

A NEWSLETTER FOR  
FRIENDS AND SUPPORTERS

# Connections

FALL 2018



## How we're battling the pediatric asthma epidemic

page 7

1

### **Giving Back After Cancer**

Lauren was only 4 when she was diagnosed with leukemia. Now a college freshman, she's committed to making a difference for other kids facing medical challenges.

3

### **The Risks of Vaping**

E-cigarette addiction is skyrocketing among teens. But new research shows it exposes them to dangerous toxins – and that may be just the tip of the iceberg.

10

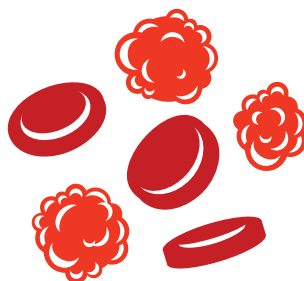
### **A Helping Paw for Kids**

Meet our new four-legged staff members: facility dogs Vente and Sundance. They're reducing pain and stress for our patients through the healing power of cuddles.



## PATIENT STORY

# A Decade of Giving Back



Something wasn't right. Emma Bishopp couldn't explain it, but she knew instinctively that her daughter, Lauren, was seriously ill. For weeks, the 4-year-old had experienced baffling symptoms including fatigue, leg pain, headaches, and a racing heartbeat.

Emma's instinct was correct: At UCSF Benioff Children's Hospital Oakland, Lauren was diagnosed with acute lymphoblastic leukemia – the most common type of pediatric cancer – which affects the blood and bone marrow.

"It felt like being stabbed with knives," Emma says of learning her daughter's diagnosis. "I couldn't breathe. To my knowledge, anyone who has cancer dies. I honestly thought we were going to lose her."

Luckily, the nurses and doctors at UCSF Benioff Oakland delivered empathy and compassion along with our world-class pediatric cancer care, which consistently ranks best in Northern California.



## The hospital gave so much to us: my treatment, but also emotional support.

— Lauren,  
grateful patient

“I’ll never forget how one nurse sat on the edge of the bed and comforted me,” Emma recalls. “She said, ‘All you can do is take one day at a time.’ That advice has always stayed with me.”

For more than two years, Lauren underwent chemotherapy that at times completely wiped out her immune system, leaving her vulnerable to infection and requiring periods of strict isolation.

Nonetheless, Lauren, now 18, has many positive memories of the hospital: shaping puffy blue foam with an art therapist, watching a child life specialist explain her condition using felt dolls, and marking milestones with Beads of Courage.

“For every round of chemo or blood draw, I would get a bead,” Lauren remembers. “Instead of being a victim, it made me feel like it was an achievement, like I was in control. I will always keep them.”

Soon after Lauren was declared cancer-free in 2007, the Bishopps went from patient family to advocates. The Psychology Oncology Program (POP), which helps families cope with the emotional fallout of cancer, faced budget cuts. The Bishopps galvanized a successful fundraising effort to ensure that therapy could continue; philanthropy continues to fund POP today.

For a decade, Emma and Lauren have given back through events like St. Baldrick’s, an annual fundraiser for cancer care and research. They also provide comfort directly to our patients by delivering snack packs with treats like granola bars, juice, and holiday-themed stickers so families can enjoy these

## September is Childhood Cancer Awareness Month!

Learn how you can make a difference for kids with cancer at [begold4kids.org](http://begold4kids.org)

small comforts when facing medical challenges.

