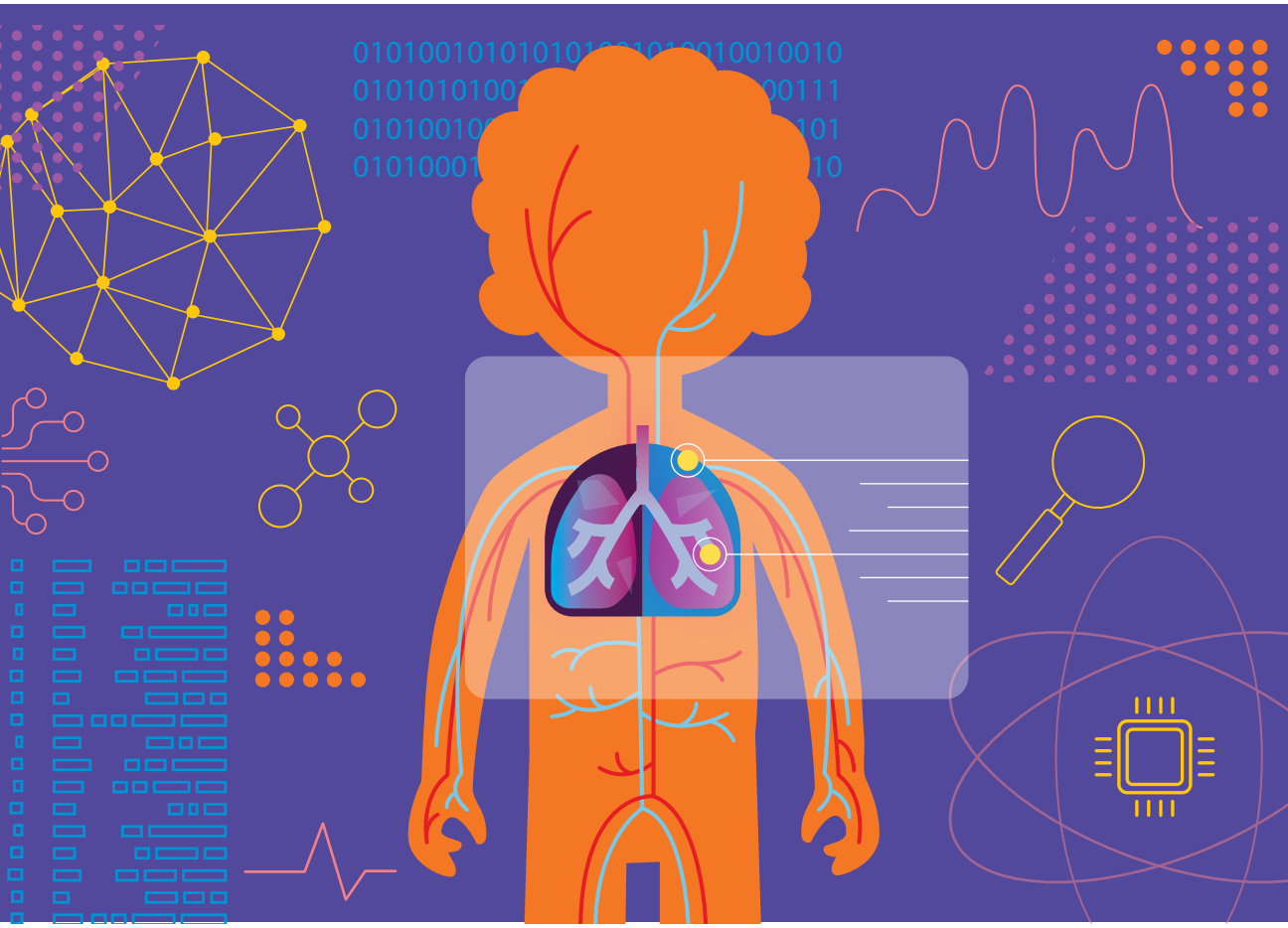
UCSF Benioff Children's Hospitals

A NEWSLETTER FOR
FRIENDS AND SUPPORTERS

Connections

SUMMER 2024



Artificial Intelligence and the Future of Pediatrics

page 5

I'm a big fan of superheroes, and 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, and eventually, a fellowship in pediatric urology, at UCSF. It was a pivotal time in my life – I met my husband, and I found my calling: pediatrics.

