

Cancer and Blood Disorders Center



2023 Annual Report







Valley Children's provides nationally recognized care to 1.3 million children in California's Central Valley. As a leading pediatric cancer facility on the West Coast and the only provider of pediatric hematology and oncology services between Los Angeles and the Bay Area, Valley Children's Cancer and Blood Disorders Center treats a wide range of common to the rarest conditions.

Collaboration at every level – within the organization and nationally – is essential to our unwavering commitment to improving health outcomes for kids and providing the best treatment and therapies at the forefront of our industry.

In this report, you will learn about the strategic measures taken to optimize collaboration and the multidisciplinary approach that gives kids who are facing a life-altering diagnosis hope and a greater chance at getting back to being a kid. Valley Children's is renowned for its commitment to providing specialized clinical care that is tailored to the individual needs of each patient. Our team possesses a deep understanding of the specific challenges and complexities that children face when it comes to their health, and this expertise allows us to deliver targeted, evidence-based care that yields remarkable outcomes.

What sets Valley Children's apart is not just the exceptional clinical care we provide, but also the extensive ancillary care and support that accompanies it. The ancillary team plays a crucial role in ensuring that our patients receive comprehensive and holistic care. They provide a wide range of support services, including specialized therapies, coordination of appointments and consultations and emotional and psychological support for both the patients and their families. The end result is a collaborative approach that ensures every aspect of a patient's well-being is addressed – and that is how we achieve improved outcomes and a better overall healthcare experience.

Together, through specialized clinical care and comprehensive ancillary support that goes beyond any expectation, we are truly able to make a difference in the lives of our patients and their families.

Cancer and blood disorders, in their many forms, are a diverse adversary. To ensure that each and every patient has access to and receives the most appropriate and effective care for their condition and ever-changing state of progression, the team at Valley Children's Cancer and Blood Disorders Center relies on the many roles within a single child's care team to address the complexity of their diagnosis. Beyond the clinical care provided to children, ancillary support services available to them and their families contribute significantly to guarantee health outcomes. The collective efforts of case managers, nurse navigators, child life specialists, physical therapists and more play a pivotal role in enhancing a child's overall care experience and providing crucial support to families during their most difficult times.

Together, the Center's team has achieved unprecedented milestones for our region such as national designations for sickle cell and neurofibromatosis care, to name a few. These achievements serve as a testament to our unwavering dedication to our patients, tenacious pursuit of excellence and reinforced credibility of our clinics and specialty areas. Although such designations go beyond mere notoriety; it's about the doors they open to access specialized cancer

treatment for the kids we serve. These accolades signify that our hospital is not just a building, but a fortress of specialized training, equipped with cutting-edge resources and fortified by vital partnerships that makes the most advanced and specialized treatments and therapies available to the rural region we serve.

Our collective mission is clear: to heal and support our patients, and to do so, we are committed to working together – within and outside of our hospital walls – every step of the way.

The future of our patients depends on the best care that addresses every aspect of a child's needs. And through our combined expertise, we develop and diversify resources needed to face the multifaceted challenge of cancer and offer hope and healing to kids who depend on us.

An Oncology Nurse Who
Makes a Difference
Within and Outside
Hospital Walls

If you ever want to humble yourself in life, take a moment to watch a child battle cancer. It is beyond the bravest thing you will ever see.

Guadalupe "Lupe" Dominguez, Valley Children's Pediatric Oncology Nurse

Guadalupe "Lupe" Dominguez was a nursing student at Fresno State when she was diagnosed with acute promyelocytic leukemia. At 22 years old, Lupe recalled a time during her fifth semester when she went from critical care nursing class to an appointment at the cancer center. She then spent the next six months receiving chemotherapy.

Today, Lupe is 23 years cancer-free and a pediatric oncology nurse at Valley Children's, where she has dedicated her personal life and career to helping others.

As her colleagues can attest, there is certainly no limit to what Lupe can achieve. "As a valued nurse and brave cancer survivor herself, Lupe offers first-hand knowledge and experience that resonates with our kids and motivates them in a way that goes beyond any clinical knowledge and expertise," said Dr. Vinod Balasa, Valley Children's Cancer and Blood Disorders Center Medical Director. "She is compassionate in a way that is beyond measure."

