

Connections

SUMMER 2022



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Building a world-class pediatric health care system

is ambitious work – even in the best of times. During these past two challenging years, the synergy and strength of our incredible community have continued to propel us forward.

Even amid a global pandemic, there is so much to be excited about. We have partnered with supporters like you to improve our hospitals and reach more children in need. We have expanded our offerings, strengthened our care, and broadened access to our services. This is a crucial effort on behalf of Bay Area children, and we couldn't have done it without you.

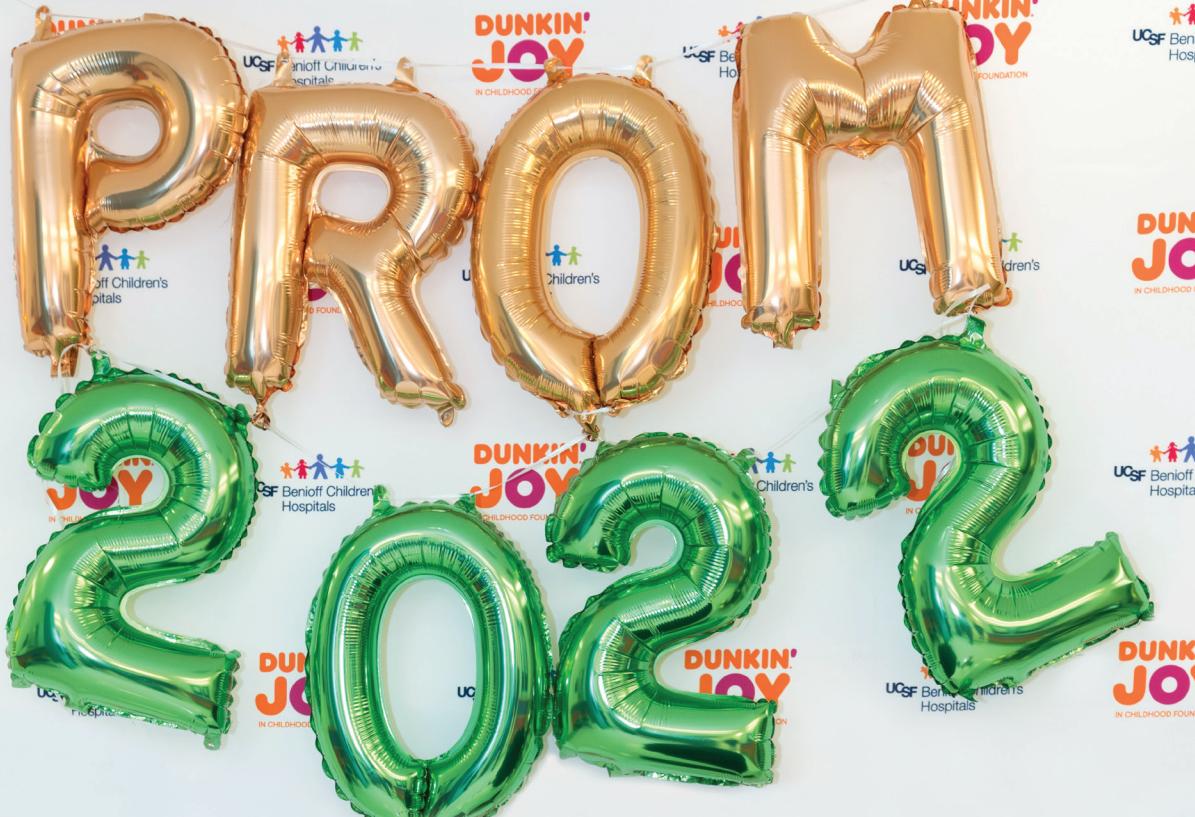
This issue of *Connections* is about enduring excellence, and the people that make our work possible. It's about our commitment to supporting a child's lifelong well-being, not just treating their physical symptoms. It's about our effort to bring state-of-the-art care closer to home for more kids. And it's about our drive to invest in research and discovery that will vastly improve outcomes for the most critically ill children.

Reflecting on these stories, I know, without a doubt, that our community will continue to make all the difference for every child – not just today, but well into the future.

Thank you for your continued partnership. We are here because of you.

