

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

UCSF Benioff Children's Hospitals Ranked Among Nation's Best

Finding the best medical care for a child with a rare or life-threatening condition is one of the most challenging experiences parents face. The *U.S. News & World Report* rankings for Best Children's Hospitals open the door to an array of detailed information to help make a family's search a little easier.

The publication's 2015-2016 rankings rated UCSF Benioff Children's Hospitals as the best in the Bay Area in five pediatric specialties:

- Cancer
- Diabetes and Endocrinology
- Gastroenterology and GI Surgery
- Neurology and Neurosurgery
- Urology

The two hospitals also were ranked among the nation's premier children's hospitals in nine pediatric specialties, including the five listed above and:

- Cardiology and Heart Surgery
- Neonatology
- Nephrology
- Pulmonology

For families of sick children, the Best Children's Hospitals rankings aggregate a wealth of information, making it an excellent resource for information, including difficult-to-find information. The report also evaluates survival rates, adequacy of nurse staffing, procedure volume, and more.

"These rankings are one more validation of our daily work to provide the best pediatric health care possible throughout Northern California," said Mark Laret, CEO of UCSF Benioff Children's Hospitals. "Patients now benefit from an even greater depth of expertise and innovation that comes from working together at our two campuses."



The complete list of children's hospital rankings is available online and will be published in the upcoming *Best Hospitals* print guide, published by U.S. News.

Full of Heart Allison, Age 17

Her parents thought Allison was just being lazy. As her dad, Rajive, recalls, "When we were in New Orleans last year, she couldn't walk two blocks. I remember her sitting on the street and saying, 'You guys do what you want; I'm going to stay here.'"

As the Dsouzas would soon learn, what plagued Allison was far from laziness.

In January, Allison listened as her biology teacher discussed heart murmurs. After class, as Allison walked up the stairs—out of breath once again—something clicked. "I thought, maybe there's something wrong with my heart."

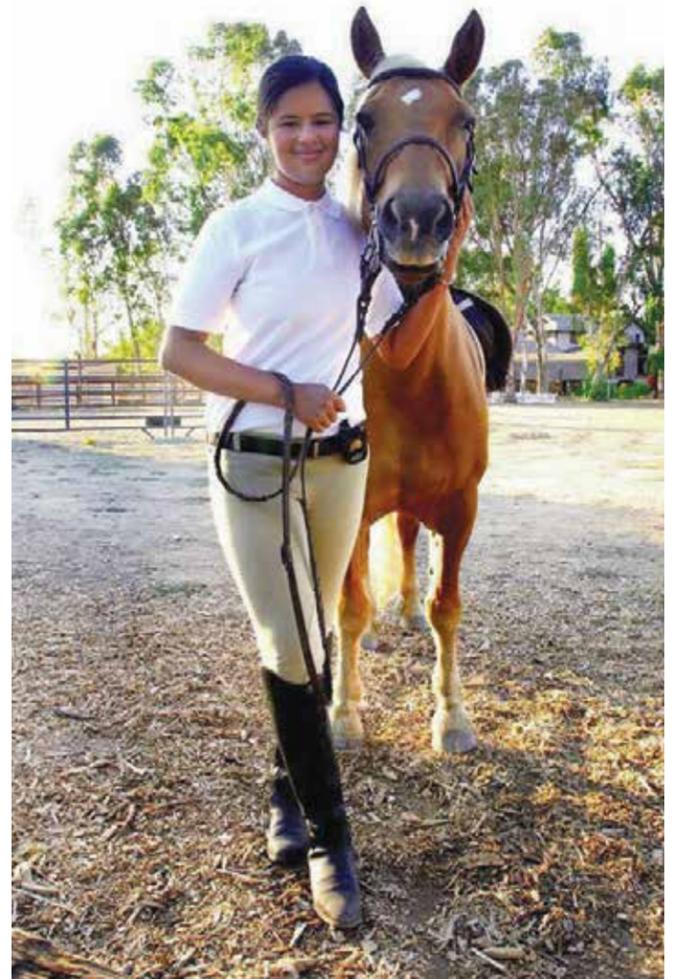
After she voiced her suspicions to her father, Rajive called Allison's pediatrician, who scheduled her for a CT scan. The results gave the Dsouzas the biggest shock of their lives: Allison's heart was enlarged. The diagnosis? Pulmonary hypertension, a rare form of high blood pressure that can lead to heart failure if left untreated.