As a respected expert in her specialized field, Lupe is passionate about Latino community outreach, educating healthcare professionals and helping children and young adults who have been diagnosed with leukemia. She has shared her clinical expertise, lived experience and best practices in her field through local and national clinical education seminars in Spanish for Promotoras and Entrevision. Lupe is also an Honored Hero for the Leukemia & Lymphoma Society (LLS) and has spent the last year participating in speaking engagements, LLS Latino outreach stakeholder meetings and as a patient ambassador.

Lupe recalled her experience after being linked with an LLS peer: "It was an inspiring feeling; it's an immediate bond when socializing with a fellow survivor. It's healing. It fills you with hope. It refuels your will to fight. It's priceless." And it is this same hope and connection that Lupe extends to others today as she continues to lead a life devoted to helping kids and families within and outside the hospital walls.

Dr. Fernandez is Recognized as the Leukemia & Lymphoma Society Physician Champion for Latino Outreach

Valley Children's hematologist/oncologist Dr. Karen Fernandez has been recognized by the Leukemia & Lymphoma Society Central Valley Region with the Physician Champion for Latino Outreach award. This worthy recognition acknowledges Dr. Fernandez for her leadership and commitment to enhancing services and support to Hispanic/Latino families facing blood cancers, in addition to providing vital education to care staff serving Hispanic/Latino communities nationwide.

"There is so much evidence that demonstrates cancer disparities in our Hispanic community, and particularly among children, but through national collaboratives and education I am confident that together, we can make a difference," said Dr. Fernandez. "To be recognized for work that is essential to the livelihood and well-being of others is a true honor."

Hispanics and Latinos are the largest minority group in the U.S., representing 18% of the total population, and despite extraordinary medical improvements in the treatment of cancer and increased survival rates for the general population, cancer continues to be the leading cause of mortality among this population.

Cancer disparities among Hispanics and Latinos are significant and the rate of acute lymphocytic leukemia and acute myeloid leukemia diagnoses among this population are astounding. Hispanic and Latino children not only have the highest incidence of these two major leukemia subtypes, but they also suffer worse overall survival rates when compared to non-Hispanic white children.

In an effort to reduce these disparities, Dr. Fernandez has shared her expertise on pediatric leukemia, access to quality treatment, the impact of survival in pediatric patients and supportive resources and services available on national platforms in English and Spanish. Her efforts have elevated this message to not only providers, but also to care teams across the U.S., which includes physician assistants, community healthcare workers, pharmacists and more.





Meet The Team

Physicians



Vinod **Balasa**, MD































Ruetima **Titapiwatanakun**, MD

Nurse Practitioners



Ratie
Baker, MSN, CPNP
Jill
Cielnicky,
DNP, FNP-C







Folmer, MSN, CPNP Giannetta, DNP, CPNP, FAANP









Sara **Jennings**, DNP,

Newly Diagnosed Oncology Cases

Brain / CNS

Pilocytic Astrocytoma

Craniopharyngioma	1
Ganglioglioma	2 5 1
Medulloblastoma	5
Meningioma	1
Pleomorphic Xanthoastrocytoma	1
Carcinoid	1
Neuroendocrine Tumor	1
Carcinomas	6
Adrenal Cortical	
Gastric Adenocarcinoma	1
Papillary Thyroid Carcinoma	
Cell Tumor	8
GCT	6
Sertoli	6 1 1
Juvenile Granulosa	1
Langerhans Cell Histiocytosis (LCH)	5
Leukemia	48
Pre B-ALL	33
Pre T-ALL	7
AML	6
APML	6 1 1
MPAL	1
Lymphomas	10
Burkitt	1
Anaplastic B-Cell	4
Classic Hodgkin	3 3 1 1
Diffuse Large B-Cell	1
Nodular Hodgkin	1
PMBCL	1
THECE	
Neuroblastoma	5
NBL	5
Nephroblastoma	g
Wilm's	ç
Sarcomas	11
Osteosarcoma	2
Rhabdosarcoma	-
Ewing's	2
NOS	

Service in Numbers

16

FY2023

Patient Visits

15,712

Hematology - 6,024 Oncology - 9,688

Unique Patients

4,367

Hematology - 2,859 Oncology - 1,508

Access to Care

Beyond providing the best care, Valley Children's ensures timely care that patients and families can rely on. With the best systems in place, kids can receive the lifesaving care they need and deserve. At Valley Children's, our access to care average for fiscal year 2023 is as follows:

