Ronan Is Back in Action After Facing Cancer
Celebrating Our Amazing Community!

IN THIS SEASON OF GRATITUDE, I am thankful for so much: our hospital’s courageous patients and families, and our faculty who provide world-class care and conduct research that leads to new treatments and cures. And our generous, compassionate donors who make their work possible!

We have many stories of hope and healing to share. You’ll meet Ronan, who approached treatment for a rare cancer with smiles, laughter, and the support of his amazing care team (see page 2). Our pediatric experts are translating their research into breakthroughs that will help more children like Ronan.

Stanford researchers are also probing the mysteries of a complex genetic disorder called 22q11.2 deletion syndrome (see page 10). Their findings will help children with this condition lead active, full lives.

Still others are observing children with autism in a unique preschool setting to identify the most effective behavioral therapies (see page 6). Their work is already helping families and will benefit many more.

In this issue, we also honor Barbara Sourkes, PhD, and Harvey Cohen, MD, PhD, who pioneered our hospital’s Palliative Care program (see page 8). After years of caring for children with life-threatening illnesses and their families, they are stepping into well-deserved retirements. The program will continue to expand under new leadership.

Our Foundation is growing too! We welcomed five new members to our board of directors in September: Jeff Chambers; Jennifer Duda, MD; Cindy Goldberg; Mo Makhzoumi; and Celina Tenev. They bring diverse perspectives and are all in on children’s health. I am excited to work alongside them—and with you—to continue to advance children’s health in 2023!

With gratitude,

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

IN THIS ISSUE

2 Meet Ronan, Cancer Survivor, Surfer, and Big Dreamer
A young cancer patient shows his courage.

6 A Lifeline for Families
Giving hope to families of children with autism.

8 An Invaluable Legacy
Barbara Sourkes and Harvey Cohen are retiring as pioneers in pediatric palliative care.

10 Unraveling the Mysteries of a Rare Genetic Disorder
Stanford experts are making breakthroughs in treating 22q11.2 deletion syndrome.

13 Chariot Uses Technology to Calm Kids
Stanford researchers use virtual reality and augmented reality to transform care for patients like Theo.

14 Thank You Notes

17 In the News

20 Humans of Packard Children’s
It started with what seemed like a few random symptoms: a sore pitching arm, upset stomach, a fever.

Rebecca Olson made an appointment for her son Ronan to see his pediatrician. A COVID-19 test was ordered. It came back negative.

By Sunday night, Rebecca was really worried. Her son—normally outgoing, athletic, adventurous—was complaining about how sick he felt. The fever persisted. Ronan’s mom noticed that he was breathing faster than normal as he slept.

Early Monday morning, Rebecca took Ronan to an urgent care clinic, where a chest X-ray was performed. She was advised to take Ronan to the emergency room.

When she and Ronan arrived at the Stanford Emergency Department, hospital staff had already prepared a room, where Ronan had the first of many medical tests, including an ultrasound and a CT scan.

“It wasn’t long before I heard the dreaded words,” says Rebecca. “Your son has masses on his abdomen.”

Coping with the Diagnosis

From the beginning of Ronan’s battle with what turned out to be a rare and aggressive cancer known as Burkitt lymphoma, he and his mom say they felt supported by the doctors, nurses, and staff who provided his care at Lucile Packard Children’s Hospital Stanford.

As soon as his tumors were discovered—one in his chest, one near his liver, and one near his kidneys—Ronan was transferred to the pediatric intensive care unit (PICU). There, Rebecca says, they met “the incredible resident ‘Dr. Dan,’ who would quarterback what would be a 10-day stay in the PICU, coordinating his care with a dozen other teams.”

According to everyone involved, the staff’s good nature was matched by Ronan’s incredibly positive attitude. On his second day at the hospital, he underwent a two-and-a-half-hour procedure to biopsy his lymph nodes and pelvic bones and to place a tube into his right lung to drain the malignant fluid that was accumulating. The team who worked on Ronan called him a “rock star” and laughed at stories he told about his 4-H pig, Keefe, while he was under anesthesia.

Meet Ronan, Cancer Survivor, Surfer, and Big Dreamer

BY MICHAELA JARVIS
After Ronan started chemo to break down the large masses in his abdomen, the resultant detritus in his body nearly overwhelmed his kidneys, causing nausea and lethargy and threatening him with acute renal failure. At the same time, his breathing was impaired because of fluid in the tissues of his lungs; his oxygen-carrying red blood cells were decimated; and his feet were swollen, making it difficult to walk. Despite feeling miserable, Ronan responded to queries from doctors or nurses about how he was doing by saying, “Good enough,” with as much of a smile as he could muster.

When he talked to his classmates from the hospital via a Zoom call, he told them, “Cancer is annoying. But the one I have isn’t that bad.” He also suggested they eat their broccoli.

Navigating the Treatment
During the “induction” phase of Ronan’s chemo, all his hair fell out, and he was so nauseated that he couldn’t eat, dropping 20 pounds from his 10-year-old slender frame. He also developed severe mouth sores. He was placed on a lidocaine drip to ease his pain so that he could continue eating and drinking.

In addition to all the other specialists he had seen—including hematologist-oncologist Michael Link, MD, the Child Life care team, interventional radiologists, nephrologists, cardiologists, and anesthesiologists—he was now visited by dermatologists when he developed a rash, ophthalmologists when his vision was affected, and infectious disease specialists when his rash spread.

When Ronan had to be put in isolation and couldn’t even leave his room for several days, Rebecca turned to Packard Children’s Hospital nurses and staff, and he walked in the gardens outside of the cafeteria to enjoy the outdoors. His mother speaks of only one moment throughout his nearly 100 days in the hospital when he asked, “Why me? Why did I have to get cancer?” Rebecca says Ronan was in the PICU and was curled in a ball because of bad stomach pain. His mother suggested the cancer was preparing him “for something big he was meant to do in the future, something to help others.”

“I knew that Ronan would defeat this terrible cancer and emerge on the other side strong, with a different perspective that would be the source of future greatness and happiness,” Rebecca says.

Even before Ronan had had his last treatment, even before he walked the length of the hematology and oncology department where he’d spent so much time, and got a huge round of applause, he was already looking back on his experience with characteristic enthusiasm.

