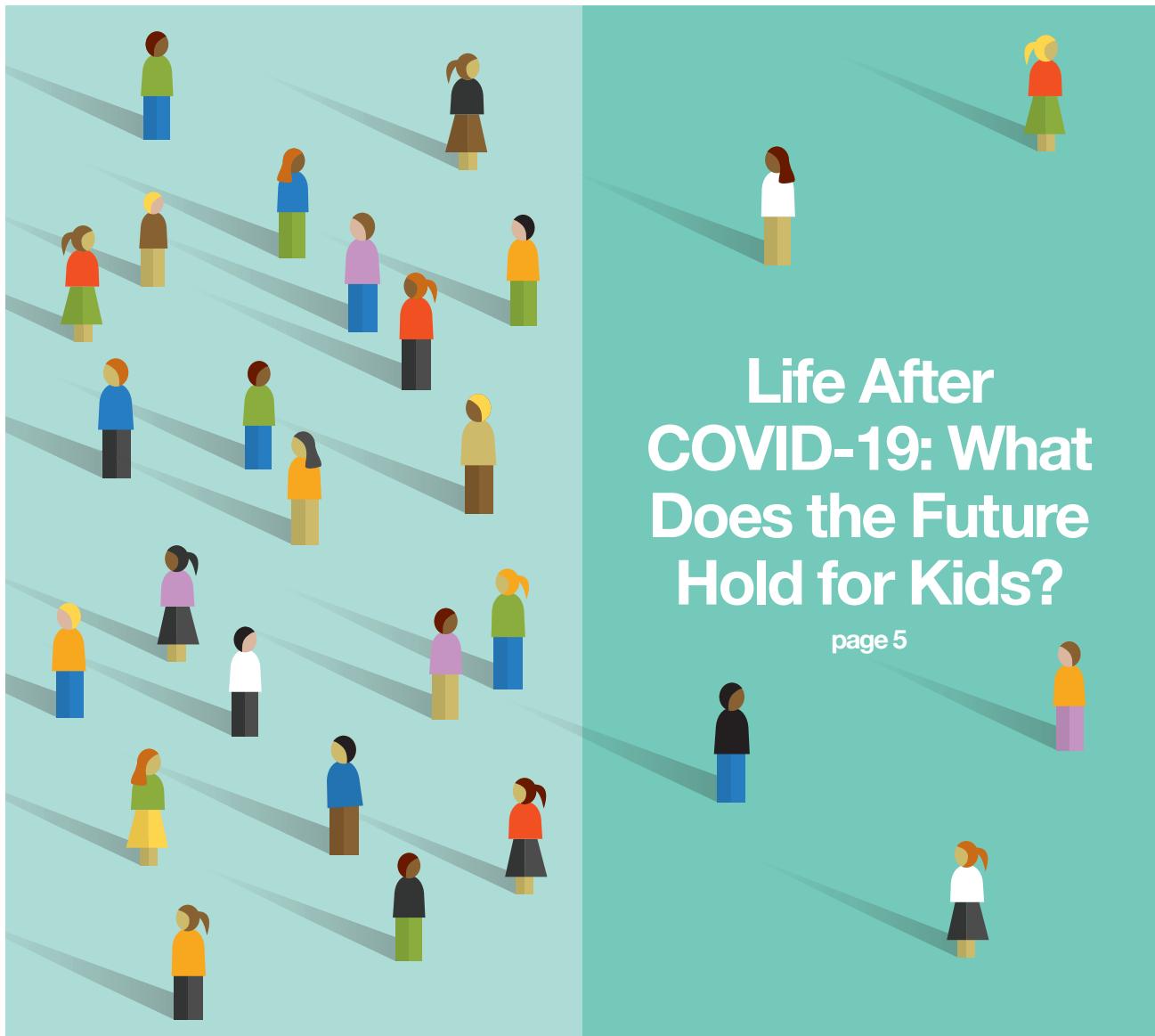


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FALL 2020



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Taking the Long View

Our experts are redefining care for kids with chronic illnesses to help them achieve wellness for life.