Sincerely,

Matt Cook
President
UCSF Benioff Children's Hospitals



Oh What a Night!

This spring, patients like Oscar got to enjoy a magical prom night at our hospitals, with an Earth Day theme, a raffle with prizes, and an online performance by popular singer-songwriter mxmtoon. Special thanks to the Dunkin' Joy in Childhood Foundation for supporting this special night for our deserving teens.

What Resilience Looks Like



Charlotte with her family in 2021

Tyler was the first to get sick. Then Dylan was diagnosed with the same rare disease. Two years later, Charlotte also fell ill with osteosarcoma, an aggressive bone cancer that disproportionately impacts children and adolescents.

All three kids were from the same small Peninsula town, south of San Francisco. All three children eventually passed away. The community was shaken to its core.

“You can imagine our range of emotions,” says Alli Murdoff, Charlotte’s mom. “This disease robbed Tyler of his childhood, so when Dylan got sick, we were reeling. When Charlotte was diagnosed, we were devastated.”

Alli and her husband Sherrick often wonder what it must have been like for Charlotte

to fight a disease that had taken the lives of two other children she knew. But when they reflect on their daughter’s journey, they don’t remember her fear. They remember her grace, strength, and determination.

Heart and Soul

Charlotte’s personality was vibrant. Friends and family remember her huge heart, her charisma, her athletic spirit, and her infectious smile. “She was kind, funny, and thoughtful,” Alli says. “And she could also be stubborn. She was tenacious. She didn’t back down.”

Alli and Sherrick believe it was Charlotte’s grit that fueled her courageous battle with cancer. Even as the illness left her weak, Charlotte fought for herself and for others. She started a sewing

business during the pandemic and donated the proceeds to osteosarcoma research. She delivered webinars on pediatric clinical trials when she could barely sit up. And she attended board meetings for the osteosarcoma nonprofit she supported, right up until the end.

“Charlotte believed, from the beginning, that she would beat this,” says Alli. “She faced so many obstacles, but she stayed positive. She just refused to give up. We had a family mantra: Hard does not mean impossible.”

Digging Deep

Shortly after Charlotte’s diagnosis, Dylan’s mother, Christina, reached out to the other two families about joining forces to raise money for osteosarcoma research.

It was a difficult time. Tyler’s parents were mourning the loss of their son. Dylan was battling a relapse. And with Charlotte in and out of the hospital for treatment, the Murdoffs were emotionally exhausted.

But Alli and Sherrick knew what was at stake. Charlotte and others like her faced an uphill battle. Osteosarcoma treatments were four decades old. Research was severely underfunded. And the survival rates were bleak. All three families – along with a few friends – agreed to take the leap.

In 2019, they launched Battle Osteosarcoma to raise funds for research through St. Baldrick’s Foundation, a childhood cancer charity. They started out small, staging local events with the goal of raising \$150,000. But their story spread, and in under two years, Battle Osteosarcoma had successfully raised \$1.43 million for the UCSF laboratory of Alejandro Sweet-Cordero, MD – one of the world’s foremost cancer researchers and Charlotte’s revered oncologist.

Those funds are allowing Dr. Sweet-Cordero and his team to investigate the genetic underpinnings of osteosarcoma; identify innovative gene therapies; and make novel treatments available to children. They are also advancing future research by investing in Betsy Young, MD, an up-and-coming UCSF physician-scientist dedicated to discovering new

immunotherapies for osteosarcoma patients.

“The support from Battle Osteosarcoma has been absolutely transformative,” says Dr. Sweet-Cordero.

“I firmly believe it will make a huge difference for children and young adults dealing with this illness by helping us move faster to find cures.”



Charlotte faced so many obstacles, but she stayed positive. She just refused to give up. We had a family mantra: Hard does not mean impossible.

— Alli Murdoff

In the final months of Charlotte’s life, Dr. Sweet-Cordero’s care went well beyond the medical.

Doctor and patient regularly exchanged texts and voice messages. He joked with Charlotte when she needed a distraction from the pain, listened to her when she was in distress, and comforted her in some of her darkest moments.

Honoring a Child

In the days after Charlotte passed away, Alli, Sherrick

and their two surviving children sat down together to plan her memorial. They wanted to create a legacy that was quintessentially Charlotte.

