Where Hope Soars

Bringing the very best science and care to kids

Inside: Small details matter on hospital’s top floor | Parents share how music heals
Welcome to the future of pediatric medicine!

In this issue, you’ll get an insider’s look at the newly opened fifth floor of Lucile Packard Children’s Hospital Stanford, where we bring the very best science and the very best care to children. On the fifth floor, the focus will be on cancer treatment, stem cell and gene therapies, and clinical trials. The treatments and cures that start here will save the lives of thousands of children—in our community and around the world.

Turn the pages to meet two children who are happy and healthy thanks to the revolutionary care they received at Packard Children’s. We’ll also introduce you to some of the physician-scientists who are working to cure diseases and make the impossible possible.

This is an exciting time, and we’re just getting started! Philanthropy plays an essential role in propelling this life-saving work forward. We hope you feel proud of how far we have come together and are inspired for the journey ahead.

With gratitude,

Cynthia J. Brandt, PhD
President and Chief Executive Officer
Lucile Packard Foundation for Children’s Health

We are grateful to the many donors who have supported our hospital and made this groundbreaking work possible. Many of the patients and families who come here have been told that there’s no hope or that they have tried every treatment. But here, we’ll give them hope. With your continued support, we will make the impossible possible.
It’s fitting that the top floor of Lucile Packard Children’s Hospital Stanford offers cures that seemed pie in the sky only a few years ago.

Then at age 8, he developed angioimmunoblastic T-cell lymphoma, a little-known cancer never before seen in a child.

“It was so rare, there was literally no data on it. We feel lucky to live near world-class doctors who could handle Peter’s complicated medical issues,” says Katharine Hanson, Peter’s mom.

**Transplant defies the odds**

Standard cancer treatments were not working on Peter’s lymphoma, so he was referred to Kenneth Weinberg, MD, Anne T. and Robert M. Bass Professor in Pediatric Blood Diseases. As Peter’s case was incredibly complex, Weinberg thought Alice Bertaina, MD, PhD, who is developing a revolutionary strategy to create compatible donor stem cells for patients who don’t have a strong enough match, could help. Bertaina is improving upon a form of stem cell transplants, called haplo-identical stem cell transplants. They’re special
Peter shares a moment with his care team while going through his stem cell transplant. In early studies, Bertaina safely cured 90 percent of children with nonmalignant diseases and nearly 70 percent of children with leukemia. She has performed transplants on over 400 patients using this technique in clinical trials. Next, she hopes to modify the process to further reduce the risk of graft-versus-host disease—a condition where donor cells attack a patient’s cells. She’s also taking what she calls a sophisticated approach to reducing the risk of infections and leukemia relapse after transplantation.

Peter’s stem cell transplant was extra challenging for Bertaina because he was one of only a few people in the world with a transplanted heart to receive a stem cell transplant. She ran the risk of Peter’s heart rejecting his new stem cells and failing. That’s why they first tried an autologous transplant using Peter’s own blood-forming stem cells. It seemed to work for a year, and then it failed. They had only one more option—the haplo-identical stem cell transplant. To lessen the risk that his heart would reject it, Bertaina removed T-cells from Katharine’s donor blood—standard for haplo-identical transplants—and then worked with a pharmaceutical company to develop a special drug to essentially turn off the transplant if things went wrong. Luckily, they didn’t.

“The stem cell transplant was by far the best treatment he received. It allowed him to feel well most of the time and be a regular kid,” Katharine says. Today—two years later—Peter is a typical sophomore in high school who enjoys playing video games with friends, practicing driving in parking lots, excelling at school, and thinking about his future. This past summer he attended an EXPLO Medical Rounds camp at Wellesley College, which strengthened his interest in medicine as a career. He attends Menlo School in Atherton, where his parents are history teachers.

For Peter, the highlight of the stem cell transplant is that he doesn’t have to go to the hospital regularly anymore, even though he’s grateful for the incredible care he received.

“The best part of my transplant hospitalization was when I was visited by my friends—and by players from the San Francisco 49ers,” says Peter.

The new fifth floor gives Bertaina and others space to increase the number of stem cell transplants performed—saving even more children like Peter.

“Read more about the fifth floor >>

“Peter shares a moment with his care team while going through his stem cell transplant.

Peter likes spending time with his family and making new friends.