Hematology



Referral to Appointment 33 days



Median Days to Schedule:

3 days

Oncology



Referral to

18 days



Median Days to Schedule:

2 days

Quality and Patient Safety

Valley Children's has been ranked among the best 3% in the country as a Top Children's Hospital by The Leapfrog Group for nationally recognized achievements in patient safety and quality of care. The Leapfrog Group is known to set the highest standards for healthcare, making the Top Children's Hospital recognition one of the most competitive awards American hospitals can receive. Valley Children's is just one 1 out of 8 children's hospitals that received this honor in the country.





Elite National Network

Valley Children's Neurocutaneous Syndromes Clinic, which is home to the Cancer and Blood Disorder Center's Neurofibromatosis (NF) Program, is now one of only 60 centers in the country to join the national Neurofibromatosis Clinic Network, established by the Children's Tumor Foundation. Valley Children's is the fourth hospital in California with this designation, which is granted to programs dedicated to improving clinical care and establishing best practices for individuals with neurofibromatosis (NF).

"When our program launched in 2020, we had ambitious goals in place to benchmark our standard of excellence and ensure the best care for kids in the Central Valley, so it is an honor to receive this designation," said Dr. Merveen Appu, Valley Children's pediatric neurologist and Neurocutaneous Syndromes Clinic director. "Our patients with neurofibromatosis undergo surveillance imaging and subspecialty evaluations and have the opportunity to discuss their questions with the appropriate specialist – all here, in one location – making us a true multidisciplinary clinic and easing the burden of families traveling far for care."

NF is the most common neurological disorder, caused by a single gene, which affects 1 in every 3,000 children and requires a lifetime of medical surveillance and care.

At the Forefront of Care

Since its inception in 2020, Valley Children's Neurocutaneous Syndromes Clinic has been the medical home to approximately 200 children with NF each year. Thorough evaluation of any child with known or suspected NF involves a collaboration with Valley Children's genetics department for confirmatory testing, as well as innovative therapies, newly FDA-approved medications and specialized screening services for those with early signs and symptoms of NFassociated cancers and lesions.

Valley Children's has experience treating neurocutaneous disorders with chemotherapy, MEK inhibitors, mTOR inhibitors, multiple tyrosine kinase inhibitors and immunotherapy treating neurocutaneous disorders. "We take an individualized approach to treatment tailored to each child," explained Dr. Audrey Green-Murphy, Valley Children's pediatric oncologist/hematologist, "with the consideration of surgery, medical therapy, combination therapy, clinical trials and multidisciplinary care."

Looking Ahead

"The NF future is bright and full of hope," added Dr. Green-Murphy. Listing several recent advances in the treatment of NF being offered at Valley Children's, she added "beyond selumetinib, the FDA-approved therapy for plexiform tumors, cabozantinib, mirdametinib and a few other therapies show promise for plexiform neurofibromas in NF1 patients. Bevacizumab is also being used in NF2 patients with great success for schwannomas."

As the Valley Children's Neurocutaneous Program strengthens, we look forward to building more support networks, bringing together local families with neurocutaneous disorders and helping patients connect so that no patient feels alone.



Meet Autumn.

Autumn was experiencing unexplained bruises, fatigue and pale skin that became so severe, it resembled the aftermath of an accident. It was August 2022 when her symptoms worsened so badly that it led her to a visit to Valley Children's Emergency Department.

After several labs and extensive diagnostic testing, Autumn found herself admitted to the hospital for further observation. It was during this hospital stay that Autumn was diagnosed with aplastic anemia.

Valley Children's pediatric hematologist/oncologist, Dr. Latha Rao explained, "Autumn had pancytopenia where all three blood cell types – white blood cells, red blood cells and platelets - were critically below the normal range. A bone marrow evaluation allowed us to rule out leukemia and all of her cell lines were not producing at adequate numbers - it was hypocellular. So, her diagnosis was based off her counts and marrow findings."

Expert Care With Compassion and Support

In the midst of uncertainty, Dr. Rao and the compassionate team at Valley Children's were beacons of much support for Autumn and her mom, Cindy.