The family reflected on Charlotte’s hospitalization at UCSF. How she had bonded with the nurses when the pandemic prevented friends from visiting. How they had inspired her to pursue a career in nursing after she beat cancer. How their compassion had made all the difference, during the hardest years of her life. The family knew what Charlotte would have wanted.

The Murdoffs reached out to their community again and raised \$100,000 for nursing education, wellness, and professional development at UCSF. Today, the nursing station on Charlotte’s former oncology ward is named in her honor.

Months after Charlotte’s passing, Alli and Sherrick are taking life, and grief, a day at a time. In May, they watched Charlotte’s siblings, Matthew and Maggie, graduate from high school and college, respectively – milestones they hoped Charlotte would also reach.

Even through their heartbreak, the Murdoffs are continuing to fundraise through Battle Osteosarcoma. They know Charlotte would have wanted them to keep fighting, just like she did.

“We must keep going,” says Sherrick. “We didn’t come this far, only to come this far.”

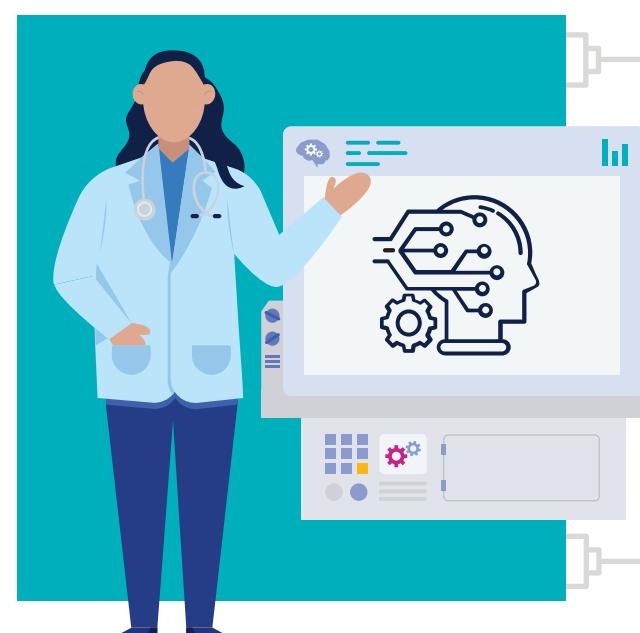
Algorithms at the Heart of the Matter

How UCSF is using machine learning to predict fetal heart defects



CHALLENGE

In the US, fetal ultrasound screening is universally recommended during the second trimester of pregnancy. In theory, this imaging could help clinicians to diagnose up to 90% of congenital heart disease. But in practice, only about half are detected by the human eye.



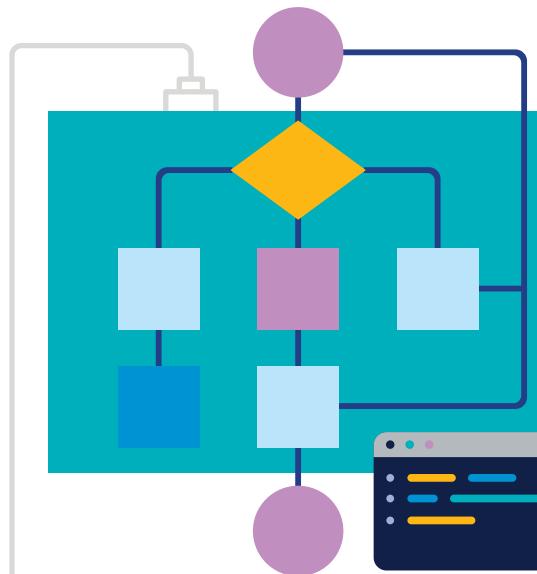
DISCOVERY

UCSF researchers have found a way to double doctors' accuracy in detecting complex fetal heart defects in utero by combining routine ultrasounds with machine learning tools. Here's how.



DESIGN

UCSF cardiologist Rima Arnaout, MD, has harnessed the power of machine learning – a method of data analysis that uses algorithms to automate learning and decision-making – to vastly improve diagnoses and give more kids a better chance of survival.

