

Connections

WINTER 2021



On a Mission: How We're Improving Pediatric Pain

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Returning to the Classroom

Science suggests it's safe for kids to go back to school, but proper planning and protocols are necessary.

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Beating the Odds

Xavier's family has been on a journey of hope as they chart the world of rare disease.

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All Are Welcome

How we're delivering specialized care to meet the unique needs of immigrant children.



A message from **Matt Cook, President**

I'm thrilled to introduce myself as the new president of UCSF Benioff Children's Hospitals. It's an honor to join an incredible team of caregivers and leaders to advance our crucial mission: providing excellent care for every child in need.

Since age 12, I've been personally invested in ensuring medical care is accessible to all. That's when, during my mother's cancer battle, our family lost our health coverage. I'll never forget how the trauma of losing insurance added to the pain and hardship of her treatment.

I was drawn to UCSF Benioff Children's Hospitals partly, of course, for their renowned clinical care, research, and education. But I'm particularly honored to join an institution that has time and again demonstrated such an unwavering commitment to social justice and health equity.

Though I'm starting at a challenging moment for our hospitals and our country, I'm filled with optimism and enthusiasm. It's impossible to know what the post-pandemic world will look like, and I believe children's hospitals may never be completely the same. But I'm confident that the changes we build together will help us provide care better than we could have imagined.

Thank you for being part of this community. I look forward to getting to know you.

With respect and gratitude,

Matt Cook

President, UCSF Benioff Children's Hospitals

“ As a Black female, I am a minority in medicine, and I have felt that isolation at various times during my training. But when I see the smiles light up on a Black family when I walk into a room, and a parent says to their child, 'Look, your doctor is Black,' that really leaves a soft spot in my heart and pushes me to keep going. ”

— Ama Baffoe-Bonnie, MD,
pediatric resident



ANDREW SHAFER

NO UNNECESSARY PAIN

Through a new initiative, we're reducing pain and fear for young patients.

When Stefan Friedrichsdorf, MD, had emergency surgery on his finger at age 9, two doctors held him down while he screamed. They seemed oblivious to his suffering. The memory still haunts him.

Like Friedrichsdorf, many adults vividly recall terrifying childhood medical experiences that still make their skin crawl and their heart race. Too often this trauma has lasting, and dangerous, consequences: a fear of doctors, hospitals, or needles that can prevent timely medical treatment for a lifetime.

Friedrichsdorf's mission is to improve pediatric pain care. After building a nationally recognized program at Children's Minnesota, he joined UCSF Benioff Children's Hospitals in April 2020 as medical director of the new Center of Pain, Palliative and Integrative Medicine thanks to generous support from Elisa and Marc Stad.

"If children are in unrelieved pain, they turn into adults with higher rates of chronic pain, anxiety and depression," Friedrichsdorf says. "It will take time and effort, but we have to change our system permanently."

Education is a crucial component of this work, since most



If children are in unrelieved pain, they turn into adults with higher rates of chronic pain, anxiety and depression.

medical professionals don't receive formal training on pain management and prevention.

"At most children's hospitals, pain is everybody's problem but nobody's responsibility," Friedrichsdorf explains.

New protocols throughout the hospitals will ensure maximum comfort during every procedure. During needle pokes, for example, kids will be offered numbing cream and an age-appropriate distraction

like bubbles or a game – and they'll never be held down.

Initial steps to grow a nationally recognized program include starting an outpatient palliative clinic, establishing a staff training program, and improving the management of distressing symptoms during end-of-life care. Friedrichsdorf and his team will also increase the availability of integrative therapies like aromatherapy, deep breathing, acupuncture, acupressure, and massage.

This work is only possible through philanthropy.

"We are honored to create a space where every family feels empowered to manage pain and considers the whole patient. We are excited to be a part of blending traditional medicine with integrative methods to improve the patient experience in a hospital setting," says Elisa and Marc Stad.

Illuminating New Connections Between Maternal and Child Health



Listen for a heartbeat.

Wait for a cry. Count 10 fingers and toes. In the delivery room, these are the steps a mother often takes to confirm the health of her newborn child. Yet the seeds for wellness are planted long before birth.

We know that long-term stress in adults wears out cells and has been linked with chronic conditions, like heart disease and diabetes. But how does maternal stress affect infants?

Nicole Bush, PhD – whose research integrates insights from social epidemiology, sociology, clinical psychology,

developmental psychobiology, and genetics to understand their effect on development – seeks to answer that question.

