get blood transfusions every three weeks, and he underwent regular chelation therapy to mitigate the iron buildup in his system caused by the transfusions. He also had skeletal issues and endocrine problems. But he learned to live with the complications, and to thrive in spite of them.

Worth the drive

Noah's mom realized early on that the care he got at CHLA was worth the 32-mile drive from their home. At first, they tried taking care of some of Noah's more routine tests and treatments at a local hospital. Delgado recalls the incident that changed that: "They ran the blood through a filter, and there was an accident—they popped the blood cells, basically, and they gave him the blood like that."

"The way the blood was prepared caused the red blood cells to break down before being transfused," says Tom Hofstra, MD, Noah's hematologist in the Children's Center for Cancer and Blood Diseases at CHLA. "The contents of the red blood cells, hemoglobin, got into his bloodstream. This caused significant injury to his kidneys, because hemoglobin is toxic."

"We said, 'No more,'" says Delgado.
"There's no one better equipped to take
care of him than here at Children's Hospital.
We've never gone anywhere else."

"This is a rare complication of a transfusion, and CHLA is best suited to care for children with transfusion complications," says Hofstra.

'A very particular set of skills'

"I have four to five patients at a time with Diamond Blackfan anemia," says Susan M. Carson, RN, MSN, CPNP, nurse practitioner in the Red Cell and Chronic Transfusion Program at CHLA, speaking of her own caseload alone. "The hospital where Noah was diagnosed—they may never have seen one before."

CHLA currently cares for 23 kids with DBA overall. "We do have, to quote Liam Neeson, 'a very particular set of skills,'" she laughs.

Noah's team at CHLA always works hard to keep him where he is happiest—out on the river. He and his family can often be found floating down the Colorado River on their boat during the summer.

"I remember trying to figure out ways to get him out on the river, trying everything we could to let him lead as normal a life as possible, despite all of the things he had to go through," says Hofstra.

Against all odds

Noah and his mom, stepdad Gilbert, sister Simone, who is 6 years older than Noah,



Tom Hofstra, MD, Noah's hematologist

(continued on next page)



stepsister Serena, 24, and stepbrother Gilby, 28, did just that, settling into their own version of normal. But when he was 16, life threw Noah another curveball. What were the odds? Noah learned not to ask that question long ago.

After a procedure to correct knock knees by surgeon Paul Choi, MD, at CHLA, doctors noticed an abnormality on Noah's follow-up X-ray. Noah had developed osteosarcoma, a cancer of the bone, in his left distal femur.

Actually, the odds were at least 33 times higher for him than for the general population, but few people knew that. Luckily, one of those people was Leo Mascarenhas, MD, head of the Oncology Section of the Children's Center for Cancer and Blood Diseases at CHLA. Mascarenhas first encountered Noah's case when an orthopaedic surgeon brought it into the biweekly interdisciplinary conference between orthopaedic and hematologyoncology specialists.

"DBA patients have an increased risk of osteosarcoma, so you should assume this is bone cancer until proven otherwise," Mascarenhas told the surgeon. Unfortunately, his suspicion proved correct.

Children with bone marrow defects do not handle chemotherapy well. To offer Noah the best chance of survival, Mascarenhas decided to treat him like any other patient with osteosarcoma, and monitor him closely. Noah had several unusual complications, but Mascarenhas and his team managed them deftly. The resulting success was anything but routine. Only six other patients with DBA and osteosarcoma have been reported worldwide, and none have survived their cancer.

Mascarenhas hopes to use Noah's case to help other kids as well. "As a general rule, when two very rare diseases happen together, this gives us a clue as to why the disease occurs in the first place," he says. "So we might understand why people who don't have DBA get osteosarcoma."

After Noah completed 10 weeks of chemotherapy, his surgeon attempted a

limb salvage procedure to remove the tumor and affected bone, implant an internal prosthesis and save his leg.

"It was a beautiful piece of work," says Delgado. "But his bone couldn't support it." The skeletal issues that often come with DBA were too much. The prosthesis became detached, and an infection ensued.

Noah's doctors worked to help him figure out what to do next. Should they keep trying to make a limb-salvaging bone implant work? That might mean many more surgeries with no guarantee of success. Should they try something more experimental that still might not work? In the end, Noah made the decision to have his leg amputated. He just wanted to move forward.

His orthopaedic surgeon amputated his leg above the knee, and ground down bone fragments from Noah's amputated tibia to fit the inside of the remaining femur. The novel technique was designed to help strengthen the bone so it could support an external prosthetic leg—another example of Noah's care team thinking outside the box to give him the best shot possible.

Actually, Noah's situation is so rare, there is no box.

"I always knew that my life was up, down, different, sideways, circles, whatever," says Noah. "I'm fine with it. Because—what else can happen? I wanted to try to get through it as fast as possible. And we did."

In the Words of a Warrior Advocate AKA "MOM"

Name: Regina Delgado

Occupation: Assistant sundries buyer, L.A. region, Costco

On Noah: "I'm very proud of my son. I'm very proud of his resilience and his endurance. I don't know adults that could have done this so gracefully and with such strength. He's a pretty rare and wonderful young man."

On CHLA: "One of the things that I love so much about the hospital is that all of his doctors have been truly vested in Noah. They care about him. They know him. And that has made some of the most difficult things bearable."

On Costco: "My company's been amazing. They have been supportive in every possible way. They are huge supporters of Children's Hospital. I'm very proud that Costco is a company that gives."



Noah and his mom, Regina Delgado

Michael Pulsipher Joins CHLA as Section Head of Blood and Marrow Transplantation

The Children's Center for Cancer and Blood Diseases at Children's Hospital Los Angeles has added another member to its power team of clinicians and scientists leading the fight against childhood leukemia.

In July, Michael Allen Pulsipher, MD, joined the Division of Hematology, Oncology and Blood and Marrow Transplantation as head of the Blood and Marrow Transplantation (BMT) Section and BMT clinical research chair. He is also a professor of Pediatrics at the Keck School of Medicine of the University of Southern California.



