

Children's Hospital
LOS ANGELES



imagine

WINTER 2017

LITTLE WONDER

A team of pediatric subspecialists gave Wit Linsky a chance at life.



Also in this issue:

BREAKING FREE

CHLA's Epilepsy Program ended Courtney Wing's nightmarish world of uncontrolled seizures.

THE PHONE CALL

Mitchell Blakey is 11 years old, but his heart is only 10.

“Our challenge is to match the level of bravery and resilience of these children with our expertise, compassion and commitment to finding new and better answers for their care.”

Welcome

On behalf of everyone at Children’s Hospital Los Angeles, I am delighted to share the latest issue of Imagine magazine.

Each year, CHLA rises to the occasion of meeting the health care needs of its patients, many of whom have overcome incredible hardship related to their physical or health issues. Our challenge is to match the level of bravery and resilience of these children with our expertise, compassion and commitment to finding new and better answers for their care.

It brings us incredible joy to share the journeys of hope that humanize what the delivery of world-class medical care can do—giving an infant a new heart and the opportunity to celebrate his organ’s 10th “birthday”; giving a young woman a fuller life by ending her seizures; ushering in a Christmas miracle for a premature baby boy; and providing a level of care that drove a national conversation on health care policy following a lifesaving surgery for the son of late-night talk-show host Jimmy Kimmel.

Our patient stories are too inspiring to share just once each year. So, moving forward, Imagine will be brought to you twice a year—in the spring and fall—so that you can follow these compelling journeys with us.

A separate annual report will complement this publication and serve as a way to highlight transformative areas of community impact across every aspect of CHLA’s mission of creating hope and building healthier futures. Thank you for joining CHLA as we strive to improve the health of the precious children in Southern California and far beyond.

Please enjoy the stories in the pages ahead with my best wishes to you and your family.

Warmest regards,



A handwritten signature in white ink that reads "Paul S. Viviano". The signature is fluid and cursive.

Paul S. Viviano
President and Chief Executive Officer
Children’s Hospital Los Angeles

About Us

The mission of Children's Hospital Los Angeles is to create hope and build healthier futures. Founded in 1901, CHLA is the top-ranked children's hospital in California and among the top 10 in the nation, according to the prestigious U.S. News & World Report Honor Roll of children's hospitals for 2017-18. The hospital is home to The Saban Research Institute and is one of the few freestanding pediatric hospitals where scientific inquiry is combined with clinical care devoted exclusively to children. Children's Hospital Los Angeles is a premier teaching hospital and has been affiliated with the Keck School of Medicine of the University of Southern California since 1932.



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Closing the Gap

CHLA Welcomes Robert Shaddy, MD, as Pediatrician in Chief



Robert E. Shaddy, MD

With a distinguished career of more than 25 years, Robert E. Shaddy, MD, is nationally recognized for his research into pediatric heart failure and heart transplantation. He is an expert in the use of echocardiography and other imaging in pediatric heart patients, transplant coronary artery disease, the effectiveness of pharmaceutical drugs in treating heart failure in children, and the use of ventricular assist devices in pediatric patients.

Shaddy joined Children's Hospital Los Angeles in June as chair of the Department of Pediatrics, pediatrician in chief and senior vice president of Academic Affairs at CHLA, as well as chair of Pediatrics at the Keck School of Medicine of the University of Southern California (USC). He oversees more than 400 department faculty at the CHLA and LAC+USC Medical Center campuses, and provides oversight for faculty appointments and educational and research activities, including those performed at The Saban Research Institute of Children's Hospital Los Angeles.

"Dr. Robert Shaddy is a nationally prominent physician leader in pediatrics and is a very welcome addition to the leadership team at Children's Hospital Los Angeles," says CHLA President and Chief Executive Officer Paul S. Viviano. "Given his comprehensive contributions to research, education and clinical care in the field of pediatrics, we are confident that his extensive experience and leadership will serve the entire CHLA community extraordinarily well."

A cardiologist, Shaddy most recently served as the vice chair of the Department of Pediatrics at the Perelman School of Medicine at the University of Pennsylvania, and chief of the Division of Cardiology and the Jennifer Terker Endowed Chair in Pediatric Cardiology at Children's Hospital of Philadelphia.

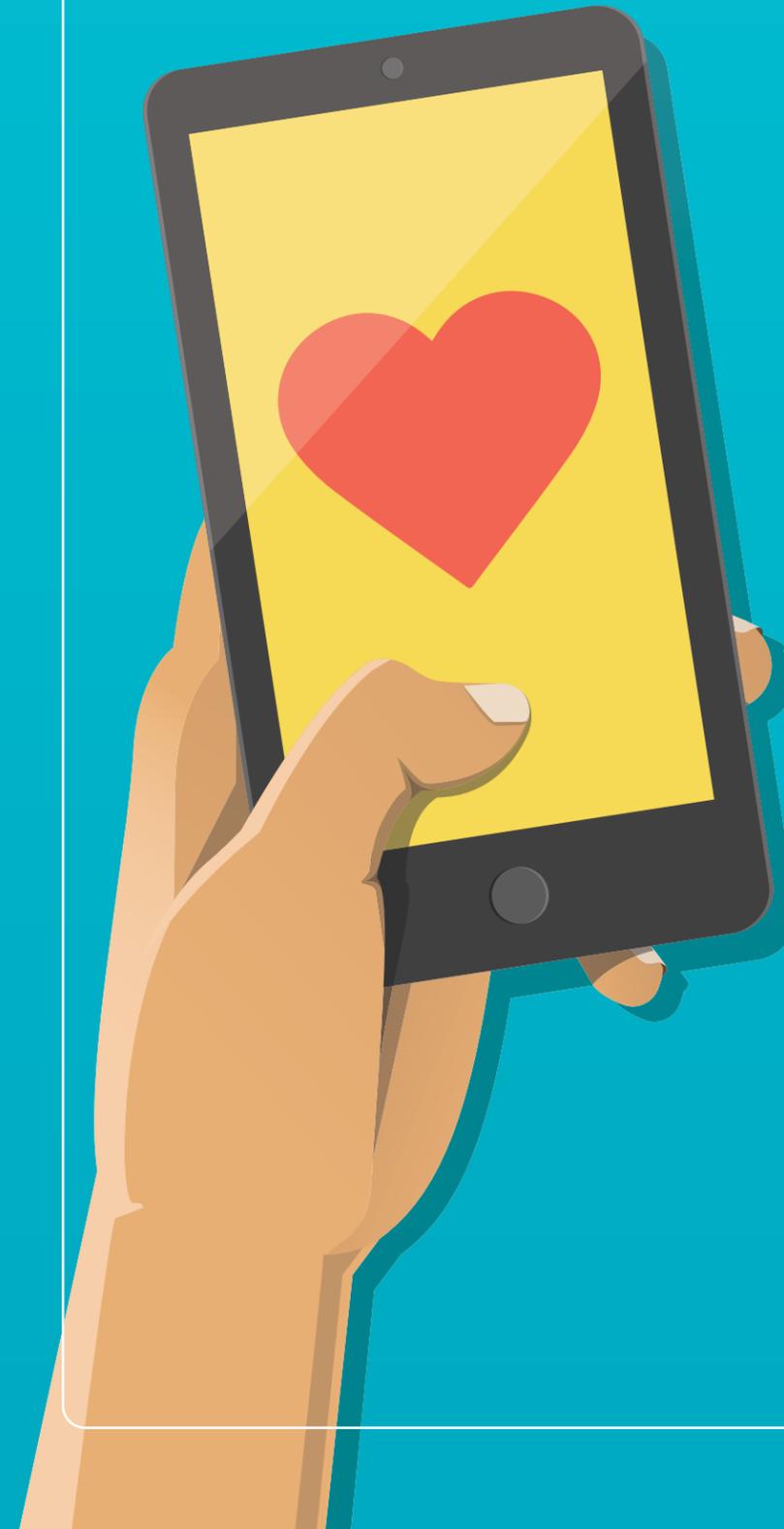
He earned a bachelor's degree in psychology from Boston College and his medical degree from Creighton University School of Medicine in Omaha, Nebraska. Shaddy completed his pediatric internship and residency at the University of Iowa Hospitals and Clinics in Iowa City, Iowa, and a fellowship in pediatric cardiology at the Cardiovascular Research Institute at the University of California, San Francisco.

