

Children's Hospital
LOS ANGELES®



imagine

WINTER 2016

THE UNSTOPPABLE FIONA ASHE

A prosthetic leg can't keep this 5-year-old dynamo down.

A LEAP OF SCIENCE

Clinical trials offer promise in one girl's fight against leukemia.

SOUL SUPPORT

Spiritual Care Services gives comfort to patients, families and staff of all cultures and faiths.

FULL SPEED AHEAD

Twins with two different heart defects give back to CHLA.

A PERFECT LANDING

An email to the wrong hospital turned one teen's life around.

DOMSTRONG

A boy with a difficult-to-diagnose cancer finds the strength to help others.



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 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 2016-17.

The Saban Research Institute comprises the basic, translational and clinical research of Children's Hospital Los Angeles, one of the few freestanding pediatric hospitals where scientific inquiry is combined with clinical care devoted exclusively to children. The Institute is an academic member of the Los Angeles Basin 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 the University of Southern California since 1932.



Welcome



In the little over a year that I have served as President and Chief Executive Officer of Children's Hospital Los Angeles, my collective experiences have resulted in a powerful conclusion: The children entrusted to CHLA each year are treated with unparalleled clinical expertise, compassion and family-centered care.

Each of us who works here is fortunate to support the medical needs of all children under CHLA's care, and this commitment benefits from our own academic training programs—through which clinicians who ultimately practice across the nation learn how to deliver care from the very best. Our institution is recognized as a pacesetter in clinical care and translational research, thanks to the scientific breakthroughs achieved in The Saban Research Institute, where the discovery of new treatments and cures is our continual charge.

In this time of industry change, organizations are looking to CHLA for guidance due to our widely recognized expertise, reputation and willingness to lead. The stories in this issue of *Imagine*, our award-winning annual report, demonstrate the life-changing care that places CHLA at the forefront as a high-performing pediatric academic medical center.

You'll read of twins born with different life-threatening heart disorders who both are thriving under the care of CHLA's Heart Institute; a young woman with an incapacitating neurological condition who saw her symptoms reverse for the first time when luck brought her to CHLA; and a boy with a tumor so complex that experts from across the country were unsure where to begin until CHLA developed a carefully coordinated plan of care.

You will also read about Spiritual Care Services, a program that is emblematic of our commitment to extend care beyond the bedside and to families of all faiths. With the opening of the new Thomas and Dorothy Leavey Foundation Interfaith Center, CHLA can now augment the solace it offers to families in the most trying of times.

Every day at CHLA we celebrate the heroism of our patients, families and medical professionals who partner together and work through harrowing health challenges. It's what has underscored the more than 115 years that we have spent delivering on our promise to care for children with expertise and compassion, and it is how we signal to our community that we will continue to create hope and build healthier futures well into the 21st century and beyond.

I am thrilled and deeply honored to be part of this institution and its mission; please join us by donating, by volunteering, by sharing our message on social media, and by telling your friends about us in any way you can.

Thank you for supporting the health of children in Southern California and from around the globe.

Warmest regards,

A handwritten signature in black ink that reads "Paul S. Viviano". The signature is fluid and cursive, with a double dot over the 'i' in Viviano.

Paul S. Viviano
President and Chief Executive Officer





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Year in Review



For the eighth consecutive year, Children's Hospital Los Angeles ranks in the top 10 nationally on U.S. News & World Report's prestigious Best Children's Hospitals Honor Roll, and as the top pediatric medical center in California.



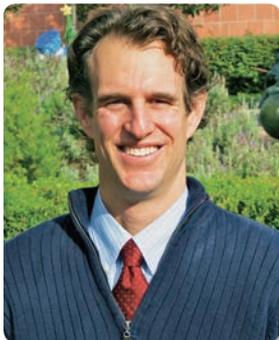
In recognition of his success in health care leadership, CHLA President and CEO Paul S. Viviano was named the 2016 Leader of Today Honoree by the Health Policy and Management Alumni Association of the University of California, Los Angeles Fielding School of Public Health. Viviano was also the recipient of the National Medical Fellowships' Los Angeles Champions of Health Award for Leadership in Healthcare. In June he was named chair of Loyola Marymount University's Board of Trustees.



CHLA was chosen as one of the "100 Great Hospitals in America" by Becker's Hospital Review. CHLA was the only freestanding children's hospital in California named to the list, and one of just 10 hospitals selected in all of California.



Tracy C. Grikscheit, MD, of The Saban Research Institute of CHLA received a \$7.1 million grant from the California Institute of Regenerative Medicine Translational Research Program to develop a cellular therapy for the treatment of nerve disorders of the digestive system.



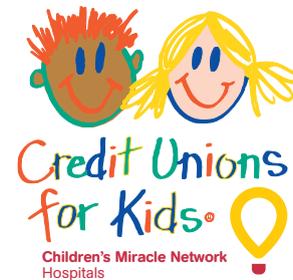
A study led by Jeffrey Bender, MD, of the Division of Infectious Diseases suggests that maternal HIV infection influences the microbiome of the mother's HIV-uninfected infants. The findings may account for some of the immunological and survival differences seen in these children.



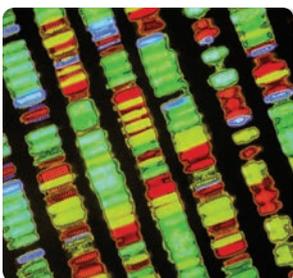
CHLA received a \$1.6 million gift commitment from Care+Cure and The Epilepsy Foundation of Greater Los Angeles. The endowment allows CHLA's Division of Neurology to create the Pediatric Epilepsy Fellowship Program.



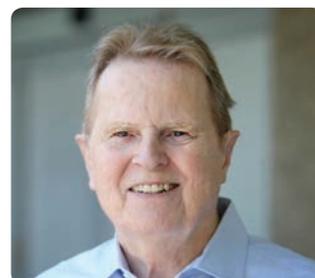
CHLA doctors performed a rare fetal cardiac procedure for the first time in Southern California. A team of doctors inserted a tiny device into a fetal heart in an effort to normalize blood flow and strengthen the newborn for open-heart surgery after birth.



CHLA received a \$5 million pledge from Credit Unions for Kids. The donation will benefit the hospital's Helping Hands Fund to support lifesaving care for young patients.



CHLA and Thermo Fisher Scientific announced plans to develop a next-generation sequencing (NGS)-based panel designed specifically for pediatric cancer research. By detecting gene mutations and targeting biomarkers associated with childhood cancer, the assay will provide a tool with the potential to advance personalized cancer treatment.



Robert Seeger, MD, head of Basic and Translational Research in the Children's Center for Cancer and Blood Diseases at CHLA, was selected for the 2016 Lifetime Achievement Award from the Pediatric Blood and Marrow Transplant Consortium.

Financial Summary

Balance Sheet

As of June 30, 2016 and 2015

(in thousands)

ASSETS	2016	2015
Current Assets		
Cash and cash equivalents	\$6,436	\$18,748
Accounts receivable, net	130,357	130,293
Other current assets	140,521	132,698
Total Current Assets	277,314	281,739
Assets limited as to use, net of current portion	499,000	510,422
Pledges receivable, net of current portion	33,423	46,762
Other assets	31,115	25,847
Property, plant and equipment, net	905,006	920,108
Total Assets	\$1,745,858	\$1,784,878
LIABILITIES AND NET ASSETS		
Current Liabilities		
Accounts payable and accrued expenses	\$78,857	\$63,752
Other current liabilities	81,662	73,083
Total Current Liabilities	160,519	136,835
Long-term debt, net of current portion	463,820	471,896
Other noncurrent liabilities	45,003	40,546
Total Liabilities	669,342	649,277
NET ASSETS		
Unrestricted	790,957	839,602
Restricted	285,559	295,999
Total Net Assets	1,076,516	1,135,601
Total Liabilities and Net Assets	\$1,745,858	\$1,784,878

Financial Summary

Income Statement

For the years ended June 30, 2016 and 2015

(in thousands)

OPERATING REVENUE	2016	2015
Total Net Patient Revenue	\$797,200	\$829,344
All Other Operating Revenue	216,769	223,673
Total Operating Revenue	\$1,013,969	\$1,053,017
OPERATING EXPENSES		
Salaries and Benefits	524,142	468,225
Professional Fees	124,034	107,132
Supplies	123,491	128,291
Purchased Services	81,823	80,165
Other Expenses	90,444	144,533
Total Operating Expenses	\$943,934	\$928,346
EBIDA	\$70,035	\$124,671
EBIDA %	6.91%	11.8%
Depreciation and Interest Expenses	84,807	80,242
Operating Gain (Loss)	\$(14,772)	\$44,429
Investment Earnings, Net of Endowment Distribution	\$(44,025)	\$(17,310)
Net Gain (Loss)	\$(58,797)	\$27,119

Statistical Report

For the fiscal year ended June 30, 2016

KEY STATISTICS	2016
Number of licensed beds	495
Discharges	16,298
Patient days	105,966
Average length of stay (days)	6.5
Outpatient visits	512,359
Emergency Department visits	79,977
Traumas treated	800
Medical transports	2,292
Surgeries	16,853
Active medical staff	843
Employees	5,653
Total National Institutes of Health funding	\$26.1 million
Total research funding	\$71.4 million
Total number of active patents	218

CHARITY CARE AND OTHER COMMUNITY BENEFITS

Charity care	\$3.4 million
Unreimbursed costs of medical services for government-sponsored programs ¹	\$187.2 million
Research activities	\$36.6 million
Health professions education	\$28.9 million
Subsidized health services	\$6.1 million
Community health improvement services and other community benefits	\$5.2 million

TOTAL COMMUNITY BENEFIT²

\$267.4 MILLION

¹ 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 \$42.9 million in Disproportionate Share Hospital Funding in FY 2016.

² 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 \$122.5 million to Children's Hospital Los Angeles in the fiscal year ended June 30, 2016.

CHILDREN'S HOSPITAL LOS ANGELES GALA

Once Upon a Time

PROUDLY SUPPORTED BY



CHILDREN'S HOSPITAL LOS ANGELES GALA

Once Upon a Time

PROUDLY SUPPORTED BY



And so the story began. Saturday, Oct. 15, 2016, more than 1,200 prominent philanthropists, local dignitaries, celebrities and supporters gathered at the Event Deck at L.A. LIVE for the Children's Hospital Los Angeles Gala, CHLA's biannual signature event. This year's fantastical storybook-themed fête, titled "Once Upon a Time," raised a record \$4 million and honored Drew Barrymore, the LA Kings and The Billy and Audrey L. Wilder Foundation with the Courage to Care Award.

"Tonight we celebrate the hope and healthier futures that Children's Hospital Los Angeles creates and provides to children across Southern California and far beyond," Children's Hospital Los Angeles President and CEO Paul S. Viviano told the audience.



Barrymore has brought joy and hope to patients and families at her annual Mother's Day pampering events, and is volunteering her time as ambassador for the hospital's Live L.A. Give L.A. holiday fundraising campaign. The Billy and Audrey L. Wilder Foundation has made generous financial contributions to a number of areas in the hospital, continuing the legacy of the Wilders' commitment to children's causes throughout their 53-year marriage. And the LA Kings are committed, supporting partners of CHLA, contributing their time, fundraising efforts and organizational donations to the hospital year in and year out.