Clockwise, from top left: Peter enjoying a visit from the San Francisco 49ers; Peter with his mom, Katharine, who has been very involved in his care; Peter goofing around with his siblings.
A life free of transfusions

Meet 4-year-old Miya Nguyen, a vivacious little girl born with alpha thalassemia, a rare genetic blood disorder that often results in miscarriage. Her parents, Cindy and Tony, already had two sons, but they really wanted a third child. They’d tried for years to conceive, with two pregnancies failing due to alpha thalassemia. Then, after giving up, Cindy got pregnant with Miya.

Cindy works as a patient service representative at Palo Alto Medical Foundation (PAMF), and Tony is a deep-sea fisherman. During her pregnancy, Cindy saw a maternal-fetal medicine specialist with PAMF who ran tests and confirmed that Miya also had alpha thalassemia, but at the same time told Cindy about cutting-edge intrauterine blood transfusions that could help the baby reach full term. Cindy had several transfusions and delivered Miya at 32 weeks.

Shortly after birth, Miya was transferred to Packard Children’s neonatal intensive care unit for lung support, and she stayed for a month. After discharge, Miya returned regularly to get blood transfusions for her alpha thalassemia.

The best treatment for most thalassemias is a bone marrow transplant—a type of stem cell transplant in which donor blood cells are harvested from bone marrow rather than from blood. To receive the transplant, Miya needed to first grow stronger. That time came when she was 9 months old. Luckily, Miya’s oldest brother, Anthony, was a full donor match.

In preparation for the transplant, Miya received chemotherapy to make room in her bone marrow for the new cells and to suppress her immune system to prevent rejection. Following the transplant, she stayed at Packard Children’s for several months to manage her post-transplant complications.

“We were so relieved that the bone marrow transplant was successful. Today, Miya is off all medications, and we only go back once a year for a checkup to make sure she hasn’t relapsed. So far, there are no signs of the alpha thalassemia,” says Cindy. “I am so thankful for everyone at Packard Children’s who helped us. It’s the only place we could get that kind of care.”

She describes Miya as a cheerful, playful girly-girl who loves to wear pink, sing, and dance. She has a little tomboy in her though—probably from her father—because she also loves to fish. “She caught a fish on her first try. Maybe that’s why she likes it so much,” Cindy says. “That, and I got her a little princess fishing pole.”

In addition to alpha thalassemia, stem cell transplants are being used to treat other rare genetic diseases, including IPEX syndrome, severe combined immunodeficiency—made famous by the “bubble boy” story—and a life-threatening multisystem disorder called Schimke immuno-osseous dysplasia, among others. There is potential to apply this treatment to many more diseases.

“I am so thankful for everyone at Packard Children’s who helped us. It’s the only place we could get that kind of care.”

CINDY NGUYEN, Miya’s mom

Read more about the fifth floor >>
The fifth floor redefines revolutionary care

The new fifth floor is a space dedicated to discovery. The 65,000-square-foot floor has 49 beds and empowers Packard Children’s to treat almost twice as many children with cancer and blood and genetic diseases each year. One half—in the south tower—offers innovative research and pioneering therapies to children receiving stem cell transplants and gene therapies, often in clinical trials with the Center for Definitive and Curative Medicine.

The north tower’s fifth floor houses the innovative Bass Center for Childhood Cancer and Blood Diseases, which uses decades of experience and the newest science to treat children with cancer and blood diseases like sickle cell, hemophilia, and more. Several clinical trials using the latest cancer therapies are taking place now, with many more in the pipeline.

One of the most promising treatments already in use on the fifth floor for certain types of cancer is immunotherapy. Chimeric antigen receptor (CAR) T-cell therapy is a type of immunotherapy that uses the body’s own immune system to fight cancer, reducing the need for chemotherapy and radiation.

Donors are making cures possible

The life-saving research and compassionate care taking place on the fifth floor and throughout Packard Children’s would not be possible without the community’s generous support. You have helped create this amazing place.

When the hospital was first designed, the fifth floor was a shelled space set aside for a future, somewhat nebulous need. But that need came quickly into focus as unprecedented discoveries in stem cell transplantation, cancer immunotherapy, gene therapy, and clinical trials showed us the future of pediatric medicine.

Donors have rallied behind this incredible work, making what once felt impossible possible. Among the gifts is a significant donation from the David and Lucile Packard Foundation to build out the fifth floor. Many others have believed in the power and potential of this work, including longtime supporters Anne and Robert Bass.