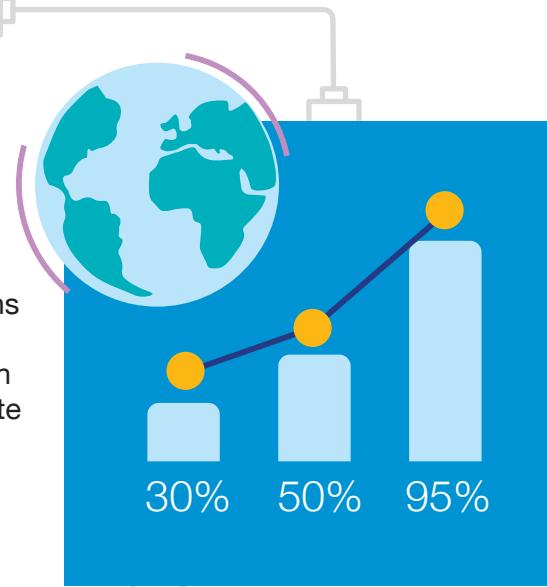


IMPLEMENTATION

The algorithm includes three steps. First, identify five views of the heart that are necessary for diagnosis. Then, determine whether or not each of these views is normal. Finally, combine the results from steps 1 and 2 to generate an accurate result.

RESULTS

Worldwide, diagnosis by humans detects only 30%-50% of congenital heart conditions before birth. When UCSF researchers combined human-performed ultrasound with machine analysis, however, the detection rate surged to 95%.

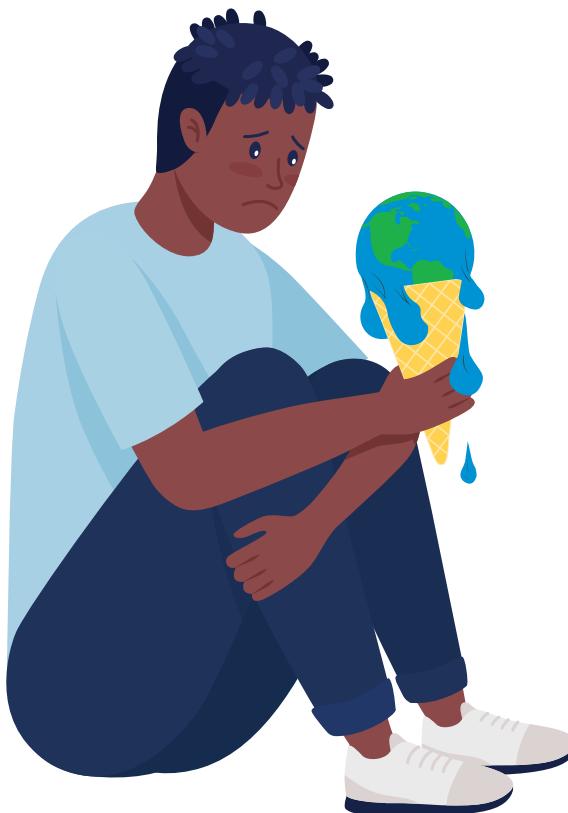


IMPACT

By vastly improving early diagnosis of fetal heart defects, we can propel crucial research and discovery forward while also helping children lead longer, healthier lives. "We hope this work will revolutionize screening for these birth defects," Dr. Arnaout says.

The Clock is Ticking: Helping Kids Cope with Eco-Anxiety

We spoke with Ellen Herbst, MD, UCSF psychiatrist and mother of two, about how the climate crisis is impacting the mental health of children and adolescents – and what parents can do to help.



When did you start thinking about climate change and its effect on the mental health of young people?

It started with my older son, who is now 13. When he was in fourth grade, he learned about the Intergovernmental Panel on Climate Change report in science class. He came home devastated. He was crying and feeling hopeless. He was saying, "What's the point?" and "No one cares."

I realized that this crisis is a huge burden for young people. Children are, appropriately, being educated about climate change in many schools and learning about it in the news, but they're not necessarily given the coping skills to handle that devastating information.

What did you do?

As an adult psychiatrist with expertise in traumatic stress, I know that the climate crisis impacts my patients. But with my own two kids, I just felt stuck. I wasn't sure how to tell my child that he was right: Things aren't certain, and they may not resolve how we want them to. I decided to educate myself about how, as a parent, I can support my kids.

