

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

## Concert for UCSF Benioff Children's Hospitals Raises \$15M



Siblings Cameron and Cailey Tennyson are the 2017 recipients of the Colin Powell Medal of Courage.

Tens of thousands of music fans packed into AT&T Park on November 7 to rock out with Grammy Award-winning musicians Alicia Keys and Lenny Kravitz at the massive party during Salesforce's weeklong Dreamforce conference. The benefit Concert for UCSF Benioff Children's Hospitals, now in its eighth year, raised a record \$15 million.

Two of the night's biggest stars were Cameron and Cailey Tennyson, Bay Area siblings who were awarded the Colin Powell Medal of Courage.

Born with four related heart defects known as Shone's Complex, Cameron, now 20, has undergone multiple surgeries and grappled with a series of medical complications. Despite his condition, he always shows determination to live a full life and help others.

Cameron's 15-year-old sister, Cailey, was born with hypoplastic left heart syndrome, one of the most serious heart defects. She has braved numerous surgeries and invasive procedures. Cailey is on a local youth advisory board and shares her story with families of children with the same condition.

Throughout their ongoing medical challenges, Cameron and Cailey maintain positive attitudes, a drive to succeed, and a desire to give back.

Over the last eight years, Salesforce has raised \$65 million for UCSF Benioff Children's Hospitals through the annual Dreamforce concert.

## UCSF: The Campaign Takes on Grand Challenges Impacting Children's Health



Breakthroughs. Insights. Cures. We live in a remarkable time – a historic inflection point in our ability to understand the complexities of children's health. On October 27, UCSF launched a landmark \$5 billion fundraising campaign aimed at tackling some of the world's most intractable health challenges.

**UCSF: The Campaign** celebrates the scientific advances, clinical innovation, and commitment to health equity that have long defined UCSF Benioff Children's Hospitals.

As part of a dynamic community of physicians, researchers, students, and partners, we are excited to passionately pursue new ways of addressing the toughest problems in children's health. The Campaign will focus on three Grand Challenges:

- **Decoding Life to Improve Health** aims to illuminate the complex biology of human beings, using discoveries made at the molecular, cellular, and circuitry levels to fight or prevent diseases.
- **Leveraging Discovery to Revolutionize Care** will translate discoveries – moving them from basic-science labs to clinical trials and into health care settings – to provide treatments and cures faster and more effectively than ever before.
- **Partnering to Achieve Health Equity** applies scientific rigor to understanding socially determined obstacles to health, such as poverty and discrimination. It also addresses health disparities to advance health for everyone, everywhere.

"Our ability to understand the mysteries of biology and the fundamentals of health is undergoing a rapid, perhaps unprecedented, acceleration," said UCSF Chancellor Sam Hawgood, MBBS. "It is a time of dramatic knowledge creation, discovery, and technological revolution."

“Our ability to understand the fundamentals of health is undergoing a rapid, perhaps unprecedented, acceleration.”

– Sam Hawgood, MBBS  
UCSF Chancellor

Whether using virtual reality to transform pediatric care or harnessing genomics as the next wave of childhood cancer treatment, the future promises to inspire. Join us as we enter a new era of healthy children, healthy communities, and a healthy world.

For more campaign news and stories, visit [campaign.ucsf.edu](http://campaign.ucsf.edu).

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## Taking a Chance on a Cure

Matthew Damm excels at water polo, biking, and CrossFit. He says he has the life of a normal high school junior, but to his family, how it became that way feels like a miracle.

When his mother, Dawn, was pregnant, she learned both she and her husband are thalassemia carriers. This blood disorder affects nearly 2 percent of the world's population with various degrees of severity and can cause organ damage, anemia, and a shortened life span.

Born with a severe form of the disease, Matthew needed monthly blood transfusions. By age 3, excess iron had accumulated in his body, requiring all-night injections of medicine five times a week.

Though they were living in San Diego, the Damms sought treatment at UCSF Benioff Children's Hospital Oakland, home to the nation's largest and most advanced thalassemia program.