The fifth floor is the place where world-renowned experts gather to bring unique research and state-of-the-art care to give children like Peter and Miya the best chance at healthy childhoods. The sky’s the limit for the possibilities it holds.

Meet some of the world-renowned experts who call the fifth floor their new home.

Crystal Mackall, MD, is a leader in immuno-oncology and director of the Stanford Center for Cancer Cell Therapy. She specializes in cancer immunotherapy, endowing a child’s immune system with “superpowers” to recognize and kill cancer cells.

Matthew Porteus, MD, PhD, is developing an innovative gene-editing system that has the potential to cure sickle cell disease and could one day be applied to cure many other genetic diseases.

Michelle Monje, MD, PhD, is pioneering three new treatments for malignant gliomas, such as DIPG, the deadliest form of pediatric brain cancer, and taking them to clinical trials.

Kara Davis, DO, is looking into the leukemia cells that indicate whether a patient might relapse, with the goal to develop therapies and tools for easy and effective diagnoses in the clinic—and prevent relapsed leukemia altogether.

Robbie Majzner, MD, is bringing a new immunotherapy for neuroblastoma, sarcomas, and brain tumors to clinical trial soon. If clinical trials succeed, a commercially viable treatment would be likely—and more children could be helped.

Tony Oro, MD, PhD, and his team are using gene editing along with stem cell technology to treat a devastating skin disease, called epidermolysis bullosa, and possibly other genetic diseases.

Alice Bertaina, MD, PhD, is using a revolutionary strategy to transplant stem cells from donors with partial compatibility, with the goal of making stem cell transplants accessible to everyone in need.
Andrew’s Song

BY ESTHER AND DAN LEVY, PARENTS

From our first week with Andrew in the hospital in December 2014, we have dreamt of having a music therapy program that would bring moments of joy to the children and families dealing with the unthinkable at Lucile Packard Children’s Hospital Stanford.

IN 2014, we walked into the emergency room not knowing why our 14-month-old “Awesome Andrew”—the best third child ever—was pale and weak. A few hours later, we first heard the word “cancer,” and a few days after that, we heard his specific diagnosis: acute megakaryoblastic leukemia. For the next 100 days, Esther lived at the hospital with Andrew, spending most of that time in isolation while he received chemotherapy and a bone marrow transplant from his brother.

From the earliest moments, music soothed Andrew. Whether it was a song on the iPad during a blood draw or a dance with his mom during late-night nurses’ rounds, music filled Andrew’s room. And it filled his heart through those long days at the hospital as he battled the cancer; his magical months at preschool when he went into remission; the lows of hospice care after the cancer came back; and all the moments in between. We lost Andrew in late 2016 (shortly after his third birthday), but his music lives on and is louder than ever.

A few months after we lost Andrew, we made our first donation to the hospital with the support of more than 500 of “Andrew’s friends.” At the time, music therapy was a dream. Just three years later, there are three music therapists. To go from nothing to three full-time music therapists (and hopefully more!) in just three years is beyond what we ever imagined.

We return to the hospital often to see—and hear!—the progress. Last summer, we joined a music therapy group in the oncology unit where Andrew spent those 100 days. We were crying again . . . in amazement.

We sat in small school chairs. The kids in this group wore masks and had IVs coming out of their arms. Esther played the triangle. Dan beat a small drum. Rebekah, the music therapist, led the music on the fifth floor

One family shares their little boy’s love of music to help comfort other children with cancer.
children in playing songs they learned and songs they wrote. The notes drifted across the unit, overpowering the beeping of machines and pagers.

Nurses and doctors stopped to join. One of Andrew’s former oncologists saw us, went back to his office to get his ukulele, and joined the session. He is learning to play the instrument in lessons from the music therapist with the kids. We were in awe.

The sad, dark, and dreary sitting room that we remembered was now the setting for a spirited group jam session. Nurses walked down the hallway and started dancing. The kids moved as best as their wires and energy levels allowed. A little girl who appeared to be 5 or 6 years old sang a song she wrote about what it is like to live at the hospital. Our bodies leaned forward to hear her small voice from behind her mask. Rebekah understood every word and encouraged her to finish the song, even though she was feeling quite shy. A few minutes later, the girl had to abruptly leave the room as her chemotherapy nausea crept back in.

This is not just a feel-good story.

While so much is done for kids’ bodies, it is also important to take care of their minds and their spirits. In one-on-one or group settings, music therapists help patients find ways to express their fears and anxieties and give children joy during their most difficult moments. Music therapy improves kids’ outlooks and moods while hospitalized. As parents who lived in the hospital, we know that when kids get to feel like kids, their bodies react better.

