

A NEWSLETTER FOR
FRIENDS AND SUPPORTERS

Connections

WINTER 2022



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As we enter the third year of the COVID-19 pandemic and continue to grapple with the realities that this crisis has brought, I remain humbled by what we have to be grateful for.

So often, I find myself marveling at the remarkable ways in which our providers have, for two plus years, persevered in the face of such devastation. They have continued to advance patient care, advocate for our most vulnerable patients, champion learning across our hospital system, and foster discoveries that will change the way we think about medicine for years to come.

I am equally moved by your commitment. Even amidst so much uncertainty, our donor community continues to come through for our children with inspiring generosity. Your support is allowing us to tackle this global pandemic with efficiency, compassion, and innovation at every turn.

In my time as chair of the UCSF Benioff Children's Hospitals Board of Directors, I have seen firsthand what happens when our community stands with us during challenging times. As you'll read in this issue of *Connections*, philanthropy plays a powerful role in creating a healthier future for our children by enabling top-notch care for young immigrants and refugees; building state-of-the art facilities for critically ill patients; and supporting innovative therapies for everything from orthopaedic trauma to hypertension.

The pages ahead detail the difference you make for our kids every day. Thank you for everything you do for our community.

Sincerely,

Shahan Soghikian
Chair, UCSF Benioff Children's Hospitals Board of Directors

COMMUNITY

SERVING EVERY CHILD

How UCSF is leading the national effort to care for refugee children

When Zarin Noor, MD, was just a toddler, she became a refugee.

Dr. Noor was 18 months old when the Soviet Union invaded Afghanistan, her home country. She was 3 when her family fled to Germany and applied for asylum in the US. And she was 5 when they settled in Union City, Calif. That was 1983.

Neither of her parents spoke English, so young Zarin learned the language quickly and became the family interpreter. She translated at doctor's appointments, filled out government forms, and even attended her own parent-teacher conferences. She says it wasn't a burden; she wanted to help her parents adapt to their new life.

That desire to help has defined Dr. Noor's career. Today, she is a pediatrician at the Claremont Pediatric Specialty Clinic on our Oakland campus, which provides comprehensive care to underserved East Bay children, 92% of whom live below the poverty line. She is also the director of Claremont's International Clinic, which cares for local immigrant and refugee patients.

"We see a lot of immigrant and refugee families," says Dr. Noor. "Half of the children in Alameda County have at least one immigrant parent, and we know that these children require a different approach given the trauma they have endured. An approach grounded in cultural humility. And it takes investment to do that well."

In this spirit, Dr. Noor and her team established the Center of Excellence for Immigrant Child Health and Wellbeing at UCSF Benioff Children's



Dr. Zarin Noor, pediatrician, UCSF Benioff Oakland and director, International Clinic at Primary Care

Hospitals. Funded entirely by philanthropy, the Center, which Dr. Noor co-directs, works with partners across the country to advocate for the health of immigrant children.

When the Taliban retook the Afghan capital of Kabul in August 2021, the Center of Excellence led the national push to organize culturally appropriate health care for the hundreds of Afghan refugee children arriving in the US, including some who came alone.

"I want to make sure that these children and families feel like they have a home here and that there are people who support them and understand their trauma and accept them for who they are," Dr. Noor says. "I know from experience that a little support can go a long way."

ALWAYS AT THEIR BEDSIDE

How one family is investing in others who are digging deep to stay strong



Nurses at work in UCSF Benioff Oakland's newly renovated Pediatric Intensive Care Unit

They made a commitment as a family: Never leave him alone.

That's how Linda Wight came to spend so much time at UCSF Benioff Children's Hospital Oakland, including weeks in the pediatric intensive care unit (PICU). After being diagnosed with a rare form of cancer and enduring countless tests, scans, and surgeries, Linda's 4-year-old grandson spent the final days of his life there. As promised, a family member was always by his side, right up until the end.

For Linda and her husband, Steve, that experience never left them, not only because of the tragedy that unfolded before their eyes but also because it was through this personal experience that they came to understand just how vital this hospital and its remarkable staff are to Bay Area children.

"We had never faced anything like this before," Linda says. "And yet, we could see that this place was extraordinary. Yes, it's excellent. Yes, it's professional. But it's also sensitive. It's caring. It's done with humility. And it's here for every child. No one is turned away. We

wanted to do everything we could to encourage that to continue."

So after time passed, the couple returned to our Oakland campus – not as grandparents but as philanthropic partners. Their personal contribution to the expansion and modernization of the PICU enabled a major step forward in the hospital's ongoing effort to build a facility that can serve every patient with world-class care for decades to come.

