

A NEWSLETTER FOR
FRIENDS AND SUPPORTERS

Connections

FALL 2024



Easing the Burden of Complex Care

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Puppy Love

Follow our facility dogs Ahbi, Arnie, Courtney IV, and Momo around the hospital for a sneak peek at how they make our patients feel safer, stronger, and less afraid.

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Raghav's Gift

We spoke with Raghav Kohli about his decision to donate part of his liver to his nephew Tej and why giving back has become fundamental to his worldview.

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Trauma Team Saves Surfer

When 15-year-old Marcos Ornellas couldn't move his body after a surfing accident, he feared the worst. The UCSF trauma team raced to save his mobility.



I fell in love with the Bay Area shortly after moving here with my husband in 2010 from Southern California. We lived just a few blocks away from UCSF Benioff Children’s Hospital Oakland, where my brother-in-law was doing his residency in pediatrics. The whole family felt at home here, and this community became our own.

Back then I was working at UC Berkeley, leading fundraising initiatives for the College of Engineering. I was thinking a lot about impact – global and local – and pinned a button to my desk that resonates to this day: “invest in bold ideas.” That mission keeps me inspired and drives my passion for working with partners like you, who care deeply enough to invest in bold, visionary people and programs that have the potential to transform lives and communities.

It’s that mission, combined with my commitment to the Bay Area, that drew me to my new role as assistant vice chancellor and chief development officer for children’s health at UCSF Benioff Children’s Hospitals Foundation. I welcome the opportunity to partner with you to advance the innovative, patient-centric clinical care and modern facilities that will elevate pediatrics for Bay Area families. When we move the dial on children’s health, we are not only changing the lives of children and families today, but we’re also putting them on a path to becoming healthier adults who have healthier kids of their own. I can’t think of many organizations where that kind of generational impact is possible.

I am so excited to dive into this work with all of you. I hope we have the chance to get to know each other in person in the coming months so I can hear your stories, learn what inspires you, and explore your boldest ideas.

Sincerely,

Jasmine Payne
Assistant Vice Chancellor
Chief Development Officer, Children’s Health
UCSF Benioff Children’s Hospitals Foundation



Hometown Heroes

Most of us know Buster Posey as the All-Star catcher who led the San Francisco Giants to three World Series championships during his 12-year career. But Buster and his wife, Kristen, are so much more than baseball royalty. When the Poseys learned that pediatric cancer garners only about 4% of cancer funds raised in the United States, they were inspired to make a difference. Over the past decade, Buster and Kristen have become champions off the field, raising over \$5 million for pediatric cancer research through their annual BP28 Gala; inspiring Pediatric Cancer Awareness Day at Oracle Park, where they raffle off signed items to benefit our hospitals; and regularly visiting our hospitals to lift patients’ spirits. Buster also serves as honorary co-chair of UCSF’s Pediatric Cancer Council, which raises awareness of UCSF’s groundbreaking oncology research. Thank you, Buster and Kristen, for everything you do for our kids!

CLINICAL CARE

Easing the Burden of Complex Care

For families who struggle to afford food, housing, and health care, supporting a child with a complex medical condition is a daunting challenge. Combine that with language barriers, pending immigration status, and single parenting, and it can be close to impossible.

UCSF's Novel Interventions in Children's Healthcare (NICH) program was launched in 2020 to support vulnerable children and teens with complex medical conditions and life circumstances. Program participants are paired with a NICH interventionist who spends hours every week with the family at clinics, in their home, and in their community. The interventionist learns about their situation, builds a personal relationship, and provides tailored support – from coordinating medical care to navigating complex treatment plans and accessing crucial resources like childcare and stable housing.

After a year with NICH, families graduate with the skills, support, and confidence they need to effectively manage a complex medical diagnosis. All NICH services are provided free of charge, thanks largely to philanthropic support.

Hear from four families about how NICH has positively impacted their lives.