I was so inspired during my time at UCSF. Everyone I encountered had this deep, almost spiritual, commitment to children. The families I worked with put all their trust in me, and I felt so much empathy and responsibility for these incredible people. It was a privilege to make a difference in their lives, and I couldn't imagine anything I'd rather do.

Even as my career took me elsewhere, that experience stayed with me. So it was with tremendous pride that I accepted the position of president of UCSF Benioff Children's Hospitals this past March. What brought me back was the knowledge that everyone here is equally devoted to putting patients and families first. I am honored to be a part of that.

What I love about this issue of *Connections* is that it shows the myriad ways that this devotion manifests. From the scientists using leading-edge technology to set new standards in children's health to the pediatricians volunteering on Saturdays to care for immigrant families, and the grateful parents who are investing back into the hospital that saved their child's life – the stories that follow exemplify the remarkable spirit of service that makes this place special.

You are a huge part of that spirit. Your commitment to this organization and your investments in pediatrics are transforming how we care for kids and families. I'm so looking forward to meeting you and thinking together about how we can continue to make a difference.

Sincerely,

Nicholas M. Holmes

Nicholas M. Holmes, MD, MBA
President, UCSF Benioff Children's Hospitals
Senior Vice President of Children's Services, UCSF Health

Oakland's Revolutionary Care for Kids who are Hearing Impaired

At 10 months old, scans confirmed that a meningitis infection had left Amir Hayden deaf. Weeks later, cochlear implants pioneered at UCSF Benioff Children's Hospital Oakland allowed Amir to hear his mother's voice again, after months of silence. Thanks in part to $750,000 raised through the Panda Cares Center of Hope, UCSF clinician-researchers continue to pioneer new discoveries to support deaf and hard-of-hearing children to hear and communicate. Read the full story by scanning the QR code.

HEALTH EQUITY

Immigrant Children at Risk

How our hospitals play an integral role in their safety and healing

Juan was 14 when he fled abuse in Guatemala. He'd left school because his father forced him to spend long days laboring in the fields. A local gang was targeting him for recruitment. Verbal abuse from gang members had escalated into physical assaults and death threats.

Juan – whose name has been changed to protect his privacy – felt he had no other choice but to make the dangerous, 1,200-mile journey to the US. Once here, he was advised to apply for asylum. Juan was referred to legal services, which scheduled a forensic exam at UCSF Benioff Children's Hospital Oakland to document the physical and psychological manifestations of abuse – crucial evidence to present with his asylum application.

At the hospital's Pediatric Human Rights Collaborative (PHRC), Juan told his story to psychologist Will Martinez, PhD, one of many providers who volunteer their time at the program monthly. During the physical exam, pediatrician Raul Gutierrez, MD, noticed scars on Juan's head, arms, and chest. Most were from gang beatings, Juan said. The rest, he admitted, he had inflicted himself.

The scarring was consistent with Juan's recollections of abuse, and the self-harm indicated post-traumatic stress disorder (PTSD). Martinez and Gutierrez summarized their findings in a report for the asylum judge and then called in the collaborative's social workers to get Juan psychiatric and medical support. All in a day of unpaid volunteer work.

A Center of Excellence is Born

In 2016, amid a surge of anti-immigration rhetoric and policies, a group of UCSF Benioff providers became deeply concerned about their immigrant patients. How would the national climate impact these children? What could they do to protect them?