Pulsipher directs the Blood and Marrow Transplantation Section's clinical care and clinical research activities, and his recruitment means that CHLA will now be the headquarters for the Pediatric Bone and Marrow Consortium. With more than 80 members in the United States, Canada, New Zealand and Australia, the consortium is the largest clinical trials group focused exclusively on blood and marrow transplants for children and adolescents.

A highly accomplished National Institutes of Health-funded investigator, Pulsipher came to CHLA from Primary Children's Hospital and the University of Utah School of Medicine in Salt Lake City. His major areas of research focus include innovative approaches for children with acute lymphoblastic leukemia and bone marrow failure conditions, reduced toxicity regimens and donor safety.



Juliette Clark feared her scoliosis would end her water polo dreams. The Children's Spine Center helped her get back in the pool—and onto the podium.

John and Manya Clark stared at the X-ray—then looked at each other in disbelief.

The ghostly, black-and-white image on the exam room screen showed a spine shaped like the letter S—with prominent curves jutting out in two places along their daughter's back.

"How can that be Juliette's X-ray?" Manya remembers thinking. "There must be some kind of mistake."

The Clarks had reason to be confused.

Juliette, then 11, wasn't suffering any
back pain. Standing up, she appeared
perfectly straight. What's more, she
was a competitive athlete and a
top player on her club water
polo team.



Juliette with her surgeon, David Skaggs, MD, MMM

But there was no mistake. When the doctor came in the room, he had bad news. Juliette's scoliosis (curvature of the spine) required surgery, and that would mean the end of her athletic pursuits. She would have to quit competitive water polo—and give up her dreams of playing the sport in high school and college.

"We were trying to take it all in," Manya says. "But it was pretty devastating."

Driving north

A strong swimmer, Juliette (called "JuJu" by her family and friends) started playing water polo at age 7.

"I like how it's fast-paced, and it involves so many different things—treading water, swimming back and forth, shooting and passing," she explains. "Plus, it's in the water. I love being in the water."

The entire Clark family shares that passion for water sports. Both of Juliette's sisters play

water polo, and the family has competed for years in stand-up paddle boarding contests, earning the nickname the "First Family of Stand-Up Paddle Boarding."

News that Juliette would have to quit her water polo team was upsetting enough, but the Clarks were concerned for another reason, too. Their daughter's surgery wasn't tentatively planned until the summer—more than seven months away.

"There was no sense of urgency at all," says Juliette's dad, John.

After doing research and talking to other families, the Clarks decided to seek a second opinion, making the 70-mile drive from their San Clemente home to see David L. Skaggs, MD, MMM, at Children's Hospital Los Angeles.

Skaggs is chief of the Children's Orthopaedic Center at CHLA and directs the Children's Spine Center, a comprehensive, world-renowned pediatric spine center, one of the largest of its kind in the country. The Center treats more than 1,000 patients annually and performs 300 spine surgeries each year, with Skaggs performing nearly half of them.

"Meeting him was a completely different experience," Manya says. "He felt the sooner she had surgery, the better. And he was very positive about her going back to water polo and continuing to be competitive."

The family breathed a sigh of relief. At Juliette's request, they scheduled the surgery for Feb. 4, 2014, shortly after her 12th birthday. When February arrived, they headed back up the 5 freeway to CHLA.

They expected to be at the hospital for only a few days. But life was about to throw them another curve.

Lost signals

Not all kids with scoliosis need surgery.

But curves that are more severe—

50 degrees or greater—are more likely to progress. Eventually, they can cause

(continued on next page)



Juliette at a water polo match with her dad, John

physical deformity, debilitating pain and even impaired lung function.

At the time of her diagnosis, Juliette's curves were around 50 degrees. By the time of her game; even walking through the mall gave her shortness of breath.

The surgery to correct such an abnormality is called spinal fusion, which involves inserting metal rods to straighten the spine and then fusing them in place with bone grafts.

But during Juliette's surgery, when Skaggs inserted the rods, something happened: Her spine stopped working, causing temporary paralysis.

It's a risk that comes with any spine surgery, but fortunately, Skaggs and the team at CHLA are prepared for such complications.

"It's kind of like being an airplane pilot. We have protocols for what to do when you lose spinal cord monitoring," Skaggs says. "The whole crew goes into high alert."

Skaggs immediately removed the rods, which returned Juliette's spine to normal functioning. Unable to straighten her spine, Skaggs decided next to implement a "halo traction" treatment. With her parents' consent, Skaggs screwed a ring, called a halo, into Juliette's skull. The halo attaches to a weight-andpulley system that gently and gradually "stretches" the spine straighter over time.

When Juliette awoke, she was confused.

"At first I didn't know what was on my



With the help of her family and CHLA nurses and support staff, Juliette got through the week. As challenging as it was, it was also fun. One highlight: participating in a songwriting workshop in the Teen Lounge with The-Dream, an R&B songwriter who has written songs for Rihanna and Beyoncé.

"The care she received was amazing," John says. "We felt very fortunate we were in the right place."

After eight days, the halo had done its job, correcting her curves to a more mild 30 degrees. Skaggs then performed a second surgery, removing the halo and inserting permanent rods to solidify the correction.

"Her body looks straight; you wouldn't know without an X-ray that she still has some curve," Skaggs explains. "Most importantly, she won't have pain, and we've prevented a lifetime of progression."

Back in the pool

Seven weeks after her surgeries, Juliette was back in the pool. Just five months afterward, she was scoring goals for her water polo team—leading her teammates to a gold medal in the National Junior Olympics at Stanford University.

Today, the eighth-grader, now 13, has improved her game even more. She recently joined a new, higher-level team and is gearing up for another Junior Olympics.