A MESSAGE FROM KELLY JOHNSON, CHIEF NURSING OFFICER

We're living through a moment in time like no other. In March, just as the COVID-19 pandemic hit, I joined UCSF Benioff Children's Hospitals as the new chief nursing officer. In a matter of weeks, nearly every aspect of the way our hospitals deliver care had to shift to keep our patients and caregivers safe.

Seeing this team rise to the challenge has been inspiring. Our generous community members have also rallied to help us respond quickly to the most urgent priorities and continue to serve the families that need us most.

As you may know, the World Health Organization has designated 2020 as the International Year of the Nurse. I can't think of a better moment to shine a light on the important contributions that nurses make on the front lines of medicine. I've seen that firsthand throughout my 27-year career as a hospital leader, and I've been impressed anew by our heroic nurses, whose commitment to the hospitals' mission is truly profound.

Every day, these competent and compassionate professionals go above and beyond to care for children in need, and I'm honored to support them in that important work. I'm excited to continue building the workforce of the future, one that more closely reflects the diversity of the communities we serve. We're also exploring new research avenues to ensure that we provide the best evidence-based care possible.

I know that big ideas require a big commitment – from hospital leadership, staff at every level, and our community. Our donors support advances that move medicine forward for all children. Thank you for being part of this family.

With respect and gratitude,



Kelly Johnson, RN, PhD, NEA-BC
Chief Nursing Officer
Vice President, Patient Care Services

Closing the Health Equity Gap

The COVID-19 pandemic is spotlighting the larger pandemic of racial disparities in health. At UCSF Benioff Children's Hospitals, we've been committed to closing these gaps for more than 100 years. You can be part of our vision: to drive systemic changes that will end the health care divide for kids.

Visit bit.ly/bch-health-equity to learn more.



When COVID-19 Collides with Cancer



When 11-year-old Krystie Gomes' leg started to hurt last year, it wasn't a shock. Driven by her fierce competitive spirit, Krystie's evenings and weekends were consumed by her volleyball and soccer teams. Injuries were expected.

But when months of physical therapy didn't ease Krystie's pain, alarm bells rang for her mother, Kathy. A blood test and X-ray came back clean, but Kathy demanded another. This time, the doctor found a large tumor on Krystie's femur.

The oncology team at UCSF Benioff Children's Hospital Oakland was waiting for Krystie that same day. They confirmed she had osteosarcoma, the most common pediatric bone cancer. Krystie started chemotherapy immediately, followed by surgery and more rounds of treatment.

From the beginning, her mother was confident that Krystie was in good hands. "At UCSF, they make you feel like a whole team has your back," she says. "I don't know if they're so kind and gentle because they work with kids or if maybe they are really, literally, angels."

During Krystie's first rounds of chemo, COVID-19 escalated from concern to crisis. A hospital room

packed with friends and family suddenly shifted to the support of a single caregiver: Kathy.

While isolation was tough, hospital staff rallied with compassion and support. Playing Bingo with other patients from the comfort of her room – via closed circuit TV – let Krystie tap into her competitive side. And thanks to donor gifts, the Child Life team kept her stocked with art supplies so she could express herself.

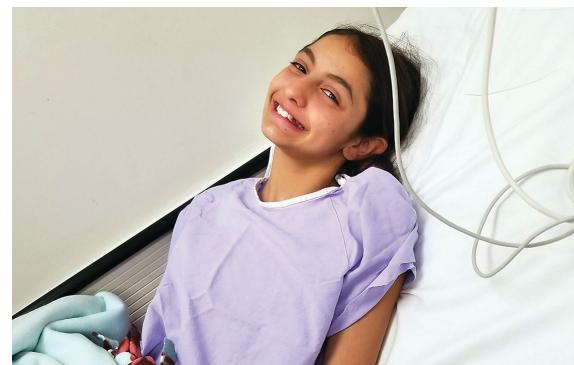
All along, Krystie's fighting spirit and positivity have served her well. She started rehabilitation therapy the day after her surgery, to the amazement of her family and medical team. When friends call to complain about daily annoyances, she's quick to put things in perspective.

"She'll say, 'If I can get half my leg taken off, you've got this,'" Kathy says with a laugh.

The global crisis has provided a silver lining to Krystie's personal one. She can't be out scoring goals or spiking volleyballs, but neither can any of her teammates – or, for that matter, many kids around the globe.