“One of the things I have learned is that I have so much support,” Ronan says. “I have learned a lot from the hospital—to appreciate everything. When I get home, I’m going to take a bike ride every day just because I can.”

And as far as the experience preparing him to do something important to help others? Those who know Ronan would have to say that absolutely seems to be the case.

“When I grow up,” Ronan says, “I’m going to be a pediatric oncologist so I can help kids fight cancer.”

Ronan kept a smile on his face throughout his treatment, thanks to support from his family, friends, and care team.

Looking Forward to Giving Back
Over the next four months, Ronan went through five more rounds of chemotherapy. He had to be admitted to the emergency department four times and endured weeks of high fevers. Infectious disease specialists were called in many more times during his hospital stays.

Despite all that, he continued friendships he had made with Packard Children’s Hospital nurses and staff, and he walked in the gardens outside of the cafeteria to enjoy the outdoors. His mother speaks of only one moment throughout his nearly 100 days in the hospital when he asked, “Why me? Why did I have to get cancer?” Rebecca says Ronan was in the PICU and

Innovations in Pediatric Oncology

**EVERY DAY AT STANFORD,** new research is improving outcomes for children with cancer. By studying everything from cancer’s minute cellular interactions to the clinical results of ground-breaking therapies, our physician-researchers are discovering more ways to enhance cancer detection and treatment.

Recently, assistant professor of pediatrics Robbie Majzner, MD, and his team developed a new way to make a powerful cancer immunotherapy useful not only for blood cancers, but for most solid tumors. The immunotherapy, using engineered immune cells called CAR T-cells, targets cancerous cells, leaving healthy tissue alone.

A different study by Majzner shows success at improving the odds of children with neuroblastoma, a cancer of the nerve cells that usually strikes children under age 5. While treatments were developed years ago to help the immune system attack neuroblastoma tumor cells, some pediatric patients did not respond. Majzner’s research discovered that an existing anti-cancer drug could bring about that immune response.

Similar research by Majzner suggests that administering two anti-cancer antibodies to patients with neuroblastoma or osteosarcoma, a bone cancer found mainly in teens and young adults, would be far more effective than administering just one of the antibodies. A clinical trial involving about 80 children and young adults with relapsed or treatment-resistant neuroblastoma or relapsed osteosarcoma has already begun.

Stanford assistant professor of pediatrics Kara Davis, DO, uses single-cell analysis of cancerous tumors to investigate the wide variety of cancer cells that can exist within a single tumor. That diversity of tumor cells may account for relapse after a tumor has responded to treatment and that may predispose development of cancer processes that lead to the development of cancer and that may predispose a patient to relapse will continue to help her and other researchers pinpoint the best treatments for childhood cancers. Her work could also reduce the toxicity and side effects of treatment, as well as the amount of time a patient goes through treatment.
When Mason* was 18 months old, he could say only one word: “Mama.” Even though his father, Sam, suspected something was wrong, Mason’s diagnosis came as a shock: autism. Luckily, Mason’s family discovered a unique resource: Stanford’s Preschool Autism Lab (PAL). Similar to a traditional preschool, at PAL, young children with autism play, draw, and learn. But they are simultaneously being treated with behavioral therapies. Parents also receive training on basic strategies to assist their children with communication, sensory processing, and more. Both PAL and ESPA are free of charge.

Since the pandemic, demand for these services has skyrocketed. More than 700 new families are served by ESPA each year, up about 40 percent. And Stanford-PAL’s waitlist has grown considerably.

With fewer in-person services available during the pandemic, Hardan says, many patients haven’t gotten consistent care, and behavioral problems and other symptoms have worsened. Hardan seeks philanthropic support to expand the program to more classrooms and to make services even more accessible via video sessions.

In doing so, he aims to help more children like Mason. Sam will never forget the day he picked up his son from PAL, and Mason said four words: “Where is your car?” His first sentence. “It was so exciting—my wife almost cried,” Sam recalls. “PAL really changed my son’s life.”

*Names have been changed.

To learn more about PAL, watch this video at supportLPCH.org/blog/lifeline-families.

Couple Advocates for Early Interventions for Autism

“NOBODY IS HELPING ME.” “I’m not a good mother.” “I feel like I’m losing my child.”

Nearly 40 years ago, when Marcia Goldman heard these words from parents of children with autism, the educator knew she had to act. Neither autism nor its treatments were well understood at the time. But Goldman decided to establish a special preschool based on emerging best practices. As word spread about the students’ progress, demand increased. Still, Goldman knew that a single school could do only so much. She wanted to change the system.

Goldman ultimately found a thought partner in Stanford’s Antonio Hardan, MD. They shared a dream of giving families the opportunities to help children achieve the best possible outcomes. These dreams crystallized into the ESPA and Stanford-PAL programs, which Goldman and her husband, John, support through philanthropy.

“When a child is diagnosed with autism, parents feel like the clock is ticking to get help, but they often don’t get any guidance,” Goldman says. “To be able to close that gap for families has been amazing.”

Goldman is also passionate about research being done at Stanford-PAL to improve best practices for treating children with autism, which she has seen evolve dramatically over her decades in the field.

“It’s been so validating that the research is proving interactive early intervention approaches work, and that the methods used at Stanford-PAL can be a wonderful model for other programs,” she says. “It helps me know that my career has had meaning.”

Hardan is thankful to have found a partner in the Goldmans.

“This program would not be possible without the support of John and Marcia,” Hardan says. “They have made an incredible difference in the lives of kids with autism.”

To learn about supporting autism programs, contact Payal Shah at Payal.Shah@LPCH.org.

A Lifeline for Families

Giving hope to families of children with autism.

BY BETH TAGAWA

When Mason* was 18 months old, he could say only one word: “Mama.” Even though his father, Sam, suspected something was wrong, Mason’s diagnosis came as a shock: autism. Luckily, Mason’s family discovered a unique resource: Stanford’s Preschool Autism Lab (PAL). Similar to a traditional preschool, at PAL, young children with autism play, draw, and learn. But they are simultaneously being treated with behavioral therapies.

What’s more, their facial expressions, interactions, and gestures are tracked by cameras, allowing Stanford researchers to analyze the effectiveness of these therapies. Stanford-PAL is one of just a few institutions in the country to combine autism care and research in this way.

