

A newsletter for friends and supporters of UCSF Benioff Children's Hospitals

## It's a Beautiful Day: Benefit Concert Raises \$10 Million



Courage award recipient Josslyn Tramel (third from left) and her family gather with members of U2.

Music was the magic that helped raise \$10 million in support of UCSF Benioff Children's Hospitals during the Concert for UCSF Benioff Children's Hospitals at the "Cloud" (Cow) Palace on October 5.

U2 headlined the sold-out concert, which was presented by Salesforce in conjunction with its annual Dreamforce cloud-computing conference.

One of the biggest stars of the night was 9-year-old Josslyn Tramel, the recipient of the 2016 Colin Powell Medal of Courage. As she stood proudly on the stage to receive her award, the image of a healthy girl belied the challenges she has overcome to earn the amazing honor.

Last March, Josslyn and her family were vacationing in Southern California. She was playing with her siblings in a swimming pool when she was electrocuted by a charge in the water. Her father jumped in to save her after she lost consciousness, but sadly, he passed away in the process.

Following emergency treatment at a local hospital, Josslyn was transferred to our San Francisco campus for specialized care. She arrived unable to move her left arm or leg or fixate her eyes and could only speak a few words. After an intensive three-month hospital stay, Josslyn has made remarkable strides and is looking forward to returning to school in the spring.

The Concert for UCSF Benioff Children's Hospitals, now in its seventh year, has raised \$46 million for UCSF Benioff Children's Hospitals.

## UCSF Benioff Children's Hospitals Announce New President

Following an extensive nationwide search, we are pleased to welcome Michael R. Anderson, MD, MBA, FAAP, as the new president of UCSF Benioff Children's Hospitals. A well-respected pediatrician and national advocate for children's health, Dr. Anderson brings to this role an accomplished career as a physician, administrator, and policy advocate.

Prior to his appointment, Dr. Anderson was chief medical officer of University Hospitals in Cleveland. He is board certified in pediatrics and pediatric critical care medicine, with special interests in clinical care, pediatric disaster preparedness, and children's health policy, as well as bioethics, system quality, and the physician workforce.

Dr. Anderson earned his medical degree from Case Western Reserve University School of Medicine and a Master of Business Administration degree in health care from Kent State University. He has chaired the national Children's Hospital Association Disaster Task Force and was appointed by President Obama as chair of the National Advisory Committee on Children and Disasters for the US Department of Health and Human Services.

"I could tell you more about Dr. Anderson's academic, clinical, and public service credentials, but that only reflects part of the reason we are so fortunate to have him join



Dr. Michael Anderson is the new president of UCSF Benioff Children's Hospitals.

the UCSF family," said Mark Laret, president and CEO of UCSF Health. "Michael is a collaborator and an enthusiastic advocate for children and children's hospitals, and he will be a great ambassador to our community for children's health."

For the last seven years, Bertram Lubin, MD, has passionately served as president and CEO of UCSF Benioff Children's Hospital Oakland. Dr. Lubin accepted this position after serving the medical center for 36 years, first as chief of hematology/oncology and then as director of medical research. He will continue to serve as associate dean of children's health, focusing on research integration, community outreach, fundraising, and advocacy.

## Food as Medicine

Are you hungry? That might seem like an unlikely question for a doctor to ask at a checkup or well-child visit, but given the potential health consequences of food insecurity for children, the American Academy of Pediatrics recommends that pediatricians start asking.

As part of ALL IN Alameda County, supervisor Wilma Chan is partnering with UCSF Benioff Children's Hospital Oakland, the Alameda County Community Food Bank, the Alameda County Public Health Department, Dig Deep Farms, and the design firm IDEO to create the Food as Medicine initiative to tackle food insecurity.

This collaborative effort was recently showcased at the American Academy of Pediatrics conference, promoting a system where doctors give "food prescriptions" to

families that they can fill at local farmers' markets, community gardens, food pantries, or through fresh produce delivered to their doorstep. The ultimate goal is to build an on-site food pharmacy where patients can fill their food prescriptions.

"A food pharmacy, which brings together health care and food access, enables the active pursuit of health through food by giving families more options and support," Chan said.



