

Packard Children's News

Fall 2024

Lucile Packard Foundation for Children's Health

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Overflowing With Thanks for You

THROUGHOUT THIS ISSUE of *Packard Children's News*, you'll find messages of gratitude from our patients and faculty—whose lives have been transformed by your support. I want to take a moment to share a few of them since they're truly meant for you, our donors.

- "We are so grateful for the garden and its impact during my daughter's battle with cancer." - Crystal, Zenaida's mom, about our hospital's gardens that offer natural spaces for play and reflection (see page 14)
- · "We both cried when we received the great news. That initial seed grant validated our plans and our dreams for what this technology could bring to kids." - Anesthesiologist Tom Caruso, MD, PhD, recalling how he and his cofounder felt when the Stanford Chariot Program received a grant from the Auxiliaries Endowment (see page 6)

Celebrating 25 years, the Auxiliaries Endowment has supported 125 programs, including #GoodforMEdia, which empowers young people to navigate social media in a safe and enjoyable way (learn more on page 8).

- "I'm extremely grateful to be where I am, to work with brilliant scientists to solve big problems." - Xiaojie Qiu, PhD, who came to Stanford to research a cure for congenital heart disease (see page 18)
- "She plays tennis, which she picked up from watching her grandpa. And she also models for my (clothing) brand. Seeing her do these incredible things means a lot." - Shubh, mom to Arya, 5, who underwent major surgery at our hospital when she was just 7 months old (see page 10)

Thank you for your support of Lucile Packard Children's Hospital, which ensures the very best care for children and advances only-at-Stanford research toward new discoveries. We are so grateful for your outsized impact!

With gratitude,

Cynthia J. Brandt, PhD President and Chief Executive Officer

Cyrche Former

Lucile Packard Foundation for Children's Health







In This Issue

In the News

Catch up on the latest headlines about child and maternal health.

A Gift That Gives Forever As the Auxiliaries Endowment turns 25, we celebrate its impact.

The 'ME' in Social MEdia Program elevates youth voices to address the good and bad of social media.

> On the Cover: At 2 weeks old, Arya was diagnosed with a rare genetic disease. Thanks to treatment she received at Lucile Packard Children's Hospital, she is home and thriving.

COVER PHOTO BY FRED GREAVES PHOTOGRAPHY

Meet Arya

She appreciates the small things after big surgery.

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Mapping the Human Heart, Cell by Cell

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Humans of Packard Children's

In the News

Catch up on the latest news and headlines about child and maternal health, Lucile Packard Children's Hospital Stanford, and the Stanford School of Medicine.



Summer Scamper Attracts Thousands, Raises Over \$660K

Thank you to the nearly 3,000 Scamper-ers who walked, ran, rolled, and sprinted across the finish line on Sunday, June 23, 2024! Together, we raised over \$660,000 for Lucile Packard Children's Hospital Stanford and the child and maternal health programs at the Stanford School of Medicine. Since 2011, Summer Scamper has raised more than \$6 million for children's health.

It was truly an event to remember! Summer Scamper was bursting with energy as we kicked off the 5k run, walk, and wheelchair race, and then the kids' fun run—every child received a medal! Meanwhile, the Family Festival offered a lively atmosphere with music, family-friendly activities, vendor booths, and food and drinks.

We're grateful to our Patient Heroes: Austen, 5 months, Santa Cruz; Armaneigh, 2, Modesto; Aiden, 12, East Palo Alto; Zenaida, 12, Hollister; Max, 13, Palo Alto; and siblings Alex, 7, Kate, 7, and Matthew, 9, Portola Valley. Making the day extra special, our Patient Heroes counted down the start of the 5k and joined us on the Festival Stage.

Special thanks to our presenting sponsor Gardner Capital and corporate sponsors: Altamont Capital Partners, Artemis Connection, C.M. Capital Foundation, The Clement Palo Alto, The Draper Foundation, Joseph J. Albanese Inc., Niagara Cares, Perkins Coie, Santa Clara Family Health Plan, Sheraton Palo Alto, Stanford Federal Credit Union, and The Westin Palo Alto.

And as always, Scamper wouldn't be possible without our amazing volunteers, including athletes from the Stanford University football and women's basketball teams.

We can't wait to see you next year!



Heart Transplant Recipient Celebrates 40 Years

Elizabeth "Lizzy" Craze recently celebrated an incredible milestone—40 years since her heart transplant at Stanford.

In 1984, only a handful of transplant centers were performing heart transplants on small children—and one of them was Stanford. "When Lizzy was transplanted, we really didn't know how long a child with a heart transplant could survive," says David Rosenthal, MD, pediatric cardiologist and the director of the Pediatric Advanced Cardiac Therapies (PACT) program at Stanford. Lizzy was the youngest heart transplant recipient at Stanford

In 1984, Lizzy was the youngest patient to receive a heart transplant at Stanford.

at the time and was expected to survive only five to 10 years.