Doctors discover new insights about their patients from the music therapists because kids open up to the therapists about their physical and emotional feelings in conversations and in their song lyrics.

Music therapists support children on their way into procedures and help them through painful treatments. They give them a language to express their loneliness to their parents, who sometimes must leave their children to work. We have also heard that families are requesting music therapists to comfort a child who is near death.

On what would have been Andrew’s sixth birthday, and just two years after the music therapy program started, we announced that our family would be endowing the Andrew M. Levy Music Therapist position for oncology based on the new fifth floor of Packard Children’s. This guarantees that children with cancer will receive music therapy at the hospital in perpetuity (forever)!

Our family is committed financially, and spiritually, to doing whatever we can to ensure this program continues to thrive. It is so critically important that kids at our hospital are not just looked at as patients, but also as children who deserve moments of joy. They should be given opportunities to experience childhood—even from a sterile hospital room while attached to cords and receiving chemo.

Today, you can join us in spreading music therapy to children in our hospital by helping to expand the funding and programming for music therapy. We hope to grow the music therapy program to at least five music therapists in the years to come. The more music therapists we have, the more profound the impact music will have on the hospital experience for our patients and their families. Our goal is to fill every floor, from the ground floor entry to the new fifth floor oncology and stem cell units, with song.

And that’s what every child deserves—not just music from an iPad but from instructors, providing the chance to forget where they are for a few moments every day.

Thank you!

YOU CAN HELP

Spread music therapy to more children in our hospital at supportLPCH.org/MusicTherapy

With donor support, music therapists could be hired to bring comfort to children on every hospital floor.
Every day, donors like you make gifts of all sizes to build a healthier future for children and expectant mothers. Your support makes our hospital a special place for our patients and families, and we are tremendously grateful.

Association of Auxiliaries Endowment Gives $1 Million to Grantees

IN APRIL, the Association of Auxiliaries for Children held its annual Celebration Luncheon where it commemorated 100 years of service, announced its 2019 Special Project, Caring for Hearts, and highlighted the Auxiliaries Endowment. The Endowment was formed in 1999 to expand the Auxiliaries’ legacy and build on their commitment to help children receiving care at Packard Children’s. Contributions to the endowment are made in various ways—primarily through the estate plans of Auxiliaries members and their families. The Association of Auxiliaries Endowment awards roughly $1 million annually to programs benefiting children and their families at our hospital. This year, the Association of Auxiliaries for Children received a record number of proposals and chose to fund the Harvey Cohen Endowed Fund (to support critical clinical programs); the Center for Professional Excellence and Inquiry (for the Revive Initiative for Resuscitation Excellence: Mannequin Training Program); the Endocrinology Department (for continuous glucose monitors); the neonatal intensive care unit and intermediate care nurseries (for bedside cameras); the Pediatric Anesthesia Department (for the nitrous oxide sedation program as well as an expansion of the Chariot Program); and Pediatric Surgery (for an e-health initiative).

Thank you, Auxiliaries Endowment donors, for your support!

Partnering to Find a Treatment for ALD

WHEN BEN LEENAIL WAS DIAGNOSED with a debilitating neurological disorder, he learned that it’s typical for people in similar situations to make one of two choices: create a bucket list of all the things they want to do before they die, or use their diagnosis to help others, turning it into something powerful and meaningful. We’re humbled and deeply grateful that Ben chose to partner with a Stanford researcher to accomplish the latter.

First, the entrepreneur, angel investor, and business mentor immersed himself in medical texts to learn as much as he could about his condition, adrenoleukodystrophy (ALD), which affects 1 in 15,000 people—mostly boys and men. When diagnosed in young boys, the disease usually leads to death within five years. Ben has a different type of ALD that doesn’t develop until men are in their 20s and 30s and progresses more slowly.

“He was always online. He kept an eagle eye out for anything that might be helpful,” says his wife, Laurie Yoler.

Ben connected with Keith Van Haren, MD, an assistant professor of neurology at Stanford University School of Medicine and a national leader in ALD research. Van Haren’s research is focused on the effect of early vitamin D exposure on ALD and other neurodegenerative diseases. His early findings show that vitamin D, when given to babies, reduces the risk of developing a common type of ALD.