In 1998, the hospital launched the first nonprofit program to bank, free of charge, umbilical cord blood of babies with siblings who need stem cell transplants. The Damms wanted another child and knew cord blood from a healthy match could end Matthew's suffering. But the baby could also be just as sick.

They decided to take their chances. In 2005, Matthew's sister Hannah was born healthy, and though the odds were only one in four, she was a donor match.

"It was just incredible," Dawn says, "a true miracle."



Matthew Damm enjoys an active life thanks to a cord blood transplant from his sister that cured him of thalassemia.

When Hannah was 8 months old, the Damms uprooted their lives and moved to Oakland. After weeks of chemotherapy, Matthew received the transplant of Hannah's stem cells. And then, they waited.

Dawn crossed off square after square on her calendar, as each day's blood draw failed to indicate that Matthew was getting better. But after about a month, he suddenly showed a slight improvement, and the next day, even more. Hannah's stem cells were doing their job.

"When he was born, I never imagined this," Dawn says. "I thought he would be sick his whole life."

To date, Matthew and eight other thalassemia patients have received sibling cord blood transplants at UCSF Benioff Children's Hospital Oakland, and all are now cured. An additional 18 have received bone marrow transplants, with a success rate of about 90 percent.

Dawn says she's impressed by the ongoing search for cures and is eternally grateful to the hospital. "I want every child to have what Matthew has: a life free of illness," she says. "It's amazing to think how different things could have been for our family."

## All Are Welcome Forum



UCSF Benioff Children's Hospitals are committed to serving all children, regardless of their medical challenges or family circumstances – including immigration status.

After recent changes to federal immigration policy, UCSF pediatrician Jyothi Marbin, MD, started fielding questions from parents: If I register for food stamps, can immigration find me? If I'm deported during the day, who will pick up my child after school?

Even Dr. Marbin's 7-year-old son told her that he didn't feel welcome in this country, despite being born here. "To know that he was internalizing that kind of message at such a young age was disturbing," she says.

On October 7, Dr. Marbin helped organize "All Are Welcome Symposium: Supporting the Health of Immigrant Families." The event drew more than 200 providers, clinicians, and politicians. Among those in attendance were Berkeley Mayor Jesse Arreguin and Congresswoman Barbara Lee.

"The need and interest this event revealed are really remarkable," Dr. Marbin says. "I'm committed to standing up in a vocal way, and many others are as well."

## Giant Supporters

On three occasions, San Francisco Giants catcher Buster Posey has proven to his fans that he's a World Series champion. Through his foundation, Posey is proving that he's a champion off the field as well.

Posey and his wife, Kristen, established the Buster and Kristen Posey Fund in 2016 to raise funds to fight pediatric cancer. The Poseys were inspired to take a stand after Kristen connected with the mother of a young neuroblastoma patient who was just four days older than the couple's twins.

Cancer is the leading cause of death by disease among children. But, the Poseys learned, only 4 percent of federal funding for medical research goes toward cures and therapies for kids. "Once I found that out, I did not want to sit back and do nothing," Kristen explained.

This year, coinciding with our Be Gold campaign to support the world-class cancer research and treatment at our hospitals, the Poseys visited young patients on our San Francisco campus, signing autographs, offering hugs, and snapping



SF Giants catcher Buster Posey and his wife, Kristen, visited patients during our Be Gold campaign for pediatric cancer.

selfies. On September 14, they also hosted an intimate gala at AT&T Park, gathering more than 200 supporters and raising over \$860,000 for pediatric cancer.

Mignon Loh, MD, whose breakthrough work in precision cancer-fighting medicine is poised to change lives around the world, spoke at the event about the importance of philanthropy.

"It's impossible to make new discoveries if there are no research dollars," she said. "I don't want to hold the hand of a teenager dying from

“It's impossible to make new discoveries if there are no research dollars.”

– Mignon Loh, MD

leukemia. I want to pat him on the back and send him off to rule the world.”

