



# **Connections** FALL 2022





#### **Our Resilient Teens**

Our school-based health clinics in Oakland are a national model. A new mental health care initiative is raising the bar even higher.



A UCSF marketing specialist recently found herself in a new role: As a parent navigating a complex medical journey for her infant son.

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#### The Power of Play

Chris Menezes has always loved games. Now his passion for gaming is bringing life-changing care to hospitalized children.



This has been an incredible year. I started my position as chief nursing officer at UCSF Benioff Children's Hospitals in November 2021, and as 2022 comes to a close, I feel so grateful to be a part of this community.

The words that I keep coming back to are "dedication" and "resilience." Our staff members went through so much during this pandemic, but they have continued to work together tirelessly to meet our mission of providing Bay Area children with the best possible care.

And it comes from the heart. Whether they're sourcing a lifesaving piece of equipment, helping a family cover the cost of transportation, or rallying around a child in critical condition, everyone – from our nurses, physicians, and social workers to our board members and fundraisers – goes above and beyond for every patient. Their dedication is palpable.

And so is yours. Everything you do – the philanthropy, the advocacy, the partnership – makes our work possible. It allows us to continue investing in improving patient experiences, safety, and outcomes, year after year.

The stories in this issue of *Connections* exemplify this remarkable spirit of giving and the impact of your generosity. I want to express my sincere thanks to all of you – my dedicated colleagues and our remarkable partners – for the hope and healing you bring to Bay Area children.

Sincerely,

Judie Brehner

Judie Boehmer, RN, MN Chief Nursing Officer, UCSF Benioff Children's Hospitals Vice President, Children's Nursing Services, UCSF Health

# **Summer Goals**

This summer, Charles-Anthony Woodfork participated in the UCSF Benioff Children's Hospitals Summer Student Research Program with Dayna Long, MD, at our Primary Care Clinic. Says Charles:

I have never been in a clinical setting before, and being exposed to one is opening me up to a new world of possibilities. Working with Dr. Long has been amazing. Her work has real-world impact. I want to be that kind of community health physician, who looks at health and well-being in multiple ways and provides more complete and relevant care. This opportunity has been priceless.



# OUR RESILIENT TEENS

Connecting local students with world-class mental health care



Saun-Toy Trotter (left) and Daniela Gomez

When Daniela Gomez was a sophomore at McClymonds High School in West Oakland, the campus went on lockdown half a dozen times in the first semester alone due to threats of gun violence.

It was Daniela's first year at McClymonds. She had transferred from a smaller school and suddenly found herself in a new school culture, with a student body struggling to cope with serious life and mental health challenges.

But Daniela also saw opportunities at McClymonds: a community eager to speak out on social issues, understand what was happening, and act to create change. She found a home for that passion in the Resilient Teens Youth Wellness Advisory Board, or Y-WAB, a student group that engages young people in peer health education.

"Y-WAB gave me the space to talk about the issues that were in the back of my mind, that I would think about or read about but that I couldn't really do anything about," Daniela says. "It gave me a community to push me and teach me how I could make an impact."

## **Resilient Teens**

For many years, Resilient Teens was just a dream.

Saun-Toy Trotter, MA, clinical director, schoolbased behavioral health for UCSF Benioff Children's Hospitals, recalls when her colleague Dayna Long, MD, co-director, UCSF Center for Child and Community Health, asked about her vision for the school-based clinics.

For Trotter, the school-based health clinics were their own dream come true. In 2005, Benioff Children's Hospitals partnered with the Oakland Unified School District, under the leadership of Barbara Staggers, MD, to provide full-service health care at McClymonds and East Oakland's Castlemont High – two schools serving overwhelmingly low-income populations. Since then, the clinics have become national models for school-based health care supporting adolescent development and wellness.

But Trotter and Dr. Long knew they could do more. With additional funding, they could expand the breadth and effectiveness of school-based mental health care. They could help kids facing serious life challenges and make a real impact on students' lives.