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## Fighting to Win Sophia, Age 3

“Cancer.” That’s a word no parent should ever have to hear. So you can imagine how heartbroken Janai Bryand and her husband, Johnny Escobedo, were when their daughter, Sophia, was diagnosed with a rare type of eye cancer before she was even 2 years old.

It started with a routine eye exam during an 18-month well-baby check. Sophia’s pediatrician noticed an abnormality in Sophia’s left eye and advised that they follow up with a specialist as soon as possible.

“My alarm bells went off in full force,” says Janai.

Soon after, she learned that Sophia had a rare type of cancer that affects the retinas in both eyes called bilateral retinoblastoma.

They were immediately referred to a specialist. “With both eyes affected, the doctor said he couldn’t risk removing her left eye. So instead, Sophia underwent months of aggressive targeted chemotherapy on both eyes,” Janai explains.

Around that time, Janai joined a Facebook group for parents of children with retinoblastoma. One of the moms suggested getting a second opinion from the pediatric oncology specialists at UCSF Benioff Children’s Hospital San Francisco.

“We were able to get in right away, and the care Sophia received was so streamlined and coordinated,” recalls Janai. “The team met



Three-year-old Sophia was treated at our San Francisco campus for a rare form of eye cancer triggered by a genetic defect.

“The team inspired us with their incredible concern for Sophia.”

– Janai Bryand

with us frequently and provided all kinds of information.”

Unfortunately, Sophia’s condition continued to worsen, and the tumors grew into an area within Sophia’s left eye that couldn’t be treated with chemo. The only choice was to have it removed.

Sophia’s progress since her surgery has been remarkable. “We are grateful to all of the donors who support the hospital,” says Janai, “and for the extraordinary care that our entire family received.”

## Conversations on Children’s Health



A full house gathered on October 19 for our fall Conversations on Children’s Health event, which focused on mental health care services and support for Bay Area youth.

“We should have no shame in saying ‘depression’ the way we say ‘diabetes,’” said Lee Atkinson-McEvoy, MD, director of child and adolescent health at our San Francisco campus. “If kids become more comfortable talking about it, they won’t be scared of it.” Pushing this conversation can lead to early diagnosis, which often can prevent serious illness later in life.

Dr. Atkinson-McEvoy was joined by Bennett Leventhal, MD, professor of psychiatry at UCSF; Petra Steinbuchel, MD, medical director of mental health and child development at our Oakland campus; and Matthew State, MD, chair of the department of psychiatry at UCSF, who moderated the conversation.

Panelists spoke about efforts at both children’s hospital campuses to address prevention and community outreach, the integration of pediatric medicine with psychiatric care, and the development of new and improved treatments for mental health conditions.

Information about our next event will be available in the spring.

## An Easy Decision to Give Back

In his four decades of practicing medicine, Dr. Robert Mines touched the lives of thousands of Bay Area residents. “Every day I see someone who was a patient, parent, or grandparent of a patient,” he said. “It’s a wonderful feeling.”

Since retiring from pediatrics in 2009, Dr. Mines hasn’t stopped giving back. His estate plan includes a legacy gift for UCSF Benioff Children’s Hospital Oakland. “Children’s gives so much to the community,” he explained. “It’s an important decision, and an easy one, to give back.”

Dr. Mines’ foray into medicine began with Thomas Clayton, MD – the family physician who brought him into the world. Clayton invited Dr. Mines to go on house calls with him, and they soon became close friends.

Inspired by Clayton, Dr. Mines went on to study at Meharry Medical College, one of the few medical schools then accepting African-American students. After graduating with



After 40 years of caring for young patients, Dr. Robert Mines is giving back with a planned gift to Children’s.

honors, he moved to Detroit for an internship at Detroit Receiving Hospital, followed by a residency at Children’s Hospital of Michigan.

In 1966, Dr. Mines was drafted and served as a pediatrician in the US Army Medical Corps. After completing his tour of duty, he joined North Oakland Pediatrics, a practice started by his medical school colleague, William Jenkins, MD. Together they were among a handful of African-American pediatricians serving the area. Years later, they added a second location in Richmond.

“A child’s pain is not an adult’s pain cut down to size.”