Mariana, 3

Mariana Gutierrez was born with a genetic disorder that left her reliant on a feeding tube. In the year before starting NICH, the Gutierrez family visited the Emergency Department at UCSF Benioff Children's Hospital Oakland half a dozen times, usually because the tube had become dislodged. When bilingual NICH interventionist Molly Robins met her, Mariana was making just a few sounds and was not yet walking. Molly realized immediately that language barriers had made it extremely difficult for the Gutierrez family to navigate their daughter's complicated care regimen, and geographic distance and demanding work schedules were making it nearly impossible to attend her appointments. With Molly's help, Mariana's mom and dad learned to operate her feeding equipment and know who to call when concerns arise. Their visits to the ED have declined dramatically, and Mariana is gaining weight, making sounds, smiling, and learning to walk. "Molly made things that were difficult easier," says Mariana's mom, Isela. "I feel so much more prepared."



Farhan, 4

Born with a rare chromosomal abnormality, Farhan Samimi lives with developmental delays, spinal and muscle disorders, asthma, and dysphagia (difficulty swallowing). He is cared for by seven subspecialists at UCSF, in addition to physical, occupational, and speech therapists. Farhan's dad, Gul Ahmad, the family's only English speaker, was struggling to communicate with so many providers and track down the supplies, educational resources, and outside therapies that Farhan so badly needed. Enter NICH interventionist Gabrielle Woodland, who provided the family with moral and logistical support. "As a newcomer [to the US], I just couldn't manage everything on my own," says Gul Ahmad. "Gabrielle is my backup in everything. Now, we don't miss appointments. We don't go to the emergency room. Farhan has a teacher and home schooling. Gabrielle even helps us personally. She supports my wife when she is crying. She encourages us, tells us everything will be OK, and it truly is."



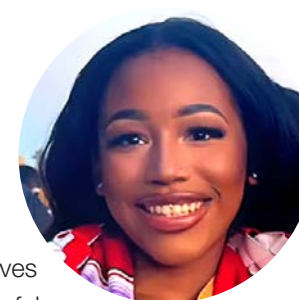
Cristel, 4

Cristel Bonilla was born with congenital toxoplasmosis, a parasitic infection that left her blind, developmentally delayed, dependent on a feeding tube, and living with cerebral palsy. A single parent and recent arrival from Guatemala, Cristel's mother, Clansy, was undocumented, drowning in financial insecurity – she was unable to afford rent and transportation to the hospital – and at risk of homelessness. Bilingual NICH interventionist Elizabeth Saenz went into triage mode, rapidly identifying existing resources that could stabilize the Bonillas' situation. She immediately connected Clansy with a free transportation service provided through her insurance, scheduled all of Cristel's referral appointments, and attended those appointments with her to make sure nothing was lost in translation. Elizabeth also secured a car seat, rental subsidies, and special-needs daycare through local community programs. A year later, the Bonillas are on solid ground. Clansy gained legal status, received her work permit, and found affordable housing, and Cristel is thriving, thanks to consistent medical care.



Nevaeh, 18

NICH has also become a vital resource for older patients, some of whom are managing complex care on their own. This was the case for Nevaeh McCaskel, who lives with sickle cell disease, a painful blood disorder. For years, Nevaeh had struggled to get herself to appointments, often ending up hospitalized for pain episodes that flare more frequently without consistent treatment. Nevaeh's grandmother – her primary caregiver – was unable to escort her due to health constraints of her own. NICH interventionist Maria Velasco stepped in to fill that role, arranging transportation, attending appointments, advocating for Nevaeh with medical staff, and scheduling referrals. But Nevaeh says Maria also became a friend: "We would hang out and talk about my appointments but also everything else. She is so nice to me. She really cares." A recent graduate of both high school and NICH, Nevaeh hopes to become a nurse so she can use her experience as a patient to help others.



Our NICH Families at a Glance

98%

are publicly insured

83%

are from historically marginalized racial and ethnic groups

Families often face:

- educational barriers
- underemployment
- housing and food insecurity
- history of trauma
- difficulty affording child's health care

PUPPY LOVE

The Healing Power of Animal-Assisted Therapy



At UCSF Benioff Children’s Hospital, a golden retriever-Labrador mix with a loving face and her devoted handler stroll the halls. As they pass by, heads turn, eyes brighten, smiles spread across faces. “It’s Ahbi!” a child calls out. The dog goes to her, and the girl’s eyes sparkle. She wraps her arms around Ahbi’s neck, and the two share a long, tender hug.

