What childhood diseases can we cure next, with your support?

In my 35 years as a pediatrician, I’ve seen amazing improvement in the way we take care of children. Many of the infectious diseases that caused kids to be hospitalized during my residency are now almost medical history. Childhood cancer survival has jumped from 50 to over 80 percent. And today, there are more surviving adults than children with congenital heart disease.

What brought about all this change? Research. Decades of innovative and painstaking work by physicians and researchers, backed with the funding to make change happen.

Our work is not finished yet. When children are seriously ill, the two main treatment options are still medication or surgery, sometimes accompanied by terrible side effects and a compromised quality of life. But through research, new hope is emerging every day. Today, with stem cell therapy, gene therapy, and immunotherapy, we are learning to use our patients’ own basic biology to fight back.

In this issue of Packard Children’s News, you’ll meet three incredible physician-scientists at the forefront of discovery. Individually, they are each stars in their respective specialties. Together, they are a force to be reckoned with. They all chose to come to Stanford University and Lucile Packard Children’s Hospital because what we can achieve here for child health is unmatched anywhere else.

From medicine to biosciences to engineering, the wealth of scientific knowledge at Stanford is staggering. But without sufficient funding, pediatric research will remain on the sidelines and move slowly. Your support enables us to focus more attention on the health problems of pregnant women and children, and to leverage all that science toward finding new cures—faster.

Donors like you give sick children hope for an even brighter future. What childhood diseases can we cure next, with your support?

David Alexander, MD
President and Chief Executive Officer
Lucile Packard Foundation for Children’s Health
These three brilliant and determined scientists all came to Stanford University to lead game-changing research in child health.

With your support, they may change the world.
Mary Leonard’s own children always know when she’s working in the hospital. They get unexpected text messages from her, reminding them to look both ways before they cross the street. It’s usually on the days when she’s walked through the pediatric intensive care unit and been acutely reminded of how devastating childhood injury and illness can be.
“Now that I am physician-in-chief, the breadth of death and suffering across our patients is much more on my mind. It motivates me every day to support our passionate physician-scientists and clinicians, who are working to develop and deliver new cures as quickly as possible.” — Mary Leonard, MD

Leonard saw this progress up close in her work as a pediatric nephrologist. Many years ago, she took care of a little boy—the same age as her own son—who had been born with a very rare genetic kidney disease. The boy struggled constantly against life-threatening episodes of high blood pressure, kidney failure, anemia, heart failure, and other complications.

“I admitted him to the hospital 14 times,” Leonard says. “What’s remarkable is that today, the gene that causes his disease has been identified, and a cure is available. Given how devastating this disease used to be, it seems almost miraculous that we now have a cure.”

She is determined to do the same for the many children who still suffer enormous challenges. Today, we can still do almost nothing for children with certain deadly brain tumors. Prematurity remains the number one cause of death in children under age 5 worldwide. And many mystery diseases remain incurable.

In her own research in bone health, Leonard has seen young adults who survived previously incurable diseases, but who now have osteoporosis that normally would only occur in elderly adults. “Now that I am physician-in-chief, the breadth of death and suffering across our patients is much more on my mind,” Leonard says. “It motivates me every day to support our passionate physician-scientists and clinicians, who are working to develop and deliver new cures as quickly as possible.”

Leonard is in the right place at the right time. Today, for the first time ever, the science has advanced to a point where we are within reach of fulfilling Lucile’s dream, in very tangible ways that were unimaginable just a decade ago. New techniques like stem cell and gene therapy are moving forward with unprecedented momentum, bringing the potential to cure hundreds of diseases affecting millions of children worldwide.

“We can now imagine a future,” says Leonard, “when we can predict and prevent devastating birth defects and childhood illnesses before they occur. And when illnesses strike, we will not just treat them, but cure them definitively—keeping children and mothers healthy not just for today, but for their entire life.”

It’s a worthy goal, to be sure, but what will it take to achieve it? All the scientific discovery in the world is of no use if there’s no way to translate those insights from the lab into real-life treatments and cures for patients. That’s where Leonard, and your support, comes in.

Building the Engine for Discovery

At the Children’s Hospital of Philadelphia, where she spent 25 years before arriving at Stanford in 2014, Leonard directed the Office of Clinical and Translational Research, which provided the resources, environment, operations, and training to support and promote the clinical and translational research of more than 300 principal investigators. Here success is not inevitable. Government funding for medical research has been declining for decades, and it does not cover the costs of the basic infrastructure needed for studies to be completed.

At Stanford University, where Leonard also serves as director of the Child Health Research Institute, she aims to build similar economies of scale. Stanford’s faculty and schools are already known for winning Nobel Prizes and topping best-of lists in medicine, biosciences, and engineering. The next step is to marshal all that scientific genius to solve the health problems of expectant mothers and children.

Leonard’s focus is on building the infrastructure and capacity needed to translate research into cures. It may not be the headline-making stuff of science-fiction-come-true, but she is diligently working behind the scenes to mentor and equip a generation of disease-fighting researchers.