That vision became a reality in 2020 when UCSF launched Resilient Teens at McClymonds and Castlemont with funding from the George Sarlo Foundation and the Lisa Stone Pritzker Family Foundation. A talented and culturally accountable team of health educators and social workers was hired to screen students for adverse childhood experiences such as abuse, violence, family separation, and sex trafficking; provide on-site behavioral health therapy; connect students experiencing food insecurity, homelessness, and other challenges with social services; and cultivate students like Daniela as community health advocates.

"Before Resilient Teens, we were turning kids away," remembers Trotter. "Now, if they walk in, if they need services, we can help them – which became crucial during the pandemic. And we are partnering with young people to get involved in this work and become advocates for health and wellness in their own communities."

## A Remarkable Impact

Over the past two years, Resilient Teens and the Y-WABs have been instrumental in UCSF's effort to tackle the pediatric mental health crisis.

At McClymonds, Y-WAB has activated teens as health advocates through dialogue, education, and direct action. During Daniela's junior year, Y-WAB mapped food resources in West Oakland, found no grocery stores in the area, and grappled with what that meant for the health of their community.

For Daniela, these discussions were transformative. In addition to food insecurity and gun violence, students have explored racism ("Our school mascot was inherently racist"), reproductive rights ("We learned how the end of *Roe v. Wade* will impact us"), LGBTQAI rights ("People are bullied at our school for their sexual orientation"), genderbased violence ("It's a culture that's still alive"), and substance abuse ("It impacts a lot of people's lives"). McClymonds Y-WAB members also participated in hands-on career development sessions – Daniela learned to operate cutting-edge ultrasound technology from a local woman doctor – and organized events drawing directly on student input. At Chamomile and Chill, a destressing event, teens ate locally sourced meals, spent time with therapy dogs, and learned about mental health resources available at school.

Daniela is passionate about the importance of mental health resources to a healthy high school environment. "Being able to release that emotion, that stress, that trauma, through a healthy alternative is so important. A lot of kids need that."



We felt like our voices were heard, like our leaders wanted to understand our perspectives and help us take action. It inspired me to keep going. – Daniela Gomez

## A Bright Future

This fall, Daniela left Oakland for Los Angeles to begin her freshman year at UCLA. She had all the typical questions – what the dorms are like, what it costs to live in LA. But she also spent the summer researching high school counseling programs near campus. She wants to build on her experience with Resilient Teens by becoming a student mentor.

"Y-WAB holds such a special place in my heart," she says. "We felt like our voices were heard, like our leaders wanted to understand our perspectives and help us take action. It made us feel like we mattered. It inspired me to keep going."

Daniela knows that without philanthropic support, Resilient Teens would still be a dream, and that the sustainability of the program rests on the continued generosity of donors and the commitment of dedicated people.

"Spaces like these are important everywhere," she says. "I want to create opportunities like Y-WAB for high schoolers where they don't exist. I want to carry this work forward."

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# How can integrative medicine make a powerful difference for our kids?

"Mary" was born prematurely, at 24 weeks gestation. Her parents couldn't hold her. Machines monitored her every breath. Her body struggled to regulate itself.

Massage therapist Marcia Degelman, CMT, first met Mary – whose name has been changed to protect her privacy – at 30 weeks. Right away, she noticed that the child seemed stressed and agitated. She reached into the incubator and held her hands above the infant's head and feet. She felt the baby calm. For two months, Degelman returned every week to provide a gentle massage. One year later, she met Mary again – a happy, healthy toddler who greeted her with a smile.

That's the power of integrative medicine, an innovative, donor-funded program offered through UCSF's new Stad Center for Pediatric Pain, Palliative, and Integrative Medicine. It's care that combines conventional medical treatments with complementary, evidence-based therapies such as massage, acupuncture, acupressure, hypnosis, nutrition therapy, and meditation – giving the most vulnerable patients a fighting chance at wellness.

Hear from our experts on what inspires them most about pediatric integrative care.