But four decades later, Lizzy is still thriving on the same donor heart, and even running marathons. She's also—with the help of in vitro fertilization, surrogacy, and genetic testing at Stanford—a mother of a child without the heart condition that affected Lizzy and her siblings.

Welcoming First Chief Health Equity Officer to Stanford Children's

In July, Stanford Medicine Children's
Health welcomed Ndidi Unaka, MD,
MEd, as the inaugural chief health
equity officer. Unaka also joined the
Department of Pediatrics as a clinical
professor in the Division of Pediatric Hospital
Medicine at the Stanford School of Medicine.

In her new role, Unaka focuses on embedding health equity into every aspect of the organization. She leads efforts to enhance care delivery systems through an equity lens, improve patient experiences, and integrate inclusive health practices into operational frameworks.

Unaka joined Stanford Children's from Cincinnati Children's Hospital Medical Center. Unaka's leadership marks a pivotal step forward in Stanford Children's deep commitment to health equity.

Dr. Marc Melcher Named Chief of the Division of Abdominal Transplantation

Stanford Medicine recently appointed Marc Melcher, MD, PhD, the

appointed Marc Melcher, MD, PhD, the new chief of the Division of Abdominal Transplantation. He oversees all aspects of abdominal transplant programs, including liver, kidney, and small bowel transplantation at Stanford Medicine Children's Health.

Melcher follows Carlos O. Esquivel, MD, who was division chief for 26 years. Esquivel was an early advocate for offering liver transplants to sick children and will continue treating patients at Stanford Children's.

"I am honored to continue the growth of the program to provide comprehensive, patient-centered care to those who are waiting for a lifesaving transplant," says Melcher.

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In the News



Dr. Mitchell B. Cohen to Join Stanford Children's as Chief Medical Officer

In January 2025, Mitchell B. Cohen, MD, will join Stanford Medicine Children's Health as chief medical officer. He will also serve as senior associate dean for maternal and child health at the Stanford School of Medicine.

Cohen is an accomplished physicianscientist with an international reputation as an expert in pediatric digestive disorders.

Cohen hails from Children's of Alabama, where he currently serves as physician-in-chief. He is described by Lloyd Minor, MD, the *Carl and Elizabeth Naumann Dean of the School of Medicine* and vice president for medical affairs at Stanford, as a "visionary leader, dedicated mentor, and prolific physician-scientist."

Unwavering Commitment to Pediatric Care Once again, ranked in all specialties BEST CHILDREN'S HOSPITALS US.NEWS 18980841883 2024-2023

Packard Children's Named a Top Children's Hospital in the Nation

Lucile Packard Children's Hospital Stanford has been recognized once again in the *U.S. News & World Report* 2024–25 Best Children's Hospitals survey, published in October.

The rankings identify the top 50 pediatric facilities across the country, listing Packard Children's as a pediatric center that delivers high-quality care across multiple specialties and shapes the future of health care and medical research. The hospital is also tied for being the highest-ranking center in Northern California.

This marks the 20th consecutive year that our hospital has been celebrated for its exceptional care and patient outcomes. For the ninth consecutive year, Packard Children's has ranked in all pediatric specialties. Three of the hospital's specialties ranked in the top 10: neonatology (No. 5), nephrology (No. 7), and pulmonology (No. 10). The hospital also ranked in cancer, diabetes and endocrinology, gastroenterology and GI surgery, cardiology and heart surgery, neurology and neurosurgery, orthopedics, urology, and pediatric and adolescent behavioral health.

"To continue to be recognized as a top children's hospital is a testament to the excellence in specialty care that has come to define Lucile Packard Children's Hospital Stanford," says Paul A. King, president and CEO of Packard Children's Hospital.

New Board Members Join Lucile Packard Foundation for Children's Health

The Lucile Packard Foundation for Children's Health is pleased to announce two new board members: Mindy Rogers and Bill Thompson.

"I'm excited to bring Mindy back to our board and to welcome Bill, who joins us from Lucile Packard Children's Hospital's board," says Cynthia Brandt, president and CEO of the Foundation. "Both have shown extraordinary dedication to children's health care—in our community and beyond! We look forward to partnering with Mindy and Bill in using philanthropy as a lever to deliver the best possible health for kids and moms."

Rogers and Thompson were appointed at the September board meeting.



Mindy Rogers

Mindy Rogers began her career at Bain & Company, a top management consulting company. Later, she joined Wells Fargo Bank and held a variety of managerial positions. After leaving the bank, she became a consultant to Wells Fargo on a variety of issues.

Rogers volunteers with and is a leader for numerous nonprofit organizations. Currently, she is vice chair of the Stanford Health Care Board of Directors. In addition, Rogers serves on the boards of the Positive Coaching Alliance, LEMO Foundation, and East Palo Alto Academy Foundation. She is a former member of the Board of Trustees at Stanford University and the boards for Lucile Packard Children's Hospital Stanford and the Lucile Packard Foundation for Children's Health.