“The childhood years are critical,” says Antonio Hardan, MD, director of Stanford’s Division of Child and Adolescent Psychiatry, who leads the Stanford-PAL program with Grace Gengoux, PhD. “With early intervention, we can work with kids as soon as a diagnosis is made, which sets them on a path to achieve the best possible outcomes for life.”

Hardan also leads the Early Support Program for Autism (ESPA), which helps families after a new autism diagnosis. At this vulnerable time, ESPA’s care coordinator shares where and how they can access services. Parents also receive training on basic strategies to assist their children with communication, sensory processing, and more.

Both PAL and ESPA are free of charge.

Since the pandemic, demand for these services has skyrocketed. More than 700 new families are served by ESPA each year, up about 40 percent. And Stanford-PAL’s waitlist has grown considerably.

With fewer in-person services available during the pandemic, Hardan says, many patients haven’t gotten consistent care, and behavioral problems and other symptoms have worsened.

Hardan seeks philanthropic support to expand the program to more classrooms and to make services even more accessible via video sessions.

In doing so, he aims to help more children like Mason. Sam will never forget the day he picked up his son from PAL, and Mason said four words: “Where is your car?” His first sentence. “It was so exciting—my wife almost cried,” Sam recalls. “PAL really changed my son’s life.”

*Names have been changed.

To learn more about PAL, watch this video at supportLPCH.org/blog/lifeline-families.
An Invaluable Legacy

Barbara Sourkes and Harvey Cohen are retiring as pioneers in pediatric palliative care.

When Harvey Cohen, MD, PhD, was chief of staff at Lucile Packard Children’s Hospital Stanford and chair of pediatrics at Stanford in the late 1990s, a pediatrician challenged him with the question: “What do we do when we know we can’t cure the child? How do we help the family?” The hospital’s intensive care program was expanding, and doctors were encountering more children with increasingly serious medical conditions.

“It was really clear that we needed a program that would specifically target the needs of children with life-threatening or chronic complex diseases and their families,” says Cohen, who has served as the Deborah E. Addicott – John A. Kriewall and Elizabeth A. Haehl Family Professor of Pediatrics at Stanford since stepping down from his leadership roles in 2006.

Cohen formed a task force to address this pressing issue. A needs assessment, spearheaded by Nancy Contro, LCSW, solicited information from both bereaved families and hospital staff about their experiences and suggestions for improving palliative care. The findings, published in prestigious pediatric journals, provided the groundwork for establishing Packard Children’s Palliative Care program.

From the outset, Cohen relied on philanthropy, beginning with generous support from John Kriewall and Betsy Haehl. He recruited Barbara Sourkes, PhD, a child psychologist at Montreal Children’s Hospital and an internationally known clinical leader and author in the field of pediatric palliative care. Upon Sourkes’ arrival in 2001, she was named the first John A. Kriewall and Elizabeth A. Haehl Director of Pediatric Palliative Care.

The program was placed in the division of Critical Care because so many palliative issues arise on the unit in caring for children with a spectrum of illnesses. This location dispelled the belief that palliative care was only for patients with cancer. Palliative care was only for patients with cancer.

The Palliative Care program at Packard Children’s was among the first such programs in the country. Sourkes assembled a team from a spectrum of disciplines: medicine, nursing, psychology, social work, chaplaincy, child life, case management, and education. “This isn’t a single-profession undertaking,” she says. “Given the challenges that these children and families encounter, it’s essential that we get as many perspectives as possible.

“There was a lot of education to explain that palliative care is for any seriously ill child—whether death is imminent or a lurking threat that the child may not live out a normal life span,” Sourkes says. “Eventually, the program encompassed children with complex chronic conditions. All of these children deal with the physical and emotional vicissitudes of serious illness—sometimes over decades—as do their families.”

The Palliative Care program at Packard Children’s is a Multidisciplinary Initiative. The program also provides training for care team members and trainees, helping them understand the impact on themselves of working with these children and families.

Over time, gifts from donors have allowed the program to add important initiatives. Healing HEARTS magazine publishes the creative images and words of children treated at our hospital and their siblings. The Annual Day of Remembrance and Rededication brings together bereaved families in commemoration of their children.

A Legacy of Caring

When Sourkes and Cohen, the current Katie and Paul Dougherty Medical Director, retire in August 2023, they will leave a legacy of expertise and care. They hope the program will continue to expand by growing the team; venturing into new arenas, including supporting expectant parents who already know that their baby has a serious medical condition; and bolstering in-home support for children. Moving forward, the program will become its own division within the Department of Pediatrics—the School of Medicine and hospital are recruiting Palliative Care’s first division chief.

As a closing achievement, Sourkes (with two colleagues) co-edited the second edition of their book, Interdisciplinary Pediatric Palliative Care. One of her chapters ends with a 6-year-old boy named Andrew, was diagnosed with a rare form of leukemia in 2014, says her life became a “living nightmare.” Cohen, Sourkes, and their colleagues guided the family through treatment, hospice care, and bereavement. “Living through a child’s life-threatening illness is not just about supporting the child, but supporting the family through the journey ahead,” Levy said, in 2017. “I truly believe that the palliative care team is why I am still standing here today.”

The program provides training for care team members and trainees, helping them understand the impact on themselves of working with these children and families.

Over time, gifts from donors have allowed the program to add important initiatives. Healing HEARTS magazine publishes the creative images and words of children treated at our hospital and their siblings. The Annual Day of Remembrance and Rededication brings together bereaved families in commemoration of their children.

A Legacy of Caring

When Sourkes and Cohen, the current Katie and Paul Dougherty Medical Director, retire in August 2023, they will leave a legacy of expertise and care. They hope the program will continue to expand by growing the team; venturing into new arenas, including supporting expectant parents who already know that their baby has a serious medical condition; and bolstering in-home support for children. Moving forward, the program will become its own division within the Department of Pediatrics—the School of Medicine and hospital are recruiting Palliative Care’s first division chief.

As a closing achievement, Sourkes (with two colleagues) co-edited the second edition of their book, Interdisciplinary Pediatric Palliative Care. One of her chapters ends with a 6-year-old boy named Andrew, was diagnosed with a rare form of leukemia in 2014, says her life became a “living nightmare.” Cohen, Sourkes, and their colleagues guided the family through treatment, hospice care, and bereavement. “Living through a child’s life-threatening illness is not just about supporting the child, but supporting the family through the journey ahead,” Levy said, in 2017. “I truly believe that the palliative care team is why I am still standing here today.”