At the pediatrician's recommendation, Rajive and Allison headed to UCSF Benioff Children's Hospital San Francisco, home to one of just two pediatric centers in the United States accredited as a Pulmonary Hypertension Comprehensive Center of Care.

An entire team of specialists from the Cardiac Intensive Care Unit, including Jeffrey Fineman, MD, was waiting for her. The next morning, Allison underwent a heart catheterization, a procedure that should have taken no more than three hours.

"It took five hours," recalls Rajive, "and Allison nearly flat-lined." The arteries to her lungs were so narrow that it was hard for blood to pass through. This raised the pressure in the arteries and caused the right side of her heart to pump harder. The right side was so overworked and enlarged that it was failing and hindering the function of the left side. As a result, Allison's lungs and body were not getting enough blood.

Allison was in the right place at the right time. As both a clinician and principal research investigator, Dr. Fineman has been instrumental in developing new therapies for pulmonary hypertension, including inhaled nitric oxide.



Expert care at UCSF Benioff Children's Hospital San Francisco helped Allison get back to riding her horse, Elsa, weeks after being diagnosed with life-threatening pulmonary hypertension.

“With my doctors and nurses supporting me, I walked the entire 5K through Golden Gate Park. I owe my life to them.”

—Allison Dsouza

Allison made a dramatic recovery in response to aggressive treatment, and just six weeks later, she participated in a 5K walk to raise money for the Pulmonary Hypertension Association.

Says Allison, an aspiring violinist, equestrian, and college-bound student: "With my doctors and nurses supporting me, I walked the entire 5K through Golden Gate Park. I owe my life to them. My family and I are so grateful to the people whose donations help support Dr. Fineman's research and events like the 5K that raise awareness about this life-threatening disease."

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Oakland Campus Set to Break Ground on Modernization Plans



UCSF Benioff Children's Hospital Oakland plans to break ground in late October on its Master Plan to renovate and expand hospital facilities. The 10-year, two-phase plan, approved by the Oakland City Council in June, will keep UCSF Benioff Oakland at the forefront of children's health. We will provide ongoing Master Plan updates throughout the construction process, highlighting major areas of investment for our community of supporters.

Master Plan Spotlight: Outpatient Pediatric Rehabilitation Center

At age 19, Russell Fowler is no stranger to therapy. He has had ongoing treatments, medication, and procedures to manage the effects of cerebral palsy since he was a baby. After a spinal fusion surgery and eight weeks of intensive inpatient rehabilitation at UCSF Benioff Children's Hospital Oakland in 2013, his life has changed dramatically.

With top-notch care from his rehabilitation team, Russell gained the strength and balance to dress, feed, and care for himself. Today, he remains in a wheelchair, but his life is completely different from one year ago. "I'm independent," he says proudly.

Russell is among the thousands of patients annually treated by the pediatric rehabilitation team at UCSF Benioff Children's Hospital Oakland. The department was established more than three decades ago by Gabriella Molnar, MD, one of the founders of this subspecialty. Today, the Oakland campus is home to the largest and most comprehensive inpatient pediatric rehabilitation center in Northern California.

As part of the Master Plan for the Oakland campus, facilities for patients like Russell will be upgraded and expanded to better serve their needs.

Central to this effort is a new state-of-the-art Outpatient Rehabilitation Center that will offer diagnostic and treatment services to infants, children, and adolescents impaired by disability, illness, or accident. The center also will provide an improved workspace for our multidisciplinary staff members who understand how these challenges can affect



Among the key features of the new outpatient center is an outdoor terrain park with a variety of surfaces to help patients practice moving safely, improving their balance and walking confidently.

children who are still growing physically and developing neurologically.

The center's features will include:

- 14 exam and treatment rooms
- Gymnasium suite
- Adaptive kitchen area
- Speech therapy room
- Procedure and medical preparation room
- Staff offices and meeting spaces
- Outdoor terrain park

Generous friends of UCSF Benioff Children's Hospitals are making this Master Plan a reality. The Colonel Harland Sanders Foundation has pledged a lead gift of \$1 million toward the construction of the new center. In recognition of this support, the facility will be named the Colonel Harland Sanders Outpatient Pediatric Rehabilitation Center.