EVENT SPONSORS

PRESENTING

LA Kings

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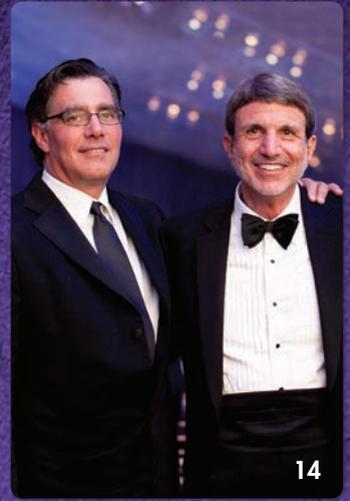
PUBLICATION SPONSOR

John C. Herklotz

RED CARPET SPONSOR

Wells Fargo







1. Singer Katy Perry electrified the audience with her rendition of "Somewhere Over the Rainbow," as well as her own hit songs "Firework," "Teenage Dream," "Dark Horse" and "Roar."
2. CHLA Board of Trustees Co-chair Lynda Boone Fetter (left), Gala host Josh Gad, LA Kings players Dustin Brown and Drew Doughty, CHLA patient Madison Elizondo, singer Katy Perry, LA Kings President of Business Operations Luc Robitaille, actress and Courage to Care honoree Drew Barrymore, CHLA patient Caiden Moran, LA Kings player Anze Kopitar, CHLA Division Head of Neurosurgery Mark Krieger, MD, Danielle Moran (mother of CHLA patient), LA Kings player Alec Martinez, CHLA Board of Trustees Co-chair Arnie Kleiner, CHLA President and CEO Paul S. Viviano, and The Billy and Audrey L. Wilder Foundation President Burt Levitch.
3. Back row: Lindsay Rachelefsky (left), Paula Rudnick, Jennifer Simchowicz, Jim Brooks and CHLA Trustee Allan Rudnick. Front row: Zoe Rudnick (left), Allison Rudnick, and Cheryl and Brad Cohen.
4. Actress Drew Barrymore accepts the Courage to Care Award.
5. CHLA Trustee and actress Alexandra Meneses Simpson with CHLA President and CEO Paul S. Viviano.
6. Fairy tales came to life in the Gala's opening entertainment number.
7. Actor, writer, singer and producer Josh Gad charmed the audience as the Gala's host.
8. Guests of Delta Air Lines—Back row: Andrea Bailey (left), John Spivey, Michelle Lee, Kristin Haase, Chris Johnson and CHLA Trustee Ranjan Goswami. Front row: Howard Edelman (left), Dana Debel, Esther Nelson and Lilia Mica.
9. CHLA Division Head of Neurosurgery Mark Krieger, MD (left), Amblin Partners and Dreamworks Studios Executive Kristie Krieger, actress and Courage to Care Award presenter Jessica Capshaw, and CHLA President and CEO Paul S. Viviano.
10. Actress, author and CHLA supporter Jamie Lee Curtis walked the Gala's celebrity red carpet.
11. LA Kings President of Business Operations Luc Robitaille accepts the Courage to Care Award, flanked by 1967-68 and 2016-17 team players.
12. CHLA President and CEO Paul S. Viviano (left) presented the Courage to Care Award to representatives of The Billy and Audrey L. Wilder Foundation: Burt Levitch, Jerry Moss and Harold Nelson.
13. CHLA Trustee Ted Samuels (left), Senior Vice President and Chief Development and Marketing Officer DeAnn Marshall, MHA, University of Southern California (USC) President C. L. Max Nikias, CHLA President and CEO Paul S. Viviano, USC Provost and Senior Vice President for Academic Affairs Michael Quick, PhD, and Keck School of Medicine of USC Senior Vice President and CEO Thomas E. Jackiewicz.
14. CHLA Trustee Jeffrey Worthe (left) with CHLA President and CEO Paul S. Viviano.
15. Guests of Rick Ghazy and the Goldwin Foundation.
16. CHLA Board of Trustees Co-chairs Lynda Boone Fetter and Arnie Kleiner addressed the crowd during the evening's program.
17. Guests of The Walt Disney Company—Back row: Jared Taylor (left), Karen Kawanami, Frank Schultz, Cheryl Kisob, Reva Revis and Gregg Sherkin. Front row: Jacqueline Ryzek (left), Andrew Santelli, Robert Laurita and John Paul Kisob.
18. CHLA Trustee Ashwin Adarkar and his wife, Sushma Adarkar.
19. Actor Eric Stonestreet spoke of his devotion to the LA Kings when he presented them with the 2016 Courage to Care Award.
20. Actress and CHLA supporter and volunteer Teri Hatcher.
21. Guests from previous Courage to Care honoree Costco Wholesale: Sean (left) and Cathy Mackin, Jason and Katrina Wyhowanec, Joe and Sarah Wehling, Humberto and Helen Yniquez, and Joan Anderson.
22. Jeffrey Assaf (left), CHLA Trustee Cathy Siegel Weiss, CHLA President and CEO Paul S. Viviano, CHLA Trustee Elisabeth Hunt Price, Ken Weiss and Ginger Sherak.
23. CHLA Trustee and past Courage to Care honoree William H. Hurt (front, second from left) and guests.
24. Back row: Rebecca Mitchell (left), Dennis Arriola, Janet Winnick, Annie Lam, California Assembly Speaker Anthony Rendon and Tracy Hernandez. Front row: CHLA Trustee Eugene "Mitch" Mitchell (left), Amanda and Paul Bauer, and Randal Hernandez.
25. CHLA patient Caiden Moran, a participant in CHLA's clinical trial of an auditory brain stem implant device for children born with damaged or missing cochlear nerves, presented Katy Perry with flowers after her performance, and the two traded sign language on stage.



“Life itself is
the most wonderful
fairy tale.”

—Hans Christian Andersen

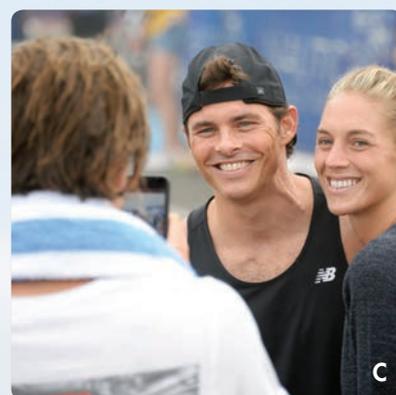
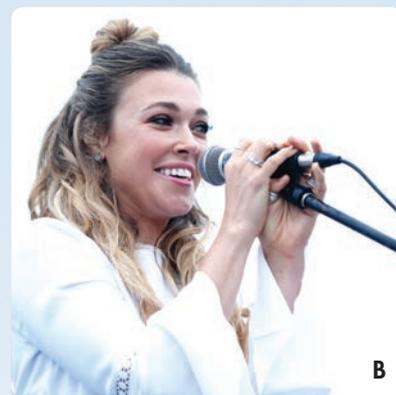
Nautica Malibu Triathlon Passes \$10 Million Mark in Fundraising for Cancer Research at CHLA

The 30th annual Nautica Malibu Triathlon presented by Equinox, held Sunday, Sept. 18, at Zuma Beach in Malibu, raised \$1.23 million this year for the Pediatric Cancer Research Program at Children’s Hospital Los Angeles. This was the 10th anniversary of the event supporting CHLA.

More than 5,000 participants competed in a half-mile swim, 18-mile bike course and 4-mile run on that misty morning at the beach. Platinum recording artist Rachel Platten sang the national anthem and performed her hit single “Fight Song.” Celebrity participants included Zac Efron (“Neighbors”), Heather Tom (“The Bold and the Beautiful”), James Marsden (“Westworld”), Max Greenfield (“New Girl”), Mark Feuerstein (“Royal Pains”), Karla Souza (“How to Get Away With Murder”) and Colin Egglesfield (“Rizzoli & Isles”), among others.

“Since starting this triathlon, we have raised over \$10 million in support of the cancer research program at Children’s Hospital Los Angeles and hope to raise even more in the years to come,” says Michael Epstein, executive producer of the Nautica Malibu Triathlon. “It is inspiring to know that each year participants from various backgrounds continue to come to one of the most beautiful sites of Los Angeles—Zuma Beach in Malibu—all in support of this amazing cause.”

“I am very grateful for the partnership with and longstanding generous support of all those involved with the Nautica Malibu Triathlon,” says Alan S. Wayne, MD, director of the Children’s Center for Cancer and Blood Diseases at Children’s Hospital Los Angeles and professor of Pediatrics at the Keck School of Medicine of the University of Southern California. “The support that our cancer research program receives from participants, sponsors and the community continues to fuel scientific discoveries and medical advancements that are changing the outlook for childhood cancer.” 🦋





A) Athletes were at the beach before sunrise. B) Rachel Platten performing the national anthem and "Fight Song" before the race. C) Actor James Marsden. D) Jack Falahee (left), Karla Souza and Alfred Enoch from "How to Get Away With Murder." E) The Children's Hospital Los Angeles triathlon team. F) Director of the Children's Center for Cancer and Blood Diseases Alan S. Wayne, MD (left), actor Colin Egglesfield and Colin's mom, Kathleen Egglesfield. G) Actor Zac Efron (center) with his triathlon relay teammates, including his brother Dylan (left). H) Swimmers heading out for the first leg of the triathlon. I) Christina Pascucci of KTLA 5 finishes her triathlon run. J) Michael Epstein (left) of MESP presents the triathlon's fundraising total to CHLA President and CEO Paul S. Viviano, CHLA patient Parker Brockaway and Alan S. Wayne, MD. K) Actor Mark Feuerstein pauses for the national anthem. L) Runners take to the course on the final leg of the triathlon. M) Sophia's Buddies team members, with CHLA President and CEO Paul S. Viviano (second from left). N) A Team CHLA member takes to the bike course.

Making Doctors Better Doctors

Honoring CHLA physician Barbara Korsch, MD, a pioneering researcher in the field of doctor-patient communication

By Sarah T. Brown



Barbara Korsch, MD

"I began to realize that it was neither the patient nor the disease nor the particular treatment, but that the roots of the problem lay in the doctor-patient relationship."

—Barbara Korsch, MD

Doctors should listen to their patients, empathize with them, and find ways to communicate effectively with them.

Sounds like common sense, right?

This hasn't always been the case, though. What was once ignored, or even scoffed at, is the standard of care today. For that, we have Children's Hospital Los Angeles physician Barbara Korsch, MD, to thank.

Korsch's life would be considered extraordinary even if she hadn't changed the face of modern medicine. Before World War II, her family fled Nazi Germany, where her father was persecuted for being an outspoken socialist. She entered one of the best medical schools in the country, Johns Hopkins School of Medicine, at the young age of 20, at a time when few women were studying to be physicians. She graduated in just three years as part of an accelerated program to train more doctors during wartime. Then, she went to work in medicine.

Early in her career, while director of the Outpatient Department at New York Hospital – Cornell Medical Center in New York City, she began to notice communication problems between doctors and the parents of her young patients. She also noticed that often these families didn't return for follow-up visits. When she investigated, she found that parents felt the doctors hadn't understood, or worse, hadn't cared about their concerns.

"Years before I started my studies, there had been articles about uncooperative patients, but they always blamed the patient. 'The patient was stupid, was uneducated, didn't accept authority,'" said Korsch in a 2008 documentary produced about her life and career. "And I began to realize that it was

neither the patient nor the disease nor the particular treatment, but that the roots of the problem lay in the doctor-patient relationship."

Never one to accept the status quo, she decided something had to be done. "In my family, there is a very long tradition of not accepting what's going on if it doesn't seem right," she said. "None of them were ever afraid to say, 'It's not right. Let's find out why.'" And she was no different.

In 1961, Korsch came to work at CHLA. Though her husband, Robert Ward, MD, was chief of the Department of Pediatrics, nepotism didn't get her on the staff. In fact, it almost kept her off of it. Leadership said it wouldn't be appropriate for her to work for her husband, so she spent some time at another hospital, where she conceived of a landmark 1,000-patient study to address the importance of doctor-patient communication. She also landed a sizable grant to fund the project. In need of a higher patient volume, she came back to CHLA with her grant in hand, and got to work.