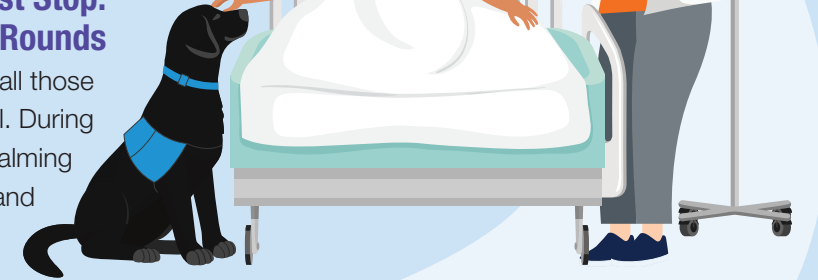
Kids, parents, nurses, physicians – everyone agrees that UCSF Benioff Children’s Hospitals’ donor-funded facility dog program is among its most powerful resources. Animal-assisted therapy provides measurable improvements in blood pressure and cardiovascular health, increased endorphin release, and many emotional and mental health benefits – including for families and staff.

What sets our facility dog program apart is its significant therapeutic value for our patients. These highly trained dogs are partnered with professional handlers – in our case credentialed child life specialists – trained to help children and families navigate illness, injury, disability, trauma, or hospitalization. Handler and dog collaborate at the highest level to build therapeutic relationships with patients and meet each child’s medical needs.

Follow Ahbi, Arnie, Courtney IV, and Tulip around the hospital for a sneak peek at how they make our patients feel safer, stronger, more centered, and less afraid.

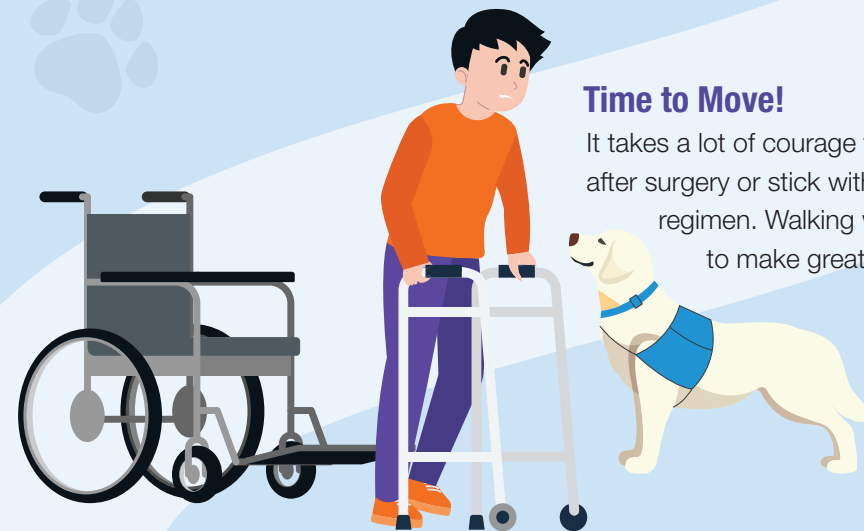
First Stop: Inpatient Rounds

For hospitalized kids, all those needle pokes can take a toll. During invasive procedures, Arnie’s calming presence reduces anxiety and distracts from pain.



Time to Move!

It takes a lot of courage to take those first steps after surgery or stick with a rigorous physical therapy regimen. Walking with Tulip can motivate patients to make great strides in rehabilitation.



Walking the Halls

There’s no telling who might need a little extra comfort in the hallways of our hospitals – doctors, nurses, parents, and even siblings. Some quality time with Courtney IV can help siblings of critically ill patients grapple with painful emotions.



Staying Close at the End

Children in palliative care spend the last days of their lives at our hospitals. Daily visits from Ahbi can create a profound new connection for the child at an incredibly difficult time and provide immense physical and emotional comfort during their final days.



We rely on donor support to continue and sustain animal assisted therapy. For more information about how you can help, please contact Allyson Hamilton at Allyson.Hamilton@ucsf.edu.