For more information about the Master Plan, visit chonext100.org or call (510) 428-3814.

Cancer-Free and Giving Back



Campbell Nolan was 7 years old when he developed flu-like symptoms that didn't go away. It took some time for him to receive a diagnosis: leukemia, and a particularly rare kind. On the recommendation of a physician friend, his parents, Elaine and Bill, brought him to UCSF Benioff Children's Hospital San Francisco.

Campbell first saw Seymour Zoger, MD, a legendary pediatric oncologist renowned for his honest, gentle, and straightforward manner with children. "Campbell was really close to Dr. Zoger," says Elaine. Working alongside Dr. Zoger was Mignon Loh, MD, who took over when Dr. Zoger, who was then in his late 70s, passed away midway through Campbell's treatment.

“

Dr. Loh is at the very top of her career in terms of the research she's doing, but even more important for us are the incredible relationships she fosters with her patients and their families.

”

—Bill Nolan, Campbell's father

Campbell enrolled in a clinical trial at UCSF for children with his specific kind of blood cancer. Elaine and Bill were apprehensive at first. But when the doctors explained that the innovative therapies employed in the trial represented Campbell's best chance of a favorable outcome, Elaine and Bill were on board.

"It was an incredibly difficult time," Bill explains. "Once we'd decided on a protocol for Campbell, we worried about the long-term side effects of the treatments he received." Happily, those did not occur. Ten years later, Campbell is a bright and athletic 17-year-old who runs cross country and varsity track.

The Nolans have since made generous gifts to the children's hospital, including a \$100,000 pledge to help create the Deborah and Arthur Ablin Chair in Pediatric Molecular Oncology, held by Dr. Loh. Bill and Elaine have only praise for the talented physician-scientist, chief of UCSF's Division of Pediatric Hematology/Oncology.

"She's at the very top of her career in terms of the research she's doing, but even more important for us are the incredible relationships she fosters with her patients and their families," Bill says.

CHORI Summer Research Program

Amarjit Bath wakes up at 6 a.m. every day to travel from her home in Antioch to participate in Children's Hospital Oakland Research Institute's (CHORI) Summer Research Program. As the California State University – East Bay senior walks through the corridor in her white lab coat, she still can't believe that she is really here, working alongside some of the best in the field.

Born in India, Amarjit spent most of her childhood in Dubai before moving to the United States in 2003. The daughter of a truck driver and stay-at-home mother, Amarjit has always dreamed of being a doctor. Her parents encouraged her to pursue a career in computer science, but the budding physician learned early on that she was more interested in cardiology than coding.

Amarjit and 46 other students are taking part in the CHORI program, which provides education and training to high school, undergraduate, and post-baccalaureate students with a broad range of experience. Under the watch of research investigators who serve as mentors, participants spend three months conducting research in the hospital's laboratories.

Amarjit has participated in the program for the past two summers. In 2014, she worked in the Oakland lab of Deborah Dean, MD, MPH, researching chlamydia trachomatis infection. This year, she collaborated with San Francisco-based researchers Joel Palefsky, MD, and Aung Chein, PhD, on a human papillomavirus vaccination study. Other students explored topics ranging from flame retardants and their toxicity to human cells to the accessibility of orthopaedic care for Spanish-speaking patients.

"Each year we identify underrepresented students with very high potential and provide them with a welcoming environment," says Ellen Fung, MD, co-director of the CHORI Summer Research Program. "In the few short weeks we have their attention, we are amazed by how they grow, not only in their



"CHORI has nurtured my curiosity about medicine by exposing me to different facets of research," says Amarjit.



“
In the few short weeks we have their attention, we are amazed by how they grow, not only in their understanding of the scientific method but also in self-awareness and confidence.
”

—Dr. Ellen Fung, co-director, CHORI Summer Research Program

understanding of the scientific method but also in self-awareness and confidence. It is a joy to be a part of their journey.”