Korsch and 10 research assistants videotaped live doctor-patient encounters. They then interviewed the patients' families immediately after the meeting, and again two to three weeks later. The results were stark; for families who said they were highly dissatisfied, only 17 percent were compliant with the doctor's orders. Her research showed that a doctor's effectiveness as a communicator had a direct connection to the quality of care the patient ended up receiving. The smartest doctors in the world were useless if they couldn't convince their patients that they had their best interests at heart.

Korsch's study was published in *Scientific American*, a magazine read by the general public in addition to the scientific community.



Korsch (front, far right) and the faculty of the Department of Pediatrics of New York Hospital – Cornell Medical Center, 1959-1960

It received one of the largest responses to any of the magazine's articles at the time.

As a result of her groundbreaking findings, she set about to create teaching methods that would help pediatric residents realize that parents were as much patients as their sick child. She landed on a supremely effective teaching tool: videotaping residents during interactions with patients, reviewing the tapes and offering feedback.

"She was a pioneer in everything that she did," says Robert Adler, MD, MEd, chief medical officer of the CHLA Health System and senior advisor to the chair of the Department of Pediatrics. Adler first met Korsch in 1973, when he was an intern at CHLA, and she helped shape his career, encouraging him to conduct his own research.

Though getting the medical community to embrace her findings was an uphill battle, she persevered, and her tenacity was recognized. Korsch was elected to the prestigious Institute of Medicine in 1981 — CHLA's first-ever member, and the first female to be elected from the University of Southern California (USC).

Among her many accolades, she received the Ambulatory Pediatric Association Distinguished Career Award, the American

Academy of Pediatrics C. Anderson Aldrich Award, and the Faculty Lifetime Achievement Award from USC in 2006. She was also awarded the first-ever Children's Hospital Academic Affairs Appreciation for Longevity of Service Award in 2011.

"Many people ask me, 'You know, you've been teaching this for 50 years. Has communication gotten any better?'" said Korsch in the 2008 documentary. "I am not egocentric enough to think I personally have made a lot of difference, but I certainly was the one who drew attention to it as a problem, and was the first to attempt to deal with the problem."

She wrote numerous books and articles on the subject, and lectured around the world as well—and her drive for effective communication wasn't confined to the exam room.



"She was asked oftentimes to speak in international forums," says Adler, "and she always made an effort to learn the language of whatever country she went to."

Already fluent in five or six languages, she would make it a priority to learn at least enough to have a conversation, he notes. "If she went to Poland, she learned Polish. If she went to Japan, she learned Japanese. Her commitment to communicating with people in their own language was remarkable."

Korsch turned 95 on March 30, 2016. Until only a few months earlier, she was still supervising residents in Continuity Clinic, where new doctors learn the skills of dealing with patients and families. Her health has necessitated that she finally retire fully from working, but the indelible mark she's left on CHLA and the entire field of medicine will cement her legacy for generations. 🌈

Many thanks to Caroline Harding Productions for archival interview footage. For more information about "Portrait of a Pioneer," the 2008 documentary on Barbara M. Korsch, MD, visit www.PortraitofaPioneer.com.

Support the groundbreaking work of physician-scientists like Barbara Korsch. Visit CHLA.org/BARBARA

A LEAP of Science

Clinical trials provide a princess warrior with a new weapon in her fight against a rare form of leukemia.

By Debra Kain

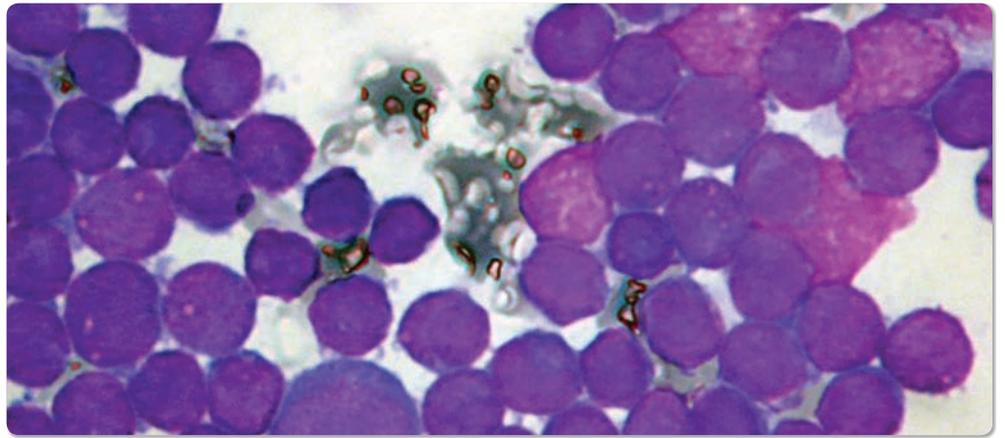
Kylie Branch's favorite color is pink. Pink like the "Princess Warrior" T-shirt she wears to her physical therapy session, or as she calls it, "playtime."

Kylie is smiling and full of energy as she clambers up and down stairs and ramps, a slight imbalance and her bright pink leg braces the only signs that she is anything but a typical, healthy 3-year-old. But just a year and a half ago, she was diagnosed with T-cell acute lymphoblastic leukemia (T-ALL), an uncommon and aggressive form of leukemia that accounts for about 15 percent of cases of the disease.

"Kylie's first symptoms were little red dots on her ears," says her mom, Katie Hiller. They looked so peculiar that Hiller immediately did a web search for "tiny red dots" and found the term petechiae—pinpoint, round spots that appear on the skin as a result of bleeding. "I read all the causes for petechiae. At the bottom of the list was leukemia, and I got a terrible ache in my stomach. 'I'm overreacting; just calm down,' I kept telling myself."

She and Kylie's dad took her to a doctor, who told them she was fine. "She was otherwise perfectly healthy," Hiller says. "She was energetic and had no complaints and didn't look sick."





T-cell acute lymphoblastic leukemia cells

It wasn't until the red dots spread and got worse that Kylie's pediatrician did a blood panel. That's when Kylie's mom and dad found out that something was really wrong. Within hours, they got a call from Children's Hospital Los Angeles asking them to bring Kylie in the next day.

When doctors at CHLA's Children's Center for Cancer and Blood Diseases confirmed that Kylie not only had leukemia, but T-ALL—a rare type that requires aggressive treatment—Hiller was in shock.

"I researched the subtypes of ALL—it was just my way of dealing with fear—and this was the worst possible diagnosis," Hiller says. "I was extremely concerned about the possibility of Kylie not being able to reach remission, and the likelihood of relapse with T-cell ALL."

So Hiller didn't hesitate when Aaron Yeo, MD, a physician and fellow in the Children's Center for Cancer and Blood Diseases, told her about the option of enrolling Kylie in a new clinical trial, one that might give her daughter a better chance of fighting the disease.

There was no time to hesitate, either. Kylie's family had to decide right away whether to participate, without knowing whether their daughter would be selected to get the trial drug, called bortezomib. The trial is testing the effectiveness of bortezomib when combined with standard chemotherapy; CHLA has been part of the national clinical trial through the Children's Oncology Group since 2014.

"Mom handled it so calmly," says Yeo. "This is one of only a few clinical trials in childhood leukemia where patients are immediately randomized up front, meaning that participants are assigned by chance alone to two different approaches to treatment—standard chemotherapy or chemotherapy combined with the trial drug."

What is a clinical trial?

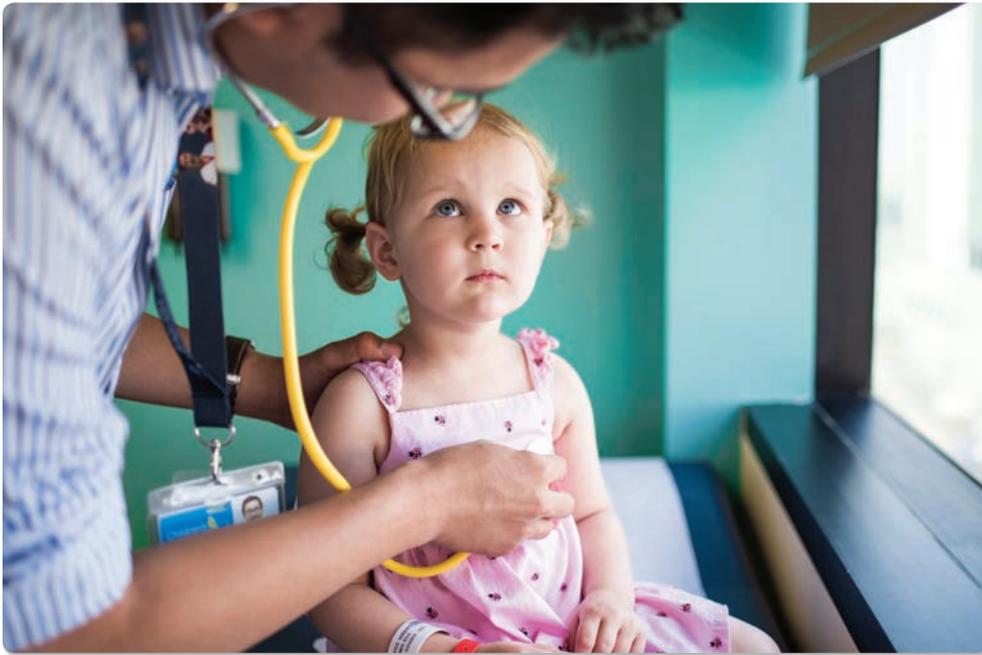
Nearly every major advance in medicine is due to a clinical trial. These research studies explore whether a new medical treatment is safe and effective for humans. They are among the final stages of a long and careful research process that often begins in the lab, where scientists first develop and test new ideas. Trials follow strict scientific standards designed to protect patients while producing reliable study results.

A study may find that a new strategy or therapy improves patient outcomes, or that it



Kylie Branch at age 2, during the intensive chemotherapy phase of her treatment

(continued on next page)



Aaron Yeo, MD, examines Kylie during a checkup.

“Every clinical study aims, in some way, to fulfill the promise of scientific innovation—but none of these studies can be successful without the participation of committed volunteers. There is no Department or Secretary of Cures. It’s us.”

—Michael J. Fox
Actor, producer, activist

offers no benefit or causes unexpected harm. That is why parents and their children are such important partners in these studies. Safety is always the physician’s top concern, along with ensuring that the family is fully informed of the risks and benefits of such a trial.

Researchers use a process called “informed consent” to provide potential and enrolled participants with the key information about a clinical study to make sure that parents—and children old enough to understand—are fully aware of what they are signing up for. Participants who volunteer for a trial may also withdraw at any time.



Deepa Bhojwani, MD

Clinical trials are an important way that CHLA and other academic medical centers differ from other hospitals. Each year, CHLA enrolls hundreds of children in such studies, in areas ranging from health behavior and disease prevention to investigational drugs, treatments and devices.

“Through leading and participating in clinical trials, Children’s Hospital Los Angeles is able to offer state-of-the-art therapies to children before they are available anywhere else,” says Michele Kipke, PhD, director of Clinical Research for The Saban Research Institute of CHLA. “Participation is so important to advancing new cures, because such studies are the only way to test—over time and in a large number of children—whether a new medicine or surgical intervention improves their long-term outcomes.”



Kylie and her mom, Katie Hiller

The magic word: remission

Kylie’s parents wanted to give her the best possible chance to avoid a relapse of her leukemia, and consented to be part of the study. Kylie was selected to begin receiving the trial drug.

She has been on the trial regimen since January 2015, and is expected to continue coming to CHLA for chemotherapy, follow-up visits and physical therapy until at least spring 2017. “Kylie is doing well and is in remission,” says her primary oncologist, Deepa Bhojwani, MD, director of the CHLA Leukemia and Lymphoma Program.

Remission and cure are the magic words every parent of a child with cancer wants to hear. Kylie's parents believe the clinical trial has saved Kylie's life, and they are optimistic that a cure is in her near future.