"We're all missing out together," Kathy says. "Everyone jokes that when Krystie is ready to come back to the world, the world will be ready for her."

Until then, with her medical team at her side, Krystie remains focused on winning.



INNOVATION

MOVING MEDICINE FORWARD



When Alejandro Sweet-Cordero, MD, talks about what he does – treating children with cancer – people often assume it's depressing.

"Actually, it's just the opposite," he says. "I constantly get to see the best of what humans are capable of doing for each other."

This sentiment also applies to his own work. As the director of UCSF's Molecular Oncology Initiative (MOI), Sweet-Cordero is redefining possible for the most vulnerable patients.

When children have cancer that's advanced or difficult to treat, the MOI maximizes the most sophisticated technology and expertise to offer them hope. With a unique diagnostic test called the UCSF500 Cancer Gene Panel, tumors

I constantly get to see the best of what humans are capable of doing for each other.

– Alejandro Sweet-Cordero, MD

can be sequenced and their genetic makeup better understood. The Molecular Tumor Board – a group of oncologists, pathologists, genetic counselors, and informatics experts – uses this information to configure the most appropriate treatment plan.

In the most difficult cases, this gene panel sequencing can be expanded to include

more comprehensive sequencing of the entire genome and RNA. Sweet-Cordero's lab is a leader in the application of these genomic technologies to understand pediatric cancer and provide the best possible care.

"Over the course of my career, the new understanding of the genetics of cancer and the practical ability to implement that in real time to help patients has just been amazing," Sweet-Cordero says. "But it's still the tip of the iceberg; we have a long way to go."

So far, more than 800 UCSF Benioff Children's Hospitals patients have benefited from having their tumors sequenced, thanks to the timely and potentially lifesaving insights that would have been impossible to access even five years ago, says Sweet-Cordero.

Community support is essential to saving these young lives.

"Without philanthropy, we couldn't do any of this," Sweet-Cordero says. "We absolutely rely on donors to help us advance this field."

September is Pediatric Cancer Awareness Month!

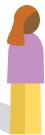
Visit bit.ly/bch-cancer-support to support care and research.

ASK THE EXPERTS

What's your biggest concern about the pandemic's impact on children? How can we help?

Q

& answers



Eileen McCree

Child Life Specialist and Facility Dog Handler

My greatest concern is that due to the lack of socialization with peers, children's development might not progress as it would normally. Children need to learn how to share, build relationships, and communicate with others. We're working to close the gap with live interactions through our closed-circuit TV programming. We are also providing toys and games for families to play together, along with more bedside visits with our Child Life specialists, music therapists, teachers, and art therapist.



Lee Atkinson-McEvoy, MD

Executive Medical Director, Children's Primary Care

I am concerned about whether children are learning appropriately through technology-based modalities, particularly children with learning differences. At UCSF, a group of physicians is consulting with local school districts to help them understand federal, state, and local guidance and safely reopen. We have also partnered with summer camps and day-care facilities to identify reopening strategies and ways to track their safety as they have reopened.



Theodore Ruel, MD

Chief, UCSF Division of Pediatric Infectious Diseases and Global Health

While COVID-19 appears to be less severe for children, a number of key gaps remain in our understanding. We now believe that some children develop a severe post-infectious, multisystem, inflammatory syndrome that can lead to heart problems and shock. It's important that we continue researching health impacts. Members of our division are also studying the immune response of infants to perinatal exposure.



Shabren Harvey-Smith, LCSW

Director, Medical Social Services

The pandemic has stretched children and their families to the limits. Many children experience worry and fear as they observe their caregivers coping with the global impact. At our Oakland campus, with generous donor funding, we've been able to help families meet basic needs such as food, clothing, and supplies. We're relieving some of the stressors they face during an uncertain time.



Dayna Long, MD

Medical Director, Center for Child and Community Health

I worry about our children's social-emotional well-being and about their ability to feel safe and to develop and maintain relationships. I also worry about the mental and physical health of Black people, especially Black children. We work steadfastly to create a healthier tomorrow by addressing inequities through clinical practice transformation, research and system change.