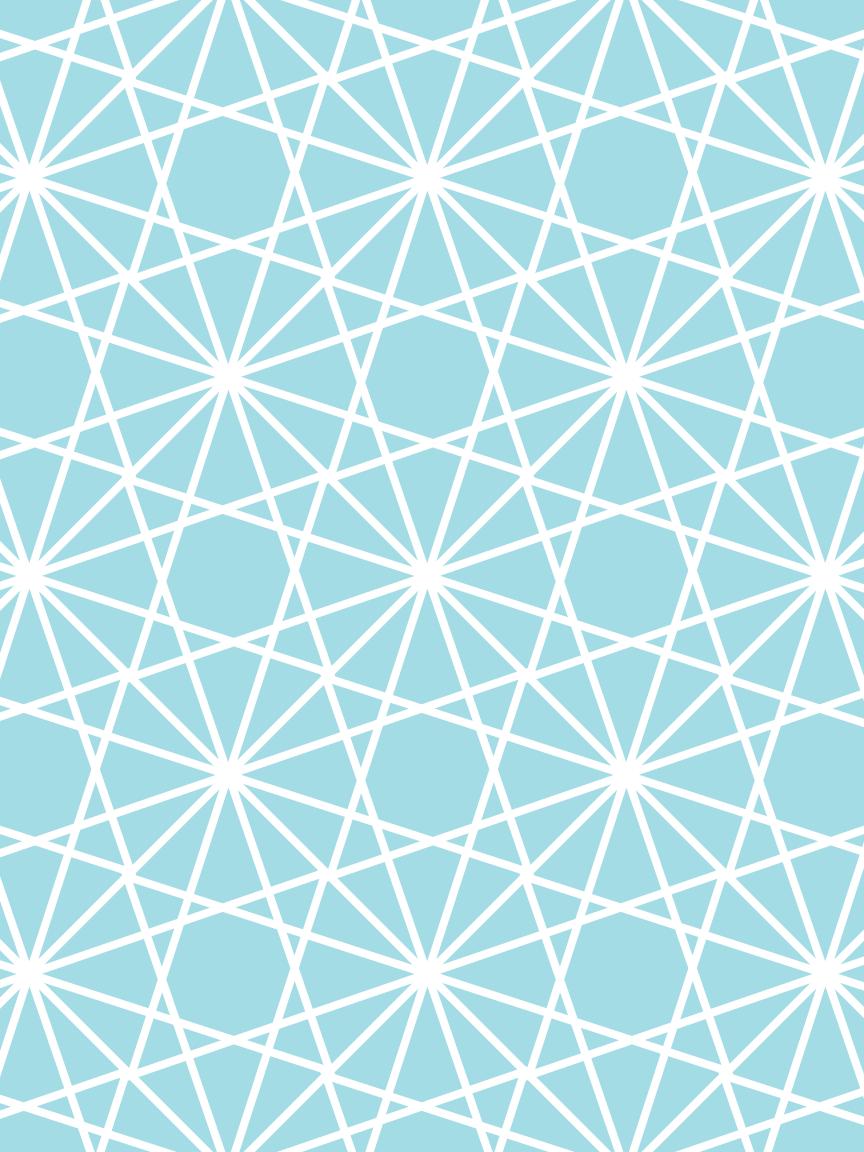
The scars from where the halo was once attached are barely visible now. And she's more determined than ever to reach her goals.

"I feel a thousand times better," she says. "I'm more comfortable moving in the water, and I can play more aggressively. Now I don't have anything holding me back." 🦫



"I feel a thousand times better. I'm more comfortable don't have anything holding me back."













Ruiz reaches into a giant file drawer and begins pulling out his supplies: colorful Sharpie pens, white out, glitter and more. In a few short minutes, he quickly creates a colorful drawing on each cast—and reaps his reward.

a child in as little as five to 10 minutes.

Then, it's time to have some fun.

"The kids just light up in smiles," he says.

An orthopaedic technician at Children's Hospital Los Angeles for the past seven years, he got the idea for the drawings three years ago, when a little boy asked him to draw a happy face on his cast.

Ruiz said no, worried he might mess up the drawing.

"Pleeease?" the boy pleaded.

He relented. Seeing how happy it made the young patient, he decided to ask other kids if they would like a drawing on their casts.

"At first I was terrible!" he says with a soft chuckle. "But the kids were nice about it. And practice makes perfect, I guess. Now I can pretty confidently draw whatever kids want."

Popular requests include Disney characters such as Minnie Mouse, or Olaf from "Frozen," superheroes like Batman and Superman, soccer balls, penguins and professional sports team logos. One patient had his Dodgers cast signed by Tommy Lasorda and Steve Garvey; another had his Lakers cast inscribed by Pau Gasol.



Ruiz says he never did any drawing before he became "the cast artist."

The artwork not only helps ease kids' fears, it also turns their cast into a conversation piece at school. Upon request, Ruiz even refurbishes the casts after removal so kids can keep them as souvenirs.

Ruiz, who has two grown children of his own, insists he never did any drawing before finding his calling as "the cast artist." And while his imaginative illustrations have brought him recognition throughout the hospital, he humbly casts the attention aside. His motivation: seeing those smiles.

"Making kids happy is the greatest feeling in the world," he says. "That's what life is all about."



Within 20 seconds, the seizure ends. Josie announces, "Done," and returns to her soup. These short-lived "focal" seizures—coming in doses of 20 to 30 a day—are among the many afflictions that have kept Josie in treatment at Children's Hospital Los Angeles for more than a decade, since being surgically separated from her conjoined twin sister, Teresa, at age 1. The story of the two Guatemalan girls born attached at the head was covered at length at the time of the procedure. Their biological parents gave both sisters over to families in Southern California, where they would have a better chance at survival. After returning home for a visit following the surgery, Teresa contracted a devastating case of meningitis. The illness left her unable to walk or talk.

Josie has been more fortunate—though only by comparison. The separation took a hunk of bone from her skull, leaving her brain vulnerable to injury. She has endured spinal fusions, hip surgery and epilepsy. Thankfully, the violent grand mal seizures that once menaced her are under control.

At 14, she has grown into a life no one predicted for her: that of a mainstream middle schooler. Little gets in her way as she rambles about on her Standing Dani, described by its manufacturer as a "mobile prone stander"; to translate, imagine a wheelchair crossed with a Segway. She attends a regular school, has regular classes, enjoys Disneyland, takes dance, and more often than not would rather be swimming. Everything she does defies what her brain scans suggest she should be doing.