Meanwhile, Kylie happily visits CHLA on a regular basis, telling her little sister, Kaylie, "We're going to my hospital." One side effect of the chemotherapy has been nerve weakness, or neuropathy, which causes weakness and numbness in Kylie's feet, necessitating weekly physical therapy appointments.

"Obviously, she hated the catheters and surgery and the numerous procedures the doctors needed to do at the beginning of her treatment, but she forgave us easily," Hiller says, noting that resources such as CHLA's Child Life Program, Reading Room and Amerman Family Foundation Dog Therapy Program were a great help. "Kylie loved the dogs. Now she asks me when she can go back. Even with the pokes and the chemo, she really does like going to CHLA."

What would Hiller tell other parents about coming to CHLA and participating in a study? "It can be scary when there are options in your child's health care, and you are the one that has to make the decision without knowing what the outcome might be," she says. "But clinical trials like the ones offered at Children's Hospital Los Angeles can give your child a better chance at fighting their cancer. If a clinical trial is the right fit for your child and your family, then take advantage of the opportunity when it arises." 🦋

**Support important research that helps patients like Kylie.
Visit [CHLA.org/KYLIE](https://www.chla.org/KYLIE)**



Kylie is escorted to her appointment by Brewster, a CHLA therapy dog.

Renowned Neurologist Douglas Nordli Jr., MD, Joins CHLA

On April 1, 2016, pediatric epilepsy expert Douglas Nordli Jr., MD, joined Children's Hospital Los Angeles as chief of the Division of Neurology and co-director of the Neurological Institute. He is also serving as vice chair of Neurology at the Keck School of Medicine of the University of Southern California.



Under the leadership of Nordli and Mark Krieger, MD—the Billy and Audrey L. Wilder Endowed Chair in Neurosurgery—CHLA's Neurological Institute is providing a comprehensive continuum of care by bringing together services from Neurology and Neurosurgery with Clinical Nutrition, Occupational Therapy, Physical Therapy, Psychiatry, Radiology and Social Work.

"With the advent of precision medicine and novel diagnostic tools, this is a pivotal time in the field of child neurology, particularly at an academic pediatric medical center with a large patient population," Nordli says. "I see this as an unprecedented opportunity to make a real impact in the lives of children with neurological disorders here in Los Angeles and beyond."

Prior to his arrival at CHLA, he served as the Lorna S. and James P. Langdon Chair of Pediatric Epilepsy and division head of the Epilepsy Center at Ann & Robert H. Lurie Children's Hospital of Chicago, as well as a professor of Clinical Neurology and Clinical Pediatrics at the Northwestern University Feinberg School of Medicine.

Nordli has published more than 70 original, peer-reviewed studies, with research focusing on epilepsy classification, epilepsy surgery, febrile seizures and the ketogenic diet, which is used primarily to treat difficult-to-control epilepsy in children. 🦋





Holly and Tom Gores

Leading-Edge Treatment and Research at the Gores Family Allergy Center

By Debra Kain

An estimated 1 in 13 children in this country are affected by allergies to foods like milk, eggs, peanuts, fish and shellfish. But despite this number's steady rise, very few academic centers specialize in treating severe food allergies in children.

At Children's Hospital Los Angeles, a generous gift from Tom and Holly Gores is helping to pair diagnosis and treatment with an active research program to prevent and cure food allergies in children. The Gores Family Allergy Center at CHLA has been named one of 28 centers of excellence across the country by the Food Allergy Research & Education (FARE) Clinical Network.

As part of its work, the Center is engaging patients in a series of clinical trials, including one in partnership with Stanford University that uses oral immunotherapy to address multifood allergies. A second oral immunotherapy trial is

focused on peanut allergies, and a third trial is examining atopic dermatitis.

Ten-year-old Jackson Mayer was one of the first patients enrolled in the peanut oral immunotherapy trial. His severe allergies to peanuts and cashews made it dangerous for him to eat at restaurants or attend school gatherings and childhood parties. Consuming even one-tenth of a peanut would cause him to experience anaphylactic shock, a severe, potentially life-threatening allergic reaction.

Under close medical supervision at the Center, Jackson has been gradually exposed to nuts while receiving a dose of Immunoglobulin E (Anti-IgE). Researcher and Gores Family Allergy Center Medical Director Jonathan Tam, MD, describes Anti-IgE as "an antibody against the allergic antibody" that causes such a strong reaction in Jackson and others with severe allergies.

For some children, a chance brush with trace amounts of the wrong food can mean a battle for their lives.

The premise is that slowly increasing the amount of nuts Jackson ingests and administering the therapy at the first signs of an allergic reaction will allow Jackson's immune system to eventually stop identifying nuts as an invader. "This allergy desensitization program has already had an impact on his life," Tam says.

"This trial has been a great experience and life-changing for Jackson and our whole family," says his mother, Lisa Mayer.

Jackson agrees. "For the first time, my mom is letting me go on an overnight trip with my class at school. It's going to be really fun!" 🦋

To support advances in care like the Gores Family Allergy Center, visit [CHLA.org/GiveLA](https://www.chla.org/GiveLA)

SOUL SUPPORT

By Katie Sweeney

Phan Leopando, RN, reflects in the Thomas and Dorothy Leavey Foundation Interfaith Center.

In the midst of crisis and illness, CHLA's Spiritual Care Services Program offers comfort and support to patients, families and staff from all cultures and faiths.

The thick glass door swings softly shut behind Rev. Dagmar Grefe, PhD, and instantly, the voices and footsteps from the busy hospital corridor vanish. In here, the only sound is silence.

"This is what we wanted," Grefe explains in a low, hushed voice, "a tranquil place where people could come for prayer, meditation or reflection."

That place is the Thomas and Dorothy Leavey Foundation Interfaith Center, which opened in January at Children's Hospital Los Angeles. And tranquil is a fitting word to describe it.

Soft natural light fills the center, and a communal sanctuary opens out to the Sharon D. Lund Reflection Garden, which offers restful benches, gentle water veils and soothing pebbled pathways. Meanwhile, five quiet, semi-enclosed prayer and meditation alcoves are each devoted to different faiths: Catholicism, Western and Eastern Christianity, Judaism, Islam, and Buddhism and Hinduism.

The 2,400-square-foot center—supported by generous philanthropy and an ongoing fundraising campaign—is the newest way that CHLA's Spiritual Care Services Program is providing support, comfort, and emotional and spiritual respite to patients, families and staff of all cultures and faiths.

"We serve everyone: people from all religions and those with no religion at all," stresses Grefe, who has managed the program since 2002. "We don't have an agenda, and we don't impose our beliefs. Our task is to listen."

Comfort and compassion

Numerous studies have shown that spiritual care plays an important role in a healing environment—not only helping people cope with crisis, but also decreasing anxiety, improving pain management and more.

At CHLA, chaplains serve as integral members of a child's health care team, performing spiritual assessments and attending interdisciplinary rounds with medical staff. In addition to Grefe, the program includes three full-time chaplains, a part-time Catholic priest and an on-call Jewish chaplain, as well as fellows, residents and interns from diverse faiths.

The team offers 24/7 comfort, compassion and spiritual support to families of all faiths—during what are often the most difficult and wrenching moments of their lives.

Lead Chaplain Rev. Janie Ito recounts the time last year when, as the on-call chaplain, she was called into the hospital at 3 a.m. to help a couple whose 2-year-old daughter had been airlifted to CHLA. The toddler had just



Studies have shown that spiritual care plays an important role in a healing environment.

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The Center was designed to bring people from diverse faiths together, but give each a private, sacred space.

non-religious families. Johnson recalls approaching one such mother on the Oncology floor. She was crying.

"She said, 'Oh, no, I don't need a chaplain. It's just, today's been so hard.' And then she talked to me for half an hour," he recalls. "At the end she said, 'Oh! I guess I did need to talk all that out!'"

A place for every faith

On a recent Monday at lunchtime, three people are praying in the Leavey Interfaith Center—one in the Catholic alcove, one in the Christian alcove and another in the Muslim alcove.

The Center was designed for this very purpose: to bring people from diverse faiths together, but give each a private, sacred space.

"Many interfaith chapels have only a neutral space, or provide separate chapels for major religions," Grefe notes. "We took a different approach. We wanted to affirm the diversity of faiths at our hospital, but also affirm our unity, this sense that we are all one."

While the communal sanctuary is for everyone and hosts religious services, meditation classes and art therapy, each alcove is tailored to a specific faith, with carefully selected spiritual artwork, materials and special touches. For example, the Jewish alcove's windows face east, to Jerusalem. In the Muslim alcove, prayer rugs can be pointed to Mecca.



Five quiet, semi-enclosed prayer and meditation alcoves are devoted to different faiths.

"We serve everyone: people from all religions and those with no religion at all. We don't have an agenda, and we don't impose our beliefs. Our task is to listen."

—Rev. Dagmar Grefe, PhD

been diagnosed with an advanced brain tumor and was undergoing emergency surgery.

When Ito arrived, she found the parents huddled together in the surgery waiting area, crying.

"They were devastated," she recalls. "Part of their process was they just needed to talk: 'But she was fine yesterday.' And so I sat with them; I stayed with them; I listened."

Chaplain Joshua Johnson remembers helping one particular teenage boy and his family over a two-year period as he came in and out of the hospital. The teen's cancer had relapsed.

"He was grappling with questions like: 'Why is this happening to me? Does God hate me?'" Johnson says. "More than anything, he needed me to acknowledge his pain and his search for hope and meaning."

Other times, chaplains support families by connecting them with spiritual resources from the community—arranging for an imam from a local mosque to pray with a Muslim father, or bringing in a Thai Buddhist monk for a family who wanted a special ceremonial chanting done for their child in Pali, a sacred Theravada Buddhist language.

Of course, some families don't want a chaplain involved in their care, and that's fine too. That said, chaplains often help

The Catholic alcove features an Our Lady of Guadalupe devotional, and families can post prayers on an adjacent wall using large sticky notes. On this particular Monday, 32 prayers are posted.

"Amada Virgen," reads one note, "please protect my little girl as she continues in this fight. Please let her lungs develop and grow so she can come home to us."

Tea, cookies and dragonflies

During the darkest circumstances—the death of a child—chaplains give extensive support. They are there to perform or facilitate baptisms and blessings, to pray with parents or to simply sit by their side.

Patient deaths are emotional for staff, too. Chaplains are available to consult with staff members individually, and they also offer an informal "Tea for the Soul" ritual—bringing tea and cookies to a unit and giving staff a chance to talk.

Each December, the Spiritual Care Program hosts a candlelight memorial service honoring all patients who died during the year. Approximately 300 family members and staff attend the service, which is supported by the Spiritual Care Guild, one of the hospital's many Associate and Affiliate fundraising groups.