Bryan H. King, MD, MBA

Vice President, Child Behavioral Health Services

A substantial number of young people have lost the social connections and structure that school and community provide. I am concerned that the mental and emotional toll will contribute to mental illness in a world where access to care is already grossly inadequate. Fortunately, we are growing our mental health team and expanding our use of technology to reach more children. The experience we're gaining during the pandemic will serve us going forward.

Infectious Enthusiasm

Dr. Ann Petru treated the Bay Area's first pediatric HIV patient. Now she's helping navigate COVID-19.



The young girl's condition was baffling: a severe case of chickenpox combined with an unusual bacterial infection. Ann Petru, MD, knew something was wrong with the child's immune system, but the cause was a mystery.

It was 1983. The girl, who had received an infected blood transfusion, would turn out to be the Bay Area's first pediatric HIV patient.

With this landmark case, Petru was plunged into caring for kids plagued by a deadly new disease. She would emerge as one of the leading clinicians and researchers in the rapidly developing field of pediatric HIV.

Now, as chief of pediatric infectious diseases at UCSF Benioff Children's Hospital Oakland, Petru is helping

Bay Area families weather another crisis, this one far more widespread. With 40 years of expertise and enduring passion, she's well prepared for the fight.

A Fledgling Leader

The early days of the AIDS epidemic were tough but rewarding for Petru, a new doctor. For more than a decade, therapies offered little in the way of effectiveness or hope. Petru pioneered new treatments and enabled her patients to join clinical trials.

By the late 1990s, this work had helped change the landscape. Infected women could get treatment that prevented passage of HIV to their babies, and patients had access to transformative medications.

"It's been very gratifying to help our patients live full lives,"

Petru says. "We started out with no drugs, and we lost many children. Now we can combine multiple drugs into one pill that patients take just once daily, and it changes their lives forever."

A New Crisis

After decades of making progress on HIV and overcoming other outbreaks, COVID-19 brings unprecedented challenges.

"This is the biggest health crisis in 100 years in this country," Petru says, "so the impact on our society is far greater than anything we've all lived through."

While the virus itself has largely spared children, the hardships families are enduring, like housing and food insecurity, directly threaten kids. Petru believes addressing these needs is a vital role of the hospital. She also underscores the importance of contributing to research on the spread of COVID-19 among children and its long-term impacts.

While Petru never imagined her career would be bookended by major health crises, she's grateful to have had the opportunity to make a difference.

"I feel incredibly fortunate that I've had the life I have," she says. "This is my work. This is my passion."

A VOICE FOR THE VOICELESS

After more than 20 years of serving abuse victims, Shelley Hamilton, LCSW, carries thousands of stories with her.

They are the little girl in a group therapy session who happily proclaimed that she felt “normal.” The supermarket checker who recognized Hamilton and thanked her – she had cared for him when he was in third grade; he’s now a student at UC Berkeley. The mother who tearfully confided that her daughter’s therapy has helped her heal from her own abuse.

The Center for Child Protection (CCP) at UCSF Benioff Children’s Hospital Oakland offers comprehensive medical and mental health services to children impacted by violence and abuse. It’s the only program of its kind in the Bay Area, reaching about 700 families each year.

“The services we provide truly save children’s lives,” says James Crawford-Jakubiak, MD, CCP’s medical director. “We can point a child’s life in a direction that might not otherwise happen if people didn’t advocate for them. It’s so important for kids to know that someone cares.”

Serving the Entire Family

In addition to medical care immediately following abuse, the CCP team delivers healing therapy sessions, guides families through the court system, and organizes an annual summer camp for victims.



Philanthropy is crucial to support this work.

“Without donors, we wouldn’t be able to provide our full spectrum of critical services,” says Hamilton, CCP’s manager. “Donors help with everything, like providing options for new clothing to children when their clothes need to be taken as evidence. These are the kinds of things that seem small but really empower kids.”

Gale Love, a speech-language pathologist in Marin, is one generous donor to the Center. “My hope is that by supporting this important work, I’m helping kids in horrific situations so they can grow up without letting that experience overwhelm who they are,” she says.