He has had more than 180 articles published in journals such as *Pediatrics*, *Pediatric Cardiology*, *Pediatric Transplantation*, the *Journal of the American Medical Association*, *Circulation* and *The Journal of Thoracic and Cardiovascular Surgery*. He has authored or co-authored 21 book chapters for textbooks used by students and practicing physicians, and authored or co-authored six books about heart defects and heart failure.

Shaddy also is extensively involved in dozens of professional organizations, including the American Heart Association, the International Society for Heart and Lung Transplantation, the Society for Pediatric Research, the International Pediatric Transplant Association and the Congenital Heart Professional (CHiP) Network. 🦋

The Phone Call

By Katie Sweeney



Mitchell Blakey is 11 years old, but his heart is only 10.

Marnie Blakey doesn't remember anything about Feb. 5, 2007—anything before 10 p.m., that is. The phone call came at 10. She will always remember it, and of course, everything that followed.

Prior to that call, though, the day is a blank. Did she force herself out of bed that morning, the familiar dread and despair in her stomach, and drive from her Irvine home to the heart of Los Angeles? Did she arrive at 7 a.m. and spend the next 12 hours beside her 10-month-old son, Mitchell, watching helpless as he lay dying in his intensive care crib?

Or was it her husband, David, who went to see Mitchell that day, while she stayed home with their then-3-year-old son, Dylan? Or, with Mitchell so close to death, had they both gone to the hospital, instead of trading off like they had done for 78 straight days?

"I really don't remember," Marnie says now. After all, it didn't matter. All that mattered was the call from Children's Hospital Los Angeles at 10 p.m., and the words she heard coming from the phone:

We have an offer for a heart for Mitchell.

(continued on next page)

'Our lives changed forever'

When Mitchell was born, his parents had no idea of the heartache they'd soon be facing. He was a healthy, full-term baby, and for the first six months of his life, he was growing and developing right on schedule.



Mitchell in January 2007, while waiting for his heart in the CHLA Pediatric Intensive Care Unit

But in September 2006, everyone in the family caught a terrible cold. Marnie, David and Dylan soon recovered, but Mitchell continued to cough and wheeze.

Marnie, who is a pediatrician, didn't like the sound of it. A chest X-ray revealed that Mitchell's heart was enlarged, and after a visit to a cardiologist, the family learned the devastating diagnosis: Mitchell had dilated cardiomyopathy.

"Our lives just changed forever," Marnie remembers telling her husband.

Dilated cardiomyopathy is a condition in which the heart becomes enlarged and weakened and cannot pump blood efficiently. Mitchell's heart was severely affected and was pumping at only a small fraction of its capacity—he was in severe congestive heart failure.

When medication failed to reverse his condition, Mitchell's only hope was a heart transplant. He was airlifted from a local hospital to CHLA and admitted to the Pediatric Intensive Care Unit, where he was put on potent heart medicines and placed on the waiting list for a transplant.

The family settled in for a torturous wait—hoping a heart would be available in time. During their stay, Marnie developed a new appreciation for the nursing profession.

"I had never understood that the nurses are really the glue that holds the family together during their loved one's illness," she says. "It was the nurses who were with us day to day and helping change Mitchell's lines and giving Mitchell a bath and helping get his bottles and helping us emotionally."

Days stretched into weeks, and then months. Mitchell slowly slid backward. He stopped crawling and playing. His smile went away. Eating and breathing became difficult, and his skin turned gray and sweaty. "It was horrible," Marnie says. She pauses, then says it again: "It was horrible."

Disbelief, joy—and gratitude

When the call came about the heart for Mitchell, the Blakeys were in disbelief.

"I kept saying, 'What? What?'" Marnie recalls. "I couldn't believe what I was hearing. I just had this overwhelming sense of hope and relief that he would at least have a chance."

The next day, Feb. 6, 2007, Mitchell received his new heart. Internationally renowned pediatric cardiothoracic surgeon Vaughn Starnes, MD, co-director of the Heart Institute at CHLA, performed the surgery, and Mitchell emerged with his skin glowing pink and warm.



Vaughn Starnes, MD

"It was like one baby got wheeled in," his mom says, "and a completely different baby got wheeled out."

Three weeks later—a month before his first birthday—Mitchell went home. Since then, he's done fantastically.