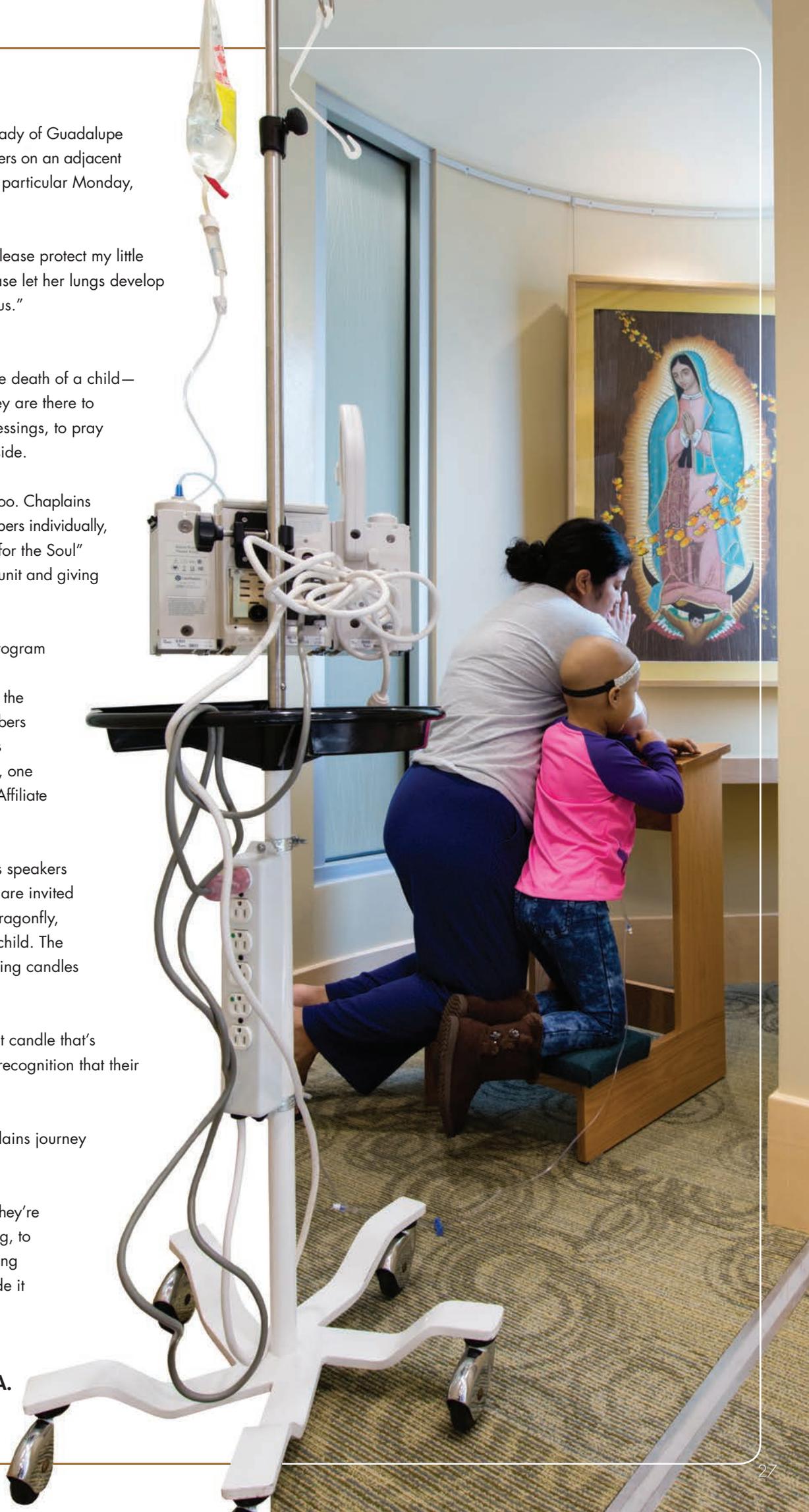
As part of the service, which includes speakers and bereavement resources, families are invited to make and hang a special paper dragonfly, a symbol of transformation, for their child. The evening culminates with families lighting candles in memory of the child they lost.

"There's something about lighting that candle that's extremely powerful," Ito says. "It's a recognition that their child won't be forgotten."

The service is one last way that chaplains journey with families—and help them heal.

"Being invited to walk with people as they're suffering, to learn what they're learning, to be comforting to them ... there's nothing like it," Johnson says. "I wouldn't trade it for anything." 🦋

**Support vital programs like
Spiritual Care Services at CHLA.
Visit [CHLA.org/GiveLA](https://www.chla.org/GiveLA)**



Full Speed Ahead

Born with different heart defects, twins Colin and Brooke Queen are living life full throttle—and giving back to CHLA.

By Katie Sweeney

VRRRRR ... The steady, high-pitched wail of more than a dozen go-kart engines pierces the air, and from an observation tower overlooking the racetrack, Gretchen Queen has to shout to make herself heard.

"Watch this," she yells over the din, pointing to a white kart zipping around the far corner of the track. "Colin's going to pass this kid right here."

Sure enough, a moment later, Colin, the kart's driver, makes his move coming down the straightaway. In a flash, he squeezes around the right side of the kart ahead of him and scurries past it, his blue helmet bobbing as his kart bumps along the rough asphalt track.

"When he sees an opening, he doesn't hold back," says Gretchen of her son, watching him navigate the next zigzagging turn. "He goes for it."

That competitive, determined nature has helped Colin, 11, become a champion go-kart driver who competes around the country. Behind the wheel of his kart—which sits an inch off the ground and looks like a miniature Formula 1 race car—he routinely reaches speeds of 50, 60 and even 70 mph.

His collection of racing trophies is impressive. Yet, his biggest come-from-behind wins have taken place off the track—at Children's Hospital Los Angeles.





Brooke (right) visits her twin, Colin, during one of his early hospitalizations at CHLA.

A shaky start

Colin and his twin sister, Brooke, were born 8½ weeks early, just 12 seconds apart. Brooke was small, but OK. Colin was even smaller—barely 3 pounds. Worse, he had hypoplastic left heart syndrome (HLHS), a life-threatening condition in which the heart's left side is severely underdeveloped.

Hours after birth, he had his first high-speed ride: an ambulance to CHLA, home to one of the country's largest and top-ranked pediatric cardiac centers. His parents, Gretchen and Rob Queen, who live in Coto de Caza in Orange County, had chosen CHLA after researching hospitals nationwide during pregnancy, when Colin's heart problem was discovered.

"Everyone at Children's Hospital was amazing," Gretchen says. "They see the worst of the worst all the time. That was where we wanted to be."

To have a chance at life, babies with HLHS need a series of three open-heart surgeries in their first years. The surgeries aren't a cure, but they "re-plumb" the heart so that the right side can do what the left side can't: pump oxygenated blood to the body.

The first surgery is typically done just days after birth, but doctors feared Colin was too tiny to survive it. They waited seven weeks, trying many different measures, but Colin couldn't gain weight.

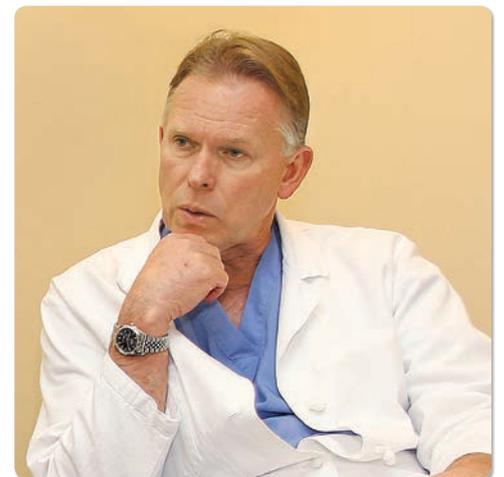
"He was tanking fast," his mom remembers. "There was no choice but to take him to the OR. It was that or nothing."

Vaughn Starnes, MD, co-director of CHLA's Heart Institute, performed the complex, intricate surgery, and Colin pulled through. In the next weeks, Colin suffered multiple setbacks, but each time, he dug deep and rallied. After three months at CHLA, he finally went home. Starnes did Colin's second surgery a few months later, and the final one when Colin was 2½.

As if that weren't enough, at age 1, Brooke—who'd always been healthy—began having episodes in which her heart raced up to 300 beats per minute. The diagnosis: Wolff-Parkinson White syndrome (WPW).

"WPW basically means that you're born with an extra nerve in your heart. You're supposed to have one; she had two," explains Yaniv Bar-Cohen, MD, Brooke's pediatric electrophysiologist at CHLA. "That extra nerve can cause your heart to go very fast, and in very rare cases, it can cause cardiac arrest."

Despite medication, Brooke continued to have frequent episodes. When she was 4, Bar-Cohen performed a catheter "ablation" procedure—attempting to destroy the extra nerve in Brooke's heart with the pen-like tip of a catheter. Initially, the nerve regained function, but a second procedure worked. Brooke was cured. The family celebrated. "We were ready," Gretchen says, "to be normal."



Vaughn Starnes, MD

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Life in the fast lane

Talking with Brooke and Colin, you'd never suspect they were born with heart conditions. You would, however, know they were siblings.

When Brooke says she's a healthy eater, Colin brings up the time he found candy wrappers under her bed. When Colin mentions breaking his arm, Brooke quickly answers that she broke her arm first, while riding a scooter.

The sixth-graders share the same sandy blonde hair, ocean-blue eyes and faint sprinkling of freckles. But they insist that's where their similarities end.

"Ohhhh, we're really different," Colin says. "By far," Brooke stresses.

Brooke is the talkative one, with numerous favorite activities, including reading and writing stories, riding horses, playing soccer and drawing. Like her brother, she has a black belt in tae kwon do. Her dream: to write books and become a raptor biologist.

She definitely doesn't like racing—which is, of course, what Colin loves most.

Rob first took Colin karting for his 7th birthday. It was meant to just be fun, but, as Colin explains, "it just clicked. I fell in love with it." He began bugging his dad to take him to the track.



Brooke's many interests include horseback riding.



Colin proudly displays the hospital's logo on his kart and racing suit.

His parents called his cardiologist at CHLA, Alan Lewis, MD.

"Go-kart racing has its own risks, the risks of accidents and trauma," Lewis says.

"But Colin's particular condition and the medicines he takes don't preclude him from participating. My general approach is, when possible, to let patients participate in activities that they love."

Colin has raced for four years and competes on the national U.S. Pro Kart Series circuit. In 2014, he was among the youngest to race against the 105 best cadet drivers in the world at the Mini ROK International Finals in Italy, placing 18th in the Bridgestone Final. His goal: become a NASCAR or Indy 500 race car driver.

He's quieter than Brooke and intensely focused; his eyes light up and he beams when detailing his racing adventures. "It's just really fun," he says. "I'm a competitive person, and I like racing against the best."

His parents admit that the dangers of motorsports make them nervous. But they've seen the benefits. It's given Colin a world of confidence and a more level playing field with other kids. On foot, he'll never be fast. In the kart, it's full speed ahead.

"He'll wake me up sometimes at 5 a.m., bags packed, ready to practice," Rob says. "The track opens at 9! To see how much he loves it, to see him perform at such a high level, to know everything he's been through ... how do you say no?"

'Never give up'

Despite Colin's success, he does have limitations. He can't do nearly as much physical conditioning as his competitors; he has to take breaks when exercising.

Long term, patients with HLHS can develop problems such as heart-valve abnormalities and liver issues, Lewis says. At CHLA, cardiologists collaborate with liver and other specialists to closely monitor patients.

"It all starts with great cardiac surgery and great postoperative care, but the long-term follow-up care is also critical," Lewis notes. "CHLA has a large population of patients with HLHS, and we've developed a comprehensive, unified approach to providing optimal care. Our goal is to maximize patients' function so they can live normal, healthy lifestyles."

The Queens are extremely grateful for the care they've received at CHLA. That's why the twins joined the Junior Ambassadors, a group of kids and teens who fundraise for the hospital.



“Everyone at Children’s Hospital was amazing. They see the worst of the worst all the time. That was where we wanted to be.”

—Gretchen Queen



Earlier this year, Brooke organized a coin-collection campaign at school, raising more than \$800 for the Heart Institute. She also raised \$1,100 for CHLA’s Dreamnight event at the Los Angeles Zoo.

“I want to give back because of all the great things the hospital did for me,” she explains. “I want other kids to have a chance to live their lives and thrive.”

Using his racing connections, Colin has raised more than \$5,000 for the Heart Institute. His racing suit and go-karts sport the CHLA logo, and the family plans to auction off a kart for CHLA.

“I want to give back and help other kids with conditions like me,” he says.

The twins also hope to inspire other kids who are struggling with heart disorders. Their advice?

“Never give up. Never surrender,” Brooke says firmly. “Anything is possible,” adds Colin. “You just need to push through and fight.” 🦋

Support lifesaving care for kids like Colin and Brooke. Visit [CHLA.org/HeartKids](https://www.chla.org/HeartKids)



A Perfect Landing

By Jeff Weinstock



A desperate email, sent to the wrong hospital, inadvertently reached the one doctor who could turn Bianca Celis' life around.