You know that feeling when you’re driving a great car? You get in, and everything just works. It gets you from Point A to Point B so seamlessly that you don’t even have to think about what’s happening under the hood.

That’s what Leonard aims to build at Stanford for child health and maternal research: a better engine for discovery that hums like a well-oiled machine, functioning in a systematic and efficient way. “What most excites me right now,” she says, “is seeing the spark of excitement for research in our junior trainees. I want to do everything I can to support them to reach their full potential.” Her goal is to allow scientists to focus on the research rather than having to piece together a new engine every time.

That stuff under the hood, which will accelerate the discovery of new cures, includes support for recruiting clinical trials participants who fit strict criteria for each protocol; budgeting and reporting to meet the requirements of funders and regulatory agencies; biostatistics and data management; oversight to enhance safety for patients; and training for the next generation of qualified investigators.

It’s a massive, admittedly unglamorous, and absolutely essential foundation for research that will not only shape the future of pediatrics, but potentially transform the lives of millions of children.

Success is not inevitable, however. Government funding for medical research has been declining for decades, and it does not cover the costs of the basic infrastructure needed for studies to be completed. In the United States, philanthropy is now the single most important source of funding for fundamental, early-stage research and clinical trials. Without it, research will sputter along, and few if any true cures will ever reach the children who need them.

“We are on the cusp of major breakthroughs in many life-threatening diseases in children,” she says. “Lack of funds slows down the engines that move these discoveries into clinical care. “But with philanthropic support,” Leonard adds, “we can get there—faster.”
Maria Grazia Roncarolo, MD, has already cured “Bubble Boy” disease. What incurable disease will she cure next?

Fixing a single gene gave a child back the immune system he’d lacked at birth, allowing him to function normally in a dirty world within a year of treatment.

That mission accomplished, Maria Grazia Roncarolo, MD, left Italy’s top medical research job and came to Stanford University in 2014. Here she’s leading efforts to fast-track stem cell and gene therapy out of the laboratory and into clinical trials. This year, she launched Stanford’s ambitious new Center for Definitive and Curative Medicine.

In this Q&A, Roncarolo, professor of pediatrics and of medicine, talks about her Center’s urgent near-term goal: to fully cure another 50 diseases ASAP, beginning with sickle cell anemia.

Philanthropists, start your engines. It won’t be cheap.

Why did you go into medicine in the first place?

My husband always says, “Maria Grazia went around the world to pursue her dream, which was to cure patients with incurable diseases. And in the journey she encountered her husband and produced two beautiful children.” That’s how he always introduces me. And it’s true!

[She laughs, then turns serious.]

From when I was a medical student, I was exposed to the situation where many of these children, we just had to say to the parents, “Sorry. We cannot do anything for your child.” And that was incredibly frustrating.

It was in my mind when I was even a teenager: to really make a difference for people who are sick. And the idea was always for children.

Were you “destined” for a medical career?

I come from a family of business people. My father had a completely different agenda for me. He expected me to head the research department at the family-owned company [industrial paints for cars]. Unfortunately the problem was solved because he passed away when I was in my last year of high school.

My mother and my elder sister who took over the company said, “The worst thing you can do to yourself is to go into a job where you don’t have the passion.”

So they gave me a green light. Especially my elder sister, who’d just gotten her MBA. I am the only one in my family who’s in the medical field. And this was something unexpected for my family.
In March 2017, news from Paris reported the first patient cured of sickle cell anemia through an experimental gene therapy, in which bone marrow stem cells were extracted from the boy, altered so that they would make normal hemoglobin, and then put back into the boy’s body. Was that the same technique you pioneered in Italy?

It’s a similar approach. But I can tell you that what we’re doing here now at Stanford is much more advanced.

Don’t get me wrong: the old approach works! But it needs to be rendered more precise to be broadly useful. The major problem with the old approach? We never know where this healthy gene lands in the genome of the cells.

It’s like, you have a genetic dictionary with many words. And there is one word that is misspelled and you put the correct word back in randomly all over the dictionary, without alphabetical order. That’s the best example I can give.

So what Dr. Matt Porteus does here at Stanford with genome editing is very different. Because what we do is remove the misspelled word from the dictionary and replace it with the correct gene, the correct word, exactly in the same position as it should be.

In 2018, will there start to be clinical trials?

Correct. You know, severe combined immunodeficiency, what we call “bubble boy” disease, is very rare. But sickle cell anemia is a nasty disease that affects millions of people worldwide, including certain populations of people in India and Africa who do not have access to medical services. This could make a big difference.

Currently, sickle cell can be treated with stem cell transplantation, but this therapy comes at a high cost for the patient’s quality of life. For at least six months, he needs to be protected. He cannot go to school. He cannot play with other children. He cannot live in a normal household. And it comes with a risk of mortality.

If we can come in with an approach that is curative, without the toxicity and risk of the stem cell transplantation that we do today, it would be a major benefit.

The precision medicine approach here at Stanford is really the future of gene therapy. We are working very, very intensively to bring sickle cell treatment to the clinical stage next year.

