UCSF Benioff Children's Hospitals

A NEWSLETTER FOR
FRIENDS AND SUPPORTERS

Connections

FALL 2025

Big Breakthroughs, Beautiful Futures

How medical research is transforming pediatrics

page 3

Dear Friends,

I have been at UCSF Benioff Children's Hospital Oakland for more than two decades now, first as a trainee and now as the section chief of pediatric emergency medicine. Every day, I am reminded of what makes this place so special. I have the privilege of working alongside a team that shows up with extraordinary dedication, compassion, and skill for every child, every time.

We are a hospital built on a promise: All children deserve world-class care, regardless of demographics or circumstances. That promise is what first drew me here, and it continues to inspire me today. In our Emergency Department, in our trauma bays, in clinics and research labs across our campuses — some of which are featured in this issue of *Connections* — we care for children as if they were our own.

I take such pride in knowing that we are here for everyone. Every child who comes through our doors is somebody's world, and we treat them that way.

We are now preparing for an exciting new chapter. Next year, we will break ground on a new hospital in Oakland with a vastly expanded Emergency Department. This new medical home for Bay Area kids will reflect the excellence of our care, expand access for families across the region, and create a healing environment designed for the next generation of pediatric medicine.

This project represents more than bricks and mortar; it is a bold step toward the future our children deserve. Thank you for believing in this mission and for standing with us every step of the way.

With sincere gratitude,

Karim Mansour, MD
Section Chief, Pediatric Emergency Medicine
UCSF Benioff Children's Hospitals

A Salute to Service

The UCSF Founders Day Distinguished Nurse Award

From the time she was a teenager, nurse Iris Kauf, RN, has always turned little problems into big solutions. Iris is revered for her work at UCSF Benioff Children's Hospitals, where she has embraced the UCSF spirit of collaboration and ingenuity to find better health outcomes for our most vulnerable patients. In 2025, Iris was honored with the UCSF Founders Day Distinguished Nurse Award in recognition of her exemplary service to the university, our communities, and our work to advance health worldwide. Scan the QR code to watch her story.

DISCOVERY

Transforming Pediatrics

How UCSF Research Is Changing Lives

In 2024, research funded by the National Institutes of Health and private philanthropy drove groundbreaking care for kids with strokes, heart defects, and immune system disorders. Here, we share just a few of the countless stories of children whose lives have been transformed thanks to investments in discovery and innovation. As UCSF navigates a rapidly evolving health care landscape, we are partnering with our donor community to continue advancing children's health — today and for generations to come.

Gabby: Stroke Survivor Marches Forward

At UCSF Benioff Children's Hospitals, each research paper, clinical trial, and lifesaving treatment starts with a question: How can we offer hope for the future of every child?

That includes children like Gabby Lopes, who suffered a stroke at age 12 due to a rare brain disease. Gabby was rushed to UCSF Benioff Children's Hospital Oakland, where she received a novel treatment that later became the basis of the first clinical trial in the nation for acute stroke in children. Led by UCSF pediatric neurologist Heather Fullerton, MD, and spanning 25 centers across North America, the trial is bringing transformative therapy to children who might otherwise have faced lifelong disabilities, at best. Today, Gabby is back at school and playing in the band.

HT: Gene Therapy Pioneer is Back to Playtime

Only days after Hataalii Tiisyatonii "HT" Begay was born in Arizona, he was airlifted to his local hospital and diagnosed with Artemis-SCID. Children with this condition have no immune system, and without treatment, they usually die before their third birthday. But UCSF researchers are leading a clinical trial that enabled HT to become the world's first Artemis-SCID patient to receive gene-correction therapy with his own cells — eliminating complications associated with receiving donor cells. After successful treatment, HT is back to enjoying a normal childhood.

UCSF pediatric researcher Christopher Dvorak, MD, co-leads the Primary Immune Deficiency Treatment Consortium (PIDTC), which brings together 47 centers nationwide to research and treat rare immune deficiency diseases. Dvorak's team is developing a platform to share the consortium's research with centers across the country, ensuring that patients in every state have access to cutting-edge, evidence-based care.