– Dr. Robert Mines

For 40 years, Dr. Mines practiced at the same Market Street location, about a mile from our Oakland campus. He worked closely with the medical staff at Children’s and understands firsthand that when it comes to health care, kids’ needs are unique.

“A child’s pain is not an adult’s pain cut down to size,” he said. “Young people require extra time, monitoring, specialized medication, and care by professionals who really understand kids. That’s what Children’s is all about.”

## Paving the Way to a Sickle Cell Cure

A team of physicians and laboratory scientists has taken a key step toward a cure for sickle cell disease, using CRISPR-Cas9 gene editing to fix the mutated gene responsible for the disease in stem cells from the blood of affected patients.

For the first time, they have corrected the mutation in a proportion of stem cells that is potentially high enough to produce a substantial benefit in sickle cell patients.

The researchers from UC Berkeley, UCSF Benioff Children's Hospital Oakland Research Institute, and the University of Utah School of Medicine hope to re-infuse patients with the edited stem cells and alleviate symptoms of the disease, which can lead to anemia, painful blood vessel blockages, and shortened life expectancy.

"This is an important advance because for the first time, we show a level of correction in stem cells that should be sufficient for a clinical benefit in persons with sickle cell anemia," says co-author Mark Walters, MD, a pediatric hematologist and oncologist and director of UCSF Benioff Oakland's Blood and Marrow Transplantation Program.

"There is a clear path for developing therapies for certain diseases," says co-senior author Dana Carroll, PhD, of the University of Utah. "It's very gratifying to see gene-editing technology being brought to practical applications."



A sickled red blood cell, left, next to a normal red blood cell. The shape of sickled blood cells causes them to get stuck in vessels and block the flow of blood, which can result in severe pain and infections in those with sickle cell disease.

This work is the fruit of the Innovative Genomics Initiative, a joint effort between UC Berkeley and UCSF that aims to use CRISPR-Cas9 technology to correct the underlying DNA mutations that cause human disease. The project also leverages the expertise of physicians and scientists at UCSF Benioff Children's Hospital Oakland, a major center for research and treatment of sickle cell disease, and Carroll's expertise in the field of genome engineering.

“It's very gratifying to see gene-editing technology being brought to practical applications.”

– Dana Carroll, PhD

Research support has been provided by the National Institutes of Health, the Li Ka Shing Foundation, the Siebel Scholars Fund, the Jordan Family Fund, and the Doris Duke Charitable Foundation.

## Playing for Kids: Extra Life 2016



Extra Life gamer Ashley Mandel played in honor of a close friend who passed away from cancer.

"Play games. Heal kids" was the motto that inspired Bay Area gaming enthusiasts to hunker down for the 24-hour Extra Life gaming marathon on November 5. Now in its ninth year, Extra Life has raised more than \$1.7 million for UCSF Benioff Children's Hospitals.

One of these participants is Ashley Mandel. Six years ago, one of her best friends was treated for an aggressive form of cancer at our Oakland campus. While given only six months to live, her friend held on for two years.

"I remember visiting her at the hospital and seeing how vibrant the rooms were and how nice the staff was," Ashley said. "I know how much that affected her will to survive just a little bit longer. I am so thankful to the staff at Children's for giving her more time."

Thanks to gamers like Ashley, this year UCSF Benioff Children's Hospitals proudly ranked as the top Extra Life fundraiser in the country.

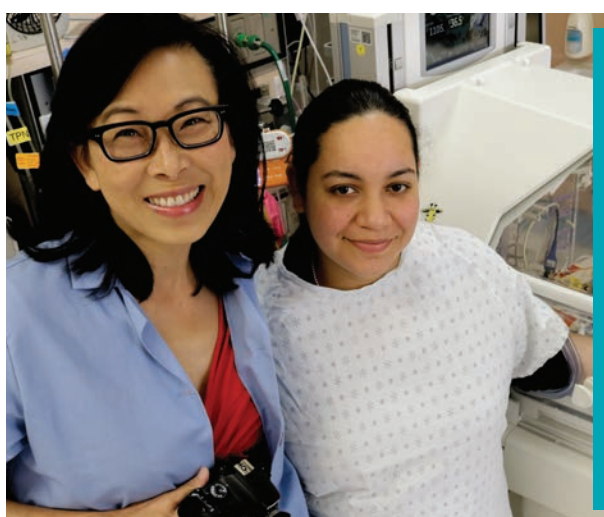
## Capturing Hope and Healing

The phrase "A picture is worth a thousand words" is often thrown around, but when it comes to capturing moments that can never be repeated, photographer Debbie Lee truly understands the meaning.