The Courage in Being Human

How Elena Sweet Survived Cancer and Found Her Voice



When asked about herself, 13-year-old Elena Sweet doesn't hesitate. "I'm the biggest drama queen you'll ever meet," she says.

Liz, Elena's mom, shares a more generous framing: "She has a strong spirit. She lives out loud. She has always let us know exactly how she's feeling and what she needs."

As a young child, Elena's penchant for drama manifested as elaborate imaginary games. As she grew, she explored new worlds as an avid reader and passionate stage performer. Elena was participating in a theater class in San Francisco when her father, Josh, first noticed the limp.

It was the summer before her 11th birthday when Elena began to feel an ache in her right leg, which a pediatrician attributed to growing pains. But over Thanksgiving break, the pain got worse, and one night, Elena collapsed on her way to the dinner table.

Josh and Liz rushed their daughter to UCSF Benioff Children's Hospital Oakland, where she was diagnosed with Ewing sarcoma, a rare form of bone cancer. As a doctor relayed the news to Liz in a crowded hospital hall, she thought to herself, "This is the moment that everything changes."

Living with Cancer

Elena's prognosis was good, but the journey would be arduous. Over 10 months,

she received 14 cycles of chemotherapy, spent 115 nights in the hospital, and underwent multiple surgeries, including a 15-hour procedure to save her leg.

"Suddenly, she's exhausted," Josh recalls. "She's sleeping all the time from the pain medications. She's on the couch because she can't walk up the stairs. She's in so much pain. She's very, very sick. Nothing was making her feel better."

As Elena's parents agonized over how to comfort their child, and doctors ran the gamut of pain-management options, relief came in surprising places. One day, Hania, a child life specialist, brought Ahbi, one of UCSF Benioff Oakland's beloved facility dogs, for a visit. Ahbi put

his paws on Elena's bed, then climbed up next to her, and she put her arms around him and held on. "I think it was the first time she actually felt some real comfort," says Josh.

The hospital's Braddock Emotional Support Team (BEST), which offers psychological services for hospitalized children, worked closely with Elena to address her fear of needles. Together, they came up with a "poke plan," empowering Elena to dictate the timing of the poke, vocalize her concerns, and advocate for herself. "They helped me realize that I could get through this by expressing my feelings," she says.

"Everyone – the doctors, nurses, child life specialists, psychologists, music therapists, massage therapists, educators – they were all focused on treating our whole child and keeping her spirits lifted," says Liz. "UCSF Benioff Oakland became our family, our home. We felt so held."

Designing Survival

Elena always believed she would survive the cancer. "I'm an optimist," she says. But coping with debilitating illness and prolonged hospitalization took creativity.

Elena sought connection with the people around her. She designed dream apartments for her nursing team based on detailed individual

consultations. She organized events, including a talent show (which she directed) and a rousing game of "Sharks and Minnows" in the hospital halls. She ran a henna service for patients out of her hospital bed.



They helped me realize I could get through this by expressing my feelings.

–Elena Sweet

Elena sought inspiration in the experiences of others coping with illness and injury. She devoured the stories of children who had battled and survived cancer. And after a year in a wheelchair, she developed a deep empathy for people with disabilities. Elena has since become a vocal advocate for inclusion and equal opportunity for people with physical impairments.

Elena's experiences have inspired her to pursue a career in health care. After considering nursing ("But I don't want to give needle pokes," she says), becoming a doctor ("I don't want to be in school that long"), and child life ("I'm not sure they get paid enough"), she settled on becoming a social worker "so I can help more people and do a little bit of everything for everyone."

Elena's Courage

Elena is now in remission. After missing most of her fifth-grade year, she rose from her wheelchair to walk across the stage, assisted only by a crutch, and accept her diploma – to deafening applause.

And she's back to doing what she calls "the normal things" – watching TV, reading books, hanging out with friends, and going to school. But life has also grown richer. For the past year and a half, Elena has served as a patient ambassador for UCSF Benioff Children's Hospitals, sharing her story at events across the Bay Area to help raise awareness and funds for the hospital that saved her life. She is also working on a graphic novel about what it was like to survive bone cancer.