During the clinical stage, a potential cure is tested on humans to prove its worth and uncover any side effects. Clinical trials are a prerequisite for approval by federal regulators.

Where are we going to be in five years?

The potential at Stanford is unique. And when I say unique, I mean unique in the world.

In 2017, the MIT Technology Review featured Dr. Maria Grazia Roncarolo’s work in its annual review of “breakthrough technologies.” In an article titled Gene Therapy 2.0, the review wrote: “Scientists have solved fundamental problems that were holding back cures for rare hereditary disorders. Next we’ll see if the same approach can take on cancer, heart disease, and other common illnesses.”

We have to ask: Do you have hobbies?

OK, now I go full disclosure: my job is my passion. And I think that I’ve been incredibly lucky.

My children know about my job. They know about the science and the patients I treated. They were engaged in that all the way.

My husband is also a scientist. He understands what it takes. And he could tolerate a wife who was always very busy. And when she was not busy, she was exhausted. [Laughs again.]

I’m a woman. I have two children; a husband who has been with me 30 years. And a job that is a passion. There was no space for anything else.

People say to me, “Oh, this was a big sacrifice for you.” Not really. It was not a sacrifice. It was a choice.

I lived in the Bay Area from ’89 to ’97. That is not a short period of time.

People say to me, “Oh, you went to Yosemite.” I say, “No, we didn’t.”

“Oh, you went to Big Sur.” I say, “No, we didn’t.”

“Oh, you went to Las Vegas.” “No, we didn’t.”

“They would go on and on and on. “You went to Cabo San Lucas.” “No, we didn’t.”

“What did you do?”

I worked. And I produced two children. [Laughter.]

My sister says, “Maria Grazia, how do you live?” I live as I choose to live. I have two beautiful children who are amazingly balanced despite this mom who was always busy, busy, busy. And I have the incredible luck to have a job that is a passion. }
There is no better battle to wage in this world than to fight cancer in kids.

CRYSTAL MACKALL, MD

Unleashing Cancer Immunotherapy Against a Diabolical Disease

BY JULIE GREICIUS

It was in 6th grade that Crystal Mackall, MD, associate director of the Stanford Cancer Institute and professor of pediatrics (hematology/oncology) and of medicine at the Stanford University School of Medicine, first knew she wanted to become a doctor. “I had a female science teacher who was very inspiring to me,” says Mackall. “We did a lot of work on anatomy and physiology, and I just thought it was the coolest stuff in the world.”

Mackall, who is also medical co-director of the Stanford Laboratory for Cell and Gene Medicine, stayed true to her dream, even as she refined her goal during training. “I thought I wanted to be a heart surgeon,” Mackall says, “but it turned out I really wasn’t that good with my hands, and my nose always itched when I had to go in the operating room.”

Soon enough, she found the perfect fit: pediatric cancer medicine. “I thought, this is where I want to put my energy. There is no better battle to wage in this world than to fight cancer in kids.”

Since then, Mackall’s own work has helped define the battle lines. In 1984, she read an early article about cancer immunotherapy—an approach that uses the body’s own immune system against cancer cells. “Nobody ever thought it would really work,” says Mackall, who still vividly recalls the early days when “we were kind of a fringe element in oncology. People thought we were a little bit ‘out there.’”

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Cancer is diabolical. It’s adaptive, and keeps finding ways to come back. We have to outsmart it.”

— CRYSTAL MACKALL, MD

**Bold Mentoring**

By 1989, she was studying the immune system in cancer at the National Institutes of Health under the direction of Philip Pizzo, MD, who was chief of the National Cancer Institute’s Pediatric Department and who would later go on to serve as dean of the Stanford University School of Medicine from 2001 to 2012.

“From early on, Crystal was committed to immunology and the potential for immunotherapy,” Pizzo recalls. “I was really struck by that, and gratified to watch her evolve at the National Cancer Institute, under Mackall’s leadership.”

Philip Pizzo taught me to be bold in terms of clinical investigation in children with dread disease, and in creating new therapeutics for kids,” says Mackall.

That boldness fueled Mackall’s persistence for more than two decades, as she and her colleagues gradually unlocked the secrets of immunotherapy. Initial approaches began to show promise. “Cancers that were resistant to every other type of therapy were being able to be controlled and put into remission with immunotherapy,” Mackall says.

Then “everything changed in 2003,” when the National Cancer Institute, under Mackall’s leadership, reported one of the first clinical successes with a targeted approach to activating the body’s own immune response. “The whole thing just exploded wide open,” Mackall adds. “Now it’s the biggest thing in cancer medicine.”

Despite many advances in childhood cancer treatment and survival over the past four decades, more work in cancer immunotherapy is still badly needed. With treatments like chemotherapy, radiation, and stem cell transplantation, five-year survival for children with cancer now reaches above 85 percent, where it was once 10 percent. Yet survival rates are much lower for rare cancers, and standard treatments can be lengthy, sometimes taking years, and with brutal side effects. (See “Even Wondergirl Needs Heroes,” page 18.) And there are children for whom the existing treatments do not work, or who suffer multiple recurrences, with the disease becoming less responsive to treatment.