"Oops."

That was the best Bianca Celis could muster after learning that the email she had sent off to Children's Hospital Los Angeles was headed well wide of the target her father intended.

"My dad, he was like, 'That's not the hospital I made your appointment at!' He just said Children's Hospital; he didn't say which one. I didn't even know there was more than one."

It was the luckiest mistake she would ever make. The email, in which Bianca explained her condition and pleaded for help, found the inbox of neurologist Terence Sanger, MD, PhD, the most favorable landing it could have had. Sanger, head of CHLA's Pediatric Movement Disorders Program, was singularly capable of tackling her illness—dystonia, a brain disorder that disrupts muscle movement and had tormented Bianca since she was 9.

Dystonia warps the signals that the brain delivers to muscles to prompt them to move, causing them to spasm involuntarily and the body to contort into painful, crooked positions.

"Every time you try to move, you get more than you want," Sanger says, explaining the barrage of nerve impulses fired out by the affected part of the brain against one's will. "It's as if you try to move one thing, and six other things are active at the same time. All of those things make it impossible to do the things that you want to do, and essentially can prevent all functional movement."

"It's as if you try to move one thing, and six other things are active at the same time. All of those things make it impossible to do the things that you want to do, and essentially can prevent all functional movement."

—Terence Sanger, MD, PhD



Early in 2014, electrodes were implanted into Bianca's brain to set the stage for deep brain stimulation.

That's the point Bianca had come to when she typed out an email to CHLA, her body beyond her control, beset by cramped and bent wrists, toes that curled inward and a bowed-over back that hindered breathing. She was 16 and had been in a wheelchair since age 12. Every attempted remedy—including medications, pool therapy, massage, supplements, and braces for her feet, legs and back—had failed. For a full year, her father drove her twice a week from the family home in Pomona to Tijuana, Mexico, where Bianca would get injected with nutrients. They were told the shots would rid her blood of toxins. That didn't work either.

Years earlier, a doctor had told Bianca that dystonia was incurable; blood tests had revealed hers was in her DNA, caused by a mutation to the DYT1 gene. But she developed workarounds to help her manage, going so far as to make herself a lefty after the disease disabled her right hand. She would use her teeth to pull things apart. She taught herself to concentrate on a given muscle to get it to follow her command, allowing her to walk for 20-30 seconds.

"I was never sad," Bianca says. "It wasn't affecting my social life. With my disease, never, to this day, have I let it put me down."

But once or twice a year, she'd feel desperate. It was on one of those days that she wrote to CHLA.

"The only way to recover from this was to take things into my hands," she says. "I wanted an answer. I wanted help. I wanted a cure."

CHLA answered her email, and within a week she was in Sanger's office. He presented her with another option: deep brain stimulation, or DBS, a technique that implants electrodes in the malfunctioning areas of the patient's brain that control movement. Pulses are delivered to those electrodes through wires connected to a small device—a neurostimulator—embedded in the chest; Sanger calls it "a pacemaker for the brain." The stimulation is something of a misnomer, he explains.

"Although we call it stimulation, these wires are probably serving to actually block the electrical activity coming from nonfunctioning areas of the brain." Why probably? "We don't fully understand why this works," Sanger says. "But the fact of the matter is that it does work."

The most common use of DBS is in adult patients with Parkinson's disease, but dystonia responds to it "exquisitely," says



CHLA neurologist Terence Sanger, MD, PhD, offered Bianca a way forward.

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"I still have moments when my right hand gets a little bit tense when I'm driving, but it's tolerable."

—Bianca Celis

CHLA neurosurgeon Mark Krieger, MD. "We can actually turn off pathways that may be affecting function negatively."

Early in 2014, in separate procedures, Krieger, CHLA's head of Neurosurgery, and neurosurgeon Mark Liker, MD, implanted two wires into Bianca's brain and the neurostimulator into her chest.

For the first few months afterward, the results weren't as powerful as she had hoped, as Sanger tinkered with the electroactivity being transmitted to the brain. A certain strength, for example, might loosen her wrist but cramp her feet.

A turning point came in April 2014, when on an outing to a Los Angeles Dodgers game, a friend urged Bianca to ditch the wheelchair and start walking. "You know what? I did it," she says. "I did it from the car to the seat and from the seat back to the car. It helped me see that the DBS was working."

By July, she had stopped using the wheelchair altogether. "I never touched it again to this day."

Nearly three years since the surgeries, DBS has kept virtually all the symptoms of her dystonia in check. "I can walk, I can stand,

I can speak," Bianca says. "I actually went jogging yesterday with my mom."

As of last January, she added another activity to the list. "It was unimaginable," she says of the notion that she would ever drive. "I couldn't even put the key inside the ignition because my hands wouldn't let me. I still have moments when my right hand gets a little bit tense when I'm driving, but it's tolerable."

That right hand is still a struggle. It was the part of her body where dystonia first manifested when she was 9, and as she turns 20 in December, it's the one area that DBS hasn't been able to solve. She sees Sanger every three months for Botox injections to relax the hand.

The disease will always be present, Sanger says, but "overall, her function is much, much better."

"This is really one of the greatest things that I've ever done in my career," Krieger says. "I promised Bianca that if this works, we'll all be able to dance at her wedding."

And that, miraculously, will include the bride herself. 🌈

Support life-changing care for patients like Bianca. Visit [CHLA.org/BIANCA](https://www.chla.org/BIANCA)



Bianca at the family's home in Pomona with her dad, two younger sisters and dog Layla



The Unstoppable Fiona Ashe

A prosthetic leg can't keep the exuberant 5-year-old from dancing, bike riding, or hiding from her mother when they're out shopping.

By Jeff Weinstock

Don't believe what Fiona Ashe may tell you. Her parents did *not* purchase her at Target, though after hearing that claim enough times, her mother finally agreed to it.

"Two weeks ago in the car," Angie Ashe says, "she was like, 'Where did you buy me from?' I just kind of chuckled. 'We didn't buy you from anywhere. Do you mean where were you born?' 'No, where did you buy me?' I couldn't answer her correctly. I kept saying, 'You were born in China; we adopted you.' Finally, I said, 'You want me to say we bought you from Target?' She just smiled. 'Yeah, you bought me from Target.' OK!"

As charming a story as that would make, the truth is equal to it—and considerably more plausible. It starts with longstanding plans that Angie and her husband, Rob, had made to adopt a child. "That was on the table even before we got married," Angie says.

Their intentions became more focused after their first daughter, Elliot, was born with arthrogryposis, a disease that disrupts joint movement. Elliot's case is extreme: Born with her arms stuck straight and her legs bent, she has been a patient at Children's Hospital Los Angeles since infancy and has undergone numerous surgeries and years of physical therapy.



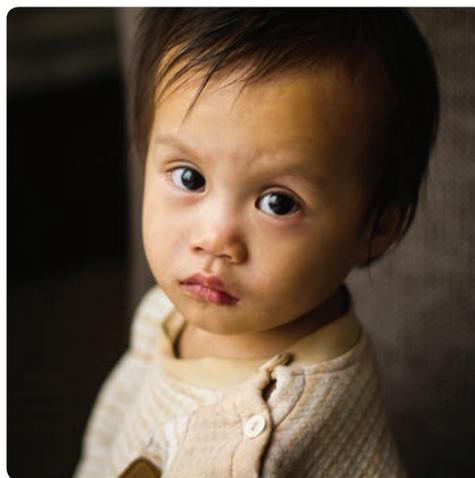
Her condition led Angie and Rob to look abroad for a second child with special orthopaedic needs, one they could spare from an orphanage. "We were hoping to use all the same doctors," Angie says.

Searching the adoption agency's website, they found 1-year-old Zi Qin in an orphanage in the city of Luoyang, in central China. The girl, to whom they would give the name Fiona, suffered from amniotic banding syndrome, wherein stringy bands of tissue form on a baby's body in utero, wrapping around limbs, making deep creases in the skin, obstructing circulation, and deforming legs, feet, arms and fingers, potentially to the point of severing them.

Fiona suffered banding on all her extremities. The right leg got the worst of it, growing to a much shorter length than the left, with a misshapen foot on the end of it that was hardly a foot at all, but a swollen, calloused lump that Fiona would drag around, unable to slip a shoe over it. She would bend her left leg to nearly 90 degrees to compensate for the shorter right leg and allow her right foot to touch the ground. She walked in kind of a crouch, Angie says, "like a pirate."

When Angie and Rob arrived in China late in 2013 to receive Fiona, they were taken by how little she was. "She was 2 years old and like 14 pounds," Angie says. "The smallest kid of all of them."

She wasn't malnourished, just tiny. She would cup her food in her hand as if trying to shield



"The smallest kid of all of them," her mother says, recalling Fiona at the time of her adoption from an orphanage.



Months in a cast after having her right foot amputated couldn't dim Fiona's spirit.

it, a habit Angie took as an indication that the bigger kids in the orphanage would steal from her. "We'd get a muffin at the hotel buffet, and she would hold it for three or four hours till it finally started crumbling in her hand. I think she was trying to hide more for later."

Once home in Santa Clarita, Angie brought Fiona to CHLA to see orthopaedic surgeon Deirdre Ryan, MD, and plastic surgeon Joan Wright, MD. She anticipated the right foot couldn't be saved. "You could just see that no brace was going to shape it into a usable foot," she says.

Nor was the way Fiona walked viable for very long, Ryan explains: "If you walk on the side or top of the foot, the skin is more likely to break down and you can get infections and other problems." Replacing the foot with a sturdy, weight-bearing surface, she says, "is sometimes just easier for lifelong well-being."

Before Ryan could operate, the amniotic banding had to be treated. In May 2014, using a plastic surgery technique called a Z-plasty, Wright cut away the abnormal tissue and leveled out the deep indentations created by the bands, leaving behind just some faint scarring.

(continued on next page)



Angie Ashe (left) says her daughter knows she has a prosthetic leg; she just doesn't know that it's supposed to matter.

No surgery is planned to address her fingers, most of which are stubs, casualties of the banding. "In the fingers you want feeling," Wright says. "A prosthesis would get in her way and she wouldn't use it. It's like a Halloween hand. Put one of those hands on and try to do things. The rubber is in the way and you can't really feel things, so you take it off as soon as you can."

As is, Fiona manages just fine. Fortunately, the one digit to develop in full on both hands was the thumb. She pinches it with the other partial fingers to grasp things. "As far as she knows, she's completely functional," Angie says. "She can draw, cut with scissors—do everything."

One exception is gripping the monkey bars on the school playground. That's not a bad problem to have, Angie says. "We're fine with her not being able to do that."

At this point, Fiona's orthopaedic issues are secondary. "Right now the bigger deficit is behavior," Angie says, laughing. "She has a habit of hiding in the racks at Target and refusing to tell me where she is. Things like that."

Plus, there's her fondness for removing the prosthesis and throwing it at her mom from the back of the car. "She knows that it gets a rise out of me if she throws it at me 'cause I don't want it to crack and break any more than it already has."

In sum, their new normal seems altogether ... normal.

"We've reached a point where we've forgotten all the disabilities she had and realized she's just kind of an obnoxious 5-year-old." 🌈

Help kids like Fiona run, jump and just be kids. Visit [CHLA.org/FIONA](https://www.chla.org/FIONA)

After allowing several months for Fiona's skin to heal, Ryan moved ahead with amputating her right foot. Angie says they tried to make it a happy occasion, imagining for Fiona the new capabilities she would have with her powerful new prosthesis. "We told her, 'You're going to get a robot leg, you're going to be able to wear two shoes, and you're going to be able to ride a bike,'" she says. "The thing that stuck with her most was getting to wear two shoes."