Brooklyn: Heart Hero Finds Holistic Healing

By the time Brooklyn Bertilacchi reached her first birthday, she'd had four surgeries at UCSF Benioff Children's Hospitals to correct a congenital heart defect. As Brooklyn grew older, her mother, Katie, started to notice her child struggling to read and write. Katie learned that children with congenital heart disease have an increased risk for neurodevelopmental differences such as attention-deficit/hyperactivity disorder (ADHD) and autism. Brooklyn and her family returned to UCSF, where Brooklyn was seen in the Healthy Hearts and Minds program and diagnosed with ADHD. Thanks to the decades of research into neurologic outcomes in babies with congenital heart disease, Brooklyn was connected to treatment, education, therapy, and parental support that put her back on a forward path.

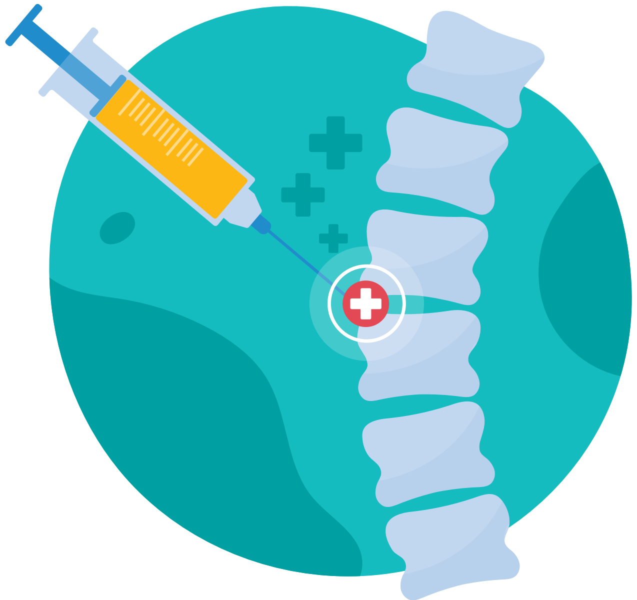
More than 40,000 babies are born with a heart defect every year. A group led by UCSF pediatric critical care specialist Patrick McQuillen, MD; pediatric cardiologist Shabnam Peyvandi, MD; and biomedical engineer Duan Xu, PhD, pioneered neuroimaging in newborns to detect heart defects and associated brain injuries that can lead to neurodevelopmental delays and intellectual impairments. McQuillen and his team are now exploring ways to treat heart defects and prevent brain injuries before birth, with the goal of eliminating developmental challenges before they begin.

Through the support of countless donors and funders like you, Gabby, HT, and Brooklyn are among the thousands of kids whose lives have been changed by research funded through philanthropy. Together, we can continue to tackle the most pressing questions in children's health and elevate pediatrics to new heights. For more information on how you can support pediatric research at UCSF, contact Jasmine Payne at **Jasmine.C.Payne@ucsf.edu**.

FETAL MEDICINE

A Step Forward in Treating Serious Genetic Disorders Before Birth

Evidence is mounting that clinicians can treat serious genetic disorders prenatally by injecting medicine into the amniotic fluid, thus preventing damage that begins in utero.