What did you learn?

I learned that this is not an isolated experience. My son was communicating what many kids are feeling: betrayal, uncertainty, and disempowerment. Some are terrified.

A study recently came out that surveyed 10,000 young people in 10 countries.* Across this diverse sample, the majority of respondents were worried about climate change, reporting feelings like sadness, anxiety, anger, and helplessness. These are grief-related emotions. What struck me is that climate grief and distress are becoming universal, particularly for youths.

We know that low-income communities and communities of color in developing countries are disproportionately affected by the climate crisis. People in these areas are experiencing

acute trauma related to losing their homes, a sense of safety, even loved ones. Then there are kids who are experiencing chronic impacts during and after climate disasters, like poor air quality or schools and buildings that are damaged beyond repair. Communities closest to the crisis deserve resources, time, and serious attention.

Kids like my son are coping with an existential dread. He hasn't lost his home; he hasn't lost loved ones. But he feels like the clock is ticking. We know a great deal about how to cope with the effects of acute disaster and trauma, but the existential grief related to climate change is a new phenomenon that also requires our attention.

How do we help our kids cope?

An emerging area of inquiry, including here at UCSF, is around building psychological resilience to climate change. That means being able to cope internally, so when a child is faced with disturbing information and realities, they have a way of grounding themselves, of continuing to function, of not going straight to despair. They can live with this heavy knowledge and still reach their potential and thrive.

There are many ways of promoting resilience in kids. It might involve spending time in nature with other kids who care as deeply as your child does. For some children, climate activism can be gratifying. It could involve writing a letter to a policymaker, starting a school club, or restoring a wildlife habitat. Social activities set in nature can help a child feel more connected and like they're making a positive impact. Age-appropriate mindfulness practices can also help.

My kids and I participated in an activity with Nature in the City, a San Francisco-based organization. We restored a butterfly habitat in the Sunset District. Both kids really loved it because it involved a direct connection with nature. It felt like a concrete, positive impact.

We also try to talk about what we can do as part of our regular conversation as a family, as opposed to ruminating on the worst-case scenarios. That has made a difference. And we talk about the disproportionate impact that this crisis has on the most vulnerable communities.

5 Tips for Helping Kids Cope with Climate Change

-  Spend time together in nature
-  Get involved in climate activism
-  Explore age-appropriate mindfulness practices
-  Talk as a family about what we can do
-  Remind them that you're in it together

What would you tell a parent who asked you for advice?

Kids, especially younger children, often think in black and white. If they read a news article or climate report, they may think that the world is ending. I try to explain that it's not all or nothing. If some species and ecosystems are saved, that matters.

It is also so important to remember that the primary need of the child is to feel safe. If we cannot provide that within the external world, we must try to promote safety between the parent and the child. So be honest with them. Tell them that you're not sure what's going to happen but remind them that you care and will be there with them no matter what.

Dr. Ellen Herbst is a clinical professor in the UCSF Department of Psychiatry and Behavioral Sciences and a member of the UCSF Mental Health and Climate Change Task Force and the Climate Psychiatry Alliance. She can be reached at Ellen.Herbst@ucsf.edu.

*Hickman, C. et al. "Climate anxiety in children and young people and their beliefs about government responses to climate change: a global survey," [https://doi.org/10.1016/S2542-5196\(21\)00278-3](https://doi.org/10.1016/S2542-5196(21)00278-3).

Caring for the Whole Child

BY DR. JENIFER MATTHEWS

The pandemic has been hard on young people in so many ways. One patient that stands out for me is a teen I'll call "Jay." He was dealing with anxiety, struggling in school, and experiencing acute abdominal pain. The pain became so severe that Jay was admitted to our Oakland hospital.

The medical team did everything they could, but Jay wasn't improving, so I went to see him to discuss other options. He agreed to try acupuncture.

Jay and I developed a lovely relationship. He relaxed and opened up during our sessions. We talked about the mind-body connection, and he started to understand how stress might be affecting him. We talked about what he could do to care for himself.

He didn't magically get better, but Jay did begin to improve, and his parents were so appreciative. They had previous experience with acupuncture and were excited that we offered it because it wasn't something that they could afford for Jay on their own.