#### HYPNOSIS Stefan

## Friedrichsdorf, MD

Medical Director, UCSF Stad Center for Pediatric Pain, Palliative, and Integrative Medicine When people think of



hypnosis, they imagine I say a few magic words and snap my fingers and you give me all your chocolate.... That's not how it works. Hypnosis is an alternative state of awareness. Sometimes it's spontaneous, like when we study for a test or shoot a free throw. Sometimes it's guided, with the expressed, explicit purpose of reducing discomfort like headaches or nausea, coping with stress, or falling asleep more easily. I have had so many patients who, after hypnosis, feel for the first time that they can control a distressing symptom that medication hasn't helped.

# NUTRITION

Sanford Newmark, MD Medical Director, UCSF Osher Center for Integrative Medicine Ninety-five percent of my

patients have autism or

attention-deficit/hyperactivity disorder (ADHD), and I do a full integrative medicine consult with them. Nutrition is extremely important in these children. It can affect their symptoms dramatically. Kids with ADHD or autism might have nutritional deficiencies or be sensitive to certain foods that can make their symptoms worse. When you correct these things, you can change behavior. We see kids with ADHD becoming less hyperactive, more attentive, and better learners. We see children with autism improving their language and social skills. It is crucial that these children have a solid nutritional footing as a basis for other interventions.

## MASSAGE

#### Marcia Degelman, CMT

Massage Therapist, UCSF Stad Center for Pediatric Pain, Palliative, and Integrative Medicine



work with children. I see preemies, infants that have undergone heart surgeries, and kids preparing for bone marrow transplants. We have a lot of kids with pancreatitis, and I have developed a massage protocol specifically for this group. It helps the nervous system relax. That's primarily what I'm interested in – having people switch their nervous systems from fight-or-flight to rest-and-digest, because that's where healing takes place. For a baby, when they're less agitated, they're growing and healing. I want to provide that healing, loving touch for kids.

## ACUTHERAPY

## Robyn Adcock, DACM, MS, LAc

Director of Integrative Medicine, UCSF Stad Center for Pediatric Pain, Palliative, and Integrative Medicine



Almost any patient can benefit from acutherapy. Our resources are limited, though, so we can only provide services to those patients most in need. We see a lot of palliative care patients who have complex conditions or life-limiting diagnoses or who are facing end-of-life situations. We also see patients with pain or other symptoms that are not easily treated. I know how effective acutherapy is, and I'm still amazed by how much it helps. Even on the hardest days, after surgery or during chemo, kids will receive acupuncture and say, "I feel so much better. I feel calmer and more relaxed. I feel like me again."

# A Matter of Heart



Millie Tovar was five months pregnant, and she and her husband, Billy Kerr, were excited for their 20-week ultrasound: the "anatomy scan," when the baby's body would be examined from head to toe.

As the scan got underway, something seemed off. One doctor was called in, then another. Millie – a marketing specialist for UCSF Health – recognized their names and faces. "I thought, 'Oh, no, something's wrong,'" she recalls. "Eventually, they told us they were having trouble finding part of his heart."

Days later, the baby was diagnosed with hypoplastic left heart syndrome, a condition in which the left side of the heart – the part that pumps oxygenated blood to the rest of the body – is underdeveloped. At 32 weeks, genetic testing led to another diagnosis: KBG syndrome, a rare genetic disorder that can lead to physical differences, including heart defects.

These conditions would have profound implications for the baby and his parents. Millie would be induced at 39 weeks, and the newborn would immediately be taken to intensive care. He would face two open heart surgeries in his first six months of life. And Millie and Billy would navigate a complex medical journey for their infant son with providers from across the UCSF Benioff Children's Hospital system.

#### **Julian** at play

"It was wild," Millie says. "Even before he was born, we had this huge team of doctors, many of whom I knew. I remember one appointment, with our cardiologist, Dr. Nicole Cresalia, and about 10 other clinicians from cardiology, neurology, and intensive care. It was like a meeting of the minds. They walked us through everything."