Rogers earned an undergraduate degree from Stanford University and an MBA from the Stanford Graduate School of Business.
Rogers and her husband, Jesse, have three children.



Bill Thompson

Bill Thompson has more than 20 years of institutional portfolio, risk management, and leadership experience.
As director of Institutional Consulting at Beacon Pointe Advisors, Thompson advises clients on strategic investment planning and portfolio construction. Prior to joining Beacon Pointe, Thompson led the business practice as director of the Endowments and Foundations Group at Litman Gregory Wealth Management.

Thompson earned a bachelor's degree from Denison University and an MBA from The University of Chicago Booth School of Business. Thompson previously served on the Board of Directors of Lucile Packard Children's Hospital Stanford, where he chaired the Audit, Compliance, and Enterprise Risk Committee.

Thompson currently serves on the board of Fit Kids, which focuses on children's physical and mental health. Thompson and his wife, Claire, have three children.

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Celebrating 25 Years of the Auxiliaries Endowment A gift that gives forever



By Julie Hannon

In 1999, the Auxiliaries Endowment was created with \$7 million in estate gifts from four members of the Association of the Auxiliaries for Children—a dedicated group of volunteers and supporters of Lucile Packard Children's Hospital Stanford.

Today, that visionary investment and six "sister funds" added over time have swelled to a combined \$34 million. Over the past 25 years, it has paid out a remarkable \$20.3 million in grants to 125 programs and services benefiting children, families, and care team members in nearly every corner of the hospital.

This endowed gift is carefully invested—and each year it generates about \$1 million in interest, which the Auxiliaries thoughtfully deploy to sustain crucial programs and seed inspiring new ideas. "It is working capital," says Susan Lamkin, Auxiliaries Endowment Committee chair, "and our true legacy to the hospital."

LPFCH.org

Lisa Cole, president of the Association of Auxiliaries, adds that "the Association of Auxiliaries receives grant proposals from dozens of hospital teams that total some \$3 million in support each year. While we can't fund everything, we've supported an incredible number of initiatives."

These include establishing a patient education program and virtual bedside visits for families with newborns in the Neonatal Intensive Care Unit; expanding the Packard Paws facility dog program; and purchasing critical equipment such as a portable CT scanner, wireless fetal monitors, and life-changing diabetes supplies for children and adolescents on public insurance.

Over time, the Auxiliaries established sister funds for the Teen Health Van, Social Services, Family **Guidance and Bereavement, Critical Clinical** Care, the Cleft and Craniofacial Center, and, most recently, the **Stanford Chariot Program**. The funds provide a reliable source of operating income for the programs totaling nearly \$335,000 annually. transformational gift we have ever received," says

A gift of \$5 million built the Auxiliaries Endowment Treatment Center Waiting Room. The project is the fund's largest award.

Six Sister Funds

"The creation of our endowment is the most Jon Bernstein, MD, PhD, medical director for the Cleft and Craniofacial Center.



Critical Gift at a Critical Moment

Designed to be both nimble and responsive to evolving needs, it's no surprise that the endowment was the source of the first significant gift to our hospital at the outset of the COVID-19 pandemic. The endowment committee answered the call for a second LightStrike Germ-Zapping Robot to add its ultraviolet disinfection capabilities to our hospital's extensive cleaning measures.

Milestone Books for the NICU

Endowment awards generally range from \$1,000 to \$200,000. They often have an outsized impact, such as a \$1,654 grant that helps nurses create keepsake books for families to celebrate milestones reached during a child's stay in the NICU. Big wins include coming off the ventilator, first day outside of the incubator, and first time being held.

Tomorrow's Cures

The endowment's very first gift in 2000 supported cystic fibrosis research. In 2021, research became a renewed priority with the support of a study designed to harness the power of CAR T-cell therapy, our greatest advance since chemotherapy in improving outcomes for kids with difficult-to-treat leukemia. With the 30 top pediatric oncology centers in the country participating, the study will help our experts identify strategies to further improve outcomes and analyze biomarkers.



Immersive Technology to Alleviate Pain and Anxiety

"We both cried when we received the great news," says anesthesiologist Tom Caruso, MD, PhD, recalling how he and his cofounder felt when the Stanford Chariot Program received the first of five endowment grants, the most awarded to a single program. The Chariot team develops immersive technology tools proven to calm young patients and reduce fear, anxiety, and the need for sedation and pain medication. "That initial seed grant validated our plans and our dreams for what this technology could bring to kids."

value of endowment and six sister funds

\$20.3M

awarded in grants

programs funded

Be part of this amazing legacy!

Contact Jeanne.Berube@LPFCH.org for more information.

The 'ME' in Social MEdia

Program elevates youth voices to address the good and bad of social media

By Jennifer Yuan



According to a Common Sense Media report in 2016.

23% of all tweens have their own social media account













Visit
goodformedia.org
to access these
resources for
youth and parents.