Gutierrez, pediatrician Zarin Noor, MD (pictured left), and social worker Chela Rios-Muñoz, LCSW, took action. They applied for funding from the hospital, Alameda County, and private donors, and in 2019 launched UCSF's Center of Excellence for Immigrant Child Health and Wellbeing, an initiative to address the health of immigrant children through advocacy, education, and evidence-based clinical services.

First, they coordinated stakeholders to implement the Safe Hospital Policy, which articulates UCSF's response to raids from US Immigration and Customs Enforcement, and began training future pediatricians on how to provide trauma-informed, culturally responsive care. Next, they partnered with UCSF's Human Rights Collaborative, a student-run program that provides medical and psychological forensic evaluations for asylum-seekers.

"But the trauma that younger patients experience is very different," Noor says. "How they experience and remember trauma really depends on developmental factors, so we worked with that team to create pediatric-specific programs in Oakland and San Francisco."

The UCSF Pediatric Human Rights Collaborative-East Bay

Juan is finally safe, and partner organizations are providing the treatment he needs to heal. PHRC staff members follow up with him regularly.

The program has a powerful impact on kids like Juan. Currently, there are over 123,000 immigration cases pending in San Francisco, including 51,000 concerning children and youth. Access to forensic examination has shown to make a significant difference in their outcomes. Ninety percent of asylum seekers who have an attorney and a forensic medical affidavit win their cases, compared with 10% without these resources.

What sets UCSF's program apart is its emphasis on trauma-informed and culturally responsive care specific to young people. Providers recognize the impact of trauma on children's lives and respect each patient's unique background, fostering deep connections between providers and patients and encouraging kids like Juan to open up, and in doing so, strengthen their cases for asylum.

The work is conducted in close partnership with legal providers, who initiate the asylum process and refer clients to the PHRC; and community-based organizations, which provide lifesaving follow-up care.

Everything is done by volunteers. The collaborative's pediatricians, psychiatrists, medical students, and social workers work pro bono one Saturday a month. Their contributions are deeply personal: Many come from immigrant families themselves and built their careers on a desire to give back.

"This work really fills me up," says Noor, whose family immigrated to the US from Afghanistan when she was 5. "This is why I became a doctor. Knowing we're able to make a difference for these children is amazing."

More Kids, More Clinics

Globally, millions of young people are displaced or living as refugees. Political unrest, climate change, and violence and abuse related to gender, sexual minority status, or ethnic background are all increasing.

Martinez says he sees many kids arrive with PTSD, anxiety, and depression, and the work can take a toll on the care providers too. "The need is just so massive," he says. "It feels like when you plug one hole, 10 more appear. It almost seems unstoppable.

"What helps me is knowing I'm working with folks who are trying to make a difference at a higher level," Martinez continued. "People who are thinking about building a system of care around these kids – for asylum and everything else they need: medical and psychological care, housing, legal support, and on and on. This is a whole generation of children who can contribute to our society, but first we need to get them the help they need to heal."

Noor says philanthropy remains central to their ability to continue the PHRC and care for the rising number of children in need. "Insurance doesn't reimburse for this," she says. "The providers do these evaluations in their free time. But we rely on philanthropy to pay our administrators and provide patients with transportation and meals. With more financial support, we could help even more kids."

Q|A

How is UCSF harnessing artificial intelligence in pediatrics?

Technology has become ubiquitous in our daily lives. Over the past four decades, technological advances have increased our productivity, reshaped how we interact with one another, catalyzed scientific research, and changed the way we deliver and document health care. And now, a new technology – artificial intelligence – has become widely available to us all.

Artificial intelligence, or AI, is a technology that enables computers and machines to simulate and amplify human intelligence and problem-solving capabilities. At UCSF, we recognize the enormous responsibility we have to deploy AI safely, equitably, and efficiently to elevate healthcare, while also protecting the patients we serve.