The program also provides training for care team members and trainees, helping them understand the impact on themselves of working with these children and families.

Over time, gifts from donors have allowed the program to add important initiatives. Healing HEARTS magazine publishes the creative images and words of children treated at our hospital and their siblings. The Annual Day of Remembrance and Rededication brings together bereaved families in commemoration of their children.

A Legacy of Caring

When Sourkes and Cohen, the current Katie and Paul Dougherty Medical Director, retire in August 2023, they will leave a legacy of expertise and care. They hope the program will continue to expand by growing the team; venturing into new arenas, including supporting expectant parents who already know that their baby has a serious medical condition; and bolstering in-home support for children. Moving forward, the program will become its own division within the Department of Pediatrics—the School of Medicine and hospital are recruiting Palliative Care’s first division chief.

As a closing achievement, Sourkes (with two colleagues) co-edited the second edition of their book, Interdisciplinary Pediatric Palliative Care. One of her chapters ends with a 6-year-old boy named Andrew, was diagnosed with a rare form of leukemia in 2014, says her life became a “living nightmare.” Cohen, Sourkes, and their colleagues guided the family through treatment, hospice care, and bereavement. “Living through a child’s life-threatening illness is not just about supporting the child, but supporting the family through the journey ahead,” Levy said, in 2017. “I truly believe that the palliative care team is why I am still standing here today.”

The program also provides training for care team members and trainees, helping them understand the impact on themselves of working with these children and families.

Over time, gifts from donors have allowed the program to add important initiatives. Healing HEARTS magazine publishes the creative images and words of children treated at our hospital and their siblings. The Annual Day of Remembrance and Rededication brings together bereaved families in commemoration of their children.

A Legacy of Caring

When Sourkes and Cohen, the current Katie and Paul Dougherty Medical Director, retire in August 2023, they will leave a legacy of expertise and care. They hope the program will continue to expand by growing the team; venturing into new arenas, including supporting expectant parents who already know that their baby has a serious medical condition; and bolstering in-home support for children. Moving forward, the program will become its own division within the Department of Pediatrics—the School of Medicine and hospital are recruiting Palliative Care’s first division chief.

As a closing achievement, Sourkes (with two colleagues) co-edited the second edition of their book, Interdisciplinary Pediatric Palliative Care. One of her chapters ends with a 6-year-old boy named Andrew, was diagnosed with a rare form of leukemia in 2014, says her life became a “living nightmare.” Cohen, Sourkes, and their colleagues guided the family through treatment, hospice care, and bereavement. “Living through a child’s life-threatening illness is not just about supporting the child, but supporting the family through the journey ahead,” Levy said, in 2017. “I truly believe that the palliative care team is why I am still standing here today.”

The program also provides training for care team members and trainees, helping them understand the impact on themselves of working with these children and families.

Over time, gifts from donors have allowed the program to add important initiatives. Healing HEARTS magazine publishes the creative images and words of children treated at our hospital and their siblings. The Annual Day of Remembrance and Rededication brings together bereaved families in commemoration of their children.

A Legacy of Caring

When Sourkes and Cohen, the current Katie and Paul Dougherty Medical Director, retire in August 2023, they will leave a legacy of expertise and care. They hope the program will continue to expand by growing the team; venturing into new arenas, including supporting expectant parents who already know that their baby has a serious medical condition; and bolstering in-home support for children. Moving forward, the program will become its own division within the Department of Pediatrics—the School of Medicine and hospital are recruiting Palliative Care’s first division chief.

As a closing achievement, Sourkes (with two colleagues) co-edited the second edition of their book, Interdisciplinary Pediatric Palliative Care. One of her chapters ends with a 6-year-old boy named Andrew, was diagnosed with a rare form of leukemia in 2014, says her life became a “living nightmare.” Cohen, Sourkes, and their colleagues guided the family through treatment, hospice care, and bereavement. “Living through a child’s life-threatening illness is not just about supporting the child, but supporting the family through the journey ahead,” Levy said, in 2017. “I truly believe that the palliative care team is why I am still standing here today.”

The program also provides training for care team members and trainees, helping them understand the impact on themselves of working with these children and families.

Over time, gifts from donors have allowed the program to add important initiatives. Healing HEARTS magazine publishes the creative images and words of children treated at our hospital and their siblings. The Annual Day of Remembrance and Rededication brings together bereaved families in commemoration of their children.
Unraveling the Mysteries of a Rare Genetic Disorder

Stanford experts are making breakthroughs in treating 22q11.2 deletion syndrome.

BY SALLY WADYKA

Umless your family is affected by 22q11.2 deletion syndrome (22q11.2DS), you may have never heard of it. It’s estimated that one in 2,000 to 4,000 babies is born with this genetic disorder. While this might sound rare, it affects many areas of the body and can result in cleft palate, heart defects, poor immune system function, ear infections or hearing loss, seizures, autism, behavioral and emotional issues, and other conditions that dramatically impact a child’s health and quality of life.

Children with 22q11.2DS are missing a tiny piece of their 22nd chromosome, at a spot in the middle of the chromosome called q11.2. This complex disorder affects each child differently, ranging from mild symptoms to serious health problems. In adolescence and adulthood, the prevailing challenge becomes brain health—social anxiety, struggling to learn in a classroom setting, and sometimes more severe psychiatric disorders.

While there is currently no cure, most children with 22q11.2DS can live long, healthy, active lives if they receive early and effective interventions from specialists such as cardiologists, plastic surgeons, immunologists, neurologists, speech and physical therapists, and behavioral experts working together to provide comprehensive care.

And now, thanks to philanthropic support, physicians and scientists at the Stanford School of Medicine and Lucile Packard Children’s Hospital Stanford are making breakthrough discoveries in understanding the disease’s underlying mechanisms and improving treatments for its varied symptoms.