“Cancer is diabolical,” says Mackall. “It’s adaptive, and keeps finding ways to come back. We have to outsmart it.”

**A Targeted Approach**

One key to her progress in outsmarting cancer lies in the difference between pediatric and adult tumors. Immune cells seek out abnormalities, which are easy to find in adult cancers because they have so many mutations. Because pediatric tumors have fewer abnormalities, “they look more like an immature cell, so the immune system can’t see it,” says Mackall. It’s counterintuitive, but the relative flawlessness of pediatric tumors is also what makes them harder to fight.

That’s why Mackall has focused her efforts on the promise of an approach that targets the cells identified in a specific type of tumor, like leukemia, for example. Using what she calls synthetic biology, “we create something new. We hijack the immune system,” she says. “It’s sort of like a bloodhound. You give it a scent and say, ‘Go get this.’” In pediatric cancers, it’s not enough to direct the immune system to an abnormality or mutation, because there aren’t enough of them. “We have to actually direct the cells to the tumor.”

T cells—the “bloodhounds”—are removed from the patient, engineered with “the scent” in Mackall’s analogy, which is the chimeric antigen receptor (CAR), and then returned to the patient’s bloodstream to begin their targeted immunotherapy response. The CAR points the T cell to a specific tumor cell, such as CD19 in acute lymphoblastic leukemia (ALL). When treated with CD19-CAR immunotherapy in the active dose range, children in clinical trials with ALL—all of whom had prior relapses or no other treatment options left—are already seeing response rates of 80 percent. It’s also a shorter course of treatment than standard approaches, and one she anticipates will have fewer long-term side effects. Mackall expects FDA approval of the CD19-CAR in the near future.

Building on strong results with CD19-CAR, Mackall and her team have investigated a second target: CD22. Clinical trials for CD22 began in 2015, and Mackall will soon publish the results. Having a second target in hand now provides the opportunity for physicians to do more than try each target in succession, but to hit the two targets simultaneously. “Doing it one step at a time seems to give the tumor too much time to adapt,” says Mackall. “So we are now coming in with the first double-CAR.”

The first human testing of the double-CAR, targeting CD19 and CD22, will begin clinical trials at Stanford and the National Cancer Institute in a few months.

In addition to building on the progress of immunotherapy, Mackall is also determined to continue research on its side effects, which can include, in very rare instances, neurotoxicity. “When you turn on the immune system, you’ve got to turn it on really strong to fight cancer, and that sometimes can cause bad side effects, which can sometimes be life-threatening,” Mackall says. “We’re working diligently not only to discover better ways of treating cancer, making new therapies, and getting them into the clinic, but also to learn about the toxicity and making the treatment safer.”

**Accelerating Research**

Two organizations that began supporting children’s cancer immunotherapy research early and with sizable investment were Stand Up 2 Cancer and St. Baldrick’s Foundation, which in 2013 began funding the Pediatric Cancer Dream Team, a group of eight institutions co-led by Mackall. Lucile Packard Children’s Hospital Stanford became part of the Pediatric Cancer Dream Team in January 2016, when Mackall joined the Stanford University School of Medicine faculty. The new Parker Institute for Cancer Immunotherapy, led by philanthropist and entrepreneur Sean Parker, also provides support for infrastructure and research.

Even with this funding, children’s cancers still present vast opportunities for support. “Cancer is not one disease,” says Mackall. “It’s a bunch of different diseases. Each of them has a different set of targets that are going to need a different group of investigators that have to develop it, because you can’t target a disease unless you understand the disease. That’s the beauty of this new CAR approach. It looks like it could be amenable to the treatment of solid cancers or blood cancers, and we could give it in combination with other treatments.”

“There are a whole lot of opportunities out there for what we could tackle next,” Mackall adds. “But right now, we have to choose based on resources. More money would allow us to address more cancers simultaneously.”

With Mackall at the helm of this research, Stanford will be helping to lead the field of pediatric oncology into a new realm of discovery and treatment, redefining not only how we understand pediatric cancer, but how we work to eradicate it. It’s inspiring work from a former 6th-grade girl who was just enjoying her science class.
TAKE THE TOUR

See for yourself how your philanthropy at Packard Children’s can change the future for hopelessly sick kids.

Once upon a time, philanthropy for medical research was “nice” to have. These days, it is absolutely essential.

With your support, researchers like Drs. Leonard, Roncarolo, and Mackall can make serious progress in children’s medicine. With your help, we’ll move new discoveries from the lab bench to the bedside—and cure sick children, faster.

FIND OUT MORE.
Call to schedule your tour.
Contact Sophie Emmerson at (650) 498-6168.

IN CURABLE

Thanks to donors like you, Hyrum received the lifesaving care he needed.
Even Wondergirl Needs Heroes

Giselle, aka Wondergirl (right) and her sister, Siena (left), won't stop fighting until there's a cure for all kids with cancer.