Over the last two years, Debbie has volunteered her time to photograph hundreds of babies in the neonatal intensive care unit at UCSF Benioff Children's Hospital Oakland. These photos are for the families – precious images that document the beginning of their child's life. What Debbie gets in return is just as meaningful.

"I fall in love with every child I photograph, and I've been told that love comes through in my photos," says Lee. "That's the best compliment."

The mother of two grown children, Lee started volunteering at the hospital's Katie's Clinic for Rett Syndrome when her kids were in high school. Housed on our Walnut Creek campus, this clinic specializes in Rett syndrome, a rare neurological disorder that primarily affects girls and is marked by developmental reversals.



Volunteer Debbie Lee photographs NICU babies and their families to provide them with "a bit of joy" during difficult times.

"One thing all the girls have in common is that they are excellent communicators using their eyes," shares Debbie. "I try to capture that in my photos. I want to portray every girl the way her parents see her, the way I see her, the way the world should see her."

Debbie started photographing NICU patients in 2014. "Having a child in the hospital is intense and emotional," she says. "Most parents take their babies home soon after birth, take family photos and have visitors. That's not the case in the NICU. I hope that taking photos offers these families some normalcy and a bit of joy in a very abnormal situation."

“I fall in love with every child I photograph, and I've been told that love comes through in my photos. That's the best compliment.”

– Debbie Lee

Volunteering her time at Children's has special meaning for Debbie. Years ago, her good friend Cathy lost a son in the NICU. They only have one family photo, taken with a Polaroid. It's faded now, and Cathy wishes she had more images of those tender last moments. That's what motivates Debbie to take meaningful photos for families during the most trying of times.

"I love being around the incredibly talented doctors, nurses, and staff in the NICU. I'm privileged to witness and document the miracles they perform each and every day," says Debbie.



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Saturday,  
March 11, 2017  
9 am - 2 pm

Children's Hospital Oakland  
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**CONNECTIONS**  
WINTER 2016

**Building a New Generation of Builders**

UCSF Benioff Children's Hospital Oakland, in partnership with the Oakland Unified School District, has launched a construction pre-apprenticeship program designed to create workforce opportunities for the community the hospital serves.



The new 89,000-square-foot Center for Advanced Outpatient Care will be completed in Fall 2017.



Program participants Anai Melendrez and Brenda Rico with Emiliano Sanchez, director of career technical trades and apprenticeships at Oakland Unified School District

The five-week pilot program kicked off last July with eight students from Fremont, Castlemont, and McClymonds high schools. Participants received an inside look at the hospital's new outpatient center, an 89,000-square-foot facility that will house clinics for cardiology, rehabilitation, neurology, and other subspecialties.

Students received guided construction site tours, construction safety seminars, tool-handling workshops, and project-based learning opportunities.

"As a leader in the community, the hospital believes that the development of our future workforce is foundational to sustained growth in the City of Oakland," said Barbara Stagers, MD, MPH, executive director of the hospital's Center for Community Health and Engagement. "The pre-apprenticeship program is just one way in which we are using our resources to ensure this growth."



**Join our Giving Circles!**

At UCSF Benioff Children's Hospitals, providing the best possible medicine for young patients is our passion. So is ensuring that these children have the best chance at a healthy future. That hope and healing is what you invest in with your annual support.

As a member of our Hand-in-Hand Giving Circles, you join a community dedicated to making care more accessible, more advanced, and more compassionate for children through personal philanthropy. Your support will make a vital difference for children and families who depend on us each and every day.

For membership information, contact Marlene Penny at (415) 476-6341 or [marlene.penny@ucsf.edu](mailto:marlene.penny@ucsf.edu).