On a recent Friday afternoon, about 30 young people attended the first #GoodforMEdia Maker Day at allcove, an integrated youth health center in San Mateo. The event invited young people ages 13-22 to share their perspectives on healthy social media use.

In a time when 95% of teens have smartphones and 35% report using at least one of the top 5 apps constantly, the need for guidance is clear.

"Four years ago, the pandemic forced us all out of regular social spaces. We relied entirely on social media and virtual connection to have a semblance of community," says Emily Chan, a college student and cofounder of the #GoodforMEdia program.

The pandemic showed that social media can be a lifeline and a powerful tool for connection, support, entertainment, and inspiration. At the same time, it can harm mental health through overuse, unhealthy content, and unrealistic comparisons.

#GoodforMEdia launched in 2020 when youth leaders and adult allies—including Vicki Harrison, MSW, from the Stanford Center for Youth Mental Health and Wellbeing—came together to help teens and tweens learn how to navigate the virtual world in a safe, fun, and positive way. The capital "ME" in #GoodforMEdia underscores the importance of youth perspectives in addressing social media's complexities.

Rather than assuming a black-and-white stance that social media is all bad, #GoodforMEdia takes a more nuanced approach. The leadership team, ages 16-22, works with Stanford advisers to consider both positive and negative aspects of social media, drawing upon the young people's own experiences to model healthier interactions for their peers.

By Youth, for Youth

The #GoodforMEdia program focuses on peer mentoring and has expanded from there. Youth are experts in their own experiences and as avid social media users can often guide and influence peers more effectively than adults.

Their wisdom is also valuable to parents, teachers, and key decision makers. #GoodforMEdia youth leaders have participated in prominent forums like the White House Kids Online Health and Safety Task Force and IDEO's Play Lab, and advocated for policies like California's Age-Appropriate Design Code Act—bringing their young but experienced voices to Big Tech and lawmakers. "If you're designing a product that will be used by or affect youth, then you should engage youth," says youth adviser Khoa-Nathan Ngo, a college student.

The Maker Day (see images on opposite page) is just one of many ways teens can take part in #GoodforMEdia to share their strategies and foster open discussions about social media's inherent challenges. The program accepts blog posts, video testimonials, and ambassadors on a rolling basis.

"We can't make what's wrong with digital media right for young people without taking their suggestions and demands for accountability, privacy protections, and healthier product design," wrote Harrison and Anne Collier, MA, who along with Steven Adelsheim, MD, co-edited a new book, *Social Media and Youth Mental Health* (see opposite page). "Improving youth mental health means giving youth power, purpose, support, and the ability to influence their own futures."

#GoodforMEdia was launched with support from the Auxiliaries Endowment and the Responsible Technology Youth Power Fund.

Additional donor support can expand youth-developed resources, train more youth in peer mentoring, and bring youth voices to industry leaders and policymakers.

To learn more, contact Jennifer.Stameson@LPFCH.org.

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Enjoying an Active, Full Life

For a little girl who has already endured a lot, Arya is able to find joy in the little things in life, thanks to her Lucile Packard Children's Hospital Stanford care team.

"She plays tennis, which she picked up from watching her grandpa," Shubh says. "And she also models for my [clothing] brand called Dreamy Sunday. Seeing her do these incredible things means a lot."

Arya's life started with an emergency C-section at a Sacramento hospital about an hour away from her family's home in Yuba City. Shubh's pregnancy had been very difficult, but there weren't any significant signs that something was wrong until the third trimester. Shubh's amniotic fluid was measuring unusually high, necessitating the emergency delivery of her baby at 38 weeks.

As soon as Arya was born, the care team knew something was wrong, but they weren't sure of the underlying cause. Arya's lower jaw was severely underdeveloped, she had a cleft palate, and her airway was incredibly narrow. She was rushed to the hospital's neonatal intensive care unit, two floors away from her mother.

"The first two weeks of Arya's life we didn't have a diagnosis," Shubh recalls. The care team kept Arya on her stomach 24 hours a day so her tongue wouldn't slide back and block her airway. It was a stark beginning to parenthood for Shubh and her husband, Akash.

Then a geneticist delivered the news that would finally give the family some answers: Arya had auriculocondylar syndrome (ACS), a rare genetic condition that affects facial development, particularly the ears and lower jaw. The Sacramento doctors started proposing extensive surgical solutions that made Shubh and Akash uneasy.

The couple and their family dove into research and came across H. Peter Lorenz, MD, a craniofacial surgeon at Packard Children's Hospital.



A Call That Changed Everything

"We reached out to Dr. Lorenz via the website, and he called us back personally," Shubh recalls, reflecting on how calm and thoughtful the doctor was and how confident he was that he could help Arya. "We were in the car when we spoke to him, and by the time we were back up in the unit, everything was in motion. The Packard Children's Critical Care Transport Team was on their way to get Arya, and we were in Palo Alto that afternoon. It was just so smooth and a big relief."