BY GISELLE CONTRERAS, AGE 5, AND HER MOM, GABRIELLA MEDRANO-CONTRERAS

We celebrated Giselle’s 3rd birthday in the hospital ... with a bone marrow aspiration and her first chemo.

She became very ill during her first week of treatment and spent two months in the Pediatric Intensive Care Unit at Packard Children’s. Once she was released from the hospital, our family knew we had a long fight ahead.

When she has a fever, because of these kids’ compromised immune systems, the doctor always says to drive to the nearest hospital. I’ve learned that as soon as she gets a fever, I start driving to Packard Children’s. By the time the on-call oncologist calls us back to tell me to go to the nearest hospital, I’m already at Packard! When you have a child with cancer, there’s just no other place I would go.

I still remember when the nurses gave Giselle a toy that someone had donated. It meant the world to us because we had been stuck in a hospital room for weeks. It made us feel that we hadn’t been forgotten.

In spite of how sick she was, Giselle never lost her bright smile.
GABRIELLA: Giselle lost her ability to walk due to the chemo. She ended up in leg braces for some time. Her kidneys started to produce stones, she became septic several times, she had skin issues, her immune system constantly needed a boost, the list goes on and on.

She saw it happen to other children in the hospital too. She would ask me, why is he not playing, or why does she have a tube in her nose? She asked me why, if the medicine (chemo) was so bad, did they keep giving it to her? I explained that we had nothing else but this medicine.

My baby was so sick from chemo. But she smiled and stayed positive through it all. So we started calling our brave and strong superhero “Wondergirl.”

For her 5th birthday, Giselle decided she didn’t want toys or gifts. Instead she wanted her friends and family to donate to the hospital. I asked her what we should do with the money raised.

GISELLE: I want to raise money for my cancer friends, for medicine that doesn’t hurt.

November 16, 2016, was a momentous day. Giselle and her family delivered hundreds of toys to Packard Children’s for patients. With their friends from Team G Childhood Cancer Foundation, they also presented a $4,885 check to Dr. Crystal Mackall for cancer immunotherapy research. (Dr. Mackall was not involved in Giselle’s care, but Giselle’s family was interested in the potential for her research to provide better options to Giselle’s “cancer friends.”) In return, Giselle’s nurses in the Bass Cancer Center surprised her with a cake to celebrate finally being cancer-free.

Why Wondergirl still needs heroes like you

GABRIELLA: Packard Children’s was there when our family needed them. We are so grateful for the many donors who gave to this hospital so that she could fight and beat her cancer. However, this isn’t enough for Giselle. As you’d expect from someone named Wondergirl, she won’t stop fighting until there is a cure for all kids with cancer.

Giselle does not like to see others suffer. She’s having a very hard time understanding that the medicine she raised money for won’t come today. She’s heartbroken. I’ve done my best explaining how research works, but she’s not convinced.

She wants the medicine for her cancer friends now!

My hope is that immunotherapy will become frontline therapy for children with leukemia. I want it to solve the horrible issues and the life-threatening side effects chemo has on children. If the cancer doesn’t kill our children, the chemo will. That is NOT okay. We need to allow research hospitals like Lucile Packard Children’s Hospital Stanford to unlock the mystery of less invasive methods with fewer side effects.

My hope is also that Giselle will live a full and normal life. That she draws strength from this experience to work harder in life to reach her goals.

GISELLE: When I grow up? I want to be a singer and a doctor to help kids with cancer.
We welcomed 4,585 babies into the world.

40% of patients benefited from financial assistance.

2016 REPORT ON GIVING

In 2016, 14,430 donors like you gave a total of $207.4 million to Lucile Packard Children’s Hospital Stanford and the child health and obstetric programs at Stanford University School of Medicine.

Your generous support made all this and much more possible for patients and families over the last year.

Thank You!

GIFTS MADE BETWEEN SEPTEMBER 1, 2015, AND AUGUST 31, 2016

5,057 patients were seen in our Brain & Behavior Center, a national leader in care and research for epilepsy, brain tumors, concussions, autism, and more.

2,715 free visits to our Teen Health Van by at-risk youth. Each $1 spent now for care and prevention = $10 saved in future health care costs.

Nearly 400 community members attended our first Adolescent Mental Wellness Conference.

In the first program of its kind in the country, 15 trained parent mentors offered care management strategies, as well as a shoulder to cry on, to parents of newly diagnosed patients.

25 years of innovation, excellence, and care for children and expectant mothers.

5 chaplains provided spiritual care to patients and families, 24 hours a day, seven days a week.

509,852 clinic visits.

We served patients from 50 states & 40 countries.

1 cancer patient received tickets and a limo ride to Super Bowl 50.

Nearly 50 children ages 8 to 18 enjoyed just being kids at the 22nd annual Solid Organ Transplant Summer Camp.

15 trained parent mentors offered care management strategies, as well as a shoulder to cry on, to parents of newly diagnosed patients.
Thank You NOTES

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.