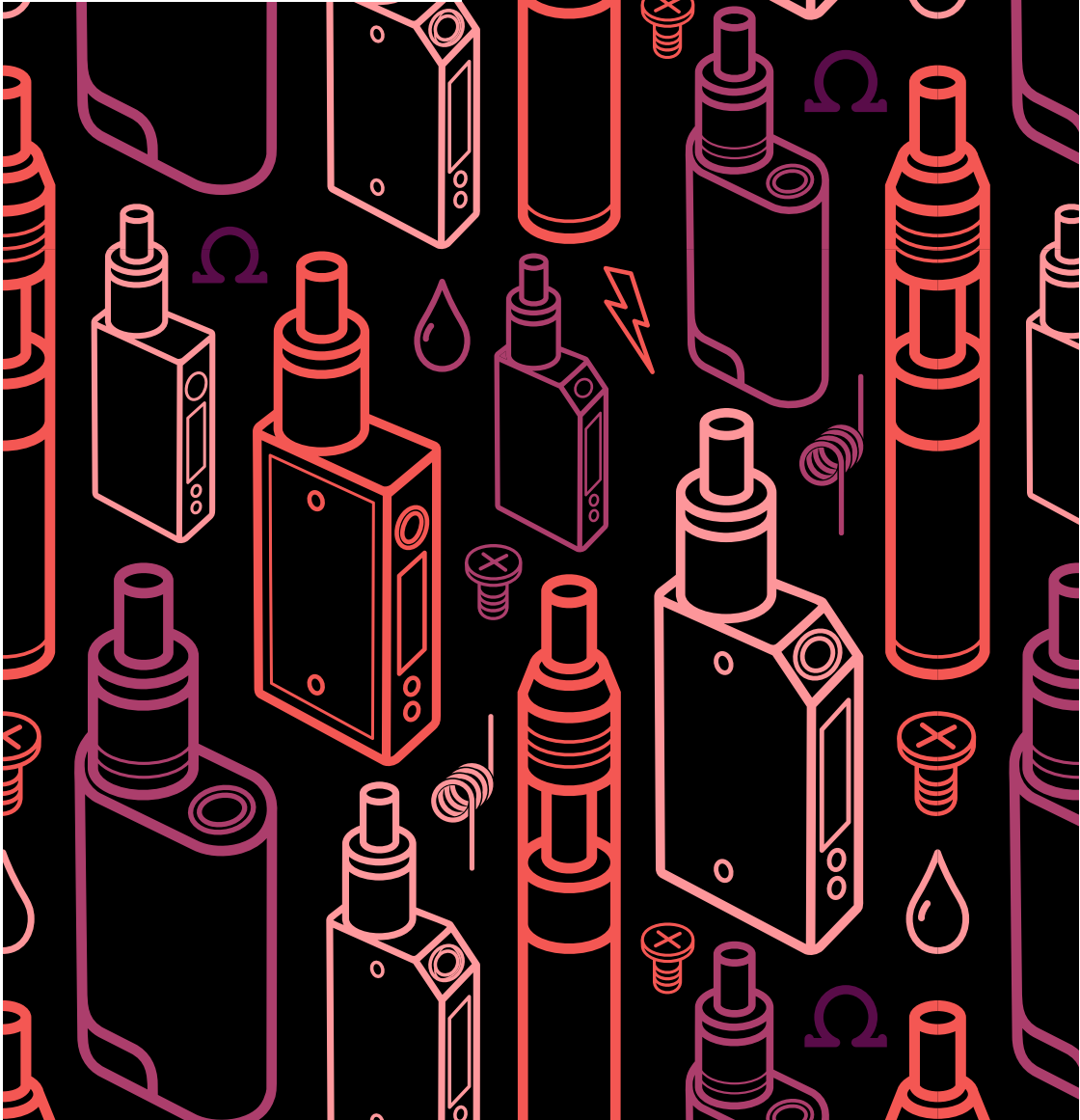
“The hospital gave so much to us: my treatment, but also emotional support,” says Lauren, who recently started her freshman year of college. “We are so unbelievably grateful, and whatever we can do to give back is a small way to say thank you and help others going through the same thing.”

**Lauren at an art therapy session** during her cancer treatment.



# A New Generation of Nicotine Addicts

Vaping has taken off among teens, but new research reveals major risks.



A few years ago, adolescent medicine specialist Mark Rubinstein, MD, started noticing an alarming trend: His teen patients increasingly admitted to smoking e-cigarettes and began asking him if they were safe.

"I could only tell them, 'I just don't know,'" Rubinstein says. "So I thought I should try to find out."

In March, the results of his study revealed that e-cigarettes in fact expose teens to significant levels of toxic, cancer-causing chemicals. And Rubinstein fears this may be just the tip of the iceberg.

"The specific chemicals we looked at were ones found in regular cigarettes, but there could be thousands of others we did not look for that could be just as harmful, or even more so," he says.

## A Risky Teen Craze

This is a growing concern because e-cigarette use among teens is skyrocketing. A whopping 16 percent of high school seniors vape, as well as 14 percent of sophomores, and even 9 percent of eighth graders.



**It's particularly difficult to know what the risks are with these products because they aren't controlled by the US Food and Drug Administration at all.**

– Dr. Mark Rubinstein

"We've never seen a drug take off so quickly among teens," Rubinstein says. "You can't smoke traditional cigarettes at home because your mom will smell it, and you can't smoke at school because your teacher will smell it. With these, you can smoke throughout the day. This is hooking a whole new generation on nicotine."

Study participants said they vape because it's fun and makes them feel cool. But the biggest draw is the sweet, fruity flavors like cotton candy, strawberry, and mango.