"Arya's family was extraordinary. They asked good questions and were so brave. They had such trust in the team."

Elena Hopkins, RN, MS, CPNP

Two-week-old Arya's first stop was our NICU where she was stabilized and evaluated. Thankfully, Arya's condition was less severe than most other children with ACS, so the team didn't need to conduct a tracheostomy to provide an airway. But they did put together a plan for a mandibular distraction surgery to lengthen Arya's jaw so she could breathe and, eventually, eat more easily.

"What is so unique about Packard Children's is our multidisciplinary approach," explains Arya's nurse practitioner, Elena Hopkins, RN, MS, CPNP, program manager for the Cleft and Craniofacial Center. "We used imaging studies and a clinical exam to inform our cross-team conversation where we determined the timing and specific procedure that would lead to the best outcome for Arya."

To prepare, Lorenz and his team performed a virtual surgery, using CT scan images and computers to simulate the surgical process as well as the placement of hardware needed for movement of the jaw.

Ultimately, the discussions, review, and evaluation showed that Arya was too little and did not have enough bone for the surgery to be successful.

"We were blown away by their ability to learn so much from the virtual surgery," Shubh says. "Obviously, it was hard to hear that they couldn't proceed yet, but I am grateful they did their part as doctors and told us it wasn't the right time."

The care team trained Shubh to insert the nasogastric (NG) tube that would be used to feed Arya and sent the family home to Yuba City so Arya could be comfortable, gain weight and bone growth, and be prepared for a successful surgery when the time was right.

But the time at home was short-lived. Two weeks later, Arya contracted a virus and returned to the Packard Children's NICU. Her underdeveloped airway made respiratory infections even more dangerous, but the team helped her recover and be in a stronger place for the surgery to have the best outcome.

The Wait Was Over

Lorenz performed a mandibular distraction on Arya's lower jaw when she was 7 months old. The procedure entails affixing hardware that allows for the gradual expansion of the patient's jaw. "Arya's family was extraordinary," recalls Hopkins. "They asked good questions and were so brave. They had such trust in the team."

Following the surgery, Arya was in the hospital for three weeks before she was able to return home. Over the following year, she met with occupational therapists to help her learn how to talk and eat, and she underwent additional procedures to address hearing challenges. It was an exciting day when her NG tube was finally removed—to Shubh and Akash's delight, Arya loves to eat. She has developed a special passion for In-N-Out Burger fries and Panera Bread's macaroni and cheese.

"I told her once, 'You can't have macaroni and cheese every day,' "Shubh laughs. "She said, 'I cannot wait to be a grown up, because then I'll have my own car, and then I'll go to Panera every day and get mac and cheese.' "

Shubh is grateful for the hope and compassionate care that our hospital provided when she and her husband were overwhelmed new parents navigating their baby's difficult diagnosis.

Today Arya is 5. As she continues to grow, there will likely be more surgeries to address the effects of ACS, but today she is home and thriving. She plans to have a Trolls-themed 6th birthday party, loves watching *Moana* and *Frozen*, and is the apple of her parents' and grandparents' eyes.

Your donation this holiday season makes futures bright for children like Arya. Give today at **LPFCH.org/PCN** or by scanning the code.



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The Healing Power of Nature

Hospital gardens provide solace for patients and families

By Beth Tagawa Photos by Ana Homonnay

Dappled light on swaying leaves, bright blue sky peeking between trees, the scent of lavender, calming quiet. A dose of nature's serenity can be restorative, especially for families of children who need medical care.

> Zenaida has spent months in our hospital over the years while being treated for neuroblastoma. During her stays, she enjoys being surrounded by nature in our hospital's gardens.





he benefits of hospital gardens have been scientifically proven over the decades. Multiple studies have shown that access to nature speeds up the healing process for patients of all ages, particularly children.

Lucile Packard Children's Hospital Stanford's emphasis on nature is rooted in the visionary ideals of our founder, Lucile Salter Packard. She was an early adopter of the philosophy that nature benefits healing. In designing the hospital, she imagined a place where kids and families could receive holistic care, and where gardens were not just beautiful spaces but an essential component of the patient journey. Today, more than 3.5 acres of green spaces are easily accessible throughout the hospital.

And now, thanks to a generous gift from philanthropist Susan Ford Dorsey, the Atrium Garden will be reimagined as part of the original hospital building's transformation, creating a seamless indoor-outdoor space. Located in the West building, home to the Neonatal Intensive Care Unit and maternal health spaces, this revamped 5,000-square-foot garden will provide a tranquil haven for expectant parents and families navigating challenging times. Parents will be able to find a quiet refuge while staying close to their medically fragile children.

"It means so much to help provide a calming oasis for families facing some of the greatest challenges of their lives," says Ford Dorsey, chair of the Lucile Packard Foundation for Children's Health Board of Directors. "It's wonderful that the hospital makes access to nature a priority, and I am excited to partner in that commitment."

