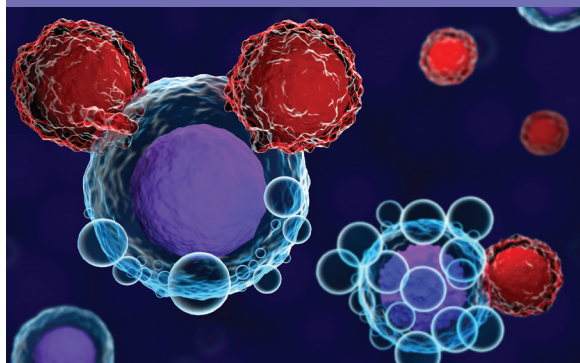


A newsletter for friends and supporters of UCSF Benioff Children's Hospitals

UCSF First in State to Provide CAR-T Therapy



Juan Rodriguez was an active 5-year-old who loved taekwondo. Then one morning in June 2016, he woke up in intense pain. "We took him to the hospital, and they told us he had cancer," recalls his mother, Mariana. "There was no warning."

After a year of treatment near his Modesto home, Juan underwent a bone marrow transplant at UCSF Benioff Children's Hospital San Francisco, but it didn't wipe out his cancer. Luckily, UCSF recently had become the first medical center in California to provide a groundbreaking new treatment for children and young adults with acute lymphoblastic leukemia (ALL), the most common pediatric cancer.

For years, the foundations of ALL treatment have been surgery, chemotherapy, and radiation therapy. CAR T-cell therapy offers a radically different approach. A patient's T-cells are extracted, engineered in the laboratory to fight cancerous cells, then returned to the patient, where they multiply and attack the cancer.

"This is a complete game-changer," says Jennifer Willert, MD, Juan's oncologist.

After the therapy, Juan's cancer went into remission. "He was back on his feet in no time," Mariana says. "It wasn't hard on him like chemo or other treatments he's been through."

This is a huge advantage for treating pediatric patients, Willert says. Standard treatments are toxic and often cause later complications like secondary cancers, hormone problems, and memory loss.

"We hope to get to the point where we don't have to do chemotherapy, only cell therapy," Willert says. "Here at UCSF, we're on the forefront of precision cancer medicine. This is a powerhouse place, and it's an exciting time."

A Milestone for Bay Area Kids

Oakland Campus Opens Newly Expanded Outpatient Center



Front row, from left: Patients Isabel Bueso and Bisan Alkherej; middle row, from left: Oakland City Councilman Dan Kalb; UCSF Benioff Children's Hospitals president Dr. Michael Anderson; Oakland mayor Libby Schaaf; patients Emma and Isabelle Ziegler and their mother, Elizabeth Epstein; patient Leah Carroll and her mother, Lindsay Bolin; back row, from left: UCSF Health president and CEO Mark Laret and UCSF Chancellor Sam Hawgood.

Community members, hospital staff, and elected officials commemorated the grand opening of the new outpatient center on our Oakland campus in April.

This state-of-the-art facility adds 89,000 square feet of exam rooms, treatment facilities, and family support services, making UCSF Benioff Children's Hospital Oakland the East Bay's largest specialty care center for kids.

Decked out in bright colors and kid-friendly art, the center provides clinic space and enhanced technologies to the infants, children, and teens who visit for outpatient care nearly 230,000 times every year. For our families, this means more streamlined navigation when consulting with our specialists in cardiology, dermatology, outpatient surgery, physical rehabilitation, neurology, and neurosurgery.

A rehabilitation center offers a spacious physical therapy gym and an outdoor agility course. Designated rooms for our cystic fibrosis patients are equipped with special air filters to reduce cross-infection.

The completion of the expanded outpatient center is the first major milestone in the hospital's master plan project, which aims to modernize the campus and meet the state's updated seismic safety standards by 2020.



Physical therapists demonstrate the hospital's new exoskeleton, a robotic brace designed to help young patients recover from conditions that have hindered their motor skills.

"By constructing new facilities and modernizing existing ones, we can continue to provide highly specialized health care to all children in the region and beyond, regardless of their family's financial circumstances," says Michael Anderson, MD, president of UCSF Benioff Children's Hospitals.

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A Winning Plan Elam, Age 11

Amanda Mallory will never forget the moment Kurtis Auguste, MD, appeared in the waiting room on the day of her son Elam’s brain surgery.

She’d been told the operation to combat Elam’s crippling epilepsy would last until after 9 p.m. But it wasn’t even noon, and the surgeon was standing in front of her.

Dr. Auguste asked the Mallorys to join him in a nearby conference room. “It was the longest walk of my life,” Amanda recalls.

Elam was stable, but Dr. Auguste shared alarming news: Elam’s heart had stopped twice during surgery. There was no choice but to call off the operation.