$50 Million Gift from Gordon and Betty Moore Transforms the Children’s Heart Center

In March, Gordon and Betty Moore made a $50 million gift, the largest from an individual to Packard Children’s since the hospital’s founding gift from David and Lucile Packard. In honor of this gift, Packard Children’s internationally renowned Children’s Heart Center will be named the Betty Irene Moore Children’s Heart Center. The gift provides funding for clinical and research facilities, an endowment for the Center’s highest strategic priorities, and endowed positions for faculty to lead specialized care and research.

“Dr. and Mrs. Moore’s gift comes at a critical juncture—enabling us to advance beyond surgical repair to the discovery of transformative treatments and interventions and, ultimately, to true cures,” said Frank Hanley, MD, the Lawrence Crowley, MD, Professor in Child Health and executive director of the Betty Irene Moore Children’s Heart Center. Stephen Roth, MD, MPH, chief of pediatric cardiology and director of the Betty Irene Moore Children’s Heart Center, also extended his gratitude to the Moore family, noting their partnership enables an unprecedented opportunity for the Center to expand its state-of-the-art clinical and research facilities, train future leaders of cardiovascular medicine and surgery, and improve the fields of pediatric and adult cardiology and cardiovascular surgery through innovative research.

Stanford Dance Marathon Raises $110,000 for Bass Cancer Center

MORE THAN 1,000 STUDENTS danced their way to a high-kicking $110,000 at the annual Stanford Dance Marathon. Over 24 hours on February 18–19, students, faculty, and staff dined and danced in honor of children affected by pediatric cancers. Event proceeds supported uncompensated care at the Bass Center for Childhood Cancer and Blood Diseases.

Dancers were inspired by cancer patients like 7-year-old Ellie from Redwood City, who was diagnosed with acute lymphoblastic leukemia at age 2 and spent 852 days bravely battling cancer. Today, thanks to donor-supported care received at Packard Children’s, Ellie is three years cancer-free.

Stanford Dance Marathon, founded in 2005, is the Bay Area’s largest student-run philanthropic event. On their Facebook page after the event, organizers mirrored the sentiments of so many of our patients: “Thanks to everyone who has given us unyielding support ... this journey was long, but it is far from over. The strides we made the past few months are just the beginning!”

$10 Million Gift from Julia and David Koch Establishes Clinical Research Unit for Allergy and Asthma

A NEW CLINICAL RESEARCH UNIT will be established thanks to Julia and David Koch’s visionary $10 million gift to Packard Children’s. The unit will operate within the Sean N. Parker Center for Allergy and Asthma Research at Stanford, home to the groundbreaking allergy and asthma clinical trials led by Kari Nadeau, MD, PhD.

Currently, Nadeau’s lab research is on the Stanford campus, while her clinical research is at a Packard Children’s licensed unit within El Camino Hospital in Mountain View. The Koch gift will enable Nadeau and her team to expand their clinical research to a redesigned unit at Packard Children’s in 2018.

Severe food allergies are a growing epidemic, with rates having doubled in the last decade. The Koch family has experienced firsthand the anxiety of living with food allergies, as well as the life-changing effects of a clinical trial to safely desensitize the allergies. “We made this gift with the goal of bringing better treatments to more children and adults suffering from dangerous allergies,” said Mrs. Koch. Nadeau notes this “investment will have a tremendous impact on the care and treatment we provide. Together, we will make a difference for all those who may benefit from research toward better, safe, and lasting therapies.”

Inaugural Shop for Packard Raises $50,000 for Packard Children’s

IN MARCH, 39 local retailers, restaurants, and fitness studios hosted in-store shopping days that benefited the Children’s Fund at our hospital. The shopping festivities kicked off with a party hosted by Shreve & Co. and LumillaMingus, and continued over several weeks, with participating retailers donating a portion of sales to Packard Children’s. In total, the inaugural event has raised over $50,000 to date. We are grateful to the wonderful community of retailers and shoppers that partnered with us to support Packard Children’s.
Thank You NOTES

The Ambassadors for Lucile Packard Children’s Hospital 2016-2017 Board of Directors.
(Below) Co-president Margaret Munzing, Dr. Lucy Kalanithi, and co-president Kristen Wilsey.

Ambassadors for Lucile Packard Children’s Hospital Raise More Than $164,000 at the 10th Annual Lunch and Learn

ON MARCH 14, the Ambassadors for Lucile Packard Children’s Hospital celebrated 10 years of giving, learning, and volunteering together at their annual Lunch and Learn at Sharon Heights Country Club. Guests heard from Dr. Lucy Kalanithi, the widow of Dr. Paul Kalanithi, a Stanford neurosurgeon and author of the New York Times bestselling memoir, When Breath Becomes Air, for which she wrote the epilogue. During a fireside chat with NBC contributor Liza Meak, Dr. Kalanithi shared her experience caring for a terminally ill spouse and a newborn. Guests were also honored by fellow Ambassadors member Esther Levy, who shared her family’s experience with our hospital’s palliative care program.