"It's amazing how much we learn about strength and resilience from these young patients. Mitchell is one of those patients I've learned that from."

—Jackie Szmuszkovicz, MD



Feb. 10, 2007, just days after Mitchell's heart transplant

"He's absolutely thriving," says Jackie Szmuszkovicz, MD, a pediatric cardiologist at CHLA who has taken care of Mitchell since he was 7 months old. "It's amazing how much we learn about strength and resilience from these young patients. Mitchell is one of those patients I've learned that from."

Mitchell, 11, is now a healthy, active sixth-grader. Because he takes immune-suppressing medicines to prevent rejection of his transplanted heart, he does get sick a little more often, and he goes to CHLA for regular checkups of his heart and other organs.

Still, he lives "an almost completely normal life," his mom says. An excellent student, he is the proud holder of a third-degree black belt in taekwondo, plus he plays flag football and Little League baseball. His mom describes him as tenacious, empathic and "a little bit of a rascal."

"He loves pushing his limits and getting into trouble!" she says with a laugh.

She admits that she and David occasionally have "Mitchell moments"—moments when they worry about the future. The era of pediatric heart transplant began in earnest in the mid-1980s; immune suppression therapy has greatly improved since then, and today, the oldest survivors of infant heart transplants are in their 20s.

"When we were putting Mitchell on the list for a transplant, they told us, 'You're getting a treatment, not a cure,'" Marnie says. "Mitchell's done so well, we have every reason to believe he'll live many, many more healthy years. But there are no guarantees."

She and David think more often about the donor of Mitchell's heart. They never forget that their son's life has been made possible by the generosity of another family—who, when faced with their own tragedy, chose to give another child a chance at life.

"I think about how heart-wrenching their situation must have been," Marnie says. "The feeling is just true, pure gratitude."



Jackie Szmuszkovicz, MD, gives Mitchell a checkup.

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Mitchell is a third-degree black belt in taekwondo.

A special celebration

On Feb. 6, 2017, Mitchell and his family celebrated the 10th anniversary of his heart transplant.

Mitchell's "Heart Day" has become like a second birthday for him, and in typical 10-year-old fashion, he wanted to spend it at Universal Studios. It was a Monday, but who cared? His parents let him miss school—a rare treat—and the family spent a wonderful day at the park.

Just as they were getting ready to leave, though, they spotted one of the park characters, Curious George. They stopped in their tracks.

"When Mitchell was waiting for his transplant, his favorite thing was to watch 'Curious George' on PBS. He watched it every morning in the hospital," Marnie explains.

They took a photo with Curious George. It was a special ending to a special celebration—and yet another moment they will always remember. 🦊



Mitchell and his mom pose with an old friend on the 10th anniversary of his heart transplant.

THE HEART INSTITUTE AT CHILDREN'S HOSPITAL LOS ANGELES

ANNUALLY:



1,000
CARDIOTHORACIC
SURGERIES



11,000
CLINIC VISITS

AVERAGE 8 HEART TRANSPLANTS

HEART TRANSPLANT FAST FACTS:



230
HEART
TRANSPLANTS
TO DATE



CHLA'S FIRST
PEDIATRIC HEART
TRANSPLANT: **1993**

CHLA'S
THREE-YEAR
PEDIATRIC PATIENT
SURVIVAL RATE: **100%**



NATIONAL AVERAGE: **88.89%**

WHY WE ARE DIFFERENT

CHLA can often successfully repair a complex cardiac issue and avoid transplantation. Other centers may skip straight to a transplant instead.

Breaking Free

By Katie Sweeney

For years, Courtney Wing lived in a nightmarish world of uncontrolled seizures. Then, she found the program that could set her free.



You are sitting on the couch, ready for school, waiting for your brother. The next thing you know, you are waking up in bed. It is 5 p.m. and you are still in your school clothes. You have slept for 10 hours.

On the days you make it to school, you get massive headaches. You forget where your classes are and where you sit. You take a test on a book you've read, but you can't remember the book. Luckily, your teacher doesn't count it against you.

At home, your parents ask, "Are you OK?" You say yes. Then you wake up in bed. Often, your mom is there, watching over you. Someone is always watching you. You are 14. You wish you could be a normal person. You wish the seizures would stop.

Courtney Wing didn't always have epilepsy.



Before her illness and epilepsy, Courtney was a healthy kid who loved to swim and go dirt-bike riding with her brother, Brendan (bottom left).

For the first 10 years of her life, she was a happy and healthy kid who loved to swim and go camping and dirt-bike riding with her parents and older brother, Brendan.

But at age 10, she developed a life-threatening infection in her brain and spinal cord. Doctors don't know how she got sick, but she couldn't move her arms, hold her head up or even breathe on her own. She spent two months in a hospital to defeat the infection and several weeks in a rehabilitation facility, trying to regain her strength.

A year later, she was still weak and her right arm hung mostly useless, but she was making strides. Her parents, Jill and Troy Wing, thought the worst was behind them. They were wrong. As the family sat watching TV one night after dinner in August 2010, Courtney, then 11, had a grand mal seizure on the sofa.

Jill saw it first and started yelling for help. Brendan, then 13, ran to call 911. Troy got his daughter on the floor and turned her on her side as she convulsed, her eyes rolling back in her head.

"It lasted about 45 seconds," Troy remembers. "It was an eternity."

Over the next weeks, months and years, Courtney's seizures—electrical disturbances in the brain—kept coming. Sometimes she had grand mal ("tonic-clonic") seizures, but more often, she'd stare at the ceiling or suddenly be incoherent. Other times, she'd start twitching or shaking. Many mornings, she'd wake up exhausted—she'd had tiny seizures in her sleep.

The Wings—who live in Nipomo, a small town near the central California coast—took Courtney to the only pediatric neurologist in their area. But after trying multiple medications, Courtney was still having seizures—sometimes daily. Her neurologist sent her to a Los Angeles-area medical center, but doctors there said they couldn't help her.

(continued on next page)

"It was depressing. It was difficult to see how she was going to have a productive life," Jill says. "And the seizures affected the whole family. How many days on end can you sit with someone having seizures and not lose your mind for them?"

Courtney, meanwhile, did her best to keep up with school and participated in a local 4H program, raising chickens, turkeys and lambs. But she, too, was frustrated.