Jay's family isn't unusual. In 2019, we began piloting



Dr. Jenifer Matthews is a pediatrician and integrative medicine specialist

acupuncture at our Claremont Pediatric Specialty Clinic in Oakland, where 92% of our patients live below the poverty line. In a survey, we found that more than half of clinic families were interested in receiving integrative health services such as nutrition coaching, meditation training, and acupuncture.

We secured a grant and began offering acupuncture at the clinic regularly, but when the grant ran out, we lost our acupuncturist. Now I offer acupuncture when I can, and a few of my colleagues with training in mind-body healing provide integrative services when their schedules allow.

We want to do more. We want to expand our acupuncture and massage services to our

school-based clinics in Oakland. We want to offer these services to families that come through our clinic for asylum-seekers. And we are committed to establishing a dedicated outpatient clinic for integrative medicine in Oakland.

The demand is there. So many of our families, especially those served by our specialty clinic, are struggling right now. The number of patients we see who are coping with trauma, anxiety, and depression has exploded. But the reality is that integrative medicine is not covered by insurance, so it's out of reach for a lot of families.

I got into medicine because I wanted to spend time with my patients. I want to hear their stories, talk with them about healing, and explore holistic options together like I did with Jay. And I'm not alone. I think most of the people I work with at UCSF Benioff Children's Hospitals crave the time and space to provide this kind of support to their patients.

We know that integrative medicine can be life-changing – for kids like Jay, for their families, and for their providers. We just need the support to do more.

A SIMPLE GESTURE

A life-changing experience inspires a grateful family to give back

It was a pivotal time in Olivia's life: finishing her senior year at Berkeley High, delivering meals to people isolated by the pandemic, and looking forward to college in the fall.

Then Olivia got sick. At first, it seemed like a nasty stomach bug, but within days, it became clear that something was terribly wrong.

"It was appendicitis that turned into septic shock," says her mom, Jennifer. "But it didn't present like appendicitis until it was almost too late."

Olivia was rushed to UCSF Benioff Children's Hospital Oakland. Jennifer believes that more than 50 people – firefighters, paramedics, emergency-department staff, and intensive care providers – helped keep her child alive that first night.

Olivia's appendix was successfully removed, but she was in organ failure. For a month, Jennifer and T. Jay, Olivia's dad, sat by their daughter's bedside. They slowly adjusted to the tubes running through Olivia's body to keep her alive. They watched as a unique technology – Continuous Renal Replacement Therapy (CRRT) – cleaned her blood and helped her organs recover. And they grew close to the hospital staff, who they believe contributed as much to Olivia's emotional healing as her physical recovery.

"I didn't expect that," says T. Jay. "They were there for us emotionally throughout the entire experience. It's a testament to the quality of the staff and the culture of this hospital."

Their anecdotes are endless. One doctor wheeled Olivia outside for a few minutes in the sun during his lunch break. Another talked her through an overwhelming night after hours. A music therapist became her confidant. The nurses bonded with her over shared loves of movies and local cuisine.

Then there was the CRRT machine, which the family nicknamed "Phil" for its effort to filter the toxins from Olivia's blood while her kidneys healed. They learned that CRRTs perform a range of functions, including saving children who have been poisoned and treating critical cases of COVID-19.

The family also learned that CRRTs are unique: Only a handful are available in the US and UCSF is one of the only medical centers in the country equipped to deliver this innovative therapy. But the cost of purchasing additional CRRTs is beyond the hospital's budget.



They were there for us emotionally throughout the entire process.

– T. Jay Fowler, grateful parent

The day Olivia was discharged, her doctors and nurses staged a belated graduation celebration to honor the milestone that she had missed during her hospital stay. Two months later, Olivia left for college. Today, she is healthy and thriving.

Jennifer and T. Jay are in awe of Olivia's recovery and her hospital experience. In 2021, they established the Renal Replacement Therapy Fund, which will support the purchase of CRRTs and staff development for Oakland's Pediatric Intensive Care Unit.

"We thought, if Phil could save our daughter's life, it can probably save a lot of other kids' lives too," T. Jay says. "It seemed like a pretty simple gesture after everything the hospital gave our family."

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