Investing in the future

In the years since the Wights walked the halls of UCSF Benioff Oakland, the hospital has come a long way. In 2015, UCSF launched a phased plan to modernize the campus, including the addition of a new six-story outpatient center and renovations to several existing inpatient departments. On September 21, 2021, the hospital unveiled the latest milestone in this modernization plan: a newly upgraded PICU on the second floor.

Four times larger than the former space, the new state-of-the-art facility has vastly enhanced the patient and family experience while also providing clinical teams with the environment and tools they

need to deliver the safest, highest-quality care. The project also reflects UCSF's commitment to investing in Oakland and guaranteeing access to care for every child in need.

"This is such an important and pivotal expansion for UCSF Benioff Children's Hospital Oakland's critical-care unit and the children we serve," says Kelley Meade, MD, the hospital's interim chief medical officer. "The pandemic has really showed us how important it is for patients and families in crisis to have private safe spaces that promote healing."

A space for healing

When Linda talks about the decision to support the PICU renovation, she calls it an opportunity for which she feels grateful. An opportunity to honor the incredible people who cared for her grandson and continue to care for children like him every day. An opportunity to help families like her own, who are digging deep to stay strong at their child's bedside.

"You are so depleted in those moments," Linda says. "Providing a place for a family member to lie down and be there at night – that's huge. It has nothing to do with providing a luxurious space. It has to do with helping the family get some rest so they can find the strength to focus on caring for their child."

One of the most striking features of the new facility is the 46-foot-wide mural – commissioned in honor of the Wights' gift – that greets patients and families in the PICU waiting room. The mural depicts a lush green landscape with children at play under an expansive sky, a tree that seems to sway in a soft breeze, and a familiar cityscape in the distance.



We could see that this place was extraordinary. Yes, it's excellent. Yes, it's professional. But it's also sensitive. It's caring. It's done with humility. And it's here for every child.

– Linda Wight, grateful grandparent

It also features simple, grounding words – "hope, courage, care, comfort" – expressed in a few of the many languages commonly heard in the halls of UCSF Benioff Oakland.

"In those moments of waiting, reality hits you hard, and it hits you quickly," Linda says. "I found myself holding my breath a lot in that waiting room. I hope the families there, from all backgrounds, look at those words and think, 'I can exhale.'"



A section of the mural, commissioned in honor of the Wights' gift, that greets families in the new PICU waiting room

A History of Childhood Vaccines

For thousands of years, right up to the present day, remarkable innovations have driven the quest to eradicate disease and protect the most vulnerable among us: our children.



1879

GERM THEORY MAKES ITS MARK

After demonstrating that germs spread disease, Louis Pasteur produces the first lab-developed vaccine for chicken cholera.

1940s

MASS VACCINATIONS TAKE SHAPE

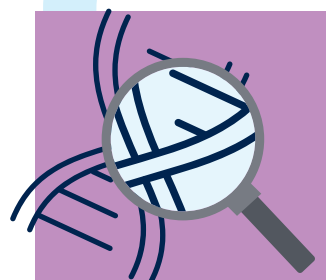
Large-scale production of diphtheria, pertussis, and tetanus (DPT) vaccines pave the way for protecting millions of children.



1991

THE DNA REVOLUTION

With advances in molecular biology, the hepatitis B vaccine is produced using DNA, and the disease is virtually eliminated in children.



1996

NO MORE SPOTS

Remember chicken pox? Your kids won't. With the addition of the varicella vaccine, the number of infections in the US decreases by 90%.



1972

GOODBYE, SMALLPOX!

After thousands of years, smallpox is finally eradicated, and the vaccine is no longer recommended.



1000 CE

EARLY INOCULATION

The Chinese employ early inoculations known as variolation to fight smallpox – one of the deadliest childhood diseases ever.



1796

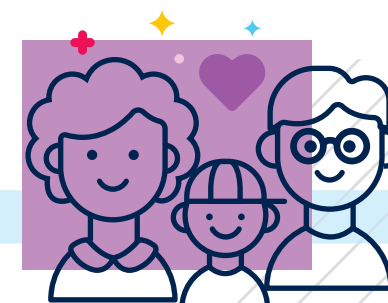
THE FIRST VACCINATION

Edward Jenner's innovative use of cowpox material to create immunity to smallpox quickly makes the practice widespread.

1955

ERADICATING POLIO AT LAST

When the polio vaccine is licensed, parents everywhere breathe a sigh of relief.