"Social life was very hard," she says. "I needed to be watched all the time. I thought, maybe I'm never going to be able to be alone. Maybe I'm never going to be able to drive. Maybe there's nothing that anyone can do."

Pinpointing 'bad brain'

In May 2014, near the end of Courtney's freshman year in high school, the family made another trip to L.A.—this time to visit the Epilepsy Program at Children's Hospital Los Angeles.

The Epilepsy Program's comprehensive team of experts and state-of-the-art technological capabilities has earned Level 4 certification by the National Association of Epilepsy Centers—the highest level possible.



Courtney undergoing invasive monitoring at CHLA

Because every epilepsy patient is unique, the program's expert interdisciplinary team offers a full range of highly specialized treatment options. Her doctor thought Courtney could be a candidate for one of those treatments—epilepsy surgery, which involves removing the precise portion of brain that's causing seizures.

After surgery, CHLA achieves seizure-free rates as high as 89 percent—the patients are often cured.

"The ultimate challenge of epilepsy surgery is to remove only that portion of brain that is diseased and causing seizures while sparing all other essential tissue," says Douglas Nordli Jr., MD, co-director of the Neurological Institute and head of the Division of Neurology. "Fortunately, with modern technology, a very experienced team of neurological professionals and excellent neurosurgeons, this is an everyday occurrence at CHLA."



Douglas Nordli Jr., MD

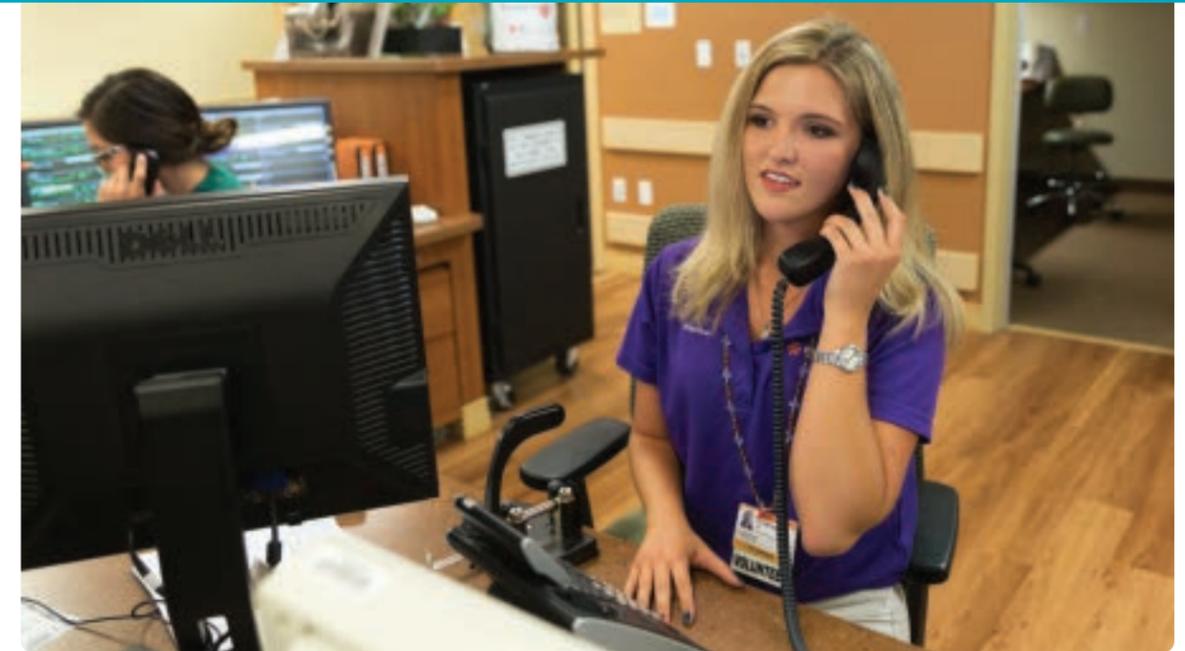
First, though, Courtney had to undergo a litany of tests to pinpoint exactly where that "bad brain" was located. The advanced testing included a stay in the hospital's state-of-the-art Epilepsy Monitoring Unit (EMU), where the team placed electrodes on Courtney's head and did video and EEG monitoring of her seizures.

After additional testing, the team identified the culprit: a 1.5-inch piece of damaged tissue on the right side of her brain, away from critical language and speech functions. The piece was too big to be removed through a less-invasive laser ablation procedure, but Courtney was an excellent candidate for a "two-stage surgery."

In the first stage, called invasive monitoring, neurosurgeons opened Courtney's skull and placed EEG electrodes directly on her brain. For the next week, the team carefully monitored her seizures and normal brain activity in the EMU.

"I'm free! Now there's nothing holding me back."

—Courtney Wing



Courtney volunteers at a local hospital, in pursuit of her goal to become a nurse.

"The invasive electrodes enable us to more precisely map the seizures and normal brain function," explains Aaron Robison, MD, attending neurosurgeon at CHLA. "We're viewing the actual electrical waves of the brain."

On April 6, 2015—two weeks before her 16th birthday—Courtney went back into the operating room, where surgeons meticulously extracted that troublesome bit of brain. Two days later, she went home. At first, she felt the same: exhausted. But something was definitely different.

Her seizures were gone.

A new life

That fall, Courtney went to school full-time for her junior year of high school. It was, she says, "the best year ever."

With her memory issues resolved, her grades shot up to straight A's. She went to every school dance, made

new friends and learned to ski. Courtney even—to her amazement—got her driver's license.

"She was hungry for everything she'd missed," says her dad. "She still is. She's really focused on her goals."

One of those goals is to become a nurse. Now 18, she recently started community college and volunteers at a local hospital. She's also returned to swimming—one of her childhood passions—and plays tennis with her dad and is active in her church. Because of her long-ago spinal cord infection, Courtney only has 50 percent use of her right arm, but CHLA is helping her explore possible treatments for that.

She hasn't had a seizure since her surgery. She is considered cured.

"I'm free!" she declares happily. "Now there's nothing holding me back." 🦋

Little Wonder

By Marla Lehner

Once upon a time, a team of pediatric subspecialists gave a baby a chance at life.

Perfect. That was the word LeAnna Linsky's doctors used throughout her pregnancy. She had a "perfect" placenta and a "perfect" baby, they all said. So, on Nov. 4, 2015, knowing that she and her unborn child were perfectly healthy, LeAnna boarded a red-eye to Atlanta to attend a family funeral. Midway through the flight, at 30,000 feet and still an hour from her destination, LeAnna started bleeding—heavily.