For Ryan, every amputation takes a toll. "Emotionally it's difficult," she says. "You never like cutting something off of somebody. But I know it was the right thing to do for her. She's functioning fantastically, much better now than when she was having to walk on top of a malformed foot."

Four months after the surgery, Fiona received her prosthetic leg. "She was up and walking

around in five minutes," Angie says. "She wore it to preschool the next day."

It fits atop the existing portion of her right leg and adjusts to the same length as the left, and includes a foot that fastens onto the end of it. She's now on her fourth detachable foot, having cracked and worn out the previous three with her energy and lack of regard for instructions. She flies around on it without any hesitation or limp, only pausing to groom it. "She sits and paints the toenails," Angie says. "Usually it doesn't look that great because she does it herself."

Wright says that any well-intentioned pity is misspent on Fiona. "We all look and say, 'Oh, gee, how sad,' while Fiona is oblivious and thinks, 'Wow! Life is fun!'"

"You have to look at it from her standpoint," Wright says, noting that all Fiona has ever known is one fully functioning leg. Two might baffle her. "She'd think, 'How would it even work if you had two good legs? How would you walk with *those*?'"

She knows she has a leg that's different, Angie says, "but I don't think she knows it's supposed to *matter* that it's different."

Certainly it doesn't matter to her. She dances, rides a bike, works a scooter. "Basically," Ryan says, "Fiona's unstoppable."



Deirdre Ryan, MD

A young girl with short brown hair, wearing a bright red sleeveless dress and green sneakers, stands on a blue trampoline. She is holding onto the black ropes of the trampoline and looking off to the side with a slight smile. The trampoline is set up outdoors in a park-like setting with a large tree trunk and a metal fence in the background. The ground is covered with grass and fallen leaves. A blue semi-transparent text box is overlaid on the left side of the image.

“As far as she knows, she’s completely functional. She can draw, cut with scissors—do everything.”

—Angie Ashe, Fiona’s mother



DOMSTRONG

Dominic Leone beats a tough-to-diagnose cancer—and gives back.

By Sara Nafie



With his bright smile and gentle disposition, 8-year-old Dominic Leone makes friends everywhere he goes. He doesn't spend as much time at Children's Hospital Los Angeles as he used to, but just say "DomStrong" to doctors or nurses at the hospital, and chances are good that someone will know exactly whom you're talking about.

Dominic Leone with CHLA therapy dog Presley, during his second round of inpatient chemotherapy in March 2015

(continued on next page)

The journey that brought Dominic from his home in San Diego to CHLA began when he was 6. It was November 2014, and the Leone family of five had just returned home from vacation in New York. Dominic's mom, Larrilyn, recalls that everyone was a bit under the weather, so she wasn't too worried when Dominic asked to stay home from school.

He felt well enough for school the next day, but when his mom picked him up in the afternoon, she was struck by the heavy, dark circles under his eyes. Larrilyn asked, "Buddy, are you OK?" to which Dominic simply replied, "My eyes really hurt."

For the next few days, Dominic alternated between feeling OK and feeling really awful. On several occasions he vomited, and when he started complaining of an excruciating headache, Larrilyn and Vince, Dominic's dad, sensed they were dealing with something more significant than a virus. They rushed him to the emergency department at their local hospital, and a CT scan confirmed their worst fears: There was a mass in Dominic's head.

With neither an oncologist nor a neurosurgeon on staff, their local hospital was no place for a kid with a brain tumor. Dominic was transferred to the nearest children's hospital for a biopsy and, hopefully, a diagnosis. Larrilyn remembers hearing, "We don't know what it is, but it needs to come out."

The delicate surgery to remove the tumor was successful, but after weeks of evaluation—by



Girish Dhall, MD



Dominic in the Joyce and Stanley Black and Family Healing and Meditation Garden during another inpatient stay at CHLA, mid-2015

pathologists at three well-respected medical institutions around the country—they were no closer to a diagnosis. Each of the pathology reports indicated it was a central nervous system (CNS) germ cell tumor, but in other respects the reports were inconsistent. No one seemed to know how to help Dominic.

"Not knowing is the worst part of it," Larrilyn says. "We kept hearing, 'It's a germ cell, so here's standard protocol.' Well that's just not good enough for some of us. I was grateful the tumor was out, but now what do we do?"

In January 2015, the road ahead started to become clear. That's when Dominic's oncologist in San Diego told Larrilyn to drive up to Children's Hospital Los Angeles—and meet with Neuro-oncology Program Director Girish Dhall, MD.

"When I first met Dominic, I realized that it had been almost two months from his initial tumor resection, yet there was still a lack of

direction as to what the diagnosis was and what the treatment plan should look like," says Dhall.

Dhall called on Alexander R. Judkins, MD, head of CHLA's Department of Pathology and Laboratory Medicine, to conduct an extensive analysis of the tumor. Together they determined it was a mixed germ cell tumor containing germinoma and embryonal carcinoma elements—a more difficult type of brain tumor to treat. Whereas treatment for a standard germ cell tumor might be four rounds of chemotherapy and four weeks of radiation, Dhall knew they needed to be more aggressive in Dominic's case.

"For the first time I thought, OK, we know what we're up against," says Larrilyn. "I just had a level of confidence in him that I hadn't had in anyone else up until that point. Although it was a complex diagnosis, Dr. Dhall had a plan, and I knew he was going to see it through."



Alexander R. Judkins, MD

cycles of chemotherapy, followed by seven weeks of radiation—with a wider field of irradiation and a higher dose of radiation to the tumor bed than patients typically get. Dhall’s plan worked; since Dominic completed radiation last August, all of his scans have been clear.

“Dominic tolerated the treatment well and he remains cancer-free,” says Dhall. “We will continue to monitor him very closely for any signs of tumor recurrence, as well as any long-term side effects.”

Every three months now, Dominic and his mom take a “mini vacation” to Los Angeles, where they stop by the hospital for labs and an MRI.

“So much of this journey is negative and difficult to endure—it becomes mentally and physically exhausting,” Larrilyn says. “So we turn it into something fun and positive. We look forward to popping in to say hi to everyone, and when our CHLA friends take a moment out of their day to offer that to Dominic, it means the world to him.”

As sure as she felt about Dhall’s ability to treat her son, the Leone family still had a tough decision to make. Larrilyn and Dominic would have to spend months away from San Diego and their close-knit community of friends and family—including Dominic’s twin brother, Logan, and sister, Addison. “As a mom, it’s not easy leaving two of your children at home,” says Larrilyn. “But it was a straightforward decision at the same time.”

From February through August 2015, Dominic underwent an aggressive treatment regimen to rid his body of cancer. Under Dhall’s expert care, Dominic endured six

Through the seemingly endless months of treatment, Dominic stayed strong—“DomStrong.” That’s the motto his family adopted, which is boldly spelled out on the T-shirt he wears every time he comes to CHLA for a follow-up. From the start, his hopes and spirits have been bolstered by the caring doctors, nurses and staff at Children’s Hospital.

“They are a very special group of individuals,” Larrilyn says, “so it was actually hard coming home. After spending so much time at CHLA and away from our family and friends, the nurses and staff become your family and friends.”



“DomStrong” is the motto Dominic’s family adopted.

With all that Dominic has been through, he is still the optimistic and generous boy he’s always been. When his friends and family threw a DomStrong party to celebrate the end of radiation treatment, Dominic asked everyone to bring a toy. On his next visit to CHLA, he delivered over 200 toys to help make time in the hospital easier for other kids. He plans to organize more toy drives in the future.

After a busy, fun-filled summer, Dominic started third grade in the fall. Although he’s still recovering from the radiation and gets fatigued more easily than his brother and sister, he always finds the energy for his favorite sport: basketball.

“In his eyes,” Larrilyn says, “he’s back and feeling good, like he can do anything anyone else can do.” 🦋

Help save the lives of kids like Dominic. Visit CHLA.org/DOMINIC



Dominic delivered over 200 toys to kids at CHLA in October 2015.

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Support Children's Hospital Los Angeles

Every holiday season, kids all over L.A. start wishing for things they really want: new dolls, new toys, the latest video games. But when you give to Children's Hospital Los Angeles, you give kids the most special gift of all—the chance to grow up healthy.

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We Focus on Children

Everything we do at CHLA is designed to help children heal, and with 350 specialty programs and services just for kids, we're ready to help children recover faster.



The Best Care in L.A.

Families also come to us from all 50 states and from more than 50 countries for the high-quality care that is available to every child right in your own backyard.



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DREW BARRYMORE explains why she became a Children's Hospital supporter.



Drew Barrymore (right) with CHLA patient Cierra Campbell

Imagine: Describe your first interaction with Children's Hospital Los Angeles.

Drew: We wanted to get involved with CHLA, and really did our homework on what we could do that would be the most impactful. After many conversations, the one thing that kept resonating with me was how dedicated these parents were to their sick children and how often they forget to do anything for themselves. We got inspired to do something the kids could do with their mom on Mother's Day.



Drew visits with CHLA patient Camilo Lozano.

Imagine: Can you talk more about that Mother's Day event?

Drew: We got our company, Flower Beauty, involved, and did a Mother's Day pampering event. We called the biggest makeup artists, nail-art people and hairstylists, set up giant Hollywood movie-lit mirror stations, brought in a ton of Flower Beauty product and set up a beauty salon. The kids signed up for an "appointment" to bring their mom and have a special makeover together.

It's a day for the moms, but it was really fun to see the kids do something special for them for Mother's Day. These moms spend 365 days a year focusing on their kids and are the ultimate superheroes.

Imagine: What would you tell your daughters about philanthropy?

Drew: When my daughters were born, I made a decision that every Mother's Day I would do something in their honor. Every year I buy a card for them and tell them what I did on their behalf that day. I keep the cards in this pink shoebox that I'll give them

when they're older. Hopefully it will show them how important it is to regularly do something outside of yourself. As it turned out, the first card I got for my daughter Olive tells her how I spent the day at Children's Hospital with these mothers and their kids. Secretly, I'm hoping she'll carry on the tradition.

Imagine: What should people understand about CHLA?

Drew: When you become a parent, all your priorities, all your perspectives—everything you used to know—shifts. Your only concern in life becomes keeping this little human safe and protected. But sometimes it's out of your control, and luckily our community has Children's Hospital Los Angeles for those times. When I'm here with the children and their families, we always talk about how kind everyone is here. The level of care is a different experience, and when you're going through what these parents are going through, for them to feel this means everything. 🦋

LIVE L.A. GIVE L.A.
If you'd like to join Drew Barrymore in supporting Children's Hospital Los Angeles, visit [CHLA.org/DREW](https://www.chla.org/DREW)



Children's Miracle Network Hospitals® Partners Fiscal Year 2016

HONOR ROLL OF FRIENDS

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 \$9 million, an increase of more than \$1 million from the prior year.

We are honored to have amazing corporate partners and their associates, leadership and customers dedicated to supporting our patients and families. Many of our CMNH Partners participated in our inaugural Make March Matter campaign this year, focusing on raising awareness and funds for Child Health Month. The month ended with a celebration and acknowledgment of the dedicated partners that support CHLA all throughout the year.

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. Their 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, visit CHLA.org/CorporatePartners.

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Children's Miracle Network Hospitals Partners throughout the year: **1.** Keith Sultemeier of Kinecta Federal Credit Union (left), CHLA Junior Ambassador Jax Malcom, and CHLA President and CEO Paul S. Viviano. **2.** Randy Wines (left) and Chad Donath of Walmart, CHLA Senior Vice President and Chief Development and Marketing Officer DeAnn Marshall, MHA, CHLA Vice President of Corporate Partnerships Dawn Wilcox, and Javier Angulo of Walmart. **3.** The CHLA Corporate Partnership Team at Mega Miracle Day celebrating Make March Matter. **4.** Amanda (left) and Ella Annear, CHLA patient family.