1960s

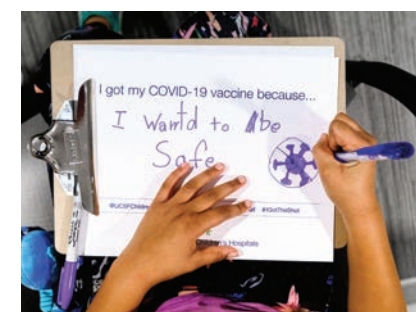
ACTIVE RESEARCH AND DEVELOPMENT

Researchers begin targeting measles, mumps, and rubella, significantly reducing the disease burden on kids.

2021

TURNING THE TIDE OF A GLOBAL PANDEMIC

COVID-19 vaccines are approved for use in children over age 5, relieving months of stress for kids and families. As one of our patients told us, getting the shot was worth it because "I wanted to be safe."



Putting the Pieces Together

One family's struggle meets one doctor's vision



Jeff Grimes undergoes blood pressure monitoring with Dr. Elaine Ku.

Jeff Grimes – an active, athletic kid – was diagnosed with hypertension, or high blood pressure, at age 16.

“I remember being confused,” Jeff says. “So many questions ran through my head. Why did this happen to me? What can I do about it? But there were no obvious answers.”

Jeff started medication but wanted other options. He did

his own research, watched what he ate, and modified his exercise routine. The turning point came when, at age 22, Jeff met Elaine Ku, MD, a UCSF nephrologist with unique expertise in pediatric and adult hypertension.

In Dr. Ku, Jeff found a partner who was willing to do everything it took to optimize his health. Doctor and patient conducted

“experiments” together, tinkering with everything from the finer details of Jeff’s plant-based diet to his medication cocktail and his home-based blood pressure monitoring tools. When Jeff’s readings improved, they recorded their approach and strategized about next steps.

“Dr. Ku is unlike any other doctor I have ever encountered,” Jeff says. “She devised a thorough plan that we could run together to manage my blood pressure – it was the scientific method mixed with her infectious energy to get to the bottom of things.”

A growing concern

An increasing number of young people in the US experience high blood pressure. As many as one in eight young adults has hypertension, and the rate is expected to rise over the next decade.

The consequences are significant. Decades of living with high blood pressure can weaken heart and brain function. And at a moment in life when passions, professions, and relationships begin to flourish, the side effects associated with blood pressure medication can diminish quality of life by decreasing energy

levels, undermining mental health, and impairing cognitive function.

Yet little is known about the lifelong consequences when hypertension starts in young adulthood. With its relatively low fatality rate compared to hypertension in older adults and the long-term nature of studies needed for younger adults, funding for research remains elusive.

“Jeff had so many questions, but I had to tell him there was no trial data on his age group,” Dr. Ku says. “Everything we knew had only been tested in older adults – there is no research center, no meaningful funding applied to understanding hypertension in young adults. It was Jeff’s questions that got me thinking about what to do next.”

A reason to give

Michael and Janelle Grimes were shocked to learn that their physically fit, diet-conscious, teenage son had high blood pressure. Then they put the pieces together: Janelle learned that both her father and sister had been diagnosed with hypertension as young adults despite also leading active, healthy lives.

Dr. Ku confirmed that hypertension is surprisingly common in healthy young people. However, without definitive data, all she could

“
Literally no
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So when we
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to get involved.”

– Michael Grimes,
grateful parent

do for patients like Jeff was develop personalized treatment plans through careful trial and error – and hope for the best.

But there was another way, she told Michael and Janelle. With philanthropic support, she could design an innovative research study focused entirely on young adults with hypertension. The study would engage patients like Jeff directly in data collection using advanced health monitoring technology and study participants over an extended period to optimize results.

“Literally no one in the world is studying this,” Michael says. “So when we heard Dr. Ku’s vision – to create the most advanced research initiative in the world focused on hypertension – we had to get involved.”

A pioneering initiative

In 2021, the Grimes made a generous gift that will help Dr. Ku launch a groundbreaking hypertension research study focused solely on young adults – an innovative effort that will use digital tools to optimize treatment and support quality of life.

Their gift will cover the project’s pilot phase, which will involve collecting preliminary data on a few dozen participants over three years. That data will inform the design of a full research study that will follow 1,000 participants from across the country for eight years.

For Dr. Ku, the hard work has only just begun. In addition to launching the pilot phase in 2022, she will need to raise \$9 million to fund the full project and fulfill her vision of establishing a world-renowned center for young adult hypertension. She considers this a wonderful challenge to have; the Grimes helped her take the crucial first step that will lay the groundwork for the project’s future.

“We realize we are only getting the implementation of Dr. Ku’s vision started,” Michael says. “She will need so much more support to see this project through to completion. We just hope others find her work as inspiring as we do and decide to join her.”