“When Keith described the research around vitamin D that he was trying to do, we were excited. We felt like we could make a difference,” says Laurie.

Ben and Laurie pledged more than $300,000 in support of Van Haren’s lab and last June hosted a dinner at their Palo Alto home that raised nearly $100,000. With matching support from the Taube Pediatric Neurodegenerative Disease Research Fund launched at Stanford, their philanthropy will hire the first postdoctoral fellow focused solely on vitamin D research. The fellow will join the lab’s small team of researchers and medical students.

“It buys time and talent to move the lab forward,” says Van Haren, who hopes to expand clinical trials to determine the efficacy of vitamin D as a treatment for ALD.

Thank you to Ben and Laurie and their family for advancing ALD research!

Talented Kids Raise More Than $10,000 for Cancer Research

OVER THE SUMMER, Aeshaan Singhal hosted two fun and magical talent shows to raise money for pediatric cancer research at Stanford University School of Medicine. In its fourth year, the Bye-Bye Cancer Talent Show has raised more than $10,000. Even more remarkable is that Aeshaan is just 10 years old and that the show’s talented stars are as young as 5.

Aeshaan played classical guitar, and other kids joined in singing, dancing, and performing martial arts for fans at Santana Row and Stanford Shopping Center.

“I love how the kids are coming together and volunteering to help other kids who need help. I can’t believe we have raised $10,000!” says Aeshaan.

“I hope with this money a few kids can beat cancer completely.”

Thank you, Aeshaan and friends, for helping children and families at Packard Children’s with your talents! Special thanks to their families and friends who supported their efforts with generous donations.

Star One Credit Union Gives $20,000 to Celebrate Parents of Sick Children

THANK YOU to Star One Credit Union for the generous gift of $20,000 to bring special Mother’s Day and Father’s Day parties to Lucile Packard Children’s Hospital Stanford this year. These celebrations provided a sense of normalcy for patient caregivers and created memories to last a lifetime.

More than 120 guests enjoyed the Mother’s Day celebration, which featured a coffee cart, breakfast treats, flowers, and crafts. For Father’s Day, a coffee cart, plenty of bacon, fresh donuts, and lawn games delighted more than 100 dads.

We could not be more grateful to Star One Credit Union for bringing joy to the parents and guardians who tirelessly care for their sick children.
Thank You NOTES

Lin and James French Embrace the Hospital Prom

WHAT DO the African jungle, enchanted ski, and French Versailles all have in common? They’ve been themes at the Hospital Prom, which is one of the most anticipated events of the year. And it wouldn’t be possible without the generous support of Lin and James French. The couple has supported the event since it started 15 years ago. Prom has grown bigger every year, and now hundreds of current and former patients of all ages and their families enjoy an evening filled with carnival games, costumes, face painting, dancing, and more.

Lin also volunteers in the Hospital School, spending most of her time with kindergarten through fifth-graders and visiting children who cannot leave their rooms. The Hospital School is part of the Palo Alto Unified School District and ensures that kids don’t fall behind in their studies during hospitalization. It also provides a sense of normalcy, giving school-age children a familiar and reassuring routine in an unfamiliar setting.

Lin became active with the Hospital School when she decided to retire from teaching and contacted the hospital to learn about volunteering. It was a perfect match. “It has been wonderful,” Lin says. “It is a great group of teachers.”

Lin and James, we appreciate all you do for our patients and pupils!

Sterlings Help Families with Neurofibromatosis

IN 2018, Marcia and Nat Sterling searched for a support group for family members of children with neurofibromatosis (NF), a genetic condition that causes tumors to form on nerve tissue. However, they couldn’t find one in the Bay Area. Their granddaughter, now age 4, had just been diagnosed with NF, and they wanted to connect with other families.

The couple’s search led them to Packard Children’s, where they met Cynthia Campen, MD, clinical associate professor of neurology and neurological sciences, and co-director of the pediatric NF clinic. Campen expressed the need for an NF support group, and the Sterlings quickly obliged.

The new NF Support Group meets quarterly at Stanford. Parents, grandparents, friends, and family of children who have been diagnosed with NF are welcome.

“We would like to create some kind of continuous core group of folks really committed to serving as a resource to parents who may be scared or exhausted,” says Marcia.

In addition, the couple supports NF research as Circles of Leadership donors, giving $1,000 or more annually to our hospital.

Thank you, Marcia and Nat, for all that you do for our hospital and patients with NF!

For more information about the NF Support Group, visit supportLPCH.org/NFGroup.