DISCOVERY

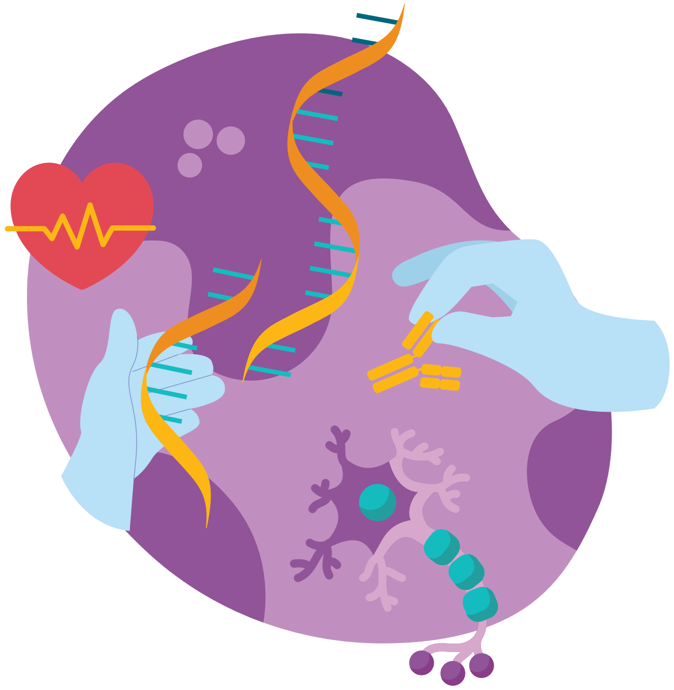
A UCSF-led study in mice and sheep found that delivering medicine via the amniotic fluid for spinal muscular atrophy (SMA) — a neurodegenerative disease that causes muscular weakness, atrophy, and death if untreated — was safe and helped prevent damage to nerve cells in the spinal cord, a part of the central nervous system that is responsible for movement.

CHALLENGE

Children with severe forms of SMA can have irreversible damage by the time they are born. Current therapies are given to patients after birth, but research has shown that SMA can be diagnosed before birth and that the expression of the genes involved in the disorder can be manipulated prenatally.

DESIGN

In the first research on treatment for SMA via the amniotic fluid — a less invasive method than the other possible route via the umbilical vein — UCSF researchers tested a therapy using molecules called antisense oligonucleotides, or ASOs, which can alter the expression of genes through interactions with RNA, which creates proteins.



RESULTS

Our study team found that mice treated prenatally with ASOs fared better in terms of survival, motor function, and motor neuron numbers than mice that were treated only after birth or did not receive treatment. In sheep, the researchers confirmed the safety of the treatment and its ability to reach the spinal cord and other organs in therapeutic concentrations via the amniotic fluid.

IMPACT

"This suggests we may be able to use amniotic fluid to deliver therapeutic RNA molecules for other severe, early-onset diseases that affect different areas of the body," says Tippi MacKenzie, MD, a fetal and pediatric surgeon at UCSF Benioff Children's Hospitals and a senior author of the study. The research team believes that with further study and U.S. Food and Drug Administration approval, correcting SMA before birth could eventually be an outpatient procedure.

BEHAVIORAL HEALTH

WRITING THE BOOK ON TEENS AND SOCIAL MEDIA

An Interview with Jason Nagata, MD, MSc

Dr. Jason Nagata, adolescent medicine specialist at UCSF Benioff Children's Hospitals, has led groundbreaking studies on eating disorders in underserved populations and social media use among teens. Currently, he is developing comprehensive national guidelines focused on adolescents and social media. His work has been featured in The New York Times *and on NPR, CNN, and NBC News.*

You literally wrote the book on eating disorders in teenage boys. What inspired you?

When I was a medical student working in UCSF's Eating Disorders Program, my first patient was a 16-year-old male wrestler. I was trying to read the then-current guidelines about how to take care of him, but there was very little specificity about boys because most of the research was on girls. I started doing that research myself, and after about a decade, I was able to update the medical guidelines on adolescent eating disorders to include specific considerations for boys and men.

That experience really showed me how important it is to conduct research and develop evidence that can inform clinical guidance for pediatricians. Physicians use these guidelines to make decisions about treatment and management every day, and they really have an impact on the quality of patient care.

What led you from eating disorders to social media?

My initial research into social media was through the lens of eating disorders: How does social media use lead to or worsen eating disorder symptoms? I was seeing this firsthand with some of my patients; the constant comparisons to unattainable body ideals and the pressure to show off their bodies to gain likes and followers was giving rise to low self-esteem and poor body image.

I started conducting studies on the topic and gained access to the Adolescent Brain Cognitive Development study, the largest study on brain health and child development in the U.S. It started following 12,000 9- and 10-year-olds in 2016 and has continued to this day, collecting a huge amount of data on contemporary adolescents, their exposure to screens, and their mental and physical health. It's basically the perfect dataset for studying the effects of social media over time.