"You look at her scans and don't think she'd be doing anything, frankly," says Wendy Mitchell, MD, CHLA's acting chief of Neurology, punching up pictures of Josie's brain and pointing out the deficits.

"There's no skull over here, and all of this tissue looks quite unusual. She's got a shunt here, then this big area—this cavity. All of this is missing, and this white splotch indicates areas that are abnormal."



Jenny Hull formally adopted Josie in 2006.

Mitchell turns away from the images. "She looks better than the scans—but she always has."

From curbside to bedside

Mitchell is one of several CHLA doctors Josie sees, led by Mark Urata, MD, DDS, chief of the Division of Plastic and Maxillofacial Surgery, who participated in the procedure at the University of California, Los Angeles, that separated Josie and her sister. Urata moved to Children's Hospital in 2004, and Jenny and Josie followed. He and Jenny became such friends that she sold him on the appeal of La Cañada Flintridge, her hometown. The two are now neighbors.

"I don't think there's two weeks that go by that I don't see Josie," he says, "either at my house or at some event where my kids are playing alongside her."

She also makes regular visits to his office. "The only thing she doesn't have is a layer

of bone between her scalp and brain. We've been working with 3-D technology to see if we can print a replacement for her skull."

He deflects any plaudits he and his fellow physicians receive for treating Josie. "The real special people in this story are Jenny and Josie. It's amazing the level of commitment."



Mark Urata, MD, DDS

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"You look at her scans and don't think she'd be doing anything, frankly. She looks better than the scans but she always has."

-Wendy Mitchell, MD

Her legal guardian since 2003, Jenny adopted Josie in 2006. As watchful as she is over her care and safety, she insists that Josie live like an ordinary teen, without undue compromises for her disabilities.

"I want her to live as independently as possible," Jenny says. "I want her to go to college, get married, have kids. I've never told her, 'You can't do that because ...' No. Get out there and live."

An enduring connection

Though they no longer share a blood supply, Jenny says that Josie and Teresa, who see each other regularly, have an intuitive telepathy that functions without words or proximity.

She recounts the time Josie awoke at 4:15 in the morning and lay awake the next four hours. Meanwhile, Jenny found out later, Teresa was in the hospital and in great distress.

"They thought they were losing her at 4 a.m.," she says. "At 7:55 they got her stabilized and she calmed down. Josie fell asleep at 8 o'clock. We had no idea what was going on. It was like Josie knew what was happening."

Even those who were never physically joined to Josie grow connected to her, Jenny says. "She's changed the lives of a lot of people just from her spirit."

That starts with her friends, some of whom date back to kindergarten. They all describe a social, popular girl whom they treat no differently than they do each other—nor allow anyone else to. "If they did, we would go after them," says her friend Rowan.

Several of Josie's friends help Jenny perform room makeovers for CHLA inpatients, refashioning the standard nondescript interior that Josie recalls from her own lengthy stays at the hospital. "When I was there, I just had a blank wall," she says.

Her friends also fundraise for CHLA through the Junior Ambassadors program. "They've been through so much with Josie," Jenny says. "Halo surgeries, hip surgeries, help with seizures. So they have been exposed, and through Josie it's not so scary anymore.

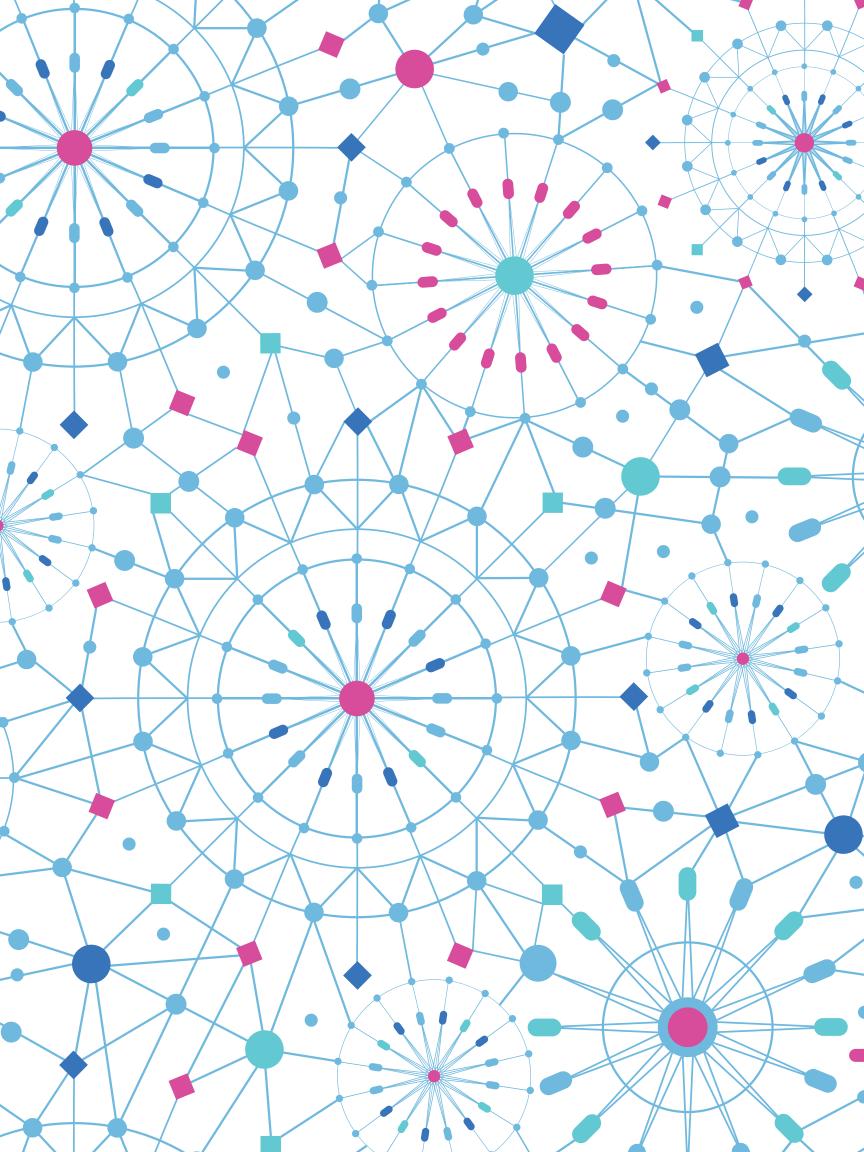
"Those kids don't flinch," she says, having just watched them hand out doughnuts at a CHLA event. "They had all kinds of kids come through, from bald to severe cerebral palsy—everything. They greet everyone with smiles on their faces and with human dignity."