Children's Hospital Los Angeles HONOR ROLL OF DONORS

For the time period of July 1, 2015, through June 30, 2016

At the turn of the 20th century, a group of caring individuals recognized that the city of Los Angeles lacked a hospital equipped to care for children—and so began Children's Hospital Los Angeles. Founded in 1901, the hospital was created with the strength and resolve of its founding members—a legacy that continues on through a generous community of supporters and philanthropic partners. More than a century later, Children's Hospital Los Angeles is proudly recognized as a worldwide leader in pediatric and adolescent health. Through expert clinical care, research and medical education, Children's Hospital continues to create hope and build healthier futures for children and families in our community and beyond.

Generous individuals, organizations and foundations have played an instrumental role in our efforts to give children the opportunity to lead healthy and happy lives. Philanthropy has supported the important work performed by our physicians, nurses and caregivers; accelerated leading-edge research to unearth innovative new therapies; and educated and trained the next generation of pediatric experts.

Our extraordinary donors make all of this possible, and we are honored to acknowledge them for their generosity during fiscal year 2016. 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.

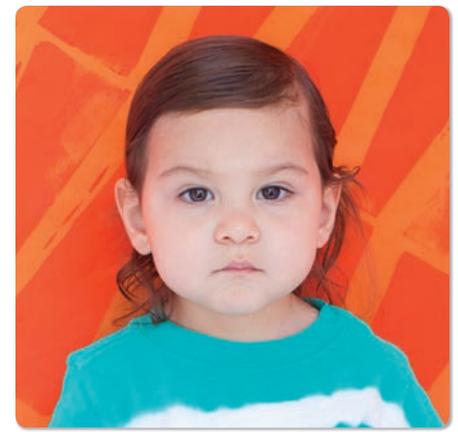
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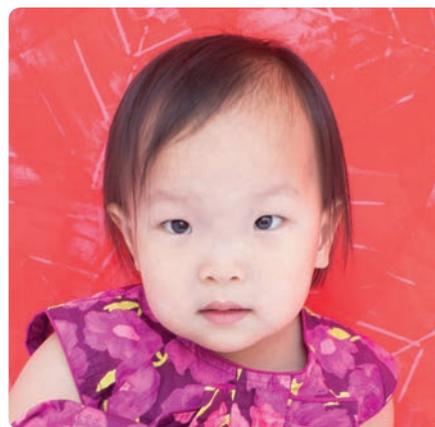


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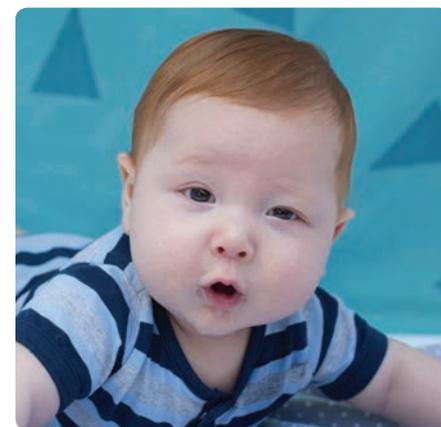
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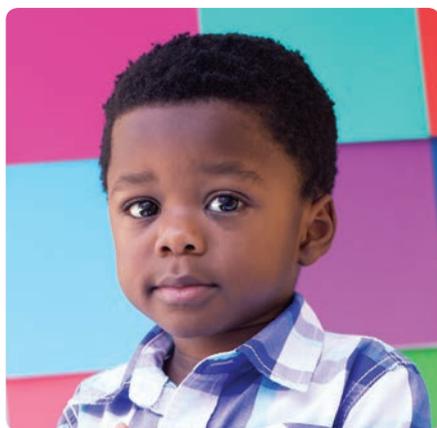
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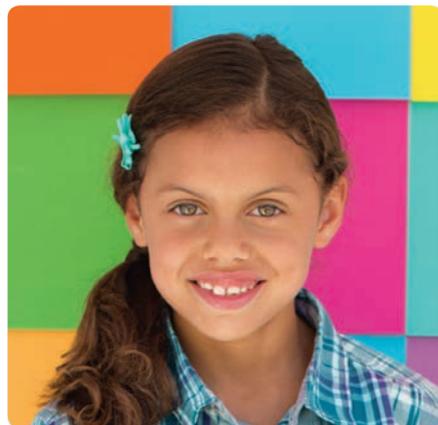
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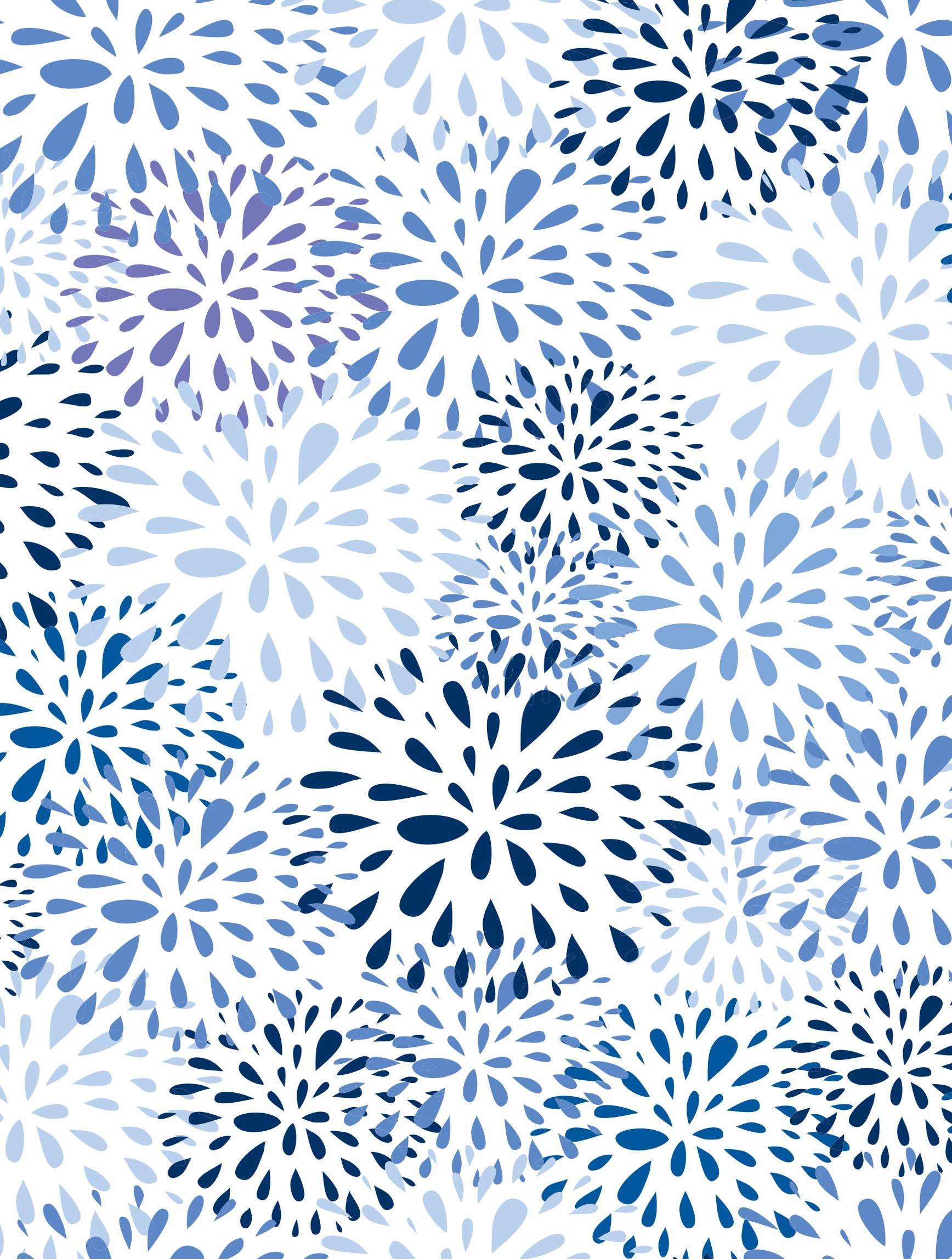
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rbianco@chla.usc.edu

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mdovale@chla.usc.edu

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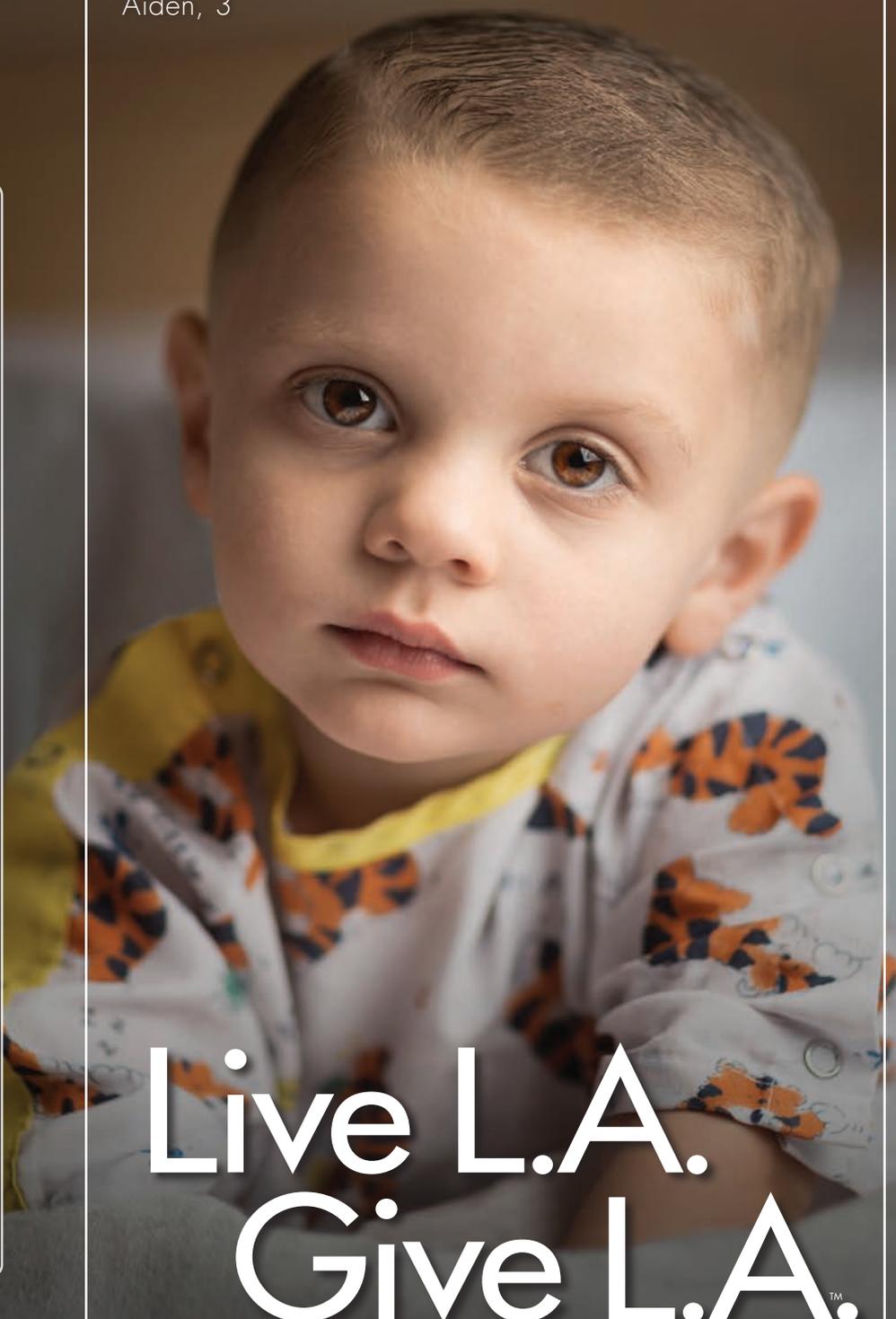
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