"My doctor had said that if I ever had any bleeding, I should not be alarmed unless it was bright-red blood. And it was bright-red blood," LeAnna, who was 29 weeks pregnant at the time, recalls.



Luckily, two medical professionals were on her flight: a longtime obstetrics nurse and a pediatrician. For the next hour, they monitored LeAnna's vitals, administered oxygen and kept her calm. On the ground, she was taken to a regional medical center, where doctors determined that she and the baby were stable. But later that morning, "things went south," says LeAnna. "I started having horrific pain. It felt like I was going to break in half, and then I just felt the blood gush."

LeAnna had suffered a placental abruption, when the placenta separates from the uterus. She was rushed to the operating room, where doctors performed an emergency C-section to deliver William Theodore Linsky. LeAnna's husband, Sam, was on a flight to Atlanta knowing only that his wife was in distress. When he landed, he learned he was the father of a 2-pound, 13-ounce boy.

"Wit," as the Linskys call their son, was stable for 48 hours, but then one of his lungs collapsed. He was transferred to a nearby pediatric hospital, where he stayed for nearly two months. Once Wit was stable enough to travel, the doctors in Atlanta contacted Children's Hospital Los Angeles and arranged to have him transferred so that LeAnna and Sam could finally take their son home to L.A.

Hanging in the balance

Two days before Christmas, Wit was admitted to the Steven & Alexandra Cohen Foundation Newborn and Infant Critical Care Unit (NICCU) at CHLA, which



Wit spent five months receiving multidisciplinary care at CHLA.

cares for the most fragile infants, like Wit. The next morning, Wit's heart rate and oxygen saturation began to drop—and his nurse discovered blood in his diaper, an early sign of necrotizing enterocolitis (NEC), a life-threatening condition. NEC, which mostly affects premature babies, causes portions of the gut to become infected and die.

The NICCU medical team mobilized to evaluate Wit's condition and initiate treatment. X-rays revealed that Wit was in the early stages of NEC, and he was put on antibiotics in hopes of knocking out the infection.

"Some patients with NEC get better with antibiotics and some don't, so we monitor them very closely and at very short intervals," says Christopher Gayer, MD, PhD, from the Division of Pediatric Surgery, who was the surgeon on call that morning and was part of Wit's care team. "If the disease progresses, you'll see 'free air,' which is air outside of the intestine, on an X-ray."

It's impossible to predict which children will respond to treatment; however, CHLA is one of the best-equipped hospitals to treat babies with NEC. Henri Ford, MD, MHA, FACS, FAAP, vice president and chief of Surgery, conducts leading-edge NEC research, and the neonatologists and surgeons in the NICCU have extensive experience treating babies with this devastating condition.



Henri Ford, MD, MHA, FACS, FAAP, vice president and chief of Surgery

That night, Christmas Eve, LeAnna and Sam curled up on the pullout in Wit's hospital room to sleep. At 1 a.m., they were awakened by alarms—Wit's condition was rapidly deteriorating. Suddenly their room was filled with doctors and nurses. "I have never seen anything like it," says LeAnna. "The professionalism was amazing and everything was so choreographed."

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“We bring together neonatologists, surgeons, gastroenterologists, occupational therapists, dietitians, pharmacists and more to optimize a child’s recovery.”

—Philippe Friedlich, MD, MSEpi, MBA, chief of the Division of Neonatology and co-director of the Fetal and Neonatal Institute



Rachel Chapman, MD, medical director of the NICCU

“The NICCU is staffed with a Board-certified neonatologist 24 hours a day, 365 days a year, so the team immediately responded to Wit’s worsening status and made an evaluation to determine the next best steps,” says Rachel Chapman, MD, medical director of the NICCU.

An X-ray revealed free air outside Wit’s bowel, an indication that the bowel had perforated, so the team prepared him for surgery. CHLA’s NICCU is uniquely designed to be able to turn any patient room into an operating suite in an emergency, saving precious minutes and avoiding the need to move tiny, fragile infants.

Within an hour, Gayer had begun operating on Wit, whose bowel had indeed perforated in two places. During the two-hour procedure, Gayer removed approximately two-thirds of Wit’s colon and 15 centimeters of his small intestine.

‘A Christmas miracle’

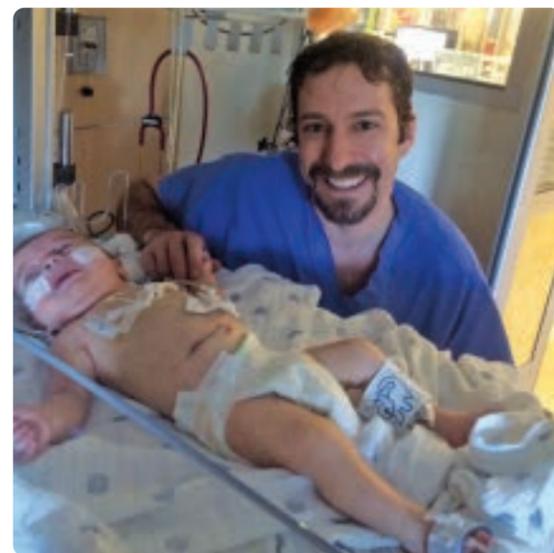
LeAnna and Sam feared their son would not survive, but when Gayer stepped out of the room, he was smiling. “He told us, ‘I can’t explain it, but when I operated on Wit, I found pink, healthy tissue. We’re going to call this a Christmas miracle,’” LeAnna says.

For the next several months in the NICCU, Wit slowly healed. He was seen by specialists from Neurology

and Pulmonology, and received occupational therapy to help prepare him to begin eating once his intestine was repaired. In February 2016, he underwent surgery to have his intestines and colon reconnected. He also benefited from CHLA’s holistic care, including massage and music therapy.

“CHLA has a unique care model in which we engage a wide spectrum of clinicians early on so that infants like Wit who have complex needs can have the best possible outcomes,” says Philippe Friedlich, MD, MSEpi, MBA, chief of the Division of Neonatology and co-director of the Fetal and Neonatal Institute.

“We bring together neonatologists, surgeons, gastroenterologists, occupational therapists, dietitians, pharmacists and more to optimize a child’s recovery.”