The Ambassadors 2016-2017 Fund-A-Need supported our hospital’s Bereavement & Family Guidance and Palliative Care Programs. Through the generosity of members and guests at Lunch and Learn, the Fund-A-Need goal was met and surpassed. They have raised more than $275,000 this year, including $165,000 through Lunch and Learn, which will fund a bereavement therapist for two years, a palliative care physician specializing in pain management for two years; and one year of the Annual Day of Remembrance for families who have lost a child. These programs rely solely on philanthropy, and we are deeply grateful for their tireless work on this signature event. On behalf of the children and families that will benefit from the event proceeds, thank you to everyone who made The Dinner a success!

HELP MITO KIDS is dedicated to spreading awareness about mitochondrial disease and helping families impacted by the life-threatening disease. Mitochondria are energy factories found in every cell of the human body. In mitochondrial disease, which primarily affects children, cells lose their ability to produce energy and sustain growth, and entire organs can be damaged or shut down. Currently, there is no cure for this disease.

Since 2011, Help Mito Kids has donated more than $60,000 to support Dr. Greg Enns’ research to identify new ways to diagnose and treat mitochondrial disorders, including the development of a panel of sensitive blood biomarkers so that patients with primary or secondary mitochondrial dysfunction can be monitored non-invasively. Thank you, Help Mito Kids, for making these advances possible!

Long-Time Partner Supports Dr. Greg Enns’ Research

HELP MITO KIDS

“THERE’S NO SUCH THING AS TOO MUCH!”

EIGHT-YEAR-OLD MAISY has a zest for fashion and philanthropy that has resulted in an amazing venture supporting kids with cancer. Maisy began by making hats out of paper for kids who had lost their hair from chemotherapy treatments. “But then I thought headbands were more fun,” she says, so she moved to making headbands with colored puffs and even some bling.

Flash forward a year and a half, Maisy Puffs have raised an amazing $4,000 for childhood cancer research! In addition to providing cute headbands for kids with cancer, Maisy Puffs also provide our patients and families something even more important—symbols of hope.

Thank you, Maisy!

Thank you, Maisy!

Happy Year of the Rooster!

THANK YOU to C.M. Capital Foundation for bringing its annual Chinese New Year celebration to our hospital for the fourth year in a row. Our patients and families were treated to calligraphy demonstrations, craft projects, and delicious food. Lion dancers were the highlight of the celebration, delighting everyone who gathered to ring in the Year of the Rooster.

Since 2014, C.M. Capital Foundation has committed $150,000 to our hospital, and is returning again as a Spotlight Sponsor for the 7th annual Summer Scamper. We could not be more grateful for their partnership. Xiè xiè!

The Dinner Raises Awareness and Support for Mental Health

ON MAY 5, we kicked off the first of many celebrations in our new hospital expansion at our biennial gala, The Dinner. Held in the gardens and lobby of the new hospital building, the sold-out dinner and live auction featured Rob Lowe and Jerry Seinfeld, and raised over $3.2 million for the child and adolescent mental health programs at Packard Children’s and Stanford School of Medicine. Special thanks to co-chairs Gisea Arrillaga, Susan Ford Dorsey, Elizabeth Dunlevie, and Stacey Siebel, and the event’s steering and honorary committees, for their tireless work on this signature event. On behalf of the children and families that will benefit from the event proceeds, thank you to everyone who helped make The Dinner a success!

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In the NEWS

Hospital Recognized with Tall Tree Award

THE PALO ALTO CHAMBER of Commerce and the Palo Alto Weekly recently awarded Lucile Packard Children’s Hospital Stanford its Tall Tree: Outstanding Nonprofit award for its longstanding contributions and service to the community. Our hospital was lauded for its work with East Palo Alto’s Ravenswood Family Health Center and Palo Alto’s Mayview Clinic, both of which offer services to low-income individuals and their families. Packard Children’s was also recognized for its support of uncompensated and undercompensated care and its dedication to community health services, including adolescent mental health, child safety programs, and community health education.

Leslee Subak Appointed New Chair of Obstetrics and Gynecology

LESLEE SUBAK, MD, has been appointed the chair of the Department of Obstetrics and Gynecology at Stanford University School of Medicine, effective May 1. She succeeds Jonathan Berek, MD, the Laurie Kraus Lacob Professor, who served as chair of the department since 2005.

Subak is an expert in urogynecology, and her research focuses on multidisciplinary approaches to treating urinary incontinence in women. “I love building and participating in collaborations—across departments, schools, and continents and across clinical, training, and research missions,” she says. Subak is also dedicated to training the next generation of leaders in women’s health. She is a 1991 graduate of Stanford School of Medicine.

Back on the Court After Complex Surgery

TWO YEARS AGO, Chris Formaker chose a procedure called rotationplasty to treat his bone cancer. Orthopedic surgeon Larry Rinsky, MD, removed the tumor in Chris’ femur and tibia, turned his foot and ankle 180 degrees, and reattached them with skin and muscle to Chris’ upper thigh. Once healed, a prosthetic leg was fitted with the backward-facing foot serving as Chris’ new knee joint. Says Rinsky, “there are advantages, particularly for kids like Chris who want to maintain mobility and continue playing sports. It is truly a long-term solution to a difficult problem.” Now 10 years old, Chris is cancer-free and doing what he loves most: playing basketball and cheering for the Warriors.