Researchers Unlock Clues in Developing Brain Cells

Candice Uytengsu Hamilton, a longtime supporter of Packard Children’s Hospital, understands the need to support neuropsychiatric challenges, especially for 22q11.2DS. The program she founded—the Uytengsu-Hamilton 22q11 Neuropsychiatry Research Program, housed within the Stanford Maternal & Child Health Research Institute (MCHRI)—is currently pursuing exciting new avenues of research for kids with 22q11.2DS. The program funds research to improve neurocognitive outcomes in children with 22q11.2DS, who have an increased risk of developing neuropsychiatric conditions such as anxiety, autism, attention-deficit disorder, and behavioral and learning disorders. 22q11.2DS is the strongest single genetic risk for schizophrenia and other psychotic disorders, making this work even more urgent.

One promising area of research includes a study led by Anca Pașca, MD, assistant professor of pediatrics in neonatal and developmental medicine at the Stanford School of Medicine. Pașca and her fellow researchers are profiling developing brain cells that carry the 22q11.2 deletion. “We are focusing on the function and number of mitochondria present early on in the development of the brain,” says Pașca. “We

Sergiu Pașca, MD

Sergiu Pașca, MD, Is Revolutionizing Research Into Brain Disorders

THERE IS NO CURE for 22q11.2DS. Stanford researcher Sergiu Pașca, MD, wants to change that. Often, understanding how cells behave is key to helping patients. Examining a cancerous tumor’s cells under a microscope, for example, can lead to targeted treatment. But neuropsychiatric conditions such as autism and schizophrenia are still diagnosed as they have been for over a century, based mainly on patient behavior.

Pașca—who trained as a physician in Romania and arrived at Stanford in 2009 for postdoctoral training—was frustrated that the underlying mechanisms of many brain conditions remain a mystery. So Pașca paused seeing patients to focus on his research. “I gave myself a deadline that if in 15 years of doing basic research, I’ll be able to have a larger impact, I’ll continue to do this,” he says. “If not, I’ll return and practice medicine full time.”

Switching gears has paid off, as Pașca has pioneered the most advanced models of the human brain that are revolutionizing medicine.

His lab collects skin cells from neuropsychiatric patients and reprograms them to become stem-like cells. Next, he aggregates these cells into 3D cultures—called organoids—and guides their differentiation to resemble specific brain parts.

These living models can be grown in a dish for years, providing insights into brain development.

“We also developed more sophisticated cellular models called assemboids that allow us to look at the cross talk between different brain regions,” says Pașca, the Bonnie Uytengsu & Family Director of the Stanford Brain Organogenesis Program at the Wu Tsai Neurosciences Institute. His models have significantly improved our understanding of Timothy syndrome, a rare form of autism. “I’m hopeful that we will be moving toward a therapeutic strategy very soon,” Pașca says.

His lab now hopes to unveil the roots of 22q11.2DS. “We’re only now starting to understand that disease,” he says, noting that more than 60 genes are involved.

Researchers from all over the world have contacted the Stanford Brain Organogenesis Program to learn more about Pașca’s organoids and assemboids. The lab also welcomes international students for weekend workshops. “It’s like a Martha Stewart-type show, where they see exactly how things are done,” Pașca says. “However, they have to pledge that they will function as ambassadors and teach others in their home institutions.”

With his 15-year deadline approaching, Pașca is optimistic. “Our work has already helped many others make discoveries about the hidden biology of the human brain,” he says. “Our hope is that this will lead to new treatments.”

—Kimberly Olson

Byline: Sally Wadyka

Cover:

Sergiu Pașca, MD

Caiaimage/monkeybusinessimages

Sergiu Pașca, the Bonnie Uytengsu & Family Director of the Stanford Brain Organogenesis Program at the Wu Tsai Neurosciences Institute. His models have significantly improved our understanding of Timothy syndrome, a rare form of autism. “I’m hopeful that we will be moving toward a therapeutic strategy very soon,” Pașca says.

His lab now hopes to unveil the roots of 22q11.2DS. “We’re only now starting to understand that disease,” he says, noting that more than 60 genes are involved.

Researchers from all over the world have contacted the Stanford Brain Organogenesis Program to learn more about Pașca’s organoids and assemboids. The lab also welcomes international students for weekend workshops. “It’s like a Martha Stewart-type show, where they see exactly how things are done,” Pașca says. “However, they have to pledge that they will function as ambassadors and teach others in their home institutions.”

With his 15-year deadline approaching, Pașca is optimistic. “Our work has already helped many others make discoveries about the hidden biology of the human brain,” he says. “Our hope is that this will lead to new treatments.”

—Kimberly Olson

Byline: Sally Wadyka

Cover:

Sergiu Pașca, MD

Caiaimage/monkeybusinessimages

Sergiu Pașca, the Bonnie Uytengsu & Family Director of the Stanford Brain Organogenesis Program at the Wu Tsai Neurosciences Institute. His models have significantly improved our understanding of Timothy syndrome, a rare form of autism. “I’m hopeful that we will be moving toward a therapeutic strategy very soon,” Pașca says.

His lab now hopes to unveil the roots of 22q11.2DS. “We’re only now starting to understand that disease,” he says, noting that more than 60 genes are involved.

Researchers from all over the world have contacted the Stanford Brain Organogenesis Program to learn more about Pașca’s organoids and assemboids. The lab also welcomes international students for weekend workshops. “It’s like a Martha Stewart-type show, where they see exactly how things are done,” Pașca says. “However, they have to pledge that they will function as ambassadors and teach others in their home institutions.”

With his 15-year deadline approaching, Pașca is optimistic. “Our work has already helped many others make discoveries about the hidden biology of the human brain,” he says. “Our hope is that this will lead to new treatments.”

—Kimberly Olson

Byline: Sally Wadyka

Cover:

Sergiu Pașca, MD

Caiaimage/monkeybusinessimages

Sergiu Pașca, the Bonnie Uytengsu & Family Director of the Stanford Brain Organogenesis Program at the Wu Tsai Neurosciences Institute. His models have significantly improved our understanding of Timothy syndrome, a rare form of autism. “I’m hopeful that we will be moving toward a therapeutic strategy very soon,” Pașca says.

His lab now hopes to unveil the roots of 22q11.2DS. “We’re only now starting to understand that disease,” he says, noting that more than 60 genes are involved.