At many hospitals, the story might have ended there. But with Elam’s quality of life degraded by debilitating seizures, what followed instead was a quest by Dr. Auguste, director of pediatric epilepsy surgery at UCSF Benioff Children’s Hospitals, to ensure Elam could get the care he needed.

After two years of treatment in Southern California, Elam’s parents brought him to UCSF. The Mallorys learned that a stereo EEG, which their previous hospital didn’t offer, could determine



After suffering from years of debilitating seizures, 11-year old Elam underwent a complex surgery performed by UCSF’s Dr. Auguste. Within an hour of waking up from the procedure, Elam reported feeling better than he had in his entire life.

where in Elam’s brain his seizures originated, making corrective surgery possible. “It was the first time I felt hope in years,” Amanda says.

They discovered the focal point was the occipital lobe, the brain’s visual processing center. Surgery could stop Elam’s seizures, but half of his visual field could be limited.

Elam had no doubt in his mind: He wanted the surgery. But that initial attempt ended soon after it began, when his heart stopped on the operating table.

“I didn’t want to go through it again, but Elam was adamant, even with the knowledge that his life was at risk,” Amanda says.

“ It was the first time I felt hope in years. ”

– Amanda Mallory, grateful parent

Dr. Auguste partnered with the cardiology department to come up with a game plan. A specialized breathing tube would be placed in Elam’s airway to electrically pace his heart if needed; an esophageal ultrasound probe would allow them to monitor his heart and air intake. A special anesthesia would help stabilize his heart’s electrical activity.

Later that day, when Dr. Auguste appeared in the waiting room, he brought the Mallorys back to the same conference room. “But this time it was a much different conversation,” Amanda says. The surgery had gone flawlessly.

“Within an hour of waking up, Elam said, ‘I feel better than I have in my entire life,’” Amanda says. Elam, now 11, has been free of debilitating seizures ever since. And he can run, draw, and even ride a bike.

In Case of Emergency, Experience Matters

Sudden health problems are never more frightening than when they involve kids. It can be hard to know when to rush a child to the emergency room – and what to expect when you arrive.

On April 26, community members joined our clinicians and other care providers for an evening of hands-on learning to discover the latest trends and technology in our emergency rooms.

Jackie Grupp-Phelan, MD, chief of the Pediatric Emergency Medicine Division, outlined why bringing kids in crisis to a dedicated pediatric emergency room makes a big difference.

“From the physicians to the nurses to the pharmacists, everyone is trained to take care of kids, and we are passionate about it,” she said. “Experience matters. We understand that one size does not fit all, and kids are not small adults.”

Interactive stations demonstrated the latest technology and care techniques, such as a needleless injection system that uses air pressure to pass a stream of liquid through the skin – virtually pain free.

“I’ve even had a little girl sleep through me putting in her IV,” said nurse Barbi Feldhauser. “That had never happened before.”




Our expert physicians gave community members a peek behind the scenes at the emergency room. From left: Dr. Karim Mansour, Dr. Jackie Grupp-Phelan, Dr. Margaret Lin, and Dr. Kevin Whitelaw.

Child life specialists shared tactics they use to help kids relax and understand what they are experiencing. These included a stuffed dog with its legs wrapped in multi-colored casts, a colorful “hurricane tube” illumination, and TheraSand, a captivating substance that behaves like wet sand but is dry to the touch.

Point-of-care ultrasound is increasingly being used to assist in decision-making when treating common pediatric emergencies. One of the pioneers in this field, Aaron Kornblith, MD, assistant professor of emergency medicine at UCSF, shared how this technology gives ER doctors important information about injuries and illnesses much faster – with life-saving results.

“You don’t have to listen to the heart,” he said. “You can look at it now.”


Fast Facts 2017

 Northern California’s leading pediatric emergency service provider

 **60,212** emergency room visits

 **741** patients were transported to our hospitals by helicopter

 **30+** subspecialties, with experts on call 24 hours a day

 **1** of only 5 ACS Pediatric Level I Trauma Centers in California

 **0** families turned away due to inability to pay

Want to join the conversation? For more information about the Conversations on Children’s Health series, please email us at foundation@mail.cho.org

Unraveling the Mystery of Pediatric Stroke

When you picture someone having a stroke, you probably envision a senior citizen, and for good reason. Each year, nearly 800,000 Americans suffer a stroke, and most are over age 65. But a small fraction — about 4,000 — are children.

The devastating consequences, including difficulty with speech, physical impairments, and personality changes, can last the rest of their lives. That’s why our experts are working to improve treatment for these kids and stop strokes before they start.

Because pediatric stroke is rare, it’s hard to understand the causes and develop treatments, says Heather Fullerton, MD, chief of child neurology at UCSF Benioff Children’s Hospital San Francisco.

“A physician might say, ‘Well, this is what I do for a 60-year-old, so that’s what I’ll do for the 12-year-old I’m seeing now,’” Fullerton says. “But they can’t be handled the same way.”