Christopher Gayer, MD, PhD, performed Wit’s lifesaving surgery on Christmas Day.



Wit shares a story with his dog, AnnaBelle.



Russell Merritt, MD, PhD

At the end of March 2016, Gayer inserted a gastrostomy tube (G-tube) used for supplementing feeding. After that, Wit spent a month receiving intestinal rehabilitation from the Division of Gastroenterology,

Hepatology and Nutrition’s Russell Merritt, MD, PhD, and the Intestinal Rehabilitation team, including doctors, nurses, a social worker and an occupational therapist who helped wean Wit off IV nutrition. Before they took their son home, LeAnna and Sam took a G-tube class at CHLA’s Family Resource Center to learn how to care for Wit. He was discharged on May 25, 2016.

Today, Wit is happy and doing well, says his mom. He receives occupational, physical and speech therapy, and undergoes child development assessments. He’s eating solid foods, walking and starting to talk—“Dada” is his favorite word.



LeAnna and Wit Linsky

“There’s a level of care at CHLA that I haven’t seen anywhere else,” says LeAnna. “It’s not just the medical aspect of the care. It’s the humanity that makes CHLA special. I didn’t feel like they were just clinicians. It felt like they were part of ‘Team Wit’ and they were rooting for him as much as we were, and that we were all in it together.” 🌈

Turn the page to learn more about CHLA’s NICCU.

THE STEVEN & ALEXANDRA COHEN FOUNDATION NEWBORN AND INFANT CRITICAL CARE UNIT

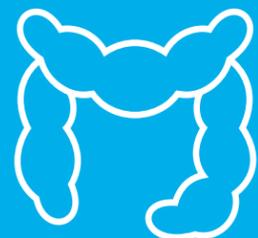
ANNUALLY:



MORE
THAN **650**
BABIES TREATED

OVER 300 
OPERATIONS PERFORMED

ROUGHLY 1/3
OF BABIES
ADMITTED
TO THE NICCU REQUIRE
AT LEAST ONE
SURGICAL PROCEDURE



ABOUT
50%

ARE FOR ABDOMINAL
AND GI SURGERY



DID YOU KNOW?

CHLA cares for **30 babies with necrotizing enterocolitis each year.**
Most are sent to CHLA from referring hospitals after diagnosis.

All of CHLA's **14 pediatric surgeons** are trained to perform NEC surgery.

One Father,
One Talk Show,
One National
Conversation on
Health Care

By Sarah Brown

*Jimmy Kimmel shared his
family's story—and the
nation listened.*



(continued on next page)

The Heart Institute at Children’s Hospital Los Angeles is the top-ranked pediatric heart center on the West Coast, according to the prestigious U.S. News & World Report Honor Roll of children’s hospitals. Each year, the Institute performs nearly 1,000 heart surgeries and provides the very best care for every child—whether or not a child’s father is famous.

Billy Kimmel is one of those children. The son of late-night talk-show host Jimmy Kimmel and his wife, Molly McNearney (co-head writer of “Jimmy Kimmel Live!”), Billy was rushed to CHLA shortly after birth with a life-threatening heart defect called tetralogy of Fallot. Like all parents faced with this situation, Kimmel and McNearney were scared. But they quickly realized their son was in the very best hands. Indeed, Billy’s successful surgery—the first of three that will be needed to correct the defect—was all in a day’s work for the surgeons, nurses and other caregivers at the Heart Institute.

“Six days after open-heart surgery, we got to bring him home,” said Kimmel during his first monologue back on the show.

But Billy’s story was about to get much bigger. His lifesaving surgery happened just as a health care debate was consuming the nation’s political discourse. Kimmel saw a unique opportunity, and used his return to the show to appeal to lawmakers and the American people, in 13 minutes that ran the emotional gamut.



Billy Kimmel on April 30, 2017, the day he came home from Children’s Hospital Los Angeles



McNearney shared this heartwarming photo of father and son on Instagram.

“Before 2014, if you were born with congenital heart disease like my son was, there was a good chance you’d never be able to get health insurance, because you had a pre-existing condition,” he noted. “If your parents didn’t have medical insurance, you might not even live long enough to get denied because of a pre-existing condition.” Kimmel’s impassioned plea went viral; in addition to reaching his regular audience of around 2 million viewers a night, the clip was viewed more than 11.5 million times on YouTube and picked up by nearly 1,900 other media outlets.

And just like that, the national conversation shifted. Kimmel brought the potential effects of the health care bill into people’s living rooms, and summed it up deftly: “No parent should ever have to decide if they can afford to save their child’s life.”

CHLA had already been mobilizing physicians, nurses, Trustees and supporters to #KeepKidsCovered,

“No parent should ever have to decide if they can afford to save their child’s life.”

—Jimmy Kimmel



The Kimmel family, after baby Billy was able to come home following his first successful heart surgery at CHLA



Billy Kimmel at 6 months of age

and the hospital’s newfound visibility as a result of Kimmel’s monologue put CHLA front and center in the national conversation about health care coverage.

“This is about the broader issue of preserving compassionate, high-quality care for all children,” said CHLA President and CEO Paul S. Viviano in an op-ed piece on TheHill.com. Viviano reinforced that message in a piece on CNN.com: “We believe children are entitled to health care provisions to protect pediatric-specific benefits providing medically necessary care determined by a child’s physician.”

To date, the fight to maintain health care coverage beneficial to children, families and the community at large has succeeded. If changes to the Affordable Care Act do pass, CHLA urges protection of Medicaid programs, on which many children with complex

health needs depend—and nearly 50 percent of newborns in the United States as well. Every time a bill has begun to work its way through Congress toward a vote, CHLA has mobilized with the message that children and families should be protected. And so has Jimmy Kimmel—admirably using his platform to help sustain health care for children and families.

Thank you, Jimmy. 🌈

Jimmy Kimmel’s quotes were excerpted from his original monologue on May 1, 2017. To view the clip in its entirety, visit [CHLA.org/SeeWhatJimmyShared](https://www.chla.org/SeeWhatJimmyShared).

A portrait of William Magee, a man with short brown hair, wearing a blue suit jacket, a light blue striped shirt, and a blue patterned tie. He is smiling slightly and looking towards the camera. The background is a light-colored wall with several framed pictures, including a large one on the left showing a group of people.