As Cindy reflected on their journey, she shared, "Everyone was so patient with us every step of the way. I had so many questions – 'what does this mean, why this, why that, how often' – but the staff was incredibly helpful and explained things in a way that helped me and Autumn better understand."

A bone marrow transplant was not an option for Autumn, so the next best course of treatment was immunotherapy. For approximately 10 days during her hospital stay, she had a central line/PICC line placed and she received an IV medication called ATG, steroids and cyclosporine.

"Her clinical course became complicated when she presented with seizures in January 2023 with very low sodium levels and elevated glucose levels," added Dr. Rao. "But through collaboration with nephrology and endocrinology specialists, we switched Autumn to a different immunosuppressive medication and she quickly improved."

A Newfound Strength

Autumn, once known for her quiet and shy demeanor, discovered a newfound strength through her experience.

"The care team not only helped Autumn, but they truly encouraged her speak up, which fostered a sense of empowerment," shared Cindy. "Now, Autumn articulates her inquiries until she understands every aspect of her care, and the team continues to validate her every step of the way."

"Immunotherapy worked for Autumn, and after approximately nine months, she was finally taken off her medication and her counts have continued to remain normal, which was the improvement we were aiming for," added Dr. Rao.

Today, Autumn feels like herself again and is happy to have her energy back.



Valley Children's Vascular Anomalies Program: Pioneering Comprehensive Care in the Central Valley

In the heart of the Central Valley, the Cancer and Blood Disorders Center provides access to specialized care to the most vulnerable kids, especially for children grappling with vascular anomalies which present a myriad of challenges for affected children.

Broadly classified into vascular tumors and vascular malformations, the evaluation, diagnosis and treatment of these lesions requires the collaboration of a team of experts including, but not limited to, pediatric hematologist/oncologists, interventional radiologists, geneticists and genetic counselors, plastic and general surgeons – all of which make up Valley Children's Vascular Anomalies Program.

Vascular Tumors vs. Vascular Malformations

The terms vascular anomalies, vascular malformations and vascular tumors have commonly been used interchangeably when referring to vascular lesions that are present in children. We know that there are many different forms of vascular lesions, but in general, they can be classified into two main groups: vascular tumors and vascular malformations.

Vascular tumors are benign tumors that are formed from blood vessels and can grow abnormally. The most common of these are hemangiomas, both infantile and congenital. Less common are more complex lesions such as Kaposiform hemangioendothelioma (KHE).

Vascular malformations are lesions that are usually present at birth, but occasionally can be acquired. These lesions can involve abnormal development of capillaries, veins, lymphatics or arteries.

Breaking Ground for Kids with PROS

Treatment for vascular anomalies may include surgery, sclerotherapy, medications and sometimes watchful waiting. The goal of the Vascular Anomalies Program at Valley Children's Hospital is to provide not only the standard treatments but also access to newer therapies. As our knowledge of genetics has expanded, several genes and syndromes have been identified that can be associated with some of these anomalies.

A significant breakthrough in the field of vascular anomalies is the introduction of Vijoice (Alpelisib), a medication designed to treat specific malformations associated with PIK3CA-related overgrowth spectrum (PROS). PROS, stemming from a mutation in the PIK3CA gene, triggers abnormal growth in tissues, leading to vascular malformations. Alpelisib, approved by the Food and Drug Administration (FDA) over a year ago, has emerged as a game-changer by directly targeting PIK3CA-positive lesions. By targeting the PI3K protein and disrupting the signaling pathway responsible for abnormal growth, we are able to offer a tailored approach that brings new hope to affected children.

Alpelisib has proven to be a ray of hope for patients with PROS disorders, providing treatment options that were at one time inconceivable. Valley Children's acknowledges that it is not alone in incorporating Alpelisib into its treatment arsenal, but the collaborative effort to share knowledge and experiences ensures that this innovative medication reaches every child who stands to benefit from it. Above all, being at the forefront of using this groundbreaking medication means relief for families who previously had limited options for their child's care.





Meet Jeremy

He enjoys playing with magnetic tiles which he uses to build a colorful city for his superhero action figures. This artificial city is full of real excitement for friends like Captain America, Hulk, Thor, Batman and Spiderman, Jeremy's favorite.

Jeremy also lives with Hemoglobin H Constant Spring, a type of alpha thalassemia. He was diagnosed through newborn screening and received his first blood transfusion when he was 6 months old. Today, eight years later, Jeremy's imagination knows no bounds, as imaginative play is how he passes the time during the three to five hour-long appointments he has every three to four weeks.