For information about how you can support the Young Adult Hypertension Research Initiative, email Jennifer Ratliff at Jennifer.Ratliff@ucsf.edu.

A Complex Journey to Recovery



Anaka Puthiyapurayil, finally on the road to recovery

The discomfort began in 2011 when Anaka was just 2. The pain grew worse, and within a year, Anaka's left leg was visibly shorter and thinner than her right. She began to walk with a limp.

Doctors were baffled. Anaka's parents, Hari and Sapna sought out a second opinion. Further examination revealed that their daughter's femoral nerve had been damaged during a hernia surgery she had undergone as a baby. The injury was so severe that doctors thought Anaka might be permanently disabled.

"They said there was no chance to get it back to normal," Hari recalls. "We didn't know what to say. We were so low. We began to lose hope."

In 2014, a friend referred the family to a neurologist at UCSF Benioff Children's Hospitals, where Anaka underwent a nerve repair procedure. After years of discomfort, the pain started to subside. Hari's faith began to grow again.

That was just the beginning of Anaka's journey with UCSF. After the nerve surgery, she underwent years of physical therapy. And in 2019, Anaka was referred to Sanjeev Sabharwal, MD, MPH, an orthopaedic surgeon who had

recently established the Limb Lengthening and Complex Reconstruction Center at UCSF Benioff Children's Hospital in Oakland.

Dr. Sabharwal was struck by the extraordinary nature of Anaka's treatment journey – a journey that he believes was only possible at UCSF.

"It's always a team approach," he says. "Anaka started with neurosurgery, then came to orthopaedics where she had rehabilitation, physical therapy, and surgery. The fact that Anaka could do all of this in-house is amazing."

In 2020, Dr. Sabharwal conducted two cutting-edge procedures to straighten and lengthen Anaka's damaged leg. The surgeries employed a groundbreaking technique: inserting a magnetized lengthening device into the center of the bone and slowly lengthening the leg over a period of months.

"This is brand new technology, and we want this kind of care to be available to every child," Dr. Sabharwal says. "We want this to become a destination program."

After struggling with her injury for years, Anaka has begun to see possibilities where there had only been limitations. She has started swimming, she's back at school, and she loves to dance.

Hari and Sapna are in awe of Anaka's emotional strength. And as they watch their child gain confidence every day, they find themselves overwhelmed with gratitude.

Shortly after Anaka's second surgery, the family decided to pay that gratitude forward and make a gift to UCSF's Institute for Global Orthopaedics and Traumatology, which addresses global disparities in orthopaedics.

"There are so many kids facing complex situations like this," says Hari. "So whatever small thing we can do to help children like ours, we want to do it."

REACHING YOUTHS IN CRISIS

An estimated 60,000 children are incarcerated in the United States every day, and young people of color are vastly over-represented among youths in contact with the justice system.

There are many documented reasons for this, including discrimination, poverty, and lack of access to services, particularly mental health care. The consequences are significant: Children of color who come into contact with the justice system are more heavily impacted by trauma and overlapping mental health challenges than their white peers.

Yet few health care initiatives focus on supporting incarcerated young people of color with the culturally appropriate and evidence-based mental health care they desperately need. Psychologist David Hoskins, PsyD, MAS, is looking to change that.

Dr. Hoskins came into health care with a passion for serving marginalized youth. His practice at UCSF Benioff Children's Hospitals – a nationally renowned center for pediatric mental health care – focuses on providing specialized mental health services for vulnerable children, including those who have had contact with the child welfare and justice systems.



David Hoskins, psychologist, UCSF Benioff Oakland

"We see so many marginalized kids, whether due to race, ethnicity, disability, socioeconomic status, sexual orientation, or gender identity," Dr. Hoskins says. "And these kids are more often in contact with the child welfare and juvenile justice system, which can have a huge negative impact on their well-being. The primary care setting can be a wonderful way to connect with these youths and their families."

Dr. Hoskins' practice combines culturally sensitive mental health care with research that explores the unique needs of Latinx youth who have been incarcerated. His research has revealed the outsized impact that trauma plays in the lives of these children. For example, one study found that three-quarters of first-time offending Latinx youth had a history of trauma.

These findings directly inform how Dr. Hoskins and his team assess and treat their patients. His research is also generating important recommendations for how the justice system can do a better job of caring for vulnerable children.

"My ability to pose questions like this, and improve how our programs care for these kids, is so dependent on finding people who are interested in financially supporting this work," Dr. Hoskins says. "It takes resources and people to create real impact."

600

young people in detention received mental health care from UCSF Benioff Children's Hospitals in 2020.

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