

A NEWSLETTER FOR  
FRIENDS AND SUPPORTERS



# Connections

FALL 2023



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### A Medical Home for Rett Syndrome

When Katie Nues was diagnosed with Rett syndrome in 2003, the disease was still a mystery. Twenty years later, Oakland patients have a clinic to call home and a cure on the horizon.



**One year into my tenure as chief medical officer** of UCSF Benioff Children's Hospitals, I could not be more proud of this incredible organization and the people I work with every day.

As 2023 draws to a close, our hospitals are on the rise. More kids have access to better care, innovations are transforming how we practice medicine, and the world is taking notice as our hospital rankings continue to climb.

My job is to sustain this momentum so that every child we serve has a brighter, healthier, and stronger future ahead. That's why I'm focused on continuing to accelerate growth across our hospital system, attract top talent, and enhance the quality of our care.

Everything we do here is for kids. That's what keeps me inspired every day. Patients like Hope, Selah, and Katie, who you'll read about in the pages ahead, are our driving force. Our remarkable team never loses sight of that.

The stories in this issue of *Connections* reflect these values and our effort to improve everything we do. We want our patients – no matter their background, their diagnosis, or their life circumstances – to thrive in our care and well into adulthood.

Thank you for your continued support as we forge ahead. Your partnership is what brings this mission to life.

Sincerely,

Joan Zoltanski, MD, MBA  
Chief Medical Officer and Interim President  
UCSF Benioff Children's Hospitals

# A REDWOOD GROVE

## at UCSF Benioff Oakland



This summer, UCSF Benioff Children's Hospital Oakland debuted "The Grove," a new installation by local artist Walter Hood that converts the breezeway leading to the main hospital into a magical redwood forest. The urban design and landscape architect's latest creation is the first of several community art projects that are part of ongoing investments on our Oakland campus.

# Black Babies Who BLOOM

A new initiative pairs newborn services with culturally responsive care



Not being heard, not being taken seriously, and being misunderstood by health care providers are common experiences for many Black parents during routine medical visits. For Black parents of young children, that lack of cultural understanding can lead to grim consequences for the health of the baby and the birthing parent.

According to the California Department of Public Health, Black babies in the Bay Area are twice to three times as likely as white babies to be born prematurely or to die before their first birthday. Scientific evidence points to structural racism and a systemic lack of cultural awareness by providers as causes of these disparities.

To address these and other health disparities and improve overall health outcomes for Black children and families, in June, UCSF Benioff Children's Hospital Oakland launched a new initiative called BLOOM: Black Baby Equity Clinic. The new clinic, which was created entirely with philanthropic support, matches Black babies and young children – from newborn to 3 years old – with Black health care teams. These

include pediatricians, social workers, lactation specialists, therapists, and health educators, all of whom are trained to understand the social, cultural, and racial challenges Black families face daily.

"This clinic is for the Black families who feel unseen and unheard and feel their concerns about their baby's care are being dismissed," said Dayna Long, MD, pediatrician and BLOOM co-founder. "Here, Black parents will know they are valued and their babies are loved."

## Trust and Understanding

Hope Williams-Burt, the mother of four children, including an 11-month-old, spent years struggling to navigate a health care system that left her feeling alienated and disempowered while she coped with a complex set of life challenges, including homelessness, food insecurity, and two pre-term births.

Williams-Burt said that her experience with Long treating her young daughter was vastly different from pediatric visits for her three

previous newborns. "Dr. Long makes me feel safe as a parent," Williams-Burt said. "I trusted her instantly because she understands my story and has the courage and freedom to adjust her care to my baby's needs. I don't have to do unnecessary explaining. She just gets it."

## Wraparound Care

Appreciating the diversity of the Black experience, intergenerational trauma, and mistrust of the health care system is at the heart of what Long and co-founder Javay Ross, MD – both pediatricians at UCSF Benioff Oakland's Primary Care Clinic – envisioned for BLOOM.

"We have seen the impact that systemic biases have had on the health and well-being of our own family members," Ross said. "We are ready to change the narrative."

Trained in cultural humility and trauma-informed care, Black pediatric providers from multiple disciplines throughout UCSF Benioff Children's hospitals in Oakland and San Francisco come together to heal, treat, and counsel families every Friday. In exam rooms at the Oakland hospital's pediatric primary care clinic on Claremont Avenue, parents share physical,

psychological, and environmental challenges and celebrate their delight in their babies. Topics include breastfeeding, first words and smiles, sleeping through the night, and any unmet basic needs, such as food and housing.

## Black Doctors, Black Families

Research from the Association of American Medical Colleges shows that racial alignment between patients and providers improves health care use and outcomes, lowers stress, and increases patient satisfaction. With a provider who is the same race as themselves, parents say they feel safer, more trusting, and not judged.