What are some key findings from your research?

Let me start by saying that social media itself isn't inherently good or bad. There are positive ways that teens can use social media — for connection, communication, or education. But there are also risks related to excessive use. Our team has shown that social media is a risk factor for the development of depression. Excessive use can also crowd out healthy activities like exercise, time spent outdoors, face-to-face connections, and sleeping — all of which are vital to mental health.

There are also elements of addiction in excessive social media use, including symptoms of withdrawal, tolerance, and relapse, which can be similar to addictions to substances like alcohol. We found that 48% of 11- and 12-year-olds report losing track of how much time they spend on their phones, 25% say they're using social media to forget about their problems, 17% say they are trying to reduce their social media use but cannot, and 11% say that screen time or social media use has negatively affected their schoolwork.

How will these findings inform the national guidelines you're developing on teens and social media?

There are currently no national medical guidelines focused on adolescents and social media. The American Academy of Pediatrics does have general screen time guidelines, but they're not specific to social media or adolescent age groups. There is also no formal diagnosis for social media addiction. My goal is to leverage these findings to create practical, actionable, personalized, age-specific advice for parents, teachers, and pediatricians on how to help teens optimize their social media use while minimizing risks and harms. I also want to formalize a diagnosis for social media addiction.

> **For me, social media is one of the most impactful issues we can focus on to support adolescent health.**

Why is this work so important?

We already know that more than 90% of teens are on social media, and that number is increasing. Over a three-year period, when participants were between the ages of 10 and 13, average daily social media use increased tenfold, from 7 minutes to 73. For me, social media is one of the most impactful issues we can focus on to support adolescent health. We have guidelines on tobacco and alcohol, but because social media is relatively new, with relatively little data, we don't have guidelines yet, despite this being one of the top concerns of today's caregivers.

What are your next steps?

Philanthropy will be essential to our ability to finalize this research and launch these guidelines. UCSF has been at the forefront of this work. We have a track record of publishing some of the seminal studies on this topic, and this is such a special place to do this kind of interdisciplinary research with so many global experts. Donor support is crucial to our ability to create robust national guidelines that are personalized for teens of different ages, backgrounds, and experiences, and then get the message out there.

NEUROLOGY

Purpose Over Pain

Andrew Santos’ Courageous Path to Healing

Growing up in Clovis, Calif., Andrew Santos was a happy child. A fun-loving jokester, a devoted Golden State Warriors fan, and a straight-A student, he had a quick wit and a knack for making everyone laugh. “He was always such an amazing kid,” says his mom, Christina. “So much fun all the time.”

By senior year, Andrew was ready to start the next chapter of his life: Clovis Community College. He spent the summer dreaming of the future and exploring the classes he might take. But early on the morning of enrollment day, Andrew suffered a massive brain hemorrhage.

A Life-Altering Diagnosis

At 4:30 a.m., Andrew woke up vomiting and clutching the back of his head. Minutes later, he lost consciousness. His parents called 911 and Andrew was taken to two local hospitals by ambulance. A CT scan revealed a massive brain bleed caused by a ruptured arteriovenous malformation (AVM) — a tangle of abnormal blood vessels formed in utero that can rupture without warning years later. For many patients, AVMs are fatal.

Andrew was airlifted to UCSF Benioff Children’s Hospital. “It was raining,” Christina recalls. “I begged to go with him in the helicopter. The pilot finally said yes. As we flew, he pointed to a rainbow and said, ‘Look, mom. He’s going to be OK. Just hold onto that.’”

> **Andrew chose purpose over pain. He didn’t just survive, he transformed. And now, he’s lighting the way for others.**
>
> – Christina Santos,
> Grateful Parent

Andrew's condition was critical. The hemorrhage had caused a major stroke and the pressure in his brain was dangerously high. Within 48 hours, neurosurgeons removed half of his skull to relieve the swelling and prevent further damage. A few weeks later, on Warriors star Steph Curry’s birthday — which the family took as the best possible sign — a team of UCSF neurosurgeons successfully removed the AVM in a six-hour surgery.