Dr. Loh was joined by Lara Stuart, whose son, Quincy, was diagnosed with a rare form of leukemia at only 4 months old. As his condition deteriorated, his team on our San Francisco campus suggested a new therapy developed by UCSF scientists.

"They asked us to trust them, and we did – a huge leap of faith," Lara said.

The risk paid off: This pioneering approach put Quincy into remission.

"The behind-the-scenes magic of UCSF is awe-inspiring," Lara said. "I can go home tonight and hug my son." With the help of MVPs like the Poseys, we can work this magic for more kids.

## The Pediatric Device Squad

Sometimes, kids need intensive medical treatment, but the cutting-edge technology available to adults simply doesn't exist for them.

Pediatric medical devices represent such a small market that many companies find them unprofitable to develop. Doctors are left to adapt adult devices to fit young patients, but the resulting improvisations usually are far from ideal.

That's where UCSF's Pediatric Device Consortium comes in. Funded by the US Food and Drug Administration, the consortium focuses on accelerating the development of medical devices designed specifically for children.

Artificial kidneys, magnets that correct skeletal deformities, and virtual-reality therapy for pain management are among the technologies being developed at UCSF to advance children's health.

This fall, more than 50 applicants joined this effort, submitting ideas for new devices to treat or diagnose pediatric conditions ranging from cleft palate to scoliosis. The top eight teams pitched their concepts to an exclusive panel of academicians, industry experts, and venture capitalists at the inaugural UCSF Pediatric Device Accelerator on November 14.

Seed funding of \$250,000, along with in-kind product development assistance, was allocated to promising inventors to advance their ideas to market – and the patients who need them.



Magnetic devices that correct chest wall deformities are among the technological advances already being used at UCSF Benioff Children's Hospitals. Photo by Susan Merrell

One winner was the team led by UCSF medical student Adam Rao, who has a big goal: to reduce mortality rates for pneumonia, the number-one killer of children worldwide. The way he's planning to do it is small – the size of an apple, to be exact.

His device, Tabla, is designed to be held up to a child's chest to detect probable pneumonia using sound waves. Tabla will cost less than \$400, and its technology can be uploaded to any smartphone. His team will use its award to fund a pilot study on children in India.

It would have been easier to develop Tabla for adults, Rao says. But his passion aligns with the consortium's mission.

"Too often we focus on the population we have access to when we should focus on the population that needs help the most," Rao says.

## Using Poetry to Fight Childhood Diabetes



How do you get teens to care about avoiding type 2 diabetes? The disease strikes young people in epidemic proportions, particularly in low-income communities and among people of color. "Shaming and blaming" won't get kids off the couch or get them to stop drinking sugary sodas.

But what about using slam poetry as an educational tool? As part of The Bigger Picture campaign, Bay Area teens use their creative juices and their own voices to change the conversation about type 2 diabetes.

Dean Schillinger, MD, founder of the UCSF Center for Vulnerable Populations, initiated a unique collaboration with Youth Speaks, an organization that challenges young people to actively apply their voices as creators of change. The effort has reached more than 5,000 students in Bay Area high schools to date.

Samuel Getachew, pictured above, says he initially thought it was strange to write poetry about diabetes. "I didn't think it was a political issue," he says. "I didn't think it was a social issue. I didn't think it had anything to do with me. Getting educated changed my perception."

## PECE, Love, and Tequila

Lew Parker could be doing fine at school or on a lazy Sunday at home. Then time stops, and a seizure hits.

"With epilepsy, you are always on high alert," says Jen Parker, Lew's mother. "You can't count on things being good from one hour to the next."

Jen and Vic Parker shared their family's struggle – and their 7-year-old son's dramatic improvement under the care of Joseph Sullivan, MD, director of UCSF's Pediatric Center of Excellence (PECE) – during a fundraiser at their Hillsborough home on September 30.

More than 300 attended, raising over \$280,000 to support the family-centered model of care that PECE is pioneering. Guests enjoyed live music and a tequila tasting led by Bertha González Nieves, CEO of Casa Dragones.