Years of watching her younger sister suffer from asthma and pulmonary edema, and her mother struggle with chronic illness, sparked Amarjit's early interest in medicine. With limited income, her family could not afford health insurance and had to pay for medical costs out-of-pocket. Amarjit took it upon herself to research patient assistance programs, and through her diligent efforts, she was able to get costly medications for her family free of charge. The experience stayed with Amarjit, driving her to be the first in her family to complete college and inspiring her to pursue medical school.

"I want to use my education to collaborate with health care professionals, advocate for the well-being of my patients, and conduct research on chronic illnesses," says Amarjit. She credits her time at CHORI as a major stepping stone toward realizing that dream.

To learn more about the CHORI Summer Research Program, visit www.chori.org.

Summer Camps Offer Boost to Young Patients



Fearless teens at Camp Winning Hands prepare for the ropes course and climbing wall. The overnight camp allows children and teens with hand differences to play and explore in a safe environment.

Ah, summer camp. The swimming, the sing-a-longs, the s'mores by the campfire. What child wouldn't benefit from the fun and freedom that camps provide?

Kids with special healthcare needs are no exception. But the idea can seem challenging to families who have the added worry of finding a camp that will support their child's specific condition.

UCSF Benioff Children's Hospitals manages a variety of summer camp options for children with special health needs. Select offerings include:

- **Camp Breathe Easy**—An overnight camp in Livermore for children with mild to severe asthma. The program emphasizes having fun while maintaining good asthma control.
- **Camp Creating Confident People**—A camp that combines the typical summer camp experience with group psychotherapy for children exposed to child abuse trauma or violence.
- **Camp de los Niños**—A one-week residential camp in the Santa Cruz Mountains for children with diabetes from all over California.
- **Camp FUN (Food and Understanding Nutrition)**—A six-week summer fitness program for obese children coordinated by UCSF Benioff Oakland's Healthy Hearts program and UCSF's Department of Pediatrics.
- **Camp Gut Busters**—A camp for children with inflammatory bowel diseases, founded by Dr. Mel Heyman, chief of pediatric gastroenterology at UCSF.
- **Camp Winning Hands**—A four-day overnight camp at Camp Arroyo designed for children and teens with congenital hand and upper limb differences.

Combining traditional summer camp fun with adaptive facilities and skilled staff, these camps are dedicated to facilitating a memorable experience for all kids. Support from grants and individuals allow our patients to attend many of these camps free of charge.

To donate to our summer camp programs, please visit give.ucsfbenioffchildrens.org.

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New Center for Community Health and Engagement

UCSF Benioff Children's Hospital Oakland recently announced the creation of the Center for Community Health and Engagement (CCHE). The mission of the center is to develop, coordinate, and implement a platform for population and preventive health care for children and families served by the hospital.

The center was initiated with a generous gift from Bert Lubin, MD, President and CEO of UCSF Benioff Children's Hospital Oakland, and his wife, Vivian Scharlach.

"For many children," say Dr. Lubin, "their zip code is more likely to affect their health than their genetic code. We all have a responsibility to consider poverty as a disease of childhood that needs to be addressed."

Building on this commitment, CCHE will bridge pediatric healthcare policy with community needs to improve the health and well-being of children living in poverty. The center will support existing community benefit programs



at UCSF Benioff Oakland and be a point of contact for collaboration with community organizations and universities. It will serve as an umbrella for five focus areas: government affairs and public policy, community relations, training and education, research, and grants and program development.

"The idea behind the center is to ensure that UCSF Benioff Children's Hospital Oakland maintains and grows its commitment to the ideals of health promotion, prevention, equity, and community," says Barbara Staggars, MD, UCSF Benioff Oakland's chief of adolescent medicine and executive director of the CCHE. "Our goal is to become a national leader at advancing understanding of health issues in diverse, urban pediatric populations."

Create Your Own Fundraiser

While kids across the Bay Area begin a new school year, young patients at UCSF Benioff Children's Hospitals hold on to hope for a healthy future.

Hosting an event or organizing a fundraiser are great ways to support our young patients. Build an event around something you enjoy, from running a race to throwing a birthday party.

By organizing a fundraiser of your own, you get yourself involved in our mission, and everyone who attends will have a chance to learn more about the incredible things we are doing to keep the kids in our hospital—and our community—healthy and safe.

If you're ready to take on the challenge, register your event on our website and we can help you make it a success.



For more information about creating your own fundraiser, call (510) 428-3814.