"Throughout the majority of my life, I have never had the opportunity to receive medical care from a Black doctor," Long said. "My three Black sons have also never had the privilege of being treated by a Black doctor, let alone a Black primary care pediatrician. I know how important this is to Black families."

*Additional philanthropic support will be essential to sustaining BLOOM and its groundbreaking model of care for Black families. For more information, contact Jennifer Ratliff at [Jennifer.Ratliff@ucsf.edu](mailto:Jennifer.Ratliff@ucsf.edu).*

## BLACK MATERNAL HEALTH DISPARITIES

Health disparities cause significant harm to Black people compared to non-Hispanic white people in the U.S.

### INFANT MORTALITY

BLACK BABIES ARE:

**2.5** times more likely to die before birth or within the first year of life.

**3** times more likely to die from sudden infant death syndrome.

**4** times more likely to die from complications related to low birth weight.



### LABOR & DELIVERY

BLACK BIRTHING PEOPLE ARE:

**45%** more likely to die in a hospital.

**46%** more likely to have delivery complications.

**57%** more likely to have a stroke.

# FROM SORROW TO SURVIVOR

When Selah Kitchiner was 13, she was diagnosed with end-stage liver failure, a rare and life-threatening condition for someone so young.

It was a tumultuous time for the Kitchiner family. Selah's father, Damon, was terminally ill. After three years in remission, an aggressive bone cancer had returned and spread throughout his body.

Damon had decided to decline treatment. Demoralized by his first cancer care experience, he had become wary of doctors and suspicious of the health care system. He wanted to spend his remaining time at home with his wife and three daughters.

When Selah's own health suddenly declined, Damon feared that his daughter would have a similar experience. At first, there was no clear cause of Selah's symptoms. She bounced from hospital to hospital, doctor to doctor, one diagnosis to another, until a Sacramento physician finally determined that her liver was failing.

## A Surrogate Family

Her health precarious, Selah needed to be hospitalized until a donor organ became available. In January 2015, she was admitted to the brand-new UCSF Benioff Children's Hospital San Francisco at Mission Bay,

which had opened just days earlier. The new facility was San Francisco's first standalone children's hospital and one of the few centers in the country with the expertise to perform a pediatric liver transplant.

**By the time I got to UCSF, I realized health care doesn't need to be this scary thing.**  
**My experience at UCSF was all the good parts of health care.**

— Selah Kitchiner

At home in the Sacramento Valley, Damon was dying. More than 100 miles away in the Bay Area, Selah was alone in a hospital room. Her mother, Lanette, spent the day taking care of Damon, Selah's two sisters, and the household affairs. Every evening, Lanette made the two-hour drive to San Francisco to spend the night at Selah's bedside. In the morning, she would drive back to Sacramento.

By day, Selah's caregivers at UCSF became her surrogate family. "There was so much

going on, so much instability," she says. "But my medical team always made me feel better. They gave me answers when they could, a hug when I needed it. They made me feel cared for. They lifted me up."

Selah focused her thoughts on Damon and her family. "Worrying about him made it easier not to worry about myself," she remembers. Unable to visit each other, father and daughter spoke on the phone every night.

## Grief and Healing

One month into Selah's hospitalization, Damon passed away. As the rest of the family grieved together in Sacramento, Selah struggled to stay hopeful in San Francisco, but the reality of her situation sank in. "When we were going through it together, it almost felt like nothing could happen to either of us," she recalls. "When something did happen, I wondered what it meant for me. Was I going to die too?"

Early one morning, a few weeks after Damon passed, a nurse gently woke Selah. A liver had become available. Three hours later, Selah would become the first patient to receive a solid organ transplant at UCSF's new children's hospital.

Her recovery was smooth. Selah was walking around the neighborhood weeks after the procedure. During the rehabilitation, her grief was tempered by gratitude. "I knew how lucky I was," she says.

"I wasn't guaranteed to come out of this, so once I did, I just felt so grateful."

The grief hit when Selah returned home. Damon's absence was palpable. Everything felt different. But Selah was determined to get back to her life, including basketball – a passion she and Damon shared. Six months after surgery, Selah was back on the basketball court. Her cheering section was diminished, but her heart was full.

## Selah's Dream

Selah is now 22. Nearly a decade has passed since her father died and she got a new liver. Earlier this year, Selah graduated from her

dream school, the University of Southern California, and began applying to medical schools, including UCSF. Her next dream is to become a doctor.

Selah has also spent much of the past decade as a public advocate for organ donation. Her activism has focused on dispelling medical mistrust within the Black community, which has its roots in the long history of medical mistreatment of Black Americans. Selah believes that medical mistrust played a role in Damon's decision not to pursue cancer treatment, as well as his fear that Selah would also be mistreated by health care providers because of the color of her skin.