In partnership with colleagues in psychiatry and pediatrics, Bush recently completed a study that sheds light on the link between a mother's mental well-being, specifically focused on stress, and her infant's physical health.

Delivering Insights

The study involved 109 low-income, racially and ethnically diverse women. They rated, using a five-point scale, how stressed they felt by challenges in their lives during middle and late pregnancy. The researchers later

assessed the health of their infants across their first year of life.

The team found that for every one-point increase in reported prenatal stress in the mothers, among their infants there was a 38% increase in infectious illness and a 73% increase in noninfectious illness. They also determined that postnatal stress and depression in the mothers were not associated with any additional increase in illness among the infants.

"These results are in line with a growing body of research indicating that stress to the mother during pregnancy – especially in late pregnancy – has a negative impact on the baby's health," Bush says.

Research that Matters

Bush noted that more than 60% of the study's participants were overweight or obese.

"Our sample may actually be more representative of American mothers than typical research populations, and that is one value of this work," she says. "We need samples that represent mothers who are most likely to experience high levels of stress during pregnancy if we are to understand and prevent intergenerational transmission of risk for poor health."

Is It Safe for Kids to Return to School?

Parents everywhere are grappling with this question. Here's why one UCSF researcher is optimistic about the answer.



We think of children as germ spreaders. When a kid comes home with a runny nose and a cough, the rest of the family often follows.

But that's not true with COVID-19. Naomi Bardach, MD, who is researching how to control the virus's spread, shares why school reopening is safe for kids – and everyone else.

Why aren't children as susceptible to COVID-19?

One reason is that COVID-19 enters into the body via something on the cell called the "ACE-2 receptor," which children just don't produce as much as adults. Elementary school kids produce less than middle-schoolers, and high-schoolers and older teens produce less than adults. If the virus has fewer doorways into your body, you don't get COVID-19 as often. And when you do get the disease, it's not as severe.

We have less data about why children don't transmit the virus as much, but there are a few likely reasons. First, children have smaller lungs, so they don't pump out as much air, and therefore less virus, than adults. Then, because they don't get as severe disease, they don't cough as much, so, again, less virus comes out of their bodies. Also, simply because kids are shorter, they tend to not pass disease to adults because

their droplets fall to the ground before reaching adults.

What would you say to parents who worry about sending their child to school?

The reality is that the risk to children who are otherwise healthy is very low. If you're willing to drive a child to school, that's probably about the same risk to their health.

As for kids bringing the virus home to other family members, it's not impossible, but based on a number of scientific studies, we have learned that most of the time, even when schools are open, kids are getting the infection from an adult in the household who brought it home.

What research are you working on?

We know that the keys for safety at school are masking, physical distancing, stable cohorts, ventilation, hand hygiene, symptom screening, and testing. I'm leading research on how best to implement these tactics so that we can stop the virus's spread and keep kids in the classroom uninterrupted.

Unfortunately, COVID-19 looks like every other viral syndrome known to children, so having cold-like symptoms is going to keep kids out of school a lot. We're trying to better understand and refine a list of the symptoms that increase

the likelihood that a child might have COVID. We might learn, for example, that one day of a runny nose is so low-risk that it should not prevent kids from attending school.

So if your child has cold-like symptoms, what should you do?

Right now, in the absence of better data, the answer is that we need to keep such kids home. There are stories of kids with really mild symptoms having COVID-19. Until we have a more robust, data-informed way to move forward, symptom screening is crucial. That being said, it's important for kids who tend to have runny noses because of allergies, or little coughs because of their asthma, to not have to constantly stay out of school.

What is the biggest key to safe school reopening?

Wear your mask, wear your mask, wear your mask – particularly adults. When school staff are eating lunch in the break room, for example, they might let their guard down, thinking that their colleagues would never get them sick on purpose. No, of course they wouldn't. But someone may have asymptomatic disease. So keep your mask on.

In December 2020, Dr. Bardach joined the Office of Governor Gavin Newsom as lead for the California Safe Schools for All team. She also will continue to serve as an associate professor at UCSF.

XAVIER: Never Give Up

After being diagnosed with a rare genetic condition, Xavier thrives with expert care.



This journey has not been easy. But that's okay, because it's our journey.