Among our hospital's other thoughtfully designed green spaces, the Dunlevie Garden, generously supported by donors Elizabeth and Bruce Dunlevie, features whimsical sculptures and winding pathways that invite exploration and imaginative play. Adjacent to this play area is the Healing Garden, which offers a

"The garden has...
become a sanctuary
where we've created
countless cherished
memories."

Crystal, Zenaida's mom

serene space for reflection and solace within the garden itself or as viewed from the Sanctuary. The Dawes Garden stands out with its sea-themed play area, as well as quieter areas to walk or sit.

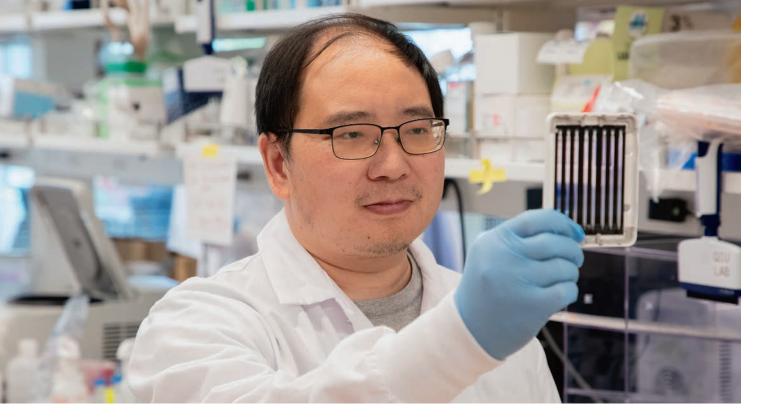
For many families, the influence of the hospital gardens is profound.

"We are so grateful for the garden and its impact during my daughter's battle with cancer," says Crystal, mom of 13-year-old Zenaida. "The ability to step out of the hospital room and breathe in fresh air was incredibly healing during her inpatient stays for chemotherapy."

Zenaida has been a patient at Packard Children's and received treatment for neuroblastoma for a number of years. The family has spent a lot of time in the gardens, holding picnics and giving Zenaida and her siblings a chance to play together.

"The garden has been more than just a place of respite; it has become a sanctuary where we've created countless cherished memories," Crystal adds. "It provided us with healing, inspiration, and strength, reinforcing our determination to keep moving forward despite the challenges."

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Mapping the Human Heart, Cell by Cell

Xiaojie Qiu, PhD, joins Stanford's bold initiative to cure congenital heart disease

By Beth Tagawa
Photos by Douglas Peck

Growing up in a remote town in rural China, Xiaojie Qiu's early life was defined by hardship. Qiu was just 10 years old when his father died in a work accident. He was sent to live with his grandparents, who had little means but prioritized his education.

"They were the best grandparents in the world," Qiu recalls. "They were not educated, but they valued the importance of education and supported me to pursue my dreams."

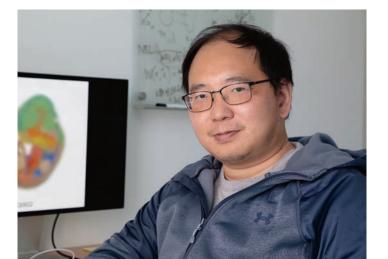
Qiu excelled academically, studying for as many as 16 hours a day and earning a spot at a top school in his region. His interest in science blossomed, and his academic journey took him to the United States, where his research garnered national attention, making the cover of the prestigious journal *Cell*.

In December 2023, Qiu came to Stanford, becoming the fourth team member of the Betty Irene Moore Children's Heart Center's Basic Science and Engineering (BASE) Initiative, a one-of-a-kind research program that aims to understand and ultimately cure congenital heart disease (CHD). BASE unites researchers from different scientific disciplines who partner on new approaches to tackle CHD, which affects 1 in every 100 babies in the U.S.

As an assistant professor of genetics and computer science, Qiu is using single-cell genomics and machine learning to tackle key challenges in heart research. Recent advancements allow for the study of millions of cells at once to help understand how organs form. But it's still impossible to know exactly where each cell is located within the organ and track cells over time. Qiu is pioneering approaches to overcome these obstacles and help researchers create a map—similar to Google Earth—that depicts where and when heart disease develops at a cellular level.

"When I started out, I knew that to understand heart disease, we would need to know when and where genes start to behave differently than they do in a healthy heart," Qiu says. "To get those answers would require studying millions of cells and thousands of genes per cell over time and space. My approach allows us to track genes expressed by individual cells

Xiaojie Qiu, PhD, leads a team of researchers working to make discoveries about the development of the human heart.



"As a 3D bioprinting engineer, I see Xiaojie's maps as instruction manuals for how to build a heart." Mark Skylar-Scott, PhD

for the first time, which will help us know which cells are associated with heart disease, and at precisely which point in the heart's development."

Qiu's research will provide the rest of the BASE team with sophisticated new insights to apply in their work.