## **A Team Effort**

Julian Kerr was born in November 2019. Seven days later, he underwent his first surgery, the Norwood procedure, performed by V. Mohan Reddy, MD. The procedure converts the heart's right ventricle into the primary engine for pumping blood throughout the body. The family spent the next six weeks getting to know each other in the cardiac intensive care unit. Little Julian recovered from the surgery, adjusted to his feeding tube, and began to flourish.

Two days before the new year, Julian was discharged. Under the guidance of Sarah Tabbutt, MD, PhD, Millie and Billy were equipped to monitor Julian's vital signs from home – thanks to the single ventricle home monitoring program, an innovative, donor-funded initiative that allows parents to care for their children at home in between corrective heart surgeries.

It was the home monitoring system that helped Millie and Billy identify a drop in Julian's oxygen levels two weeks later. They alerted Dr. Tabbutt, who performed a virtual checkup and recommended that Julian return to UCSF Benioff Children's Hospital San Francisco, where he remained for the next month.

In February 2020, just three months after his birth, Julian underwent his second surgery, the Glenn procedure, which diverts blood from the heart directly to the lungs. The surgery was a success. Millie and Billy were reeling but relieved.

"None of this is what we thought parenting was going to be like," says Millie. "But we had this incredible team with us every step of the way, and we've found ourselves in a good place."

#### **A New Perspective**

Julian is now nearly 3. He has regular appointments at UCSF to monitor his condition and determine when his next surgery will be. For now, he's focused on other, more pressing matters: moving his body, trying new foods, and growing day by day. "A proper toddler," Millie says.



Julian and his mother Millie

In the past year, Julian's development – despite the delays caused by his conditions – has taken off. A year ago, he could barely sit up. Today, he is crawling up stairs, pulling himself up to standing, and taking independent steps. He also loves music and sharks. "And he's really, really happy," Billy says. "He waves at everyone he sees."

For Millie, the experience has shed new light on her work at UCSF. "If you had asked me what was important to our patients before this, I would have told you something completely different," she says. "Now, I've sat in the waiting room. I've slept on our couches. I've eaten our food. I know what it's like. I know what our families need."

Millie recalls that during Julian's hospitalization, joy came in unexpected moments. Like when a music therapist played for Julian, and he was so soothed that for a few blissful moments, his discomfort just seemed to melt away. Or when a nurse helped Millie and Billy bathe Julian for the first time, and they enjoyed a precious new experience together, as a family.

Millie is also keenly aware of how crucial research is to her child's longevity, and the lives of so many other children like him. The surgeries Julian has undergone, and the home monitoring system that may have saved his life, were developed through research funded by philanthropy. And his prospects for the future may depend on discoveries and innovations that have yet to be uncovered.

"So many kids with Julian's condition end up needing a transplant, which may only extend their lives by a decade," Millie says. "That's just not a solution. I want Julian to have a full life, to have kids, to grow old. He's doing great now. But this is just the beginning."

# THE POWER OF PLAY

#### Chris Menezes has always loved games.

An East Bay native, Chris grew up with two working parents and spent a lot of time alone as a kid. He found comfort in video games on nights when his parents were working late. And games were also a way to make friends – some of whom remain central in his life to this day.

"Games brought me joy," Chris recalls. "When I was a kid, they helped me calm down and deal with stress. And they helped me connect with my friends emotionally. They have always been therapeutic for me."

Chris knew he wanted to pursue a career in games. He calls it his passion project. After landing a position with Electronic Arts (EA) directly out of college in 2010, Chris held positions at CrowdStar and Disney before returning to EA in 2017 as a development director for Maxis Studios, best known for creating the Sims franchise.

"I still have to pinch myself almost every day," Chris says. "Like, is this real? I get to make games for a living? It brings me so much joy to be able to make something that has a positive impact on people, just like it did for me when I was growing up."

So when Chris learned about Extra Life – a Children's Miracle Network Hospitals program that mobilizes gamers at all levels to raise funds for ill and injured children in their local communities – he knew he wanted to get involved. To date, Chris and his Maxis team have raised over \$48,000 for UCSF Benioff Children's Hospitals, all through gaming.