Josie's friends see that her presence in their lives has opened their capacity for compassion and empathy—and gratitude. "It makes us more aware of how lucky we are to not be in a hospital," her friend Eli says. Another friend, Tara, speaks up. "Josie has made us, like ..."

As she considers how to finish the thought, a third friend, Maddie, beats her to it: "Better." 🦫



Josie and her mom with Josie's sister, Teresa, and Teresa's adoptive parents, Florie and Werner Cajas





"So my name is Clai-i-i-re," the slender woman with the regal accent says as she kneels to greet little Miley, lingering on the single syllable in that splendidly British way, as if it were topped off with a swirl.

She gasps, seeing what's in the girl's hands. "Dr. Seuss! Do you know this bench right here looks like 'Green Eggs and Ham'? Look at the color. It's exactly like the book you're reading!"

It would be fair to say that Claire Austin is rounding. Like any dutiful care provider, she is checking on the patients in her charge, who include those this morning—and every weekday morning—in the Reading Room on the sixth floor of the Marion and John E. Anderson Pavilion at Children's Hospital Los Angeles, the heart of the Literally Healing Program that Austin founded 15 years ago.

The program promotes reading for all the lasting benefits of early literacy, but also for the relief and diversion it brings to patients and their families. The gifting library, kept within the Reading Room, teems with Harry Potter, Amelia Bedelia and whatever else Austin's relationships within the business and education communities can procure. The books are given to patients for keeps at the rate of one a day—two if they read for 20 minutes that day.

All told, Austin says Literally Healing distributes more than 30,000 books a year, all of them donated and the majority hand-delivered by volunteers either in the library or the hospital lobby—or bedside. Two Bookmoobiles, with their cow-painted exteriors, are wheeled room to room, carrying books to children whose conditions require them to be isolated.

"We service every floor in the hospital, every bed, every critical care unit and 20 clinics," she says. Plus, she adds after taking in the room, "it's peaceful in here."

A reading remedy

Literally Healing's crown jewel, however, is its other half—the therapeutic library, whose collection tops 1,000 books, shelved in one room of office space, comprising what Austin believes may be the largest volume of its kind in the world. The books provide patients and families a level of solace and support that is apart from clinical therapies. They cover the spectrum of childhood disorders and confront the starkest subjects. Sample titles include "When Nothing Matters Anymore," "All About Scars" and "Tear Soup," a book about grieving.

Austin oversees, handpicks and has even contributed to the library's resources. She explains that the books put words to questions that children may harbor but can't form, drawing them out on their terms. "A child will relate to a children's book," she says. "That's their world. They're less likely to relate to a hospital leaflet."

Case in point is Gracin Kerry, a CHLA patient diagnosed with kidney cancer as a toddler. Like most small children, Gracin had to be anesthetized before undergoing an imaging scan to ensure she would stay still. So it was until she received a book from the therapeutic library called "Bowregarde's Hospital Handbook," which explains CT scans and X-rays and describes what an MRI sounds like.

"It was a book written for her and what she would be thinking," says Gracin's mother, Nikki, who says her daughter, now 11, shows no evidence of disease. "Through that book we got her to calm down. They said she was one of the youngest patients who could lie still for a CT scan without being put to sleep."

Nikki says reading with Gracin meant something else to her and her husband. "It was a chance to sit back and breathe. It brought a bit of normal into a really significant life situation."

Is it a science?

As large as the therapeutic library is, Austin is scrupulous about what she allows into it. She screens every submission, and dismisses most. "For every book that goes into this collection, I read many more that don't," she says. "If you're going to ask families to trust a new genre of resources, it has to be the best."

There's not quite a book for every ailment, or what does exist falls short of Austin's standards. "There is no really great book to help children who are frightened of shots," she offers as an example.

One aspiring author hoping to add to the library is CHLA pediatrician Tamiko Jordan, MD, who has written a book titled "The Nose on Rose."

"It's about children who have a part of their body they don't like," Jordan says. "But even though they're teased about it when they're little, it turns out to be their biggest advantage when they're older."

She got favorable feedback from Austin, who set her up with a contact in the children's book industry. "It would be amazing, right, if I published a book and then got proceeds back to her program?"



Literally Healing provides bedside readings to patients who are unable to leave their rooms.

Jordan is Austin's main ally in literacy promotion at CHLA, serving as the site medical director of Reach Out and Read, a national organization whose participating pediatricians give books to patients at checkup visits. She and Austin are looking to team up on a study of a book that Austin co-authored for children with spina bifida, "Right Under My Nose."

"Our issue is finding what question we are trying to answer," Jordan says. "Does it improve kids' understanding or acceptance of their disease? Does it help their self-esteem? Does it improve compliance with therapy? If we could prove that, we could publish the results, and other spina bifida centers may adopt it as a therapeutic intervention."

Plus, that would start Austin on her longheld wish to demonstrate scientifically what she can confirm anecdotally—that reading holds genuine, discernible benefits for ailing children. An empirical study "is long overdue," she says, though for now too big an undertaking to be doable. But she has given it thought. "I've brought it up with psychologists and mental health professionals, and we know where we would start and with what conditions."

She cites one patient with a facial deformity who would draw pictures of her family during her therapy sessions, always portraying herself with half a mouth.

After the girl's initial corrective surgery, her psychologist gave her a book from the therapeutic library called "Living Well With My Serious Illness."

Not long after, Austin says her phone rang. It was the psychologist. "She was squealing with delight: 'Guess what happened! She just drew herself with a complete mouth!'"