At UCSF Benioff Children's Hospitals, our experts are at the forefront of this effort, spearheading groundbreaking research that harnesses the power of AI to transform how we care for children – from decoding cough sounds, to interpreting fetal ultrasounds, and deciphering complex datasets.

SOUNDS

Devan Jaganath, MD, MPH

Pediatric Infectious Disease Physician

What is a cough? We all do it, and we all recognize it, but how do we characterize it? Right now, when we ask a patient about a cough, it can be quite subjective: Do you have a cough? Did it get better? From a diagnosis and monitoring standpoint, that's pretty nonspecific. More objective data would be much more valuable, and we're realizing that there's so much rich data in sound – including cough sounds – that we could use to detect and monitor diseases. With AI, we can collect thousands of cough sounds, noninvasively with a mobile phone, and create algorithms that diagnose or assess the severity of respiratory diseases like RSV, COVID, and tuberculosis. This would empower providers, children, and caregivers to make time-sensitive decisions about care. It's so exciting.

DATA

Elaine Ku, MD, MAS

Adult and Pediatric Nephrologist

Cardiovascular disease is the leading cause of death in teens with kidney disease, but risk control for the disease remains poor in this population. We want to know why. Is it because providers hesitate to start treatment so young? Is it because they haven't identified the risk? In traditional research, we focus on data that's easy to extract, like how many patients received a certain therapy. But the richest data is usually in the provider's notes. That's where you learn why they did what they did. We would never be able to sift through all those notes, but with AI, a machine can go through the data and interpret intent, and we can learn about provider decision making. Eventually we'll be able to use this for blood pressure control, diabetes care, even cancer therapy.

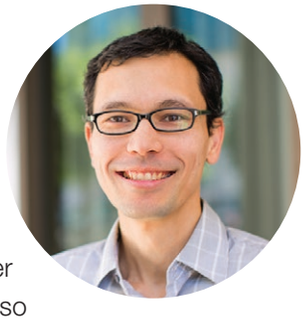
IMAGES

Anita Moon-Grady, MD, FACC, FAAP

Pediatric Cardiologist

I've spent my career trying to improve prenatal diagnosis of congenital heart disease (CHD). Diagnosing a heart defect before birth can mean the difference between life and death for the child. For 20 years, we've approached this through education, but for whatever reason, it's still really easy to overlook these defects on prenatal ultrasounds. They're hard to see, and about half of all cases of CHD get missed. So, when [UCSF cardiologist] Rima Arnaout approached me about her research using AI in prenatal ultrasound, I literally had an "aha!" moment. When we use AI to screen ultrasounds for CHD, the detection rate surges to 95%. Sign me up! This may be the only way to dramatically improve our ability to identify fetal heart defects in the womb.

EXPERIENCES



Aris Oates, MD

Pediatric Nephrologist

As a health system, we're always looking for ways to take better care of our providers so they can take better care of our patients. That includes exploring how we can use AI to reduce the time providers spend documenting visits and increase the time they spend with patients. Our study uses AI to record the visit, transcribe the notes, and formulate patient instructions. The provider still reviews the notes and instructions, but the AI takes that first pass to capture and organize the information. This has the potential to be so valuable in pediatrics. Instead of staring at a computer screen, providers can focus on interacting with children. No one became a pediatrician to write clinical notes. We went into medicine to take care of kids.

TOPICS

The Wonderful World of 3D+

At UCSF, a suite of advanced 3D technologies is ushering in surgery's most sophisticated era yet

In medicine, 3D modeling can merge hundreds of individual slices from a CT or MRI scan to form a 3D replica of anything from a vital organ to a skeletal structure to a cardiovascular network. UCSF's Center for Advanced 3D+ Technologies (CA3D+) applies advanced 3D visualization and manufacturing techniques to solve some of the most complex clinical cases at UCSF.