Adolescent Bariatric Surgery Program Receives Landmark Accreditation

THE ADOLESCENT BARIATRIC Surgery Program at Packard Children’s recently received accreditation from the American College of Surgeons Metabolic and Bariatric Surgery Accreditation and Quality Improvement Program, making it the first and only adolescent bariatric program on the West Coast and one of three programs nationally to receive such a distinction. Led by surgical director, Matias Bruzoni, MD, and medical director, Lawrence Hammer, MD, the program offers behavioral, educational, and medical services to overweight children and adolescents.

Micaela Chapa, who underwent laparoscopic sleeve gastrectomy four years ago when she was a senior in high school, says, “I feel like the whole process with Packard Children’s was transformative... I really felt like a changed person with a very powerful tool on my side.”

Even Legalized, Marijuana Is Not Safe for Teens

A REPORT, co-authored by Seth Ammerman, MD, professor of pediatrics (adolescent medicine), and published in the March issue of Pediatrics, summarizes scientific evidence for the negative effects of marijuana use on the developing brain and gives physicians information to navigate conversations with parents and teens who believe using marijuana is harmless.

Through his work with the Teen Health Van, Ammerman’s experiences providing care to adolescents and talking about drug use are plentiful. He cautions that adolescents are more vulnerable to the adverse effects of marijuana use than older users. He notes that teens who use marijuana regularly may develop serious mental health disorders including addiction and depression, and have more problems succeeding in school and work. He also notes that long-term users of marijuana may develop unrecoverable cognitive deficits, even if drug use stops.
Adolescent Mental Health Inpatient Unit Opens at Mills-Peninsula Hospital

A follow-up on our Fall 2016 issue focused on teen mental health

STANFORD CHILDREN’S HEALTH and Lucile Packard Children’s Hospital Stanford have formalized a partnership with Mills-Peninsula Hospital in Burlingame to offer new youth mental health programs and services for teens in San Mateo and Santa Clara counties. A team that includes a child-adolescent psychiatrist and Stanford doctors is now staffing up to eight beds in an inpatient setting at Mills-Peninsula. Patients seen at Packard Children’s emergency department and in other clinics can be transferred to Mills-Peninsula.

Antonio Hardan, MD, chief of child and adolescent psychiatry at Packard Children’s, and Daniel Becker, MD, medical director of behavioral health at Mills-Peninsula, believe this team approach supports a larger number of patients while providing trainees hands-on experiences in an inpatient setting. The collaboration also increases access to Stanford doctors while enhancing continuity of care and lowering societal stigma for patients and families seeking psychiatric treatment.

Virtual Heart Revolutionizes Education and Care of Congenital Heart Defects

“The heart is a complicated three-dimensional organ, and it’s really hard to describe what’s going on inside of it—especially when something is going wrong,” says David Axelrod, MD, clinical assistant professor of pediatric cardiology at Stanford University School of Medicine and co-designer of the Stanford Virtual Heart Program. “Virtual reality eliminates a lot of that complexity by letting people go inside the heart and see what’s happening themselves—it’s worth way more than a thousand words.”

The Children’s Heart Center, Oculus, and virtual reality expert David Sarno from Lighthaus, Inc., partnered to develop the Stanford Virtual Heart. The immersive technology allows users to rotate, open, inspect, and even teleport into a virtual heart. This interaction, when guided by a cardiologist, gives patients, families, and trainees a deeper understanding of the problem and treatment options for a heart defect.

Two additional virtual reality studies are under way at Packard Children’s: Project Brave Heart helps patients cope with their anxiety by using cognitive behavioral therapy techniques, including relaxation and exposure; and True3D virtual imaging technology inside the operating room helps surgeons during procedures. Though adoption is in its early stages, the team is already seeking ways for virtual reality to be expanded across the hospital in the future.

No Longer Conjoined, Sandoval Twins Return Home

ON MARCH 29, Eva and Erika Sandoval, formerly conjoined twins who were surgically separated at our hospital in December, returned to their home in Antelope, California. The 2-year-old sisters left Packard Children’s in early March and spent two weeks at UC Davis Children’s Hospital in Sacramento, where they received physical and occupational therapy to improve their mobility and learned to eat independently. “The girls have just blossomed in terms of personality,” says lead surgeon Gary Hartman, MD. “They’re very engaging and chatty.”

Their mother, Aida, notes, “Now that we’re here, it’s amazing. We’ve been waiting two years for this.” Eva and Erika will continue to receive regular checkups with Dr. Hartman and other caregivers at Packard Children’s. To date, more than 100 hospital staff across many departments participated in their care.
“When he was little, they told us he might not walk, he might not talk. I celebrate every little milestone, like the first time he talked back to me. It was really exciting to see. He’s like any other kid, pushing his limits! Despite his laundry list of health problems, he is happy 99 percent of the time.”

— TYLER’S MOM, JENNIE
Register today at SummerScamper.org