Closing the Gap

By Jeff Weinstock

Plastic surgeon William Magee is dedicated to repairing the cleft lips and palates of children near and far, while working to reduce surgical disparity in developing nations.

William Magee's personal narrative certainly doesn't need any enhancing agents, yet he does help it along by delivering it in his native Virginia drawl that sounds so much like an amped-up version of Matthew McConaughey.

"My life in surgery began with that photograph right there," he starts, punching up *that* with a finger point at the wall across from his desk. The framed, grim image of a small Kenyan boy stares back, his face largely dissolved by burns.

But before Magee, MD, DDS, a surgeon in the Division of Plastic and Maxillofacial Surgery at Children's Hospital Los Angeles, can provide the photo's history, he detours into his own, promising to circle back. "I'm going to get to that picture," he says.

He begins at age 12, in 1982, when everything changed—when his father, a pediatric plastic surgeon in Norfolk, Virginia, and mother, a nurse, traveled with a small team to the Philippines to operate on local children born with cleft lip and cleft palate. They had the capacity to serve 50 kids when 200 showed up.

Magee says his parents had no idea about the extent of the problem they had walked into. "They were under the assumption that those 150 who got turned away were the only 150 who needed help."

They returned home, formed Operation Smile, staffed up, fundraised, and then made a second trip to the Philippines to take care of the overflow from the previous visit—and found another 500 kids waiting for them. "It occurred to them that something much bigger was out there," Magee says.

Soon they were barnstorming on surgical missions to impoverished populations—in Vietnam, Mexico, Honduras. After an invitation from Mother Teresa prompted a trip to India, "the top came off," Magee says. Over the next three decades-plus, Operation Smile would repair the facial deformities of children in more than 60 countries.

In those early years, Magee was in the middle of it, breaking off from school to travel with his parents. His adolescence became a series of intense experiences. He describes a mission to the Middle East to support cooperation between Israelis and Palestinians. The nightly drive back from the hospital would stop at a checkpoint: "The soldiers would tap the window with machine guns and make us open the doors. Here my whole day had already been emotional, with all these kids and their families, and people working together. I would lie under the stars at the United Nations complex trying to understand what I was participating in."

The next recollection winds him back to Africa, walking with his father through a burn ward in Nairobi. What looked like 50 kids pushed forward to peek at them. "All you could see was the glare of the kids' eyes as you were walking down the hallway," Magee says.

"As I got older and tried to think of what I wanted to do, that moment never left me. I could never figure out something that moved me to the same degree. I was never able to find a moment, and I traveled all over the world."

The experience is preserved in the gaze of the small boy on the wall. "It's the reason I'm doing this work."

At CHLA, Magee has one of the world's leading cleft lip and palate practices. As his division's director of International Programs, he remains close to Operation Smile, traveling at his own expense on two or three surgical missions a year. He also helps design training programs for surgeons in those developing countries. He says he's building new "surgical ecosystems across the world," to make ground against the dearth of surgical care in lower-income nations.

That effort serves the home base, too. Magee sends CHLA plastic surgery residents on Operation Smile missions, enlarging their worldview along with their skills. "That's part of our curriculum," he says, "professionalism, cultural competencies."

(continued on next page)

Whether in clinic or abroad, Magee says he meets with the same question from parents of children with clefts: *Why did this happen?*

He grew tired of the imprecise answer he had always given them—some combination of genetics and environment. “At some point I said, ‘Well, why does it happen?’”

To find out, Magee launched the International Family Study, gathering the resources of his program, Operation Smile and the University of Southern California, where he is an associate professor in the Department of Surgery. The study is exploring close to 14,000 DNA samples drawn from families affected by the deformity to get at the cause of clefts. Magee credits the fellows, students and aides who comprise his staff for carrying off a project of such size; all embrace his adherence to teamwork, which he took from his upbringing.

“I’m from a big family, one of five kids,” he says. “My father’s one of 12. Fifty-five first cousins. Everything was about people.”

He’s hopeful the study can produce a cure, finding an encouraging, analogous case history in spina bifida, which is essentially a congenital cleft—a failure of

the bones of the spinal column to fuse together in utero. The risk of spina bifida is cut 70 percent by consuming folic acid during pregnancy, a treatment arrived at through the same sort of sophisticated science being applied to clefts.

“There’s a high likelihood that someday,” Magee says, “in the right lab with the right tools, people will understand clefts to the degree that many of them will be cured.”

The International Family Study was the first of several initiatives he has undertaken. A second study, *Global Barriers to Cleft Care*, confronts surgical disparity, surveying families in developing nations to find what keeps them from receiving treatment for clefts, beyond the easy assumptions of poverty and distance.

“Maybe there are philosophical and spiritual issues that we’re unaware of,” Magee says. “Maybe there are political limitations.”

One of the more compelling barriers has turned out to be internal bias. The study has found that people in these low-income countries avoid their local practitioners because they have more trust in philanthropic organizations such as Operation Smile. The irony, Magee explains, is that Operation

“I’m from a big family, one of five kids. My father’s one of 12. Fifty-five first cousins. Everything was about people.”

—William Magee, MD, DDS

Smile draws more than 90 percent of its medical personnel from the host community, yet residents figure the professionals are all imports from the U.S. and Europe. The remedy, he says, is “to teach the community about how talented their own health care workers are.”

Another evolving project is the *Cleft Severity Study*, which addresses a key omission in cleft care. Clefts come in many variations, but are sorted into only two: complete or incomplete—meaning the lip or palate is either cleaved all the way through or just partially—and unilateral or bilateral, designating whether the cleft occurs on one or both sides of the mouth.

Magee says the idea for creating a new classification for clefts—a severity index—was triggered by the extreme deformity of a child he treated in Guadalajara. The diagnosis inscribed in the patient file, bilateral cleft lip, did little to indicate the difficulty of the case.

“There should be some annotation underneath, like ‘Challenging!’” he says, so reasonable expectations for the results can be set. “It should be quantified.”

To rectify this, Magee solicited facial-recognition software developers to devise an app that could score the outcome of a cleft repair by comparing the severity of the original presentation against the cleft’s post-surgical appearance. It’s still in development, but Magee foresees a day when families choose a surgeon based on those performance scores.

“Our work is visual,” he says. “How do we know that the young surgeons we’re training across the world are doing a good job? We need to capture before-and-afters and then grade the work.”