It was forward-looking, the shape of optimism—the shape of healing.



"For every book that goes into this collection, I read many more that don't. If you're going to ask families to trust a new genre of resources, it has to be the best."

—Claire Austin



Wearable computers have hit the mainstream, largely on the wrists of gadget enthusiasts and people who want to drop a few pounds. These consumer products are more focused on fitness than health care.

Conventional medical applications have tended toward heart monitors, used most often in adults. But that reality is changing.

"We're seeing wearable technology being introduced all over the hospital," says Jessica Rousset, director of the Center for Innovation at Children's Hospital Los Angeles, "for athome data collection of blood oxygenation, heart rate, respiration and ECGs. Clinicians are also using this technology for sleep studies, obesity intervention and psychosocial applications."

"It's fun," says Jacklyn Hana, mom to 6-yearold Isabella. "And for kids, it's all about fun. My daughter actually asks me to put it on her." But the device her daughter is requesting isn't a smartwatch or a fitness bracelet.

When she was 5, Isabella was diagnosed with Moyamoya disease, a genetic disorder that causes the walls of the carotid arteries to thicken, restricting blood flow to the brain. Diminished blood supply caused Isabella to suffer multiple strokes, resulting in loss of speech and some movement. She is now in the Margie and Robert E. Petersen Foundation Rehabilitation Center at CHLA, being cared for by Terry Sanger, MD, PhD.

A neurologist and an engineer, CHLA's Terry Sanger, MD, PhD, invents specialized devices that are fun to wear and help kids heal.



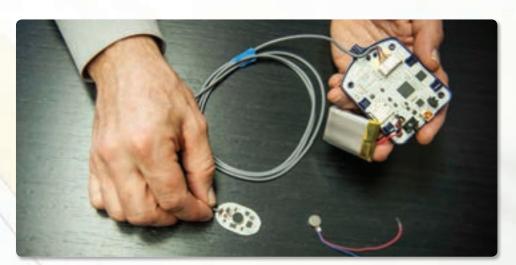
Sanger, a pediatric neurologist with a doctorate in engineering, directs the Health, Technology and Engineering program at the University of Southern California. Although he treats patients like Isabella, the majority of his time is spent in the lab inventing devices for children with movement disorders.

Isabella is currently enrolled in a clinical trial to test one of these devices—it's called surface electromyographic biofeedback, or sEMG. Electromyographic devices monitor the electrical current generated by muscle movement. This concept isn't new, but Sanger—who designed the device, the software and the algorithm—improved upon the existing technology and optimized it for kids. He also included Wi-Fi capability, enabling the data to be stored in the cloud for later analysis.

Children like Isabella who have experienced an early stroke sometimes have deficits that make moving their right arm difficult. As a result, they tend to only use their left hand. One intervention is to place a cast on the "good" hand so that the child is forced to use the other, building up muscle and strength in the weakened limb.

"The cast made Isabella uncomfortable," says her mom. "I agreed to participate in the trial because I knew she would prefer a piece of technology. It's cool."

Sanger holds up a small, blue plastic oval that vibrates like a cell phone. "Kids who've



The inner workings of Sanger's electromyographic device, which monitors the electrical current generated by muscle movement



Sanger explains the sEMG device to a patient.

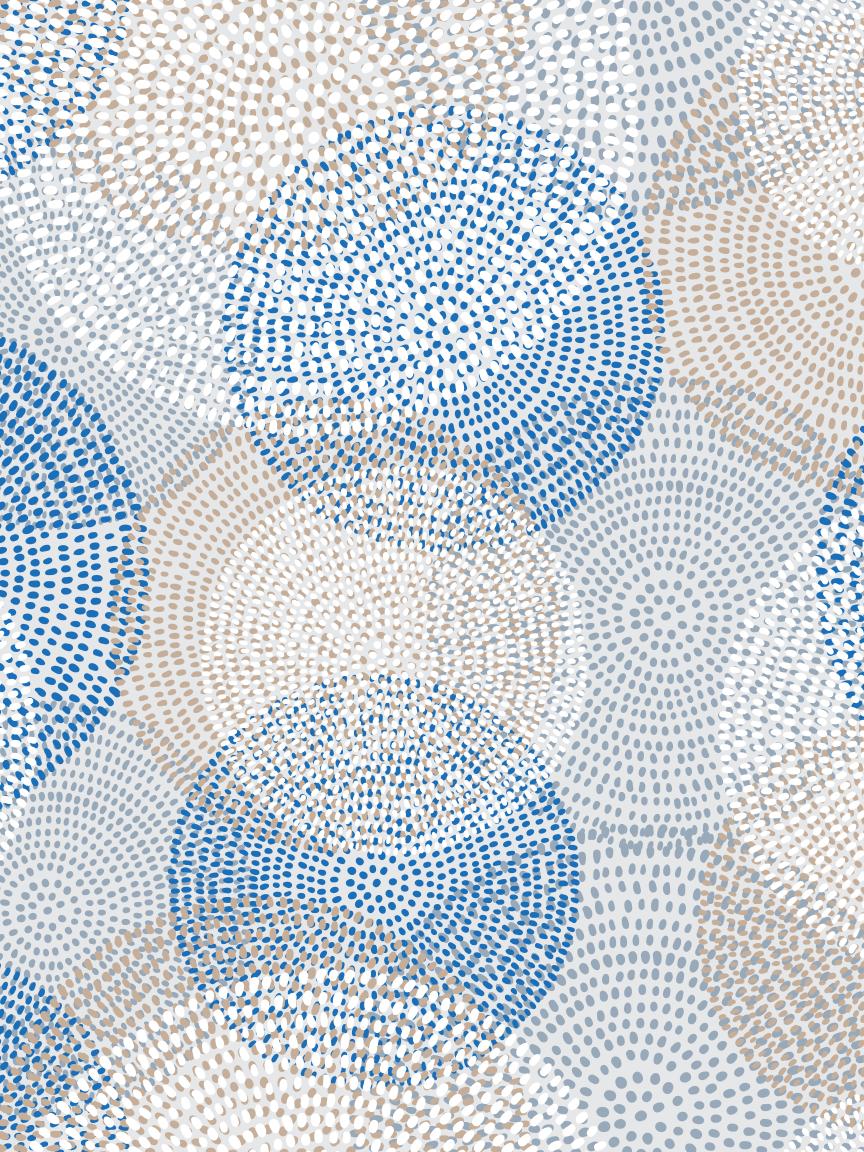
experienced early strokes may lose voluntary control of their limbs," he says. "They don't know what their muscles are doing. This device provides biofeedback. And it makes things more interesting for the child."