The UCSF team also shared a major research breakthrough: A new formulation of a drug used in the 1980s to treat children with a rare neurological condition may offer promise for patients with a severe seizure disorder.



Event attendees (L to R): Jacqueline Koo, Sheila Druskin, Kim Tramel, Linda Campbell, Julie Ann Dougery, and Julie Veit.

Dr. Sullivan and Scott Baraban, PhD, employed a surprising research model: genetically engineering zebrafish. Using CRISPR gene-editing technology, they replicated the exact genetic glitch that causes the disorder and then tested a number of treatments on the fish. The success of the clinical trial suggests that this model could lead to additional discoveries.

"Taking trials out of the lives of kids like Lew and letting fish handle it is amazing," Parker says. "It's reassuring to be at a place where that kind of thinking is going on."

“Our house is a happy house, even though we live with something heavy.”

– Jen Parker, Lew's mom

Under Dr. Sullivan's care, Lew has gone from having up to 15 seizures a day and being barely verbal to enjoying seizure-free stretches of two weeks and "going through an explosive discovery of the world."

PECE is also unique in offering comprehensive support for patients' parents and siblings. "Epilepsy is hard on every facet of family life," Parker says. "The goal is of course to seek cures and control seizures, but there's also a lot of living to be done in between. Our house is a happy house, even though we live with something heavy. So much of that we owe to Dr. Sullivan and PECE."

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SAVE THE DATE  THURSDAY, MARCH 22, 2018



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**11th Annual St. Baldrick's Brave the Shave Fundraiser**

**Saturday, March 17, 2018**  
**9:00 am - 2:00 pm**

Children's Hospital Oakland Research Institute



**CONNECTIONS**  
WINTER 2017

## Swimming to Success After Liver Transplant

Watching Miya French glide effortlessly through the water, you'd never guess that she has overcome serious health challenges.

The Novato, Calif., 13-year-old swims six days a week, lap after lap, mile after mile, and her dedication has paid off. This summer, she won multiple medals and broke two world records at the World Transplant Games in Spain.

When Miya was just 8 weeks old, tests revealed biliary atresia, a serious liver disorder that caused her bile ducts to become blocked. She had surgery to open the clogged ducts, but it was only a temporary solution; to grow up healthy and strong, Miya would need a liver transplant.

She spent a year on the transplant list, her condition deteriorating by the day. Then a donor materialized. Her sister, Miwa, on the verge of turning 18, volunteered.

In December 2009, just two weeks after her 18th birthday, Miwa donated 40 percent of her liver to her sister, becoming the youngest live



Teen swimming sensation Miya French won multiple medals and broke two world records at the World Transplant Games.

donor in the history of UCSF Benioff Children's Hospital San Francisco.

After surgery, the recovering 5-year-old took up swimming. Miya showed such promise that soon she was recruited to join the competitive Marin Pirates team.

"Miya is one of the hardest working swimmers that I have met," says her coach, Tom Evers. "The obstacles that she has to navigate make her an incredible inspiration."

Indeed, Miya still faces health challenges. She's needed two hernia repairs and has suffered bouts of liver rejection.

"We weren't even sure she could go to Spain until two days before we left," says Miya's mother, Kazumi. But Miya's medical team knew that canceling the trip would devastate her.

"Swimming gives me time when I don't need to worry about anything else," Miya says. "When I'm in the water, the only person I'm racing against is myself."



## Brighten the Holidays

No family plans to spend their holiday season at the hospital. Yet every year, families are waiting by a bedside, hoping for a miracle, dreaming of going home with their child. This is where you come in.

You can help brighten the holidays for these families with a tax-deductible gift to our Children's Fund. Generous contributions from donors like you support the compassionate care and lifesaving treatments that our patients rely on each year.

With 2017 drawing to a close, don't miss your chance to make a meaningful year-end donation to support our young patients. Make your tax-deductible gift today at [give.ucsfbenioffchildrens.org](http://give.ucsfbenioffchildrens.org) or call (510) 428-3814.