Researchers from all over the world have contacted the Stanford Brain Organogenesis Program to learn more about Pașca’s organoids and assemboids. The lab also welcomes international students for weekend workshops. “It’s like a Martha Stewart-type show, where they see exactly how things are done,” Pașca says. “However, they have to pledge that they will function as ambassadors and teach others in their home institutions.”

With his 15-year deadline approaching, Pașca is optimistic. “Our work has already helped many others make discoveries about the hidden biology of the human brain,” he says. “Our hope is that this will lead to new treatments.”

—Kimberly Olson

Byline: Sally Wadyka

Cover:
Donor support is the difference between this research taking many years versus moving fast and finding answers as quickly as possible.

— ANCA PASCA, MD
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.

Richard Frassetti Planned Ahead to Help Children

THERE WERE FEW THINGS that Richard Frassetti loved more than farming. When Richard passed away a few years ago, he was recognized for his many agricultural achievements. His obituary read, “Richard was known to say he ‘never worked a day in his life’ so great was his love for farming and the food industry.”

Thanks to his thoughtful inclusion of Lucile Packard Children’s Hospital Stanford in his trust, Richard will also have a big impact on the future of children’s health.

Richard grew up in a family of farmers. His grandfather and great-uncle emigrated from Italy in the early 1900s and bought over 100 acres of land in Gilroy. His grandfather married and went on to run a dairy farm and grew vegetables on the property. Later, Richard’s parents, Henry and Alda Frassetti, lived on the family farm. Richard grew up watching his parents farm and was inspired to continue the family’s legacy of caring for the community and the land, which was carried forward by Richard.

His generosity will benefit children and families for years to come.

Richard passed away in 2020 and is remembered by his sister, Diane, his niece and nephew, and other close relatives and friends. He left the majority of his estate to Packard Children’s Hospital. David, a certified public accountant, is responsible for administering his friend’s trust.

“He didn’t have any children,” David explains. “He felt strongly that it should be donated to children.”

In recognition of Richard’s generous gift to our hospital, David and his wife, Susan, recently chose to place a plaque in front of our hospital’s Harvest Café, which includes artwork showcasing the Bay Area’s agricultural history. The location honors the importance of farming to Richard and his parents.

We’re grateful for the Frassetti family’s legacy of caring for the community and the land, which was carried forward by Richard.

Packard Children’s Hospital Stanford is the right place for Phoebe, says Amber.

Richard always loved farming. That’s where his heart was,” says David Piccardo, a friend of Richard’s for nearly 30 years. They got to know each other when David served as controller at Hansa-Pacific Associates.

“We would often talk about the ups and downs of farming—from market conditions to weather conditions. He always looked forward to the start of the growing season—and the end,” David adds with a laugh.

David and his wife, Susan, recently chose to place a plaque in front of our hospital’s Harvest Café, which includes artwork showcasing the Bay Area’s agricultural history. The location honors the importance of farming to Richard and his parents.

We’re grateful for the Frassetti family’s legacy of caring for the community and the land, which was carried forward by Richard.

His generosity will benefit children and families for years to come.

Packard Doctor Supports Children with Transplants

KEN SUTHA, MD, PHD, has a unique connection to his patients. Not only is he a Stanford Medicine Children’s Health nephrologist who cares for children with kidney disease, he is also a two-time kidney transplant recipient. Recently, he had the opportunity to compete at the Transplant Games in San Diego.

The Transplant Games are an Olympic-style competition for people with all kinds of transplants. “Growing up with kidney disease, I never imagined it would be possible to be competitive in any kind of sport, let alone win gold medals!” Ken says. “Thanks to the amazing power of transplant and my donors—including my living donor dad—I am thriving today.”

This year was extra special for Ken as he celebrated the fourth anniversary of his kidney transplant. He used this opportunity to raise awareness about organ donations, celebrate the full and active lives that transplant allows people to live, and raise money to support pediatric dialysis and transplant programs.

Packard Children’s Hospital Stanford

Thank You NOTES

There were few things that Richard Frassetti loved more than farming. When Richard passed away a few years ago, he was recognized for his many agricultural achievements. His obituary read, “Richard was known to say he ‘never worked a day in his life’ so great was his love for farming and the food industry.”

Thanks to his thoughtful inclusion of Lucile Packard Children’s Hospital Stanford in his trust, Richard will also have a big impact on the future of children’s health.

Richard grew up in a family of farmers. His grandfather and great-uncle emigrated from Italy in the early 1900s and bought over 100 acres of land in Gilroy. His grandfather married and went on to run a dairy farm and grew vegetables on the property. Later, Richard’s parents, Henry and Alda Frassetti, lived on the family farm. Richard grew up watching his parents farm and was inspired to continue the family’s legacy of caring for the community and the land, which was carried forward by Richard.

His generosity will benefit children and families for years to come.

Richard always loved farming. That’s where his heart was,” says David Piccardo, a friend of Richard’s for nearly 30 years. They got to know each other when David served as controller at Hansa-Pacific Associates.

“We would often talk about the ups and downs of farming—from market conditions to weather conditions. He always looked forward to the start of the growing season—and the end,” David adds with a laugh.

Richard passed away in 2020 and is remembered by his sister, Diane, his niece and nephew, and other close relatives and friends. He left the majority of his estate to Packard Children’s Hospital. David, a certified public accountant, is responsible for administering his friend’s trust.

“He didn’t have any children,” David explains. “He felt strongly that it should be donated to children.”

In recognition of Richard’s generous gift to our hospital, David and his wife, Susan, recently chose to place a plaque in front of our hospital’s Harvest Café, which includes artwork showcasing the Bay Area’s agricultural history. The location honors the importance of farming to Richard and his parents.

We’re grateful for the Frassetti family’s legacy of caring for the community and the land, which was carried forward by Richard. His generosity will benefit children and families for years to come.

Family, Friends Scamper in Memory of Phoebe

LIKE MOST FIRST-TIME PARENTS, Amber and Owen Lu were excited during their pregnancy with their daughter, Phoebe. But when their doctor ordered an ultrasound of Phoebe’s heart, they learned that their unborn baby had tetralogy of Fallot, a serious heart condition.

Further testing linked Phoebe’s condition to a rare genetic disorder called CHARGE syndrome. That’s when Amber and Owen turned to Lucile Packard Children’s Hospital Stanford. “We were confident that Stanford was the right place for Phoebe,” says Amber.