## Taking Action

With Rubinstein's study providing clear evidence of the dangers of vaping, in June, San Francisco became the first city in the country

to ban the sale of flavored tobacco products, including these vaping liquids. Rubinstein is eager to learn how this impacts usage, but he acknowledges that teens may easily find ways around the ban.

Meanwhile, he's continuing to grow the body of research on the topic with studies about craving responses in teens and the effects of vaping cannabis. His goal is to do whatever he can to help his teen patients make healthy choices.

"It's particularly difficult to know what the risks are with these products because they aren't controlled by the US Food and Drug Administration at all," Rubinstein says. "But regardless, I really don't want teens putting anything in their lungs besides air."

**16%**

of high school seniors vape

**14%**

of high school sophomores vape

**9%**

of eighth graders vape



# The Rankings Are In, and We're Celebrating!



**Kenny was rushed to our NICU** at just 8 days old (below). He's now happy and healthy at age 3.

Our hospitals rank among the country's finest in 10 pediatric specialties for 2018-2019, according to *U.S. News & World Report's* annual Best Children's Hospitals survey.

That includes being recognized as best on the West Coast for neonatology, which should come as no surprise to the hundreds of families who rely on us for world-class care each year. Just ask Taryn

Larson, whose son, Kenny, was rushed to our Oakland campus when he began having seizures at 8 days old.

"Without the care at the NICU, we wouldn't be where we

are today, and we might not even have him right now," Taryn says.

Kenny, now 3, faces challenges, but he's making amazing progress. "He's the happiest kid ever," Taryn says. "We count our blessings every day that Children's helped us through that horrible start to get where we are today."



## Among the Nation's Best

We rank among the top tier in:

- Neonatology
- Diabetes / Endocrinology
- Cancer
- Nephrology
- Gastroenterology / GI Surgery
- Pulmonology
- Urology
- Neurology / Neurosurgery
- Cardiology / Heart Surgery
- Orthopaedics





# Building Community Through Art

Walking through our new Oakland outpatient center, it's impossible to overlook the art that adorns the hallways. Bright, bold, playful, and inspiring, more than 150 pieces currently on display were created just for the hospital by some very special artists: youths in our community.

For three years, Denise Clayton-Leonard, artist and founder of Artful Healing, led a series of hands-on workshops to give teens the opportunity to express their creativity and give back to local kids.

And at our hospitals, art isn't just something you see on the walls. Every day, our expert art therapists and artists-in-residence help patients explore their creativity to express their feelings, hopes, and fears.

"It's about having a voice in an environment where children don't have a lot of choices," explains artist-in-residence Sadie Wilcox. "They can express themselves and just be kids."



**This project created circumstances for young people to be creative but at the same time take on a meaningful project and make a difference.**

– Denise Clayton-Leonard, founder of Artful Healing

# How is UCSF moving the needle on pediatric asthma?

## Q | A

Approximately 7 million children in the United States – as many as 1 in 12 – suffer from asthma, making it the nation's leading chronic pediatric illness. At our Oakland primary care clinic alone, a staggering 40 percent of our patient population has asthma. Learn how our experts are playing a leading role in addressing this growing crisis.



**Ngoc Ly, MD**  
Division Chief,  
Pediatric Pulmonology

UCSF is a leader in asthma research; we have a robust research program paired with a strong clinical effort. My interest is in working with patients with the most severe or difficult-to-manage asthma and studying the predictors of asthma development.

I am currently involved in research to identify phenotypes and biomarkers to classify severe asthma, with the goal of finding new treatments for this population. That's because severe asthma patients do not respond well to conventional therapies. We are looking for targeted new therapies because we know that one treatment does not fit all.







**Esteban Burchard,  
MD, MPH**

Director,  
Asthma Collaboratory

I've been fascinated by the racial disparity among asthma patients – why minority children suffer disproportionately. We're launching a major study to understand how the first few years of life affect asthma risk. Are some children predisposed to get asthma? How do a child's environment, genetics, and gene expression contribute? It's a huge challenge to answer these questions, and nobody has done it before.

We're collaborating with 13 hospitals in Puerto Rico to recruit 4,000 newborns. This will be the world's definitive pediatric asthma study. Eventually, we hope the data we collect can be used to create a blood test that will be given to children at birth to identify gene expression patterns that predispose children to asthma.



**Dayna Long,  
MD, FAAP**

Co-Director, Child  
Health Equity Institute

We need to address the social determinants of health that make asthma rates so high in our community. At our Oakland clinic, almost 60 percent of our families are food-insecure, and half face mental health struggles – much higher than national average. That stress triggers asthma. We also see a serious lack of kindergarten readiness and third-grade reading skills. That has to do in large part with a lack of attendance, and the most chronic reason for that is asthma.