Optimizing Care and Support

Although Jeremy has an inherited condition, it was a surprise to both his parents, who later learned through genetic counseling support that they were both carriers.

"Jeremy comes to every appointment with his younger siblings, Tinsely and Ryser, who also have the same diagnosis. All three of them are transfusion dependent, which means they HAVE to be transfused every three to four weeks to maintain an adequate quality of life," explained Dr. Latha Rao, Valley Children's pediatric hematologist/oncologist. "Each appointment starts with getting labs drawn and having an IV placed either by the RN or the vascular team who use an ultrasound machine. These chronic transfusions have side effects including iron overload which needs regular monitoring – yearly ultrasounds of the abdomen, echocardiograms, MRIs, measurement of iron in the body and audiology and endocrine evaluation. All three of them have different iron levels so are being managed slightly differently."

As regular treatments marked by transfusions and meticulous care became a rhythm in Jeremy's life, it was a beat that became amplified when his younger siblings were also diagnosed.

"We have been coming to Valley Children's since Jeremy was so young and beyond the exceptional clinical care we have received, there have also been so many supporting staff members who have helped us manage this along the way," shared Kong, Jeremy's dad. "From genetic counselors, we learned about this inherited condition and family planning. From case managers, we learned what thalassemia is and came to understand the challenges of Jeremy's body functions. Through dietary and nutrition, we discovered Jeremy's limitations and that he could not have lima beans. And our nurse navigator keeps us connected with the necessary specialists who help us manage it all."

A Superhero Like No Other

Like Spiderman in Jeremy's colorful, magnetic city, Jeremy is the leading superhero who has defeated the villain of uncertainty brought along by this genetic condition.

"Our entire experience required a lot of heart and I have been able to confidently get to that place because I have witnessed medical progress and positive impact that care has had on my kids' lives," added Kong. "I am grateful to all the staff at Valley Children's who continue to help us – they are the lifeline that my kids depend on and for that, I will forever be grateful."

Sickle Cell Disease Pediatric Center of Excellence:

Comprehensive Care at Every Stage of Life

Valley Children's has been recognized as a National Alliance for Sickle Cell Disease Center of Excellence. This is the highest designation possible for sickle cell treatment programs that successfully demonstrate having all of the essential elements and capabilities needed to provide the highest level of care from clinical trials, protocols and treatments, to diagnostics, personnel and linked partnerships.

"We are honored to achieve this designation which reinforces our dedication to helping kids with sickle cell disease (SCD) and that our program is equipped with the foundational components that create a landscape essential to providing the most advanced care," explained Dr. Bindu Sathi, Valley Children's pediatric oncologist/hematologist and Sickle Cell Disease Program director.

As a designated center of excellence, Valley Children's SCD program can participate in newly approved therapies and clinical trials only available to those centers who have the fundamental elements that support these therapies.

Apheresis Program: Pioneering Pediatric Treatment

The SCD treatment program at Valley Children's is augmented by the innovative Red Cell Apheresis program, directly impacting the quality of care our patients receive. The apheresis machine allows for efficient red blood cell exchange in children with SCD and helps reduce complications of SCD by removing the sickled red blood cells and replacing them with healthy red blood cells from donor blood.

Valley Children's Healthcare has the third-largest SCD program in California and since the launch of the apheresis program, hospital admission rates for SCD crisis for patients in the apheresis program have been reduced by 100%. The exchange transfusion process at our Center takes approximately two to three hours depending on a patient's individual circumstance, which previously could have lasted up to 10 hours with manual exchange. Our team has managed to develop best practices for administering apheresis and have standardized a process for doing so successfully with a single needle.

Treatment and Transition: Covering Every Aspect of Care

At the heart of effective care lies a key element: care at every stage of life with every shift in medical and personal complexity. It is also important to transition adolescent and young adult patients to adult care without any delay.

"SCD is something someone is born with so it is essential to provide them with the appropriate care and support from newborn screening, infancy and school-aged years, to teens, young adulthood and beyond. This designation is the gateway to doing that," added Dr. Sathi.