In honor of her triumph over adversity and her contributions to our community, Elena was recently awarded the 2024 Colin Powell Medal of Courage at the Dreamfest Concert for UCSF Benioff Children's Hospitals. She insists that courage isn't about heroics or putting on a happy face, it's about being human, connecting with others, expressing your feelings, and asking for help when you need it.

"I think she's pretty brave," says Liz, with a smile. "She made this journey her own."

Raghav's Gift

In our last issue, we met 11-year-old Tej Bisarya, who fought a rare form of liver cancer with help from UCSF's Pediatric Liver Center, and his uncle, Raghav Kohli, who donated a portion of his liver to Tej in 2022. We spoke with Raghav about his decision to undergo major surgery on behalf of his nephew, and why giving back has become fundamental to his worldview.

What went through your mind when you heard Tej's diagnosis?

We were shocked. The thought of someone so young getting cancer really was difficult to process. The immediate thing you say is, "Let me know how I can help," but the reality is, you don't know how to help. So when we got the email saying that a living donor transplant would be Tej's best option for survival, I immediately filled out the donor survey. I tend to jump right into things!

What happened when you learned you were a match?

As a parent, I thought that if the same thing happened to my child, and for some reason, I couldn't donate, I would hope that someone would raise their hand. I just couldn't imagine the pain they were in, and what Tej was going through. To be honest, I didn't even think it through. [My wife] Purvi and I just said, "Let's get this process started, and then we'll learn more as we go along."



Had you ever considered organ donation before?

No, not really. But we felt comfortable right away. We watched the Netflix documentary "The Surgeon's Cut," which features UCSF surgeon Dr. Nancy Ascher, who is a pioneer in living-donor surgery. UCSF's track record, and how they handled my process from the outset, really inspired us.

Did you have any concerns?

We knew this would introduce some chaos and uncertainty into our lives, but we are a strong team, and we have a lot of support – from our employers, our families, and our friends. And we felt like our privilege put us in a unique position to help. We believed we could survive this and come out stronger on the other side.

I also felt really supported by the UCSF team. I had always thought of the medical profession as X's and O's. Diagnosis and treatment. But it was so much more than that. As a patient, you have so many ups and downs along the way, and across the board, everyone, from the doctors to the nurses to the

technicians and administrators, showed me so much empathy.

How was the recovery process?

I like challenges. I'd never had any major medical issues, so the recovery piece didn't scare me. I was like "OK, let's do this!" Fast-forward 18 months later, and I'm in the best shape I've ever been in.

How has this changed your relationship with Tej?

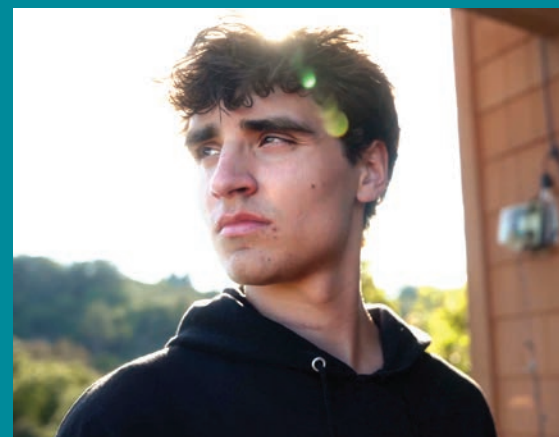
It brought us closer. I feel really emotionally invested in him now. I became an outlet for him. Whenever I went in for my appointments, I would stop by his room at the children's hospital to talk. We would play video games and text. During our recovery, we watched the World Cup together.

Did the experience change you?

It really does test your character when you go through something like that. A week after Tej went into remission, my mom was diagnosed with breast cancer. I think the surgery helped prepare us for that. Even now, I try to keep the perspective of how fragile life is and make sure we're spending our time on things that really matter.

These days, we're always asking ourselves how we can help. I am currently volunteering for the American Cancer Society and hope to serve as a sounding board for others who are considering organ donation. I'm always trying to take a step back and appreciate how lucky I am and not wait for something to happen to take action, but to be more proactive about how we can contribute to making things better.