His photo albums are a monument to severity. He swipes through one jarring image after another, faces



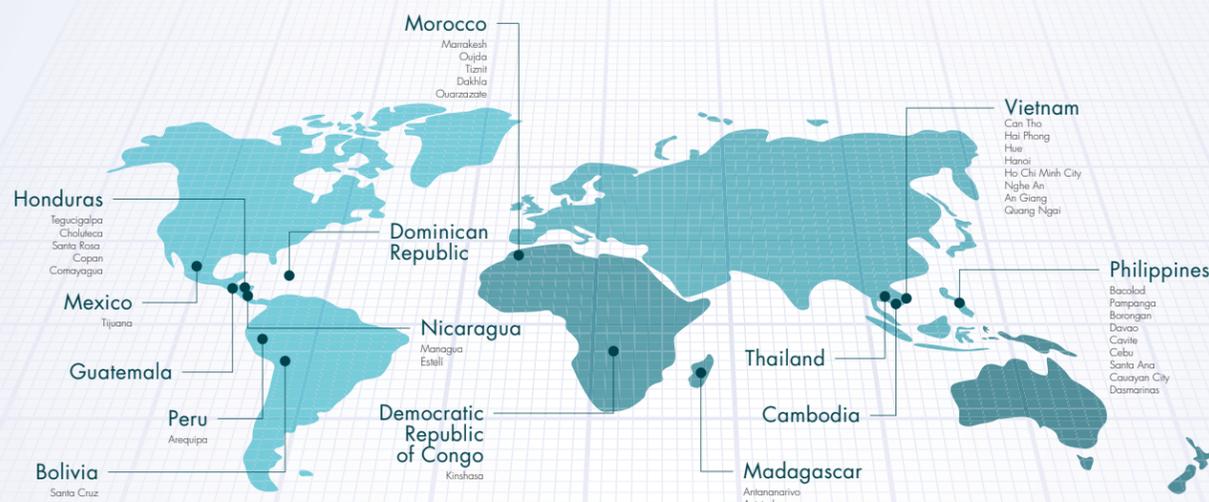
Magee checks the results of the reconstructive work he performed on patient Azariyah McLean.

split by clefts of every degree. The after shots follow, displaying how Magee’s handiwork sewed them whole. He stops on one particularly vivid deformity, a little Egyptian girl whose cleft had in effect created a duplicate face and jaw.

“Two maxillas and mandibles here,” he says, tracing with his finger. “Resect the redundant maxilla and mandible and bring the face back together again.” He adds before swiping, “That was a pretty wild case.”

The narrative continues and at one point he recalls a time in college when a prominent, wealthy East Coast figure was sizing him up for a job. He asked Magee what motivated him and Magee gave the wrong answer. “I said, ‘I’m someone who’s just moved by helping people.’”

The reply grabs in his throat, which seems to surprise him. “Now I’m telling you sappy stories,” he says. Like that one about the 47-year-old plastic surgeon who searched the world for a moment, and when he found it, hung it on his wall so all the motivation he would need was only a glance away. 🦋



Children across Southern California and around the world who have craniofacial deformities rely on the care of specialists in CHLA’s renowned Division of Plastic and Maxillofacial Surgery, who also take their expertise to underserved areas of the globe.



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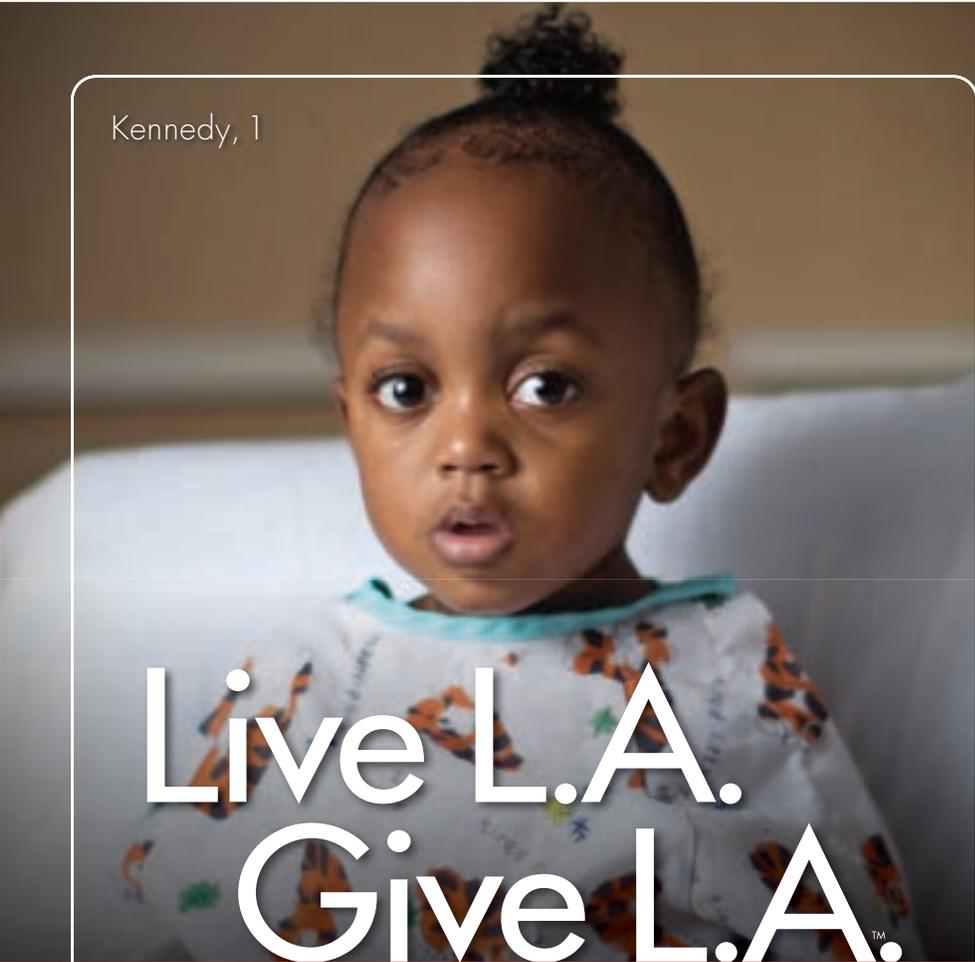
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