Cheungs Provide Model-Building Kits to Help Kids Create While in the Hospital

WE’RE GRATEFUL to donors Sandy and Harry Cheung for their ongoing gift of model-building kits to the Child Life and Creative Arts Department at Lucile Packard Children’s Hospital Stanford. The Gundam model kits are used in therapeutic play with patients to reduce stress and help children and their families cope positively with hospitalization and illness.

The Cheungs became interested in the globally popular model kits because they were excited to try a new hands-on activity with their own children. After seeing how much their children enjoyed the kits, they were kind enough to think of patients in our care.

“In this ever-increasingly digital world, we see fewer and fewer opportunities for kids to work with their hands and build something,” says Harry. “These fantasy- or science-fiction-based model kits are a great way to engage kids in an activity that speaks to their imagination. We’re happy to be working with Packard Children’s to enable their patients to just be kids.”

Beyond the joy and pride that comes from building a model, the Child Life team discovered that the intricacy of the kits allows for therapists to spend more time at a patient’s bedside and create a deeper connection.

“When playing, children are more likely to talk openly about their feelings,” says Susan Kinnebrew, MHA, CCLS, director of Child Life and Creative Arts. “The feedback from my team has been overwhelmingly positive.”

Thank you, Sandy and Harry, for giving our patients a fun and creative way to relieve stress and express their feelings!

Hyundai Hope On Wheels Supports Cancer Researchers

IN SEPTEMBER, Hyundai Hope On Wheels awarded Lucile Packard Children’s Hospital Stanford $500,000 to fund groundbreaking cancer research. Hyundai Motor America has been a significant supporter of our hospital for 15 years through its Hyundai Hope On Wheels program. Hyundai’s recent grants mark $2.5 million in donations to Packard Children’s.

This year, Hyundai Hope On Wheels gave grants to Sneha Ramakrishna and Bertaina in our hospital’s Dawes Garden during a Hyundai Hope On Wheels Handprint Ceremony.

Patients were invited to dip their hands in paint and place their handprints on a white Hyundai Santa Fe. The handprints represent the individual and collective journey, hopes, and dreams of pediatric cancer patients. Thank you, Hyundai, for funding research that is helping save the lives of children in the Bay Area and beyond!
Autism Therapy When Used by Parents Helps Kids Speak

A NEW STANFORD STUDY in children with autism showed the value of teaching parents how to use everyday interactions to motivate their children to speak. The study is the world’s largest controlled trial of an autism therapy called pivotal response treatment (PRT). The therapy works by tapping into kids’ own motivations, says pediatric psychologist and autism expert Grace Gengoux, PhD, who led the study. “Children with autism often don’t make spontaneous social connections, which makes it harder for them to learn to speak. PRT teaches parents a concrete technique that takes advantage of their child’s interests—for instance, in a specific toy—to get them speaking.”

Heidi Pim of Palo Alto participated in the study with her son, James, who was diagnosed with autism and speech delays as a toddler. “I was really worried and anxious not knowing if he would ever be able to talk,” Heidi says. She was impressed by the changes she saw in James, who was 3 at the time of the study. “I feel so grateful now to see how many words and phrases he knows. He’s able to speak clearly and socialize as well, to go up to people and ask them questions.”

Formerly Conjoined Twins Start Kindergarten

IN 2016, CONJOINED TWINS ERIKA AND EVA SANDOVAL underwent separation surgery at Lucile Packard Children’s Hospital Stanford. The toddlers had a 70 percent chance of survival and a prognosis with unknowns. This fall, the girls celebrated their fifth birthdays and started kindergarten.

“He was beloved by the hospital community for his steady leadership, warm and humble nature, passionate advocacy for children’s health, and ability to listen to those around him as he implemented bold initiatives to build an outstanding enterprise.”

When asked in a 2018 interview what he saw as his legacy, he said, “I am very proud of the work we do for children and pregnant women. Collectively, we have created an organization that is admired nationally and is a place that attracts great faculty and staff. We have a terrific future.”