The "things" he's referring to are the tough and sometimes tedious exercises of rehabilitation. Take a child who can't move his wrist. Sanger and his team place the sEMG on the affected group of muscles and direct the child to "make it buzz." The device is very sensitive and can pick up muscle activity that is too weak to cause movement. Sanger tells the child, "Don't worry about raising your wrist; just make it buzz."

Kids practice all day because they like the feeling of the vibration—it's reminiscent of a cell phone or a video game. After a while, the muscle gets stronger, and they don't need the device; they're ready for physical therapy.

"The great thing is that you don't have to give kids instructions about how to use the device," he says. "You can put it on 1-yearolds, and they figure it out."

Sanger understands technology, and he understands children—and that's why he's good at putting them together.



The Dawn of Avery

After a lifetime of struggling with gender dysphoria, a teenager finds new hope—and begins a remarkable transition.

When Carolina Sanborn talks on the phone these days to her teenage son, Avery Wallace, his deep voice takes her aback.

"He calls me and says, 'Hey, Mom,'" she says, mimicking a low, male voice. She laughs. "It's amazing. He's literally transforming before our eyes."

Avery's deeper voice is just one of the changes his parents are noticing. The 16-year-old has broader shoulders, budding facial hair and bigger muscles.

But while every adolescent goes
through changes on the road to adulthood, for Avery, there's another kind of transition taking place:

Avery is transgender.



Avery at age 3 with sister Riley, 1

Gender mismatch

"Transgender" is a broad term for people whose internal sense of their gender doesn't match their birth sex. The medical diagnosis for those experiencing distress due to this incongruence is gender dysphoria. In Avery's case, it means that when he was born, his parents announced, "It's a girl!" But that was never how he felt.

"For as long as I can remember, I've felt like a boy, not a girl," the high school junior explains. "I never felt like I fit the category I was told I fit into. I've been a boy trapped in a girl's body."

From the time he was 2, Avery told his parents he wanted to be a boy. A star athlete, he played for years on a boys' Little League baseball team and insisted on wearing boyish haircuts and clothes and playing only with "boy" toys.

His parents had a simple explanation: Avery was a tomboy.

"That's what we said; that's what everyone said," says his dad, Jed. "The word 'transgender' was not on our radar."

But as middle school—and puberty—arrived, Avery's gender identity issues came to the forefront. Attending a new school, he struggled. He tried to "act girlie" to fit in, growing his hair long and wearing skirts. He was miserable.

"It was a lie," he says. "I was trying to be someone I wasn't, and that's the worst feeling you can ever have." By eighth grade, he'd spiraled into depression. He began dressing more boyish again but couldn't make friends. He lived in fear of entering the girls' bathroom, where he was regularly bullied.

One night, he told his mom he wanted to kill himself.

"I didn't know what was wrong," Avery recalls. "I felt like a mistake. ... I can only describe what I was feeling as torture."

Early intervention

No one knows how prevalent gender dysphoria is, or why it occurs, though hormones and genetics are thought to play a role. But one thing is certain: It can cause intense despair.

According to the National Center for Transgender Equality and the National Gay and Lesbian Task Force, 41 percent of transgender people under the age of 21 in the U.S. have attempted suicide at least once in their lifetime. A United Kingdom survey found that 48 percent of transyouth under 26 had tried to end their lives.

Johanna Olson, MD, medical director of the Center for Transyouth Health and Development at Children's Hospital Los Angeles, is on a mission to lower those staggering numbers.

"Treatment saves people's lives," says Olson.
"Young people just come to life. Patients have gone from being selectively mute to talking, from multiple psychiatric medications to none, and from failing out of school to college."

The rapidly growing Center, part of the Division of Adolescent and Young Adult Medicine, is the largest in the country for transgender youth. The Center promotes healthy futures for transyouth through hormonal intervention, mental health services, health education, peer support and advocacy.

The Division has been supporting transgender patients for 20 years, but in the past, it was primarily adults who underwent physical gender "transition." In recent years, medical protocols have been established for adolescents to make that transition through the use of "puberty-blocking" medications and cross-sex hormone therapy. The goal: help patients



Avery at age 5 and age 15



Avery enjoys playing guitar as well as writing.

more closely align their bodies to their internal gender identity.

Treatment is individualized for each patient, under close physician supervision. Hormonal treatment is not for everyone, Olson cautions, and cross-sex behavior doesn't necessarily indicate a child is transgender. But when kids are "consistent, persistent and insistent" about their trans-identity over time, parents need to pay attention.

"Transgender kids often experience severe distress about the dissonance between their assigned sex at birth and their experienced gender," she explains. "As they get older, that stress gets worse."

Connecting the dots

Avery initially attributed his depression to the bullying he experienced at school. His parents arranged for homeschooling, and he began seeing a therapist. Then, a few months later, he stumbled onto a YouTube documentary on transgender teen celebrity Jazz Jennings. He watched it, stunned.

"It was a real awakening," he says. "It literally connected all the dots, and I suddenly realized I wasn't alone. I said, 'That's me. I'm transgender.'"

Two nights later, he mustered up his courage to tell his dad and stepmother, and soon after, he told his mom and stepdad. To his immense relief, his parents—and all his family and friends—universally supported him.

"My first response was, 'I know,'" Jed says.
"It's emotional. I was just grateful that Avery was able to identify with his truth at such a young age."

In search of help, they found Transforming Family, a transgender parent and youth support group affiliated with CHLA, and Avery became Olson's patient.