Phoebe was born Dec. 1, 2021, surrounded by an extensive care team. At first, she did well in the cardiovascular intensive care unit (CVICU). But a month later, she went into heart failure and was put on a form of life support called ECMO in the hope that she could be transferred to a Berlin Heart. Once on a Berlin Heart, a tiny pump designed to maintain blood flow, Phoebe could be added to the transplant list to receive a new heart.

However, moving Phoebe to the Berlin Heart proved more difficult than expected. Her care team—led by David Rosenthal, MD, director of the Pediatric Advanced Cardiac Therapies (PACT) program, and Michael Ma, MD, cardiothoracic surgeon and surgical director of PACT—came up with a new strategy to put her on a hybrid between ECMO and the Berlin Heart.

Phoebe improved in the weeks following the procedure, which helped her safely get off ECMO. Unfortunately, Phoebe’s health worsened, and after a little over three months in the CVICU, she passed away.

Although Phoebe’s time with us was shorter than any of us wished, she has made and will continue to make a significant impact at many levels, for our field, for our team, and for each of us as individuals,” Ma told Phoebe’s family. Ma has shared his team’s hybrid “Mechanical Circulatory Support” strategy with other children’s hospitals.

Last summer, Amber and Owen wanted to do something to help Rosenthal and Ma advance their research. They formed a team called the Phoebe Jeebies and raised over $2,600 in the Summer Scamper 5k and kids’ fun run. They also made their own gift. Thank you, Amber and Owen, for giving back to the programs that meant so much to you and Phoebe!
Thank You NOTES

Hyundai Hope On Wheels Supports Cancer Researchers

HYUNDAI MOTOR AMERICA has been a significant supporter of pediatric cancer research at Lucile Packard Children’s Hospital Stanford for more than a decade through its Hyundai Hope On Wheels program. Every time a new vehicle is sold in the United States, the Hyundai dealer makes a donation. To date, Hyundai Hope On Wheels has given Packard Children’s more than $3.7 million to fund groundbreaking research.

This year, Hyundai Hope On Wheels awarded $300,000 to Alice Bertaina, MD, PhD, and $200,000 to Adrienne Long, MD, PhD. Bertaina, section chief of the Pediatric Division of Stem Cell Transplantation and Regenerative Medicine and co-director of the Bass Center for Childhood Cancer and Blood Diseases at Packard Children’s, focuses her research on developing innovative approaches to stem cell transplantation. Long uses novel techniques to develop immunotherapies for pediatric solid tumors.

At a check presentation in September, Mateo Ocampo, 18, expressed his heartfelt thanks for the treatment he received at Packard Children’s last year that helped him face acute lymphoblastic leukemia.

“Thank you all for being part of my journey, and thank you, Hyundai Hope On Wheels, for donating to research so that hope and joy can be an option for other young people even after such a traumatic diagnosis,” said Mateo, who received a bone marrow transplant at our hospital six months after his diagnosis. Mateo shared his experience at our hospital, including the impact his social worker, Akilah Burford, MSW, had on his ability to move through treatment and thrive.

Thank you, Hyundai Hope On Wheels, for supporting lifesaving cancer research.

Gardner Capital Sponsors Summer Scamper

THANK YOU, GARDNER CAPITAL! Last summer, Gardner Capital became the first-ever presenting sponsor of the Summer Scamper 5k and kids’ fun run, which raised more than $614,000 for patients and their families at Packard Children’s Hospital.

Gardner Capital signed a three-year commitment of $225,000 that will ensure the continued success of this beloved community event.

“The West building will stay open as the renovation is completed in stages through 2028. “We are honored to partner with the David and Lucile Packard Foundation to grow our ability to deliver the strongest possible start for expectant moms and their babies,” says Paul King, president and CEO of Packard Children’s Hospital and Stanford Medicine-Children’s Health.

“The donation will help transform the hospital’s West building, which opened in 1991 and is the only facility in the Bay Area to offer obstetric, neonatal, and developmental medicine services all in one place. The redesign will ensure a more comfortable patient experience and facilitate lifesaving care for babies and mothers.

“We are honored to partner with the David and Lucile Packard Foundation to grow our ability to deliver the strongest possible start for expectant moms and their babies,” says Paul King, president and CEO of Packard Children’s Hospital and Stanford Medicine-Children’s Health.

“Through this gift,” Julia Koch says, “we hope to advance innovative research and allow more individuals and families to enjoy fuller lives.”

Packard Foundation Gives $100 Million To Transform Facilities for Mothers and Babies

LUCILE PACKARD CHILDREN’S HOSPITAL STANFORD has received $100 million from the David and Lucile Packard Foundation to modernize its obstetric and neonatal facilities.

The donation will help transform the hospital’s West building, which opened in 1991 and is the only facility in the Bay Area to offer obstetric, neonatal, and developmental medicine services all in one place. The redesign will ensure a more comfortable patient experience and facilitate lifesaving care for babies and mothers.

“Through this gift,” Julia Koch says, “we hope to advance innovative research and allow more individuals and families to enjoy fuller lives.”
Pediatric Emergency Department Caters to Kids

A NEW STANFORD MEDICINE PEDIATRIC EMERGENCY DEPARTMENT opened in August, offering a light-filled space designed to calm kids and families while medical professionals deliver advanced care. The facility, at 900 Quarry Road in Palo Alto, has a mountains-to-ocean river theme and is full of images of nature, interactive installations, and kid-friendly waiting areas. It includes two triage rooms and 15 patient rooms, three of which can be used for resuscitation and trauma.

“This new space gives us the opportunity to meet children and their parents where they are with design elements and visual imagery that strive to put them more at ease even when discussing potentially serious concerns,” says Andra Blomkalns, MD, professor and chair of emergency medicine at the Stanford School of Medicine.

The space is fully staffed with board-certified emergency physicians and pediatric emergency trained nurses and technicians, providing the highest level of care for ailments ranging from ear infections to major trauma.

Harvey Cohen, MD, PhD, Receives the Janusz Korczak Medal

Harvey Cohen, MD, PhD, was awarded the 2022 Janusz Korczak Medal. Presented by Jerry Nussbaum, president of the Janusz Korczak Association of Canada, the medal honors Cohen’s commitment to children’s health and well-being through his career in clinical care, teaching, and research.