"I don't think my dad felt very cared for by his medical teams," she says. "If he had, maybe he wouldn't have been so afraid to go through treatment again. When I was bouncing between hospitals,

I didn't feel very acknowledged either. But by the time I got to UCSF, I realized health care doesn't need to be this scary thing. My experience at UCSF was all the good parts of health care. It was so inspiring.

"That's why I want to be a doctor. I want to be that person for someone else – for the young woman who feels she's been neglected, or a Black person who feels they haven't been cared for, or a 13-year-old girl who is sitting in the window, just looking for some hope."

Last month, UCSF honored Selah's advocacy, commitment to health equity, and triumph over adversity by awarding her with the 2023 Colin Powell Medal of Courage at the Dreamfest Concert for Kids. She hopes to use her platform to inspire others to work together for more equitable health care.

**Selah (center) with her care team** at UCSF Benioff Children's Hospital San Francisco.



# More Than Missed ZZZs



**Doctors at UCSF Benioff Oakland's expanded pediatric sleep lab have seen increased cases of sleep apnea. The hospital houses one of Northern California's only child-focused clinics for sleep disorders.**

As many as one in four children experience some form of sleep problem, some of which can lead to serious health complications later in life. Despite this high number, many sleep disorders go undiagnosed in kids. To ensure more get the care they need, UCSF Benioff Children's Hospitals has expanded the reach of its child-focused sleep clinic with a new state-of-the-art facility in Oakland.

The clinic, which was relocated from Walnut Creek, has grown its footprint and added innovative sleep research technology – including a new pediatric sleep lab. At the sleep lab, children and their caregivers spend the night in one of the facility's mural-lined sleep study rooms, where trained specialists start the process of observing, diagnosing, and treating their sleep disorder.

Sleep technicians attach soft sensors to the child, and their parent or guardian helps them settle into bed with their favorite toy or blanket as the sensors track breathing, brain waves, heartbeat, and more. On the ceiling, cameras record any tossing and turning. From an expanded central observation room, technicians monitor a bank of computer screens that display the patient's information.

The bigger Oakland space also means more comfortable stays for parents and caregivers who spend the night in the rooms with their children, sleeping nearby in separate beds.

"Poor sleep has a lot of impacts on a child's health and well-being – it definitely impacts children's behavior, their ability to concentrate in school, and can worsen asthma and their emotional well-being," explains Gwynne D. Church, MD, professor in the UCSF Department of Pediatrics. "It also adds a general stress to

the body, and the effects of that might not be fully realized in childhood or even adolescence."

Emerging research suggests that, if untreated, childhood sleep disorders could put kids at higher risk for cardiovascular disease and diabetes later in life.

The pediatric sleep clinic treats about 800 children annually and is one of the few child-focused sleep clinics in Northern California. The Oakland clinic is one of the only facilities that accepts all children, regardless of their family's financial circumstances. For this reason, Church and her team care for families from not only Oakland but the entire Bay Area as well as many of California's far-flung rural communities.

The bulk of the sleep clinic's patients are children with obstructive sleep apnea, a condition in which snoring is associated with fragmented sleep or abnormal oxygen levels during sleep.

In addition to sleep apnea, the sleep clinic treats children with more complex medical conditions that affect nighttime breathing, such as muscle weakness, cerebral palsy, and underdeveloped lungs from being born prematurely.

Treating sleep apnea and other sleep disorders in children can lead to remarkable changes, says Church, which is why she loves practicing sleep medicine. Once they're able to sleep well again, kids become happier and do better in school. In children living with asthma or attention-deficit/hyperactivity disorder (ADHD), symptoms of those conditions are often also better controlled once the sleep problems are addressed.

But children aren't the only ones who benefit. Once a child can sleep through the night, their parents can too.

# A HOME, A MEAL, AND FINALLY, A TREATMENT

## One Family's Journey with Rett Syndrome

She was perfect. That's how Paige and Jesse Nues felt the day they met their daughter, Katie.

The pregnancy was typical, the birth was normal, and every newborn milestone came and went on time. But when she was about 4 months old, Katie started to struggle – at first with acid reflux, then with rolling over and sitting up. A few months later, she began to withdraw from social interactions. She cried inconsolably. She barely slept.

Paige and Jesse took Katie to UCSF Benioff Children's Hospital Oakland. Doctors ruled out one explanation after another but couldn't land on a diagnosis. Katie underwent batteries of tests. The Nueses combed their family tree for genetic disorders. Months passed. Finally, in 2003, when she was 17 months old, Katie was diagnosed with Rett syndrome, a rare genetic mutation affecting the brain development of one in every 10,000 girls born in the US, and even fewer boys.