By the fall of 2014, Avery felt ready to begin a physical transition with testosterone treatments. But there was a catch: It would mean the end of his athletic career. Then 15, Avery was being recruited by NCAA

Division I universities for a full scholarship to play women's softball. Testosterone is a performance-enhancing drug and would make him ineligible.

After a week, he'd made his decision.

"I knew that if I didn't transition, I would miss out on years of being who I really want to be," Avery explains. "And I wouldn't ever get those years back. I knew in my heart that this is what I had to do."

'It's been a miracle'

Six months into testosterone therapy, Avery is thriving.

Because his first name is gender-neutral, he decided to keep it, but he did change his middle name to Charles—honoring his mom by choosing a name that began with "C."

Although he quit softball, Avery loves writing and playing guitar and plans to apply to art schools for college. Most importantly, though, he wants to speak out as an advocate for transgender youth. His experience has been so life-changing, the word "transition" doesn't seem powerful enough. He calls it his "transcension."

"It's been a miracle to me," he says. "I'm really happy and content with myself. I become who I am more and more every day."



Avery with dad Jed, baby sister Peyton and stepmom Nicolette

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Let's take care of our community.



Children's Hospital Los Angeles is a leader in pediatric medicine, research and education, in large part because of our compassionate and generous donors. The cost of providing the finest medical care to children is immense—and the need is urgent.

Your gift will make a difference in the life of a child by providing hope for a healthy future. Through our "Live L.A. Give L.A." campaign, we are sharing stories of hope and healing to help Angelenos recognize that your local children's hospital deserves your support.

Why Support "Live L.A. Give L.A."



Focus on Children

Everything we do at CHLA is designed to help children heal. While some children's hospitals choose to focus

on one area of child health, we focus on every area. With 350 specialty programs and services just for kids, we're ready to help children recover faster.



We Treat More Kids in L.A.

We serve children and families from every corner of L.A. One in every 25 L.A. families brought their

child to us for care this year. That's 107,000 children a year—enough to fill the Staples Center six times—and demand for our care continues to grow.

"Children's Hospital Los Angeles treats more than 100,000 children every year, keeping our young Angelenos safe, healthy and happy. As a parent and as mayor, I can rest assured knowing our kids can count on CHLA for cutting-edge medical research and compassionate care—setting the standard for top-notch medicine right in our own backyard."

-los Angeles Mayor Eric Garcetti



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Families have come to us from all 50 states and as many as 25 countries to obtain the care that is

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CHLA is home to The Saban Research Institute, one of the few freestanding

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We Need Your Help

Your gift helps our hospital ensure that all of our patients receive the critical, lifesaving care they need.

Every year, our hospital provides more than \$232.6 million in community benefit to children and families of Los Angeles County and beyond, including \$4.5 million in charity care.

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Children's Hospital Los Angeles is supported by Children's Miracle Network Hospitals (CMNH) Partners, which work tirelessly throughout the year raising funds, one dollar at a time. This fiscal year, donations to CHLA by our local CMNH Partners totaled more than \$7.6 million. In celebration of their steadfast dedication to the lifesaving work performed at CHLA, these partner organizations came together in 2015 at our first-ever pep rally-style Mega Miracle Day to share best practices in fundraising on behalf of Children's Hospital Los Angeles.

Our CMNH Partner contributions of unrestricted gifts provide our hospital's leaders with the flexibility to direct funds to the areas of greatest need—and greatest benefit—supporting family-centered care, expert patient treatment, surgical excellence, research and discovery, and education and training. We extend our heartfelt gratitude to the employees, customers and leadership at the companies listed below, whose commitment to pediatric health care enables us to make great advances in the compassionate services provided at Children's Hospital Los Angeles. We deeply appreciate these generous contributors recognized in our Honor Roll of Friends.

To find out more about Children's Miracle Network Hospitals, please visit CHLA.org/CorporatePartners.

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In 1901, Children's Hospital Los Angeles was founded by a small group of caring individuals at a time when few people believed a hospital for children was possible, let alone that it could evolve into one of the world's outstanding pediatric health care facilities. More than a century later, the compassion of those founding members lives on, as support for Children's Hospital is carried from one generation to the next. The hospital's international recognition is a testament to years of dedicated efforts from faculty, staff and volunteers—as well as the individuals, organizations, corporations and foundations whose philanthropic support plays a pivotal role in our mission to create hope and build healthier futures for children.

As a pediatric academic medical center, we provide more than just the finest clinical care; we also remain at the forefront of research and training. Given the fundamental differences in the health care of kids and adults, the best place to discover and develop the safest, most effective therapies and devices for children is a hospital dedicated exclusively to their needs. As a global leader in improving treatment options, developing cures and elevating the next generation of pediatric professionals, we have seen our commitment to caring—and the impact of our donors' support—grow and extend far beyond Los Angeles.

Our extraordinary donors make all of this possible, and we are honored to acknowledge them for their generosity during fiscal year 2015. This Honor Roll recognizes donors for contributions of \$1,000 or more, as well as the full value of any active pledge commitments made in prior fiscal years. We are also proud to honor those who have contributed gifts of \$150 to \$999 on the Red Wagon Society Honor Roll of Donors, viewable at CHLA.org/HonorRoll. Additionally, we extend our gratitude to donors who directed their generosity through one of our Associate and Affiliate or allied groups.

On behalf of all the children and families whose lives you have impacted, and everyone at Children's Hospital Los Angeles, we offer our sincere thanks.

We strive to accurately recognize our donors. Please inform us of any errors or omissions by contacting Christian Nelson, assistant vice president of Stewardship and Donor Relations, at cnelson@chla.usc.edu or 323-361-1779.



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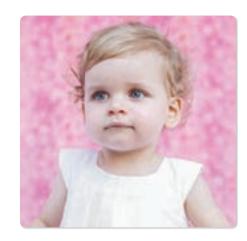
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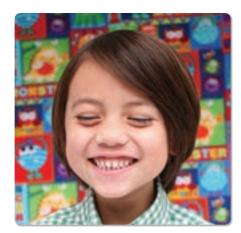
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