Janusz Korczak (1878-1942) was a humanitarian, educator, children’s author, and pediatrician. A leading figure in the Polish Jewish community of the interwar era and during the Holocaust, he cared for children in the orphanage of the Warsaw Ghetto during the Nazi occupation of Poland.

At an award ceremony in October, Cohen said, “Janusz Korczak’s heroism and selflessness are unforgettable. He was a renowned advocate for children’s rights and independence. I am humbled to be associated with him as an advocate for children.”

Cohen was nominated for the award by Tad and Dianne Taube, generous supporters of Lucile Packard Children’s Hospital Stanford. Cohen is the Deborah E. Addicott – John A. Kriewall and Elizabeth A. Haehl Family Professor of Pediatrics at the Stanford School of Medicine. For the past 12 years, he has also served as the Kitty and Paul Dougherty Medical Director of Palliative Care at Packard Children’s Hospital. From 1993 to 2006, he served as the Arline and Pete Harman Professor and chair of the Department of Pediatrics, and Adalyn Jay Chief of Staff at Packard Children’s Hospital.

Packard Children’s Ranks Among Top 10 U.S. Children’s Hospitals

F OR THE THIRD STRAIGHT YEAR, Lucile Packard Children’s Hospital Stanford has been named among the top 10 children’s hospitals in the nation by the U.S. News & World Report 2022-2023 Best Children’s Hospitals survey.

The rankings place Packard Children’s Hospital as the top children’s hospital in Northern California and include it on the Best Children’s Hospitals Honor Roll, a designation awarded to pediatric centers that deliver exceptionally high-quality care across multiple specialties. In addition, the survey once again announced state and regional rankings; Packard Children’s Hospital ranked second among all Pacific-region and California children’s hospitals.

The survey recognizes the top 50 pediatrics facilities across the United States in 10 pediatric specialties. For the seventh consecutive year, Packard Children’s Hospital has achieved rankings in all 10 specialties. This year’s survey ranked four of the hospital’s specialties in the top 10, including two in the top five. These include nephrology (No. 2), pulmonology and lung surgery (No. 5), neonatology (No. 6), and neurology and neurosurgery (No. 7).

Celebrating its 31st anniversary in 2022, Packard Children’s Hospital is the youngest institution among the top hospitals, the rest of which range in operations between 70 and 165 years.

New Leader Selected for Pediatric Cardiology and Moore Heart Center

ANNE DUBIN, MD, professor of pediatrics, was appointed chief of the division of pediatric cardiology and director of the Betty Irene Moore Children’s Heart Center at Lucile Packard Children’s Hospital Stanford. She will build upon the legacy of Stephen Roth, MD, MPH, leader of the division and the heart center for 10 years.

Dubin is widely recognized as an outstanding clinician, mentor, and educator, as well as an innovative clinical investigator for her research on arrhythmias and cardiac resynchronization therapy in children with heart failure and congenital heart disease.

Dubin, who has been at Stanford since 1995, is also founding director of the Pediatric Arrhythmia Service at Packard Children’s Hospital.

She received her MD from the University of Rochester. She completed her pediatrics residency at Columbia-Presbyterian Medical Center and her pediatric cardiology fellowship at Children’s Hospital of Philadelphia, followed by advanced clinical training in cardiac electrophysiology at Yale New Haven Hospital.

Major Donation Benefits Nurses and Patients

N URSING SCIENCE AND WELL-BEING PROGRAMS at Lucile Packard Children’s Hospital Stanford have received a major boost, thanks to a $1 million gift from an anonymous donor. This generous gift will offer our nursing staff additional support they need to contribute valuable research for our profession and the patients we serve,” says Annette Nasr, PhD, RN, director of nursing research and evidence-based practice at Stanford Medicine Children’s Health. “Nurses bring a unique and crucial perspective to science, as we are at the patient bedside 24/7.”

Toddler Receives Life-Changing Heart Reconstruction

THREE-YEAR-OLD LIAM’S favorite play structure is the jungle gym. But not long ago, climbing it was a near impossibility.

Born with only one pumping heart ventricle instead of two, Liam could barely run, let alone climb. He endured two heart surgeries in his first two years of life. Then, he received a bold reconstruction of his heart. A team at Lucile Packard Children’s Hospital Stanford rebuilt, rewired, and reconfigured Liam’s heart with two pumping chambers.

Reconstruction is highly complex “but can enable a much better long-term outcome, with less need for future surgeries and avoidance of heart transplantation down the road,” says Michael Ma, MD, surgical director of the Complex Biventricular Reconstruction Program. If a normal heart is a “carefully coordinated Lego build,” he adds, Liam was born with a heart arranged in a very dysfunctional manner. “We rearrange and reshape those pieces to improve function and blood flow.”

Liam’s surgery took 18 hours. It’s a procedure done at only a few pediatric heart centers in the world.

After the surgery, Liam’s oxygen levels soared to a steady 97 percent. “We can now think about Liam living a long life and growing into an old man,” says his mom, Mai Nguyen. Today, Liam climbs the jungle gym and dreams of making it to the top one day.
"By being able to overcome life-threatening food allergies, I learned to persevere through challenges instead of avoiding them."
—JARED CHIN, 16, CLINICAL TRIAL PARTICIPANT

When Jared Chin was 4, he was diagnosed with severe allergies to peanuts and tree nuts. Just two weeks later, while on a family trip to San Diego, he had his first anaphylactic reaction. After that terrifying event, Jared became anxious about eating and his family started home-schooling him to keep him safe.

At age 9, Jared enrolled in an oral immunotherapy clinical trial at the Sean N. Parker Center for Allergy and Asthma Research at Stanford University to desensitize his body to his allergens. A year later, Jared was able to encounter his allergens without a reaction.

Today, he is grateful for how the trial changed his life. Jared, now 16, even participated in the 2022 Alcatraz Sharkfest Swim and raised nearly $7,000 for allergy research. Way to go, Jared!
Send warm wishes!

Make your holiday gift online!
You’ll have the option to send our official holiday card to someone special.

Elliot (age 10)
Little brother of Ronan, cancer survivor and cover kid

Donate now at supportLPCH.org/warmwishes