Examining Little Bodies

3D modeling can be a powerful tool in pediatrics, given the small size and delicate nature of fetal and infant anatomy. In one example, scans of a fetus at 29 weeks' gestation revealed that a tumor the size of a soccer ball was compressing the unborn infant's airway. Several institutions declined to operate due to the complexity of the case. But the UCSF team used a 3D model to identify an airway they could access during a surgical delivery. The procedure was a success, and the child is doing well today.

Personalizing Surgery

By the time Samantha was 6, she had already endured three open heart surgeries to manage a congenital heart defect. When she was 12, her surgeons had to decide whether to perform a fourth surgery – an extremely delicate and high-risk procedure to cure the disease – or do nothing and hope for the best. Pediatric heart surgeon Mohan Reddy, MD, commissioned a 3D model of Samantha's heart and saw a clear way to construct a two-ventricle repair – a pathway that had remained elusive on CT scans. The surgery succeeded, and Samantha is feeling better than ever.

Tackling Complexity

In 2021, plastic surgeon Alexander Lin, MD, prepared to operate on an 11-year-old boy whose face had been shattered in an accident. Along with dozens of fractures, the optic nerve in the boy's left eye had been severely injured, likely causing permanent vision loss. Optic nerve repairs are extremely risky, so Lin used a 3D model of the boy's skull to practice the delicate fix before the operation. Hours later, his muscle memory guiding him, Lin performed the maneuver in surgery, and within two months, the child's vision was fully restored.

Changing How Medicine is Practiced

"Ten years ago, I never could have imagined that we would be here. We've gone from talking about 3D printing as a cool new tool to showing that it's possible, across multiple disciplines, to support an entire health system and hundreds of patients with this technology."

– Shafkat Anwar, MD, medical director and co-founder of CA3D+

LIVER CENTER

Defying the Odds

How one boy, his family, and a team of heroes are transforming care for rare pediatric liver disorders

Faster than a jet plane, more courageous than a Jedi Knight, with a captivating presence and an infectious laugh, it's Tej Bisarya, aka JEDI JET!

The force is strong with Tej (hence the nickname). At 2, he bravely conquered a life-threatening asthma attack on Thanksgiving Day. He slays severe food allergies with a maturity twice his age and a stash of healthy cupcakes for special occasions. He bolts across the soccer pitch at lightning speed, always smiling, win or lose.

But nothing could prepare Jedi Jet for his most powerful adversary yet. At just 10 years old, Tej was diagnosed with a rare and life-threatening form of liver cancer. Soccer practice gave way to marathon hospital stays. Constant sickness left him too ill for school, too exhausted for friends. Life became a messy, painful jumble of feeding tubes, chemo ports, and hair loss.

Even for a superkid like Tej, the odds are against any child diagnosed with a rare liver tumor, which can have profound and lasting impacts on physical, psychological, and emotional health. To vanquish the cancer once and for all, Tej and his family were going to need to join forces with a super team of pediatric health heroes.

Enter UCSF Benioff Children's Hospital's Pediatric Liver Center.

UCSF to the Rescue

Tej was diagnosed with cancer just a few days after arriving in Germany for a family vacation. Standing in a busy hallway at a children's clinic in Stuttgart, amid a powerful surge of fear, uncertainty, and disbelief, Tej's mom, Chetana, thought of her old college friend, UCSF pediatric liver surgeon Amar Nijagal, MD, and texted him.

As luck would have it, Nijagal's passion project was the key to Tej's situation. Diagnoses like Tej's are extremely complicated, involving chemotherapy, organ transplants, dozens of specialists, enormous expense, and serious psychosocial consequences. Nijagal and his colleagues had dedicated years to building a program designed to make the patient experience easier, more streamlined, and more supportive.

Their vision began to take shape as UCSF's Pediatric Liver Center of Excellence: an interdisciplinary hub bringing together exceptional providers from hepatology, radiology, oncology, hematology, pathology, organ transplant, psychiatry, and others. The goal: Simplify a complex care process by creating a medical home for children diagnosed with liver disorders encompassing comprehensive, coordinated medical and psychosocial services.