Extra Life gamers – either on their own or through company teams – can raise money year-round, culminating in a massive international day of play called Extra Life Game Day. Participants can play any kind of game they want – video games,



Chris at his home gaming station

board games, even outdoor games – and can integrate features like livestreaming to entertain their sponsors. Gamers at any level, from novice to seasoned, are welcome to join the fun and make a difference. All proceeds go directly to each gamer's children's hospital of choice. Since 2011, Extra Life has raised over \$4.4 million for UCSF Benioff Children's Hospitals.

While Chris doesn't have a personal connection to UCSF Benioff Children's Hospitals – he says the love of gaming and the mission to help kids are all the inspiration he needs – many of his sponsors do.

"I've had people at work come up to me and say, 'Hey, you know what? You're raising money for something that saved my kid's life. UCSF Benioff Children's Hospitals saved my kid's life.' And knowing that I have contributed to that is just amazing."

To learn how you can sign up for Extra Life, visit: give.ucsfbenioffchildrens.org/what-is-extra-life

# A Legacy of Love

Randie at 12

"

We feel so lucky

to have this

opportunity to

make a family's

life easier.

– Terve Levv

Terye says. "But my parents

carried on. That was when

they created the foundation."

"It was heartbreaking,"

In the wake of Randie's

death, Marilyn and Morton

established the Randie Lynn

Baruh Research Foundation

to advance pediatric cancer

themselves into fundraising,

tournaments, and throwing

galas that raised millions of

dollars for children's cancer

initiatives over the decades.

research. They threw

staging celebrity golf

Barry, Terye, and Randie Baruh had a happy childhood. Growing up in Atherton, Calif., in the 1950s and '60s, they enjoyed a doting, loving life with their parents, Marilyn and Morton.

Randie was the youngest child. She loved her family and friends and riding horses. Her siblings say she was beautiful, inside and out.

But at age 11, Randie began feeling ill. The initial diagnosis was mononucleosis; later, Randie underwent surgery to remove her spleen. During the surgery, doctors discovered the real cause of Randie's illness: leukemia, a common childhood cancer.

Marilyn and Morton were devastated. They decided not to tell the other children so Randie could enjoy some normalcy, even as her life was upended by hospital visits. "They told us she was anemic," says Barry. "They wanted us to treat her as if everything was normal. You know, fight with her when we needed to fight with her and love her when we needed to love her."

Randie died shortly after her 13th birthday. Marilyn and Morton told their older children the truth when they realized the end was near. Before he died, Morton dreamed of donating the remaining funds to a single cause to make a powerful difference for kids with cancer and find a permanent home for Randie's legacy.

Barry and Terve recently realized that dream. They donated the assets of their family's foundation to establish the Randie Lynn Baruh Pediatric Cancer Research Fund at UCSF Benioff Children's Hospitals. The fund will support innovative research into immunotherapy, cancer genetics, and relapsed leukemias. Today, the children's garden on the San Francisco campus – a space where children and families can rejuvenate outdoors – is named in Randie's memory.

"We were so impressed with what UCSF had to offer," says Terye, whose own daughter-inlaw had a lifesaving experience at UCSF. "It is such a fine hospital, with the best doctors and incredible research. We are so grateful for what they do."

Barry and Terye say that what their parents created in Randie's memory has been a gift – not only to children with cancer but also to them.

"We feel so lucky to have this opportunity to make a family's life easier," says Terye. "We just want to save as many children as we can."



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# SAVE THE DATE: **Giving Tuesday is November 29!**

Giving Tuesday inspires millions of people to give, collaborate, and celebrate generosity. This year, we want to raise funds to advance discoveries and innovations that will change our patients' lives forever. On any day between now and November 29, your gift will be matched dollar for dollar up to \$100,000 by our friends at OUTDOOR SUPPLY HARDWARE. Make your gift today at givingtogether.ucsf.edu/kids2022.