Marlene Rabinovitch, MD, director of BASE and the *Dwight and Vera Dunlevie Professor of Pediatric Cardiology*, is thrilled by the knowledge Qiu brings. "Xiaojie is doing something that has never been done before," Rabinovitch says. "His unique expertise, and how it complements the work of the full BASE team, creates the potential to transform the field and change so many children's lives."

Fellow BASE scientist Mark Skylar-Scott, PhD, is excited by the potential of Qiu's research. "As a 3D bioprinting engineer, I see Xiaojie's maps as instruction manuals for how to build a heart," Skylar-Scott says. "His computational wizardry is a cornerstone to BASE's success."

Right now, Qiu is focused on applying his new technologies to create a 3D map of a mouse heart, as it develops from the early stages to a fully formed heart. He aims to do the same for a human embryo.

Qiu recently received a generous gift from philanthropists Pantas Sutardja and Ting Chuk to support this project. "We are excited to partner with Xiaojie on his pioneering work to unlock new understanding of congenital heart disease," say Sutardja and Chuk. "We look forward to celebrating what Xiaojie, and the entire BASE team, will accomplish in the coming years."

"I'm extremely grateful to be where I am, to work with brilliant scientists to solve big problems," Qiu says. "I'm thankful to my family for supporting me to get here, and proud to overcome obstacles and achieve my dreams."

Thank You Notes

Our donor community continues to surprise and inspire us by the many ways they support Lucile Packard Children's Hospital Stanford. Your dedication helps us transform health care for all kids and moms. We are endlessly grateful!



First Fellow in Pediatric Epilepsy Earns National Award

In 2015, longtime donor Judi Rees created an endowed fellowship in pediatric epilepsy in honor of her granddaughter Maggie. The endowment enables Lucile Packard Children's Hospital Stanford and the Stanford School of Medicine to train the next generation of pediatric specialists.

One such young investigator is Fiona Baumer, MD, who came to Stanford in 2015 for epilepsy training as the first *Maggie Adalyn Otto Fellow for Pediatric Epilepsy*. Baumer then joined the Stanford neurology faculty in 2016.

Recently, Baumer received the prestigious Philip R.
Dodge Young Investigator Award from the Child
Neurology Society, which is presented annually to one
accomplished early-stage investigator.

"Congratulations to Dr. Baumer!" says Judi. "I am thrilled to see these young researchers flourishing and contributing to epilepsy research nationwide."

Judi has further supported training by launching the Maggie Adalyn Otto Endowed Fellow in Pediatric

Palliative Care, in memory of Maggie. Endowed fellowships, like Judi's, are integral to our hospital, educating early-stage researchers so that they can solve pressing issues related to child health.

Thank you, Judi, for supporting our award-winning faculty at Stanford!



Fiona Baumer, MD



A Grateful Mom Gives Back to Support NICU Nurses

Nurses are at the heart of any neonatal intensive care unit. Laurel Lagenaur saw this firsthand when she developed preeclampsia at 28 weeks into her pregnancy and delivered her son, Alex, 6 1/2 weeks early at Lucile Packard Children's Hospital Stanford.

"I felt like the care that he received from the NICU was stellar," Laurel says. "When you have a 3-pound infant, you're naturally concerned. The nurses were just so calming and caring."

When Laurel took her son home, he weighed just 3 pounds, 11 ounces (above, right). Today, Alex is 27 years old (above, center) and preparing to defend his PhD thesis at Harvard University. He is an ultrarunner, having completed the Leadville 100, and multiple marathons, including the Boston Marathon three times.

"Clearly, he got a healthy start from the NICU," laughs Laurel.

Over the years, Laurel has gone above and beyond to express her gratitude. "I'm a big believer in continuing education," says Laurel. She makes annual donations from a donor-advised fund to support professional development for NICU nurses at Packard Children's Hospital. Laurel's gifts help train nurses to best utilize advancements that improve care for our hospital's most vulnerable patients.

In addition, Laurel enjoys hosting events to recognize nurses for their valuable contributions. Most recently, she held a dinner for our hospital's NICU nurses at The BottleShop in Redwood City. "They really enjoyed it," she says. "They clearly enjoyed each other's company and work well together."

Thank you, Laurel, for your commitment to supporting our hospital's NICU nurses!

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Thank You Notes





Granting Wishes and Bringing Joy to Children in the Hospital

Congratulations to Little Wishes for raising \$250,000 on their community fundraising page! Little Wishes created their fundraising page in 2017, and 100% of every dollar that's donated goes to granting the wishes of children at Lucile Packard Children's Hospital.

"Little Wishes has granted so many amazing wishes at Packard Children's, including celebrating important milestones spent in the hospital such as birthdays, graduations, and end of treatment, and even providing much needed comfort during end of life," says cofounder Laura Euphrat, RN, BSN.