"We had been working on developing this really amazing service, so it was an incredible feeling to be able to offer it to this family," Nijagal says. "We knew exactly how to provide the level of care we had been envisioning for years."

Navigating Cancer

The Bisaryas flew home to San Francisco, and Tej was admitted to UCSF Benioff Children's Hospital in Mission Bay the next day. Within hours, Tej was biopsied, scanned, and prepared for chemotherapy. Chetana and Nirav, Tej's father, met with key members of the medical team, including hematologist-oncologist Arun Rangaswami, MD; and Emily Perito, MD, and Sue Rhee, MD, both of whom specialize in gastroenterology and liver disorders.

"Right away, we felt guided medically, and with so much empathy," Nirav says. "We knew we were in the right place."

Yet even with so much support from the UCSF staff, as well as flexible employers, and an active network of family and friends, the Bisaryas' lives were upended. Tej became extremely ill. The nausea, vomiting, and discomfort were constant. Chetana, Nirav, and older brother Vikram rode the emotional roller coaster of cancer treatment with Tej as everything else – work, friends, and self-care – took a backseat.

Then, another devastating blow: The chemotherapy wasn't enough. Tej would need a liver transplant immediately to survive the cancer – a costly procedure with a lengthy wait list.

But he was lucky. The Bisaryas' insurance covered the procedure, and an extended family member, Raghav Kohli, was identified as a living donor match so Tej could forego the wait. Tej and Raghav underwent a 12-hour procedure in which a transplanted portion of Raghav's liver completely replaced Tej's liver, where it ultimately would grow to full size, restore normal liver function, and eventually get Jedi Jet back to super strength.

A Center of Excellence

Today, Tej is cancer free. He's back in school and playing sports again. His side-splitting laugh has returned to full strength, and he's taking his medical appointments in stride. The Jedi Jet glint in his eye is back.

As Nirav and Chetana navigated the world of pediatric liver cancer and organ transplants, they became acutely aware of how special their experience at UCSF had been. The team had eased an otherwise agonizing experience.

The Bisaryas asked Nijagal what it would take to expand the center so more children could access the remarkable expertise and guidance that benefited Tej. Nijagal shared the team's vision that, with additional investment, they could establish a Center of Excellence that would provide the full spectrum of medical, psychological, and coordination support essential to navigating a liver diagnosis, particularly for underserved families.

Chetana, Nirav, and their family decided to make a leadership gift to launch the Pediatric Liver Center of Excellence. Their major support will allow many more families to benefit from UCSF's leading liver care. The Bisaryas are also actively assisting the center's team to spread the word and generate sustainable funding to support superkids like Tej for generations to come.

"We knew we were the early beneficiaries of their vision," Nirav says. "It was already incubated, and the structure was beginning to form. We wanted to help them take it to the next level, to enhance the experiences of every family that follows us."

To support the Jedi Jet Fund for the Pediatric Liver Center of Excellence, please visit https://tiny.ucsf.edu/PLCoE.

The team from left: Charles Rickert, MD, PhD (transplant surgery), Arun Rangaswami, MD (pediatric hematologist-oncologist), Tracy Sirota, PNP, MSN, Tej Bisarya, Benjamin Lerman, MD (pediatric hematologist-oncologist), Amar Nijagal, MD (pediatric surgery), and Shagun Arora, MD (malignant hematologist).

UCSF Benioff Children's Hospitals

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Magical Moments for Every Child

A Hedwig ice sculpture, levitating candles, butterbeer lip balm, and Hufflepuff snacks set a magical scene at this year's Hospital Prom, a special evening for hospitalized teens who often miss out on important rites of passage. At UCSF Benioff Children's Hospitals, we do more than treat injuries and illness. We care for the whole child and consider each patient's physical and emotional needs. Philanthropy makes this possible. Please scan the QR code and make a gift today.