Preparing for the Next Wave

With the shelter-in-place order, Hamilton and Crawford-Jakubiak note, many children lost the safety net of people who might discover and report abuse – teachers, friends, grandparents. As a result, though abuse cases are believed to have climbed, the number of calls to Child Protective Services has decreased by half.

“Once kids are able to be back in the world, we expect our caseload to go through the roof,” says Crawford-Jakubiak. “We’re bracing for a surge, and we’ll be here.”

Defeating the Enemy in Your Kitchen

With severe allergies on the rise, our expert offers hope.



Erinn Stephan will never forget the moment she learned her son Lucien had a severe allergy. She gave the 1-year-old a morsel of Thai chicken pizza with the tiniest dollop of peanut sauce. His reaction was immediate – and terrifying. His face swelled up and his throat closed. Had an ambulance not arrived within minutes, he might have died.

“Once you see your child go through that, you carry a tremendous amount of trauma,” Erinn says.

Lucien’s story is all too common. Over a recent 15-year period, food allergies in children increased by 50%, with about 6 million U.S. kids

now affected. Along with the rising numbers, symptoms are becoming more serious.

This trend can’t be explained by naturally evolving genes, says Morna Dorsey, MD, MMSc, director of the pediatric allergy and immunology program at UCSF. Environmental factors – like diet, pollution, the microbiome and more – clearly play a role.

Dorsey’s team is delivering new insights into the causes of food allergies and how to manage severe symptoms. One method she studies is oral immunotherapy, which gradually raises children’s tolerance of allergens through controlled exposure.

Lucien was 5 years old and riddled with anxiety, avoiding parties and restaurants, when his mother enrolled him in Dorsey’s immunotherapy clinical trial. Lucien and other participants were given small daily doses of peanut protein. Eventually, Lucien was able to consume the equivalent of three peanuts without an immediate reaction – a miracle for a child who had been rushed to the emergency room after just a nibble.

The results of this clinical trial helped secure FDA approval for the therapy in January.

“This is groundbreaking,” Dorsey says. “With peanut allergies, we could only say, ‘Avoid, avoid, avoid!’ It’s not a cure, but it’s exciting to be able to give families peace of mind that accidental exposure won’t necessarily be an emergency.”

Indeed, this therapy has given Lucien something his mother worried he might never have: freedom from fear.

“Before, every time Lucien put a piece of food in his mouth we all felt high levels of anxiety,” Erinn says. “This has absolutely changed our lives.”

CREATING A ROADMAP FOR WELLNESS

We're redefining care for kids with chronic illness.

Emma needs medicine around the clock – 32 syringes worth, administered through a gastrostomy tube because she can't swallow. This likely will be the reality for the spunky 6-year-old for the rest of her life. She has cystinosis, a rare metabolic disease.

"The challenges of caring for Emma are complicated," says her mother, Shelly. "We learn more all the time how best to keep her healthy."

With medical advances, more children are surviving into adulthood with chronic health conditions – an estimated 5 million children and adolescents in the U.S. alone.

A Better Approach

Studies show that chronic-illness care is most effective when driven by a holistic focus on wellness: achieving a healthy lifestyle, optimal nutrition, and emotional well-being for patient and family. But this is not the current standard of care for many children, says Emily von Scheven, MD, MAS, chief of rheumatology at UCSF Benioff Children's Hospitals.

"Our health care system is designed to manage acute illness that can be treated and cured, not chronic conditions with ongoing demands," she explains.

Von Scheven is working to change that. As the director of the newly established UCSF Child and Adolescent Chronic Illness Center, she's uniting patients and caregivers across disciplines to address the unique challenges faced by children with chronic illnesses. The Center will provide comprehensive services and streamline



coordination between specialists for thousands of patients with chronic health needs.

"We need to think about preventive care differently for children who will carry their disease with them into adulthood," von Scheven says. "Patients and their families want to know what can be done during childhood to prevent future problems and to optimize health and wellness over the child's lifetime."

A generous gift was made to help launch the center by Erica Lawson, MD, a UCSF pediatric rheumatologist, and her husband, Jeff.

"I feel incredibly blessed to be part of my patients' lives, to share in their challenges and accomplishments," Lawson says. "Being able to help develop a system that would decrease their struggles is tremendously meaningful to me."



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