— Jessica,
Xavier's mother

As a baby, Xavier spiked high fevers and didn't hit the expected milestones for weight gain. Then, soon after he celebrated his first birthday, he came down with chicken pox.

It's not an unusual diagnosis, but Xavier's case was surprising. He had been vaccinated just a few days prior.

"That was our first clue that something was really wrong," says Xavier's mother, Jessica.

Months passed, filled with hospital visits, and the family still had no insight into Xavier's

condition, which was rapidly declining. Finally, the Napa family was referred to UCSF Benioff Children's Hospitals.

In January 2015, UCSF experts discovered the cause of Xavier's frequent illnesses: a rare genetic disease that had left him without a functional immune system. There are only eight known cases of his

disease. "Our world got flipped upside down," Jessica recalls.

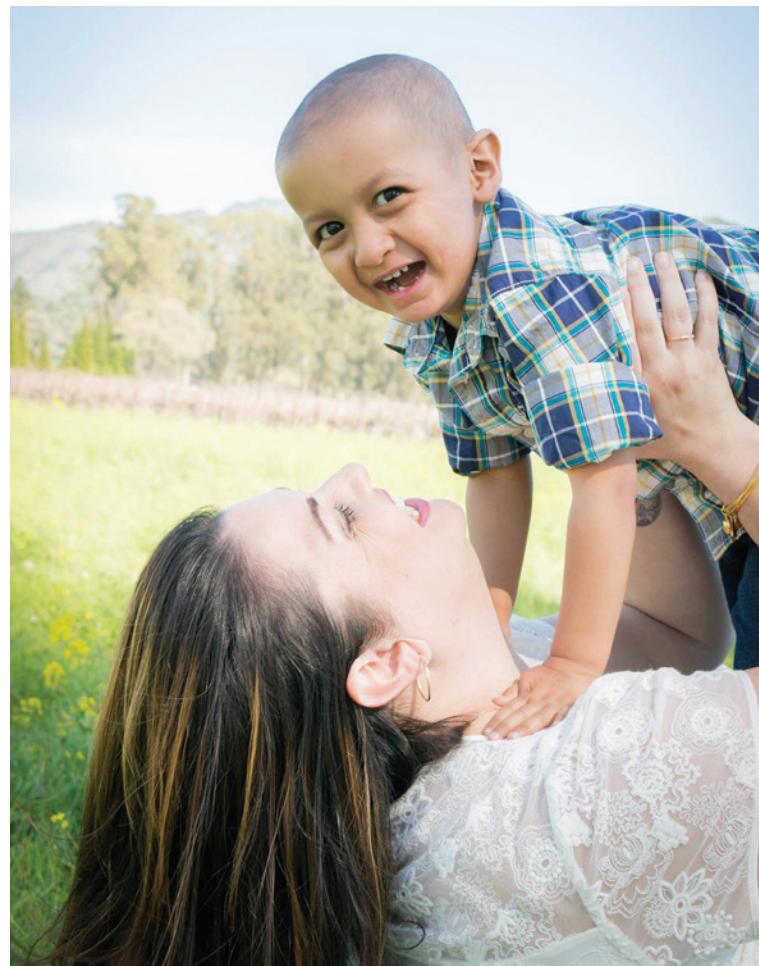
Xavier's condition was terminal; he might not even make it to his next birthday. But that didn't stop his medical team, which includes nationally recognized experts in immune deficiencies, from helping him surpass all expectations.

Beating the Odds

When Xavier faced a rare infection, the team went directly to the FDA to get permission to give him a drug that was not yet approved, saving his life in the short term and getting him healthy enough to undergo a stem cell transplant. Then, with his older brother as a match, Xavier had the transplant, which enabled him to grow a working immune system.

Through every setback – mysterious infections, prolonged hospitalizations, and more – caregivers at UCSF have stood by Xavier's side. Now 7 years old, he's treated by 14 specialist teams at UCSF, including many of the same doctors and nurses who've cared for him since day one.

"There is nobody else I would trust Xavier with," Jessica says. "There's a bond that gets formed when you go through something like this. We have come so far together, and they have invested so much time,



especially considering how rare his condition is, to figure out what will work for him."

Giving Back

To show her gratitude, Jessica joined the Family Advisory Council, a volunteer organization that guides the hospitals to understand families' needs. In December 2019, she and Xavier rallied their community to donate healthy snacks for the Infusion Center so that kids and families visiting for lengthy treatments can enjoy a treat. "It's been so great to get involved and give back, since UCSF has done so much for my family," Jessica says.