So it's imperative that we're helping kids not miss school, and that means addressing those social determinants: ensuring they have healthy food and they're not stressed out by violence. That's why we're committed to tackling system-wide issues on a larger scale.



**Michael Cabana,  
MD, MPH**

Division Chief,  
General Pediatrics

There's no known way to prevent asthma right now. But if you can stop asthma before it happens, you are going to prevent a lot of emergency department visits and hospitalizations.

I'm studying whether we can develop a probiotic – a good bacteria – for babies that stimulates the immune system so kids never develop asthma. Probiotics would be a relatively low-cost and easily accessible method of prevention. Even families that might not be able to afford expensive therapies could access this treatment, all over the world.

For more information about our asthma care, call (510) 428-3305 (Oakland) or (415) 476-2072 (San Francisco).

**7**  
million

kids in the US  
suffer from asthma

**40%**

of Oakland primary  
care patients  
have asthma

**7,200**

kids visit our  
emergency rooms  
each year for  
asthma care

# Bringing VR to the OR

Imagine if a neurosurgeon could look inside a patient's brain and see the exact location of a tumor and all that surrounds it. How much easier would it be to plan and execute a complex surgery?

MRIs offer a window into the brain, but two-dimensional images can't convey all of its nuances. Surgeons rely on their ability to mentally build these 2-D images into a 3-D rendering of a patient's brain in their mind's eye.

Now there's technology that lets them do just that. We recently became the first stand-

alone children's hospital to acquire innovative virtual-reality technology that gives our neurosurgeons a never-before-seen view of a patient's anatomy in 3-D.

"This technology is unlike any platform I've experienced," says Dr. Kurtis Auguste, director of pediatric epilepsy surgery at UCSF Benioff Children's Hospitals. "I can plan a surgery and determine the best road map to reach a target in a way I never could before."

Equally important, it also helps when communicating with patients and families. Auguste vividly remembers the moment one 10-year-old epilepsy patient donned the virtual-reality goggles.

"She starts reaching for her tumor in midair, and she's smiling – two days before having brain surgery," he says. "That was something totally new to me." Since her surgery, this patient has been seizure-free.



# Wagging Tails and Healing Hearts

This May, we welcomed two special staff members to our hospitals: facility dogs Sundance and Vente. Their job? To lift the spirits of our young patients, one fuzzy high-five and cozy snuggle at a time. Facility dogs are proven to help relieve pain, stress, and anxiety for our kids and their families, and patients love joining them for walks, which encourages mobility and rehabilitation.



## Vente

**Birthday** April 7, 2016

**Sex** Female

**Breed** Lab/golden retriever mix

**Department**

Child Life, San Francisco

**Personality**

Gentle, sweet, patient

**Likes**

Eating, running, being petted

**Coollest Trick**

Opening and closing drawers

**Special Moment** Meeting a baby that had been hospitalized for much of her young life. It was her first time ever seeing a dog, and she was amazed by Vente's soft fur and wiggly tail.

## Sundance

**Birthday** May 4, 2016

**Sex** Male

**Breed** Golden retriever

**Department**

Complex Pain and Palliative Care, Oakland

**Personality**

Mellow, laid-back, intuitive

**Likes**

Being brushed, tummy rubs

**Coollest Trick**

Turning lights on and off

**Special Moment** Connecting with a patient who didn't want to get out of bed after surgery. When she learned about Sundance, she threw off her covers and went looking for him.

# In the News

THE LATEST MEDIA BUZZ ABOUT OUR HOSPITALS

**“If you think your child is ill, the last thing on your mind should be ‘Is it safe for me to go to that hospital?’”**

- Dr. Michael Anderson, president of our hospitals, on the risks of new immigration policies (KQED)

**“It’s kind of humbling to be the first to test this. I’m willing to take that risk.”**

- Brian Madeux, the first patient ever to undergo an in-body gene therapy treatment, performed on our Oakland campus (*Diablo Magazine*)

**“Maybe one in 15 patients had diabetes when I started 25 years ago. Now one in two of my clinic visits are with patients who have diabetes.”**

- Dr. Dean Schillinger (*New York Times*)

**“They really made him feel comfortable, which made us feel at ease as well. Because when Devin is feeling good, we’re feeling good.”**

- Monica McGuiness, on her son’s cancer treatment (*PBS Newshour*)

1

2

3

4