Andrew was out of the woods but faced a long road ahead. He couldn’t speak and was completely paralyzed on his right side. In his first rehab sessions, the goal was just to sit up in bed. But every day, he made progress, and he never said no to a challenge.

Unparalleled World-Class Care

Pediatric stroke is so rare that when Heather Fullerton, MD, UCSF’s chief of child neurology, began her training, it wasn’t even part of the curriculum. AVMs like Andrew’s occur in less than 1% of the population. “I had to adapt adult stroke protocols to fit the needs of children,” she explains. “There was no road map. We were building as we went.”

That challenge became a calling. In 2007, Fullerton founded the Pediatric Stroke and Cerebrovascular Disease Center, turning UCSF into a national leader in diagnosing, treating, and researching these complex cases. Today, UCSF Benioff Children’s Hospitals are recognized as a Center of Excellence in pediatric stroke, seeing more patients than almost any other hospital and serving as the referral site for the most complex cases. The center’s research has shaped national guidelines and continues to push the boundaries of what’s possible.

Christine Fox, MD, Andrew’s neurologist and the center’s director, has been caring for Andrew for the past eight years. She has seen him through every stage of recovery — from intensive care through outpatient visits — and says his story reflects the best of what UCSF has to offer: “We don’t just treat the stroke. We treat the whole child, and we walk alongside the family every step of the way.”

Andrew and the UCSF rehab team show off the games he donates to the hospital each year.

Lighting the Way

Andrew’s rehabilitation journey was extraordinary. After surviving a massive stroke and undergoing brain surgery, he faced months of intensive therapy, including hours of daily physical, occupational, and speech therapy. He had to relearn how to walk, talk, and feed himself. Even after discharge, Andrew persisted with therapy, pushing his recovery further each day.

“In all those years, he never said ‘Mom, I can't do this anymore.’ Not once,” Christina says.

Today, Andrew is 25 and thriving. He has regained his independence and found a new sense of purpose: participating in UCSF research studies and volunteering at the rehab center where he was once a patient. Every year on his birthday and during the holidays, in lieu of gifts for himself, he asks for the games that were instrumental to his own healing — Connect 4, Uno, Jenga, Guess Who — which he donates to UCSF so other kids can experience the same joy, motivation, and success that he did.

“Most patients want to move on and leave the hospital behind,” says Marc Kristensen, PT, Andrew’s physical therapist. “But Andrew chose to stay connected, to give back.”

Andrew also participates in community events to raise awareness for brain aneurysms, AVM, and stroke. He serves as a youth ambassador for The Aneurysm and AVM Foundation (TAAF), using his story to educate and inspire.

Earlier this month, Andrew was honored at the Dreamfest Concert for UCSF Benioff Children’s Hospitals with the 2025 Colin Powell Medal of Courage for bravely turning his medical journey into a mission of hope and healing.

“Andrew chose purpose over pain,” Christina says. “He didn’t just survive, he transformed. And now, he’s lighting the way for others.”

While Andrew continues to work on his recovery and lives with the lifelong changes brought on by the stroke, he chooses to remain positive. “Love is strong,” Andrew says. “I’m grateful for every day, and I want to show that nothing is impossible.”

UCSF Benioff Children's Hospitals

University Development and Alumni Relations
UCSF Box 0248
2001 The Embarcadero, 3rd Floor
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Give Hope on Giving Tuesday

December 2, 2025

Tej found hope thanks to a lifesaving liver transplant. His Uncle Raghav was the perfect match, giving Tej the greatest gift of all — the chance to beat cancer and live out his dreams.

Now, another perfect match is making world-class care possible for more children like Tej. Nexa Equity, one of our generous benefactors, has pledged to match all year-end gifts, up to $325,000. That means every dollar you give will have twice the healing power, helping children in need find their own chance for hope and healing.

Giving Tuesday is December 2! Save the date or make your gift today by pointing your phone's camera at the QR code or visiting givingtogether.ucsf.edu/kids2025.

NEXA EQUITY