Valley Children's comprehensive care approach involves a dedicated social work team, nurse navigators, skilled nurses, rehabilitation specialists and pulmonologists, to name a few. This collaborative effort ensures that every patient's needs are not just met but addressed simultaneously, providing a full-fledged and streamlined healthcare experience.

Collaboration to the Core

Valley Children's staff provide not only healthcare, but through access to treatment therapies and trials, they are also able to give patients and families hope. This hope is strengthened with the collaboration of centers all over the country who are working together to advocate and promote for comprehensive care that improves the health outcomes, quality of life and survival for patients with sickle cell disease.

In addition to being instrumental in achieving the designation as a National Alliance for Sickle Cell Disease Center of Excellence, Dr. Sathi actively engages in discussions at the state and national levels to help elevate the standard of care across the nation. In December 2023, Dr. Sathi and co-authors shared their expertise through oral presentations at the American Society of Hematology Annual Meeting on the role of menstrual bleeding assessments in sickle cell clinics in improving quality of care for women and on disease modifying therapy shifts seen in adolescence.

"To be at the forefront of such medical advancements is a tremendous privilege because through shared insights and data with other centers in the State and across the country, we are able to continually advance the momentum that is paving the way for lifesaving treatment available to patients with sickle cell disease," added Dr. Sathi.



Valley Children's is the only pediatric National Alliance Sickle Cell Disease Center of Excellence in the Central Valley, and just

of 4 in California.

Each year, approximately

2,000

children in the United States are born with sickle cell disease.

The Fresno Truck Center Childhood Cancer Survivorship Program

Valley Children's is dedicated to providing programs that enrich the lives of our patients and their families, and the Fresno Truck Center Childhood Cancer Survivorship Program does just that. Aimed to improve the quality of life for survivors by providing ongoing support and resources, a few highlights from the last year addressed the physical, emotional and psychological needs of our patients and those from other facilities who have completed cancer treatment.

"Survivorship has become a vital component of cancer care as it enhances overall well-being and long-term health outcomes," explained Dr. John Gates, Valley Children's pediatric hematologist/ oncologist and Fresno Truck Center Program director. "We truly have a special program that promotes a sense of community and empowerment – one that I am proud to be part of – because of the genuine way it helps our survivors transition to a fulfilling life after cancer."

Embracing Change

While the theme of the Fresno Truck Center Childhood Cancer Survivorship Program's 8th Annual Conference, hosted in partnership with the Leukemia and Lymphoma Society (LLS), was "Embracing Change: One Step at a Time," it is certainly a concept that has become essential in much of our education throughout the year.

At this event, families affected by childhood cancer survivorship learned about practical ways to embrace and lean into life's changes. Participants enjoyed the opportunity to connect with other survivors and parent caregivers, including keynote speaker Michelle Marks, who is a parent and shared her passion for advancing cancer research, ensuring access to affordable care and innovative therapies, and improving the lives of cancer patients and their families.

Also, earlier in the year, Valley Children's Pediatric Oncology Social Worker Alistair Robertson participated as a keynote speaker in a national conference with LLS that addressed parenting and caregiving for children with cancer. He discussed the range of emotions families can experience at the time of diagnosis through treatment and on through survivorship.

"It was an honor to share insight with some of the bravest and brightest in the country," shared Alistair. "Events like these serve as a great reminder of the important work we do – to not only help patients and families – but to also foster opportunities for them to come together, because shared experience is powerful and can truly be life-changing."

Turning the Page: Survivorship Scholarship

The Fresno Truck Center Childhood Cancer Survivorship Program is one-of-a-kind in many ways, and one of those ways included offering academic and vocational scholarships to its members. In 2023, scholarships were awarded to 34 recipients. As part of the application process, each recipient shares their goals along with letters of recommendation and answers the question: "What does being a childhood cancer survivor mean to you?"

Zachary, a student at Fresno City College majoring in the field of social work, shared, "Being a survivor means that no matter what you are up against, no matter what you are struggling to overcome, giving up is not an option."

Soren, a Valley Children's pediatric cancer survivor, shared his goal of becoming a nurse at the hospital that saved his life [Valley Children's], "Everything happens for a reason, and my experience will help me be an empathetic and supportive oncology nurse. I wouldn't be cancer-free without the support of my family, friends and the Valley Children's nurses and doctors who worked so hard to help me fight for my life."



Educate.





Empower.

Publications

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