TRAUMA TEAM SAVES SURFER



Marcos Ornellas was a water baby. As a teenager, he loved few things more than the beach, surfboards, and catching the perfect wave.

One overcast day in June 2023, the 15-year-old and his friends took their boards to Bolinas Beach, about an hour north of San Francisco. The waves were small, but they decided to make the most of the summer weather.

Out in the ocean, Marcos turned his board into the waves and paddled. A second later, he was up on his feet with the breeze in his face – his happy place. But as the shore quickly approached, he saw a group of kids taking surfing lessons right in his path. To avoid a collision, he dove into the murky water.

The next thing Marcos knew, his head slammed into a sandbar. His neck got warm. Then, no feeling – no pain, nothing.

Here for a family's worst day

Marcos was taken by emergency helicopter to UCSF Benioff Children's Hospital Oakland – the only trauma center in Northern California focusing solely on children. About 30 minutes later, a 15-member team – including doctors, nurses, radiology technicians, and neurological and orthopaedic specialists – were working to stabilize Marcos.

In those first hours, it was essential for the Oakland trauma team to stabilize Marcos' blood pressure and other vital signs before they could perform

spine surgery the following day. "Timely care for life-threatening bleeding, brain injury, or spine injury is essential to prevent death and minimize disability from the injury," says Aaron Jensen, MD, MEd, the hospital's trauma medical director.

The team found a glimmer of hope, though: Marcos had faint feeling in his upper arms and right thigh, indicating that his spine was not severed irreversibly. There was a possibility he might regain function below his neck. But how much, if any, was unknown.

"We were panicking and trying to catch our breath to figure out what was going on," says Chris Ornellas, Marcos' dad. "But the doctors patiently explained everything and walked [us] through the surgical procedure. They were amazing. We immediately placed all our trust in them."

Glimmers of hope

The six-hour surgery was successful. In the days that followed, minuscule signs of progress began appearing. The first sign was a slight movement in Marcos' right thigh almost a week after the accident. His father asked whether it was involuntary, but Marcos said he was visualizing the movement and trying to make his body respond. He continued to push himself, aided by loud, motivating music played by his physical therapist, Anthony Ong, DPT, during grueling exercise sessions.

Nine months and hundreds of hours of physical therapy later, Marcos returned to the Redwood High School soccer field where he had been a star player – this time as a spectator supporting his former teammates. The one-time water baby hasn't returned to surfing but is already back on the beach with friends – just not Bolinas Beach, at least not yet.

"My priorities have changed now," Marcos says. "Family, friends, and my college education are what is important to me now. I know I was really lucky. This could have turned out very differently, and I'm so grateful to be where I am now."

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5 Questions for **Dr. Nicholas Holmes**

President of UCSF Benioff Children's Hospitals



1 We hear you're a big fan of superheroes and origin stories. What's yours?

Yes! I love origin stories. Part of mine begins right here in San Francisco. I was fresh out of medical school when I moved across the country to do my residency in urology in San Diego and my fellowship in pediatric urology at UCSF. It was a pivotal time in my life: I met my husband and I found my calling – pediatrics.

2 Why pediatrics?

I was so inspired by my time at UCSF. Everyone I encountered had this deep, almost spiritual commitment to children. And the families I worked with put all their trust in me. It felt like an incredible privilege to be in service to them, and I couldn't imagine anything else I'd rather do.

3 You have served in the U.S. Navy and worked at other children's hospitals. What brought you back to UCSF?

We deliver some of the highest quality care and have some of the most recognized experts in the world. We have all the elements of a top children's hospital. We just need to weave those components together to create an integrated, comprehensive system of care. That's the project that pulled me in.

4 What are you most excited about?

The new hospital building in Oakland! The UC Regents recently approved constructing a \$1.5 billion facility that will open in 2030. It's going to be transformative for our community. I can't wait to break ground.

5 Top priority for year one?

As a leader, it's important to me to get to know this organization and have this organization get to know me. I want people to understand my vision, where I'm coming from, and how I hope to achieve our goals. By my one-year mark, I hope people feel like they know me, can communicate with me, can stop me and say "hi," and can give me feedback. That's how I've had success – by connecting with people.