The family learned that Katie would gradually lose capabilities that she had only just gained, like holding toys, speaking, and eating independently. More crushing symptoms were on the horizon, including seizures, scoliosis, pneumonias, sleep disturbances, difficulty walking, and physical differences. At the time, no treatment or cure for Rett syndrome had been identified.

"It wasn't the answer we wanted, but just having an answer was transformative," Paige says. "Then the hard part came, which was learning what it meant to have and love and raise a child with a rare disease."



From left: Paige, Katie, and Jesse Nues.

### The Hard Part

When Katie was diagnosed, she was one of only two children being treated for Rett syndrome at UCSF Benioff Oakland. Her care involved dozens of appointments, shuttling from one specialty to another, including neurology, cardiology, orthopedics, pulmonology, gastroenterology, and physical therapy. Each specialist helped manage Katie's symptoms, but the underlying disease remained untreated.

"We were getting great care from all these wonderful people and receiving all this warmth and love from everyone at the hospital, but there just wasn't an anchor of medical care for Rett syndrome," says Paige. "They couldn't really help us get our arms around the syndrome itself."

Paige and Jesse learned that the nearest clinic dedicated to Rett syndrome was in Houston. After traveling to Texas for a consultation, a light bulb clicked on: The Nueses realized that UCSF Benioff Oakland had all the right people and was committed to Katie's care. It just needed a "medical home" for Rett syndrome that could bring it all together.

### An Idea is Born

Back in California, the couple posed a question to former hospital president and chief executive officer, Bert Lubin, MD: "We asked, 'What would it take to have a multidisciplinary Rett syndrome clinic here in Oakland? Can we care for children while advancing research?'" Paige recalls. "And the hospital said, 'Yes, we can. But insurance won't reimburse for that kind of service, so it will take a lot of philanthropic funding. If you can bring the resources, we can make it happen.'"

Paige and Jesse were exhausted. They were coming to terms with their daughter's diagnosis and adapting to the grueling routine of caring for a young child with special needs. But they knew they had to act for their own child and others like her, so they got to work.

The Nueses sought out initial seed funding from the Rowan Branch of the Children's Hospital Branches, a fundraising organization that has been supporting UCSF Benioff Oakland for over 100 years. Next, they established the Katie Nues Foundation to raise more money. One year to the day after Katie's diagnosis, Katie's Clinic for Rett Syndrome was born.

Nearly two decades later, Katie's Clinic has served over 250 patients and become an IRSF Rett Syndrome Center of Excellence – a recognition of the team's dedication to providing best-in-class care and research for people with Rett syndrome. The clinic remains fueled by community partners, patient families, and the Katie Nues Foundation.

### A Medical Home

Katie's Clinic is unique. It provides a medical home for Rett syndrome patients, alleviating much of the confusion and anxiety that characterizes life with a rare disease. Parents no longer need to take multiple days off work for hospital visits, manage complex care logistics, and piece together disparate treatment plans on their own.

At Katie's Clinic, multidisciplinary care is consolidated into a single day at the hospital.

Families relax together in a private room while specialists visit, one by one. A social worker is available to discuss any nonmedical needs. Inspired by the Nues family's experience, lunch is provided so that children have time to rest between appointments and parents can meet and bond. The outcome of every visit is a holistic treatment plan reflecting the input and collaboration of the entire care team.

Over the past 15 years, Katie's Clinic has also contributed essential patient data to the understanding of Rett syndrome, served as a clinical trial enrollment site, and co-authored primary care guidelines. Thanks in part to these contributions, earlier this year, the US Food and Drug Administration approved the first Rett syndrome treatment, which targets the underlying biology that gives rise to the disorder.



**We found so many special people [at UCSF] who took the time to learn about Katie and learn about this disease.**

– Jesse Nues

Now 21, Katie will never recover fully, but thanks to the new drug, she is improving. When Paige and Jesse reflect on the progress that has been made over the past two decades – for their own child and so many others – their faces reflect a combination of joy, awe, and determination.

"We are just so grateful," says Jesse. "When we first started, no one knew about Rett syndrome. We were so lost. But we found so many special people [at UCSF] who took the time to learn about Katie and learn about this disease. Now, when a patient is newly diagnosed, they don't have to feel the way we did. There's not only a home and a meal for them, there's also a treatment. That's how far we've come."



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## GivingTuesday is November 28!

Between now and November 28, you can support your community while helping ill and injured kids access life-changing health care. Make a gift to UCSF Benioff Children's Hospitals, and your impact will be **DOUBLED** by our partner, Marriott.



Thank you for making a difference in the lives of our patients and their families. Point your mobile device camera at the QR code to access a direct link to our online giving site or visit [givingtogether.ucsf.edu/kids2023](http://givingtogether.ucsf.edu/kids2023).