Dawes retired in 2018 after nearly three decades with Packard Children’s.
**In the NEWS**

**Stranger Saves Young Patient Thanks to Social Media**

**KALEB PERRY** has prune belly syndrome, a rare condition that is characterized by missing or severely weak abdominal muscles and problems with the kidneys and bladder. Doctors at Packard Children's performed fetal intervention on Kaleb’s mother, Mandy, conducting five in utero surgeries throughout her pregnancy to drain Kaleb’s bladder. Shortly after Kaleb’s first birthday, his parents learned that his kidneys were declining rapidly and that he may need dialysis. When his parents were told that they were not matches to donate a kidney to their son, they turned to the Facebook group that Mandy maintained to share updates with friends and family about Kaleb’s condition. She asked followers to consider getting tested literally give a part of themself to someone to just give him life,” Kaleb’s dad, Kevin, told NBC.

Within a month, Mandy received this message from Susie LeRoy, whom she had never met: “It looks like I’m going to be a good match for Kaleb.” On May 28, Kaleb and Susie underwent surgery at Stanford to remove the kidney from Susie and place it in Kaleb. Susie was able to return home a few days later, and Kaleb was discharged from the hospital a few weeks after the transplant.

Today, Kaleb is a thriving and energetic toddler and gets together frequently with Susie’s family in the Fresno area, where they both reside. “It’s just so surreal that this all happened and that someone would literally give a part of themselves to someone to just give him life,” Kaleb’s mom, Mandy, told NBC.

“Once these clinical symptoms appear, irreparable harm to the mother or the fetus may have already occurred,” says Stanford immunologist Brice Gaudilliere, MD, PhD. “The only available diagnostic blood test for preeclampsia is a proteomic test that measures a ratio of two proteins. While this test is good at ruling out preeclampsia once clinical symptoms have occurred, it has a poor positive predictive value.”

The team analyzed blood samples from women at various intervals during their pregnancies. They identified a set of eight immune cell responses that accurately predicted which of the women would develop preeclampsia—typically 13 weeks before clinical diagnosis. Although their results are encouraging, more research is needed before translating them to the clinic.

New Outpatient Cardiac Care Clinic Opens

**THE BETTY IRENE MOORE CHILDREN’S HEART CENTER’S newly opened outpatient clinic not only expands the capacity for patient visits—which is nearly 10,000 visits annually—it is also designed for optimal efficiency and family-centered care.**

The clinic is located on the first floor of the Packard Children’s Hospital Main building and is just a short walk for cardiac care specialists to travel between the clinic and the surgery center or the cardiovascualr intensive care unit. According to Robert Wenz, RN, MS, it makes for a more seamless model for cardiac specialists to treat both inpatients and outpatients without needing to leave the building.

The new spaces were designed with input from the hospital’s Family Advisory Council, a group of patient families who contribute their perspectives. One of the results of that collaboration in the Children’s Heart Center was establishing special consult rooms, apart from clinic rooms.

“Often we need to have lengthy conversations with families on their care plan or to explain a diagnosis,” says Wenz. “So we established consult rooms that offer privacy as well as comfort, with sofas and chairs, outside of the clinical care environment.”

Families of Young Heart Donor and Recipient Meet

**HANA YAGO** was diagnosed with an enlarged heart and severe heart failure at 6 months old. By the time she was 20 months old, she relied on a ventricular device, known as the Berlin Heart, to keep her blood flowing and extend the life of her failing heart. She needed a transplant to survive.

Leo Bibler was the same age as Hana. Sadly, in late May 2016, he passed away after a seizure. His parents, Kelly and Dave, learned their little boy could save eight lives through the gift of organ donation.

Shortly before her second birthday, Hana received her new heart.

Last summer, the Biblers drove 1,200 miles from their home in Colorado to Palo Alto to meet Hana and her family for the first time. Hana, who is now 5 years old, recently celebrated her third “heartversary.” Hana’s mom, Kathleen, told the Biblers how much their son’s gift meant: “To give a kid you never knew another chance at life, it’s kind of overwhelming and beautiful, and we are so grateful.”

Dave and Kelly took turns holding a stethoscope to Hana’s chest and listening to Leo’s heart beating inside her. “That is so cool,” Dave told Hana. “You have a good heart in there.”
“Jase decides his fate, and he has decided he wanted to be here. I think he will keep surprising us.”

—HAILEY, Jase’s mom

Born 15 weeks premature, Jase was so small he fit in his dad’s hand. Doctors at the local hospital gently suggested that Jase’s parents, Hailey and Sam, say their goodbyes. But his family didn’t give up. Jase was transferred to Packard Children’s, and thanks to donors like you, he is now a happy 1-year-old, home with his family for the holidays.
Your gift. Jase’s future.

DONATE NOW
supportLPCH.org/Holidays