Fullerton embarked on a quest to find out why kids have strokes and establish a place for world-class care. In 2006, she established the country’s first pediatric stroke center at UCSF, which now draws patients from across the nation. Three years later, she launched the first comprehensive research study to unlock the mysteries of pediatric stroke, enrolling more than 700 children at 37 hospitals worldwide.

Her team discovered that almost half of children who had a stroke also had an acute

“ These are kids who are perfectly healthy, and we watch them deteriorate in front of our eyes. I have to do something to try and stop that. ”

– Heather Fullerton, MD

herpes virus infection, which causes cold sores, chicken pox, and other common illnesses. That knowledge has influenced how pediatric stroke is treated globally.

Fullerton is taking her research further with a new study, this time tapping into groundbreaking technology developed at UCSF by Joe DeRisi, PhD, professor of biochemistry and biophysics. By comparing data from hundreds of kids, the study aims to find patterns among stroke victims and pinpoint other infections that increase risk, which will offer new clues about prevention and treatment.

The ultimate goal, Fullerton says, is to prevent pediatric stroke. She has got a long way to go, but she also has strong motivation: her patients.

“These are kids who are perfectly healthy, and we watch them deteriorate in front of our eyes,” she says. “I have to do something to try and stop that.”

Notes & Words Rocks the Fox Theater



Dave Grohl, frontman of rock band Foo Fighters, joined renowned authors on May 12 for the ninth annual Notes & Words at the historic Fox Theater. This one-night-only event raised over \$1.8 million for our Oakland campus.

Grohl had a rare treat for the audience: His 12-year-old daughter Violet joined him to perform a show-stealing Adele cover. “I remember her saying, ‘Dad, you’re not even the best singer in the family,’” Grohl joked. “And she’s right!” Younger daughter Harper also took the stage to play drums. And, in honor of Mother’s Day, Grohl dedicated the song “My Hero” to his mother, Virginia, who was in the audience.

Writer George Saunders, recent winner of the prestigious Man Booker Prize, shared his darkly humorous prose. Kelly Corrigan, who launched Notes & Words in 2010, revealed wisdom from her most recent bestseller. Guests also enjoyed creative performances by talented local teens.

Visit notesandwords.org to see photos from this unforgettable event.

Tuning Into Music’s Healing Power

Gregg and Laura Perloff know the immense power of music. That’s not just because Gregg is CEO of Another Planet Entertainment, which produces major concerts like the annual Outside Lands festival in Golden Gate Park.

They also have a more personal connection: Music helped the Perloffs’ son, Spenser, recover after he suffered a stroke at age 13. Rushed to UCSF Benioff Oakland, Spenser underwent surgery within hours. Listening to music motivated him during the months of recovery that followed.

“Music comforted and energized him,” Laura recalls. “It would get him on that treadmill.”

The hospital didn’t have a music therapy program at the time, so the Perloffs helped establish one. Celebrating its 10th anniversary this year, the Jared Kurtin Music Therapy program, named in memory of a patient, was the first of its kind in the Bay Area. Oakland therapists currently offer almost 1,300 sessions each year, and the therapy program also thrives on our San Francisco campus.



“ Will the memory they take home be of a terrible situation, or will it be of the day they wrote a song and made their mother smile? ”

– Laura Perloff, grateful parent and donor

It’s proven tremendously effective. Music therapy helps manage pain, lowers rates of depression, and calms patients in distress. Music can bridge language and cultural barriers, and it creates a sense of normalcy in the often-intimidating hospital environment.

“The music therapists are absolutely incredible,” Laura says. “They are so sensitive to what a child needs and knowing how they can help. They are my heroes.”

The program is supported entirely by generous donors like the Perloffs, who recently made a

significant new investment in the program: a matching gift of \$1 million. That means all gifts will be doubled, and more kids can benefit from the life-changing therapy.

“These kids are in the hospital just trying to be strong,” Laura says. “Will the memory they take home be of a terrible situation, or will it be of the day they wrote a song and made their mother smile? Our contributions can make that difference.”

To learn more, visit crowdfund.ucsf.edu/perloffmusictherapy

Help Us Help
Kids Like Joy



The Promise of Gene Therapy

Joy Littlesunday is an irresistible kid with a gravitational pull that triggers a hug from every person who crosses her path.

Though only 4 years old, Joy is making up for lost time. She was born with a genetic disorder that left her without an immune system – which meant that merely brushing against someone with a cold could have been life-threatening for her.

A bone marrow transplant at UCSF Benioff Children’s Hospital San Francisco when she was 2 months old saved her life.

With every gift you make, you help us help amazing kids like Joy. Your investment supports leading-edge care that brings hope and healing to young patients and their families.



Make your gift today at
give.ucsfbenioffchildrens.org
or by returning the attached envelope.



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