One child at our hospital, Pierce (above), was nearing the end of his six months of inpatient treatment and told his mom, "I want to be strong for when I get out of the hospital." He requested a stationary bike that he could use in the hospital to build his strength. "We saw hope come into his eyes when he got his wish," his mom, Meredith, recalls. "He built up his strength, rang the bell, and celebrated his end of treatment."

Thank you to Little Wishes for lifting children's spirits while in the hospital, and to everyone who has contributed to their fundraiser.

Interested in supporting patients by granting their wishes? Donate to the Little Wishes fundraising page at LPFCH.org/LittleWishes.

Bringing Innovation to Kids and Expectant Moms

Each year, the FDA approves far fewer health technologies for use in children than adults. This disparity extends to pregnant moms as well. As a result, doctors don't have access to the latest innovations when caring for their youngest and most vulnerable patients.

We're thrilled that CobiCure, a nonprofit company that is part of the Advancium Health Network, is addressing this challenge in pediatric and maternal health. Following its mission to reimagine pediatric health care by supporting the development of innovative medical devices, CobiCure has generously funded a *MedTech: CobiCure Fellow for Pediatric MedTech Innovation* at Impact1. Part of the Stanford Mussallem Center for Biodesign, the Impact1 initiative is focused on advancing the development of health technologies for children and expectant moms.

The CobiCure fellow will perform market research, content design, prototyping, and testing to eventually bring a new medical device or technology to market.

"This fellow will not only improve clinical care for children and moms but will also help us grow the field of pediatric and maternal medical device innovation," says Janene H. Fuerch, MD, co-director of Impact1 and assistant director of the Biodesign Innovation Fellowship Program.

Thank you, CobiCure, for improving care for children and moms at Lucile Packard Children's Hospital Stanford and beyond!



Young Crafters Raise Over \$1K for Packard Children's Hospital

Thank you, Amelia Claire, Sana, and Rachel! Last school year, the girls, who attend The Harker School in San Jose, were required to perform a community service project. While brainstorming ideas for their project, they learned that Amelia Claire was born prematurely at 27 weeks and spent 60 days in the NICU at Lucile Packard Children's Hospital Stanford. They were touched by Amelia Claire's story and banded together to raise funds for our hospital.

The girls like to craft, so they decided to use their skills to create items to sell, with the proceeds benefiting our hospital. Amelia Claire made bracelets and drew a picture to make her own Valentine's Day cards. Sana made bracelets and crocheted pink octopus plushies. Rachel made necklaces and earrings and drew pictures that she turned into stickers.

After weeks of preparation, Amelia Claire, Sana, and Rachel sold their items outside The Thrift Box in San Jose, a resale store operated by the San Jose Auxiliary for Children. Next, the girls were overjoyed to learn that Netflix, where Sana's father works, would double their proceeds, resulting in \$1,050 raised for children and families at our nonprofit.

"The volunteers at The Thrift Box are lucky to have witnessed such amazing, promising, and forwardthinking young women share their good works," says San Jose Auxiliary member Chrisanne Beebe.





Grateful to Couple Who Gave Cuddles and Comfort to Babies

Husband and wife duo Pat Rice and Claire Fitzgerald volunteered for over 20 years as baby cuddlers in the NICU at Lucile Packard Children's Hospital Stanford. Claire brought a gentle touch like a grandmother to the babies she held, and Pat was known for singing soothing Irish tunes.

Claire, 89, passed away in May. Pat, 90, passed away in February 2023. The dedicated couple is fondly remembered by the physicians and nurses in the NICU.

"They were treated as critical members of the care team," says Maryellen Brady, director of volunteer services at Packard Children's Hospital. "NICU parents were so grateful that their babies received so much extra love and kindness."

Claire became a volunteer at Packard Children's because she was appreciative of the care her son had received when he was hospitalized at just 3 months old at the former Children's Hospital at Stanford. She started volunteering in patient relations, soon adding baby cuddling to her commitments and persuading her husband to join her.

"They loved working with everyone in the NICU because everyone who walked into the hospital for their job was there to help," says their granddaughter Ashlyn.

Claire and Pat are survived by Claire's children, Peter, Joan, Brian, Michael, and Dan; 11 grandchildren; and four great grandchildren.

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Humans of Packard Children's



Christine Tao, **2024 Hospital Hero**

Mikayla, 6, spent March through June 2023 in our Betty Irene Moore Children's Heart Center while she waited for a heart transplant. One comfort to Mikayla and her family was child life specialist Christine Tao, MS, CCLS. Tao was one of the few people who could soothe Mikayla during her procedures and the frequent dressing changes. Today, Mikayla is feeling great with her new heart, and Tao still goes out of her way to say "hi" to Mikayla when she returns for checkups.

"My patients and families are the most resilient and bravest cardiac warriors I've ever met. ... It's such an honor to be a part of their stories, to support them during some of their most vulnerable moments, and to celebrate alongside them in their victories."

Christine Tao, MS, CCLS, child life specialist in the Heart Center





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