During the pandemic, Xavier faces heightened risk. But his mother says this challenge, like all the others he's faced, doesn't get him down.

"Even on his worst days, he's laughing and trying to make everyone else laugh," Jessica says. "This is the only life he's known, and he's the happiest kid I've ever met."

Xavier's positivity is shared by his entire family.

"This journey has not been easy. But that's okay, because it's our journey," Jessica says. "It's made us stronger as a family. We enjoy every day we have together, and we refuse to give up."

Respect, Empathy, and Understanding for All

Our new center provides specialized care for immigrant families.



For decades, UCSF Benioff Children's Hospital Oakland has been recognized for providing compassionate, culturally sensitive care for immigrant children.

That's what drew Zarin Noor, MD, to the hospital. Noor herself came to the U.S. as a refugee from Afghanistan at age 5. She recalls her parents receiving unequal treatment at her childhood doctor visits.

"I learned the language quickly, so I was often the interpreter," Noor says. "It was odd that I got more respect than my parents."

Noor's personal experience, expertise, and passion led

her to co-found the Center of Excellence for Immigrant Child Health and Well-Being, a cross-Bay initiative to deliver comprehensive care targeted to immigrants' unique needs and to educate other institutions on best practices.

This is not a niche endeavor. Half of the children in the Bay Area are immigrants or have a parent who is an immigrant. The social, political, and economic challenges faced by many of these families have serious and lasting impacts on their mental and physical health. Under the center's guidance, families have access to medical providers, mental health care, social services, legal counsel, forensic exams for asylum

cases, healthy food, and more, with interpreters available to ensure their understanding.

"Immigrant children are unique; they deal with so many different layers of trauma," Noor says. "We're coming together to provide comprehensive services with a foundation of trauma-informed care, cultural humility, and social justice."

Patients helped by the center include a Guatemalan teenager who was separated from her family at the U.S. border and didn't know when or if they would be reunited; she came to Noor with severe panic attacks. The family of a little girl from Yemen with multiple serious health challenges struggled to navigate her specialized care. And a boy separated from his mother sought help for debilitating nightmares.

"We understand there is more to every immigration story than just coming to this country," Noor says. "Our families trust us and bring up issues that are outside of what you might normally discuss with a physician. I'm so glad to be able to provide this level of care to people who might not find it otherwise."

TREATING YOUTH IN CRISIS

Our substance use clinic helps teens battling addiction – without stigma.

When Veronika Mesheriakova, MD, started out in adolescent medicine, she frequently encountered teens with the same challenge: addiction. And she had no idea how to help them.

"I was completely unprepared," she recalls. "I didn't know how to talk about it or where to send them. I felt helpless."

Mesheriakova spent years educating herself on best practices for evidence-based care. Ultimately, she became an expert in treating adolescents with substance use disorder. To deliver excellent care for young people facing this condition – and to ensure that trainees at UCSF and beyond would learn skills she hadn't been taught – Mesheriakova established the UCSF Youth Outpatient Substance Use Program (YoSUP).

YoSUP offers each patient the specific multidisciplinary services they need, without stigma or judgment, and involves the entire family. Social workers and mental health providers help families understand and overcome underlying issues.

Mesheriakova also created a training program so that future physicians will be able to better diagnose and help young people battling addiction.

"Less than 5% of young people with substance use disorder are correctly identified by providers," Mesheriakova says. "I'm working to change that."

YoSUP serves teens like Nic, who battled addiction for 10 years. His father, David Sheff, wrote the award-winning novel *Beautiful Boy* about Nic's journey.

Sheff navigated what felt like a broken system trying to find care for his son. So when he learned about YoSUP, he was inspired to get



Nic and David Sheff with their dogs

involved. He made a major contribution to support YoSUP's clinical care, research, and education programs.

"With UCSF, I felt like I was finally in the world I imagined – a world in which addiction was treated like the complicated disease that it is," David Sheff says. "The more we develop proven treatment programs, the less stigma there will be, because there will be widespread recognition that not only is this a disease, it's a treatable one."

Today, Sheff and 38-year-old Nic are neighbors. They see each other almost daily to go hiking or surfing. Sheff doesn't take their health and happiness for granted.

"With the recognition of how lucky we are, supporting this work didn't seem to be a choice – it was an obligation," Sheff says.



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