

Cancer and Blood Disorders Center



2022 Annual Report





Through a rich history, you gain insight from the past, which improves our ability to provide care in the present and fosters opportunity and innovation for the future. And for seven decades, Valley Children's has done just that through our relentless commitment to improving the health and well-being of kids in the Central Valley. In this annual report, you will see this evidence in the many stories you will find with the recurring theme of research and work that is being done today that will only continue to advance and transform care for the future.

As one of the leading pediatric cancer facilities 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, including an outpatient unit and 36-bed inpatient unit, is part of a network that provides care to 1.3 million children in the Central Valley. With the highest level of quality and measurable results, our teams remain committed to building on the strong foundation of our history to deliver the most advanced care kids can count on today, tomorrow and for generations to come.

As the trusted champion for kids in the Central Valley, our team is committed to excellence in everything we do. It is with unwavering dedication, compassion and renowned expertise that our teams have surpassed the test that is known as the healthcare storm of the century, and continue to deliver evidence-based, quality care each and every day.

With the role of healthcare systems rapidly changing, Valley Children's Cancer and Blood Disorders Center will continue to pioneer the transformation and innovation of exemplary care for kids. It is an approach to care that goes beyond providing life changing treatment, but also extends to providing an exceptional patient experience with each encounter that makes all the difference in the lives of our patients and their families.

For the passion to improve the health of kids in the community we serve, and the continued collaboration with peers across the country, it is expert care that comes from the heart that you can count on at Valley Children's Cancer and Blood Disorders Center.



Today, children who are diagnosed with cancer have a remarkable 85% survival rate, which is a tremendous improvement compared to the fraction of children who lived to see their next birthday just 50 year ago with a similar diagnosis.

The increased odds of leading a thriving and full life after a cancer diagnosis is not a spontaneous development, but a testament to the worldwide effort to cure cancer achieved through advances that have been made possible only with ongoing collaborative research, clinical trials, shared data and innovation.

As providers, we are committed to ensuring compassionate care to every patient regardless of their condition or diagnosis. And to be great providers, we need to arm ourselves with the knowledge, expertise and ongoing developments in the field because no one approach is sufficient to manage and successfully treat the infinite variety of cancer and blood disorders.

In this annual report, you will find the many contributions Valley Children's Cancer and Blood Disorders Center makes to advancing care, as well as the continuous efforts to transform and implement the most effective treatment plans for the 180 kids who were newly diagnosed with cancer at our Center in fiscal year 2022. In addition, for each of the more than 13,000 patient visits we encountered, we are proud to offer some of the latest therapies as a member and a top enrolling site in the world for oncology protocols through the Children's Oncology Group (COG), and as one of only 141 federally funded hemophilia treatment centers (HTC) in the country.

While our fight to cure these life-threatening diseases continues, our patients who fight alongside us can be assured that they have access to the most innovative and state-of-the-art care available – because they deserve nothing less than the best.



As we celebrate 70 years of Valley Children's Hospital, it serves as a reminder of how far we have progressed in medicine. At the time of our founding, the survival of children with cancer was abysmal and treatments such as chemotherapy were in their infancy. A dedicated effort was made to enroll children with cancer in clinical studies, lobby for government funding and most importantly, organize the collaboration of pediatric healthcare institutions to make rapid progress in treating children with cancer and blood disorders.

Today, Valley Children's Hospital participates in several research collaboratives to ensure that the children of the Central Valley have access to the most up-to-date and advanced therapeutic options. We consistently rank in the top 10% for enrolling children in research studies and take great pride in the excellent work we perform. Our team has been recognized nationally for our efficiency, organization and accuracy in

research work all while providing compassionate and equitable care to our community. The accomplishments of our team have led to several authored peer-reviewed publications in the fields of both hematology and oncology, showcasing the impact of our efforts. Most importantly, the incorporation of resident mentorship allows knowledge and experience to be passed on to the next generation of physicians.

Now, through all the initiatives above, the majority of children can be cured of their cancer. The availability and focus on research here at Valley Children's ensures that the future for the children of our community will be in good hands for 70 more years and beyond.

Faisal Razzaqi, MD

Valley Childen's Pediatric Hematologist/Oncologist

Meet The Team

Physicians



Vinod **Balasa**, MD



Vonda **Crouse**, MD



Karen Fernandez, MD



John **Gates**, MD



Audrey Green-Murphy,



J. Daniel **Ozeran**, MD, PhD



Latha **Rao**, MD



Faisal **Razzaqi**, MD



David Bindu Samuel, MBChB, MD Sathi, MD





Wendy **Tcheng**, MD



Ruetima **Titapiwatanakun**, MD

Nurse Practitioners



Katie **Baker**, MSN, CPNP



Jill **Cielnicky**, NP



Kelly **Folmer**, MSN, CPNP



Terea **Giannetta**, DNP, CPNP, FAANP



Pam **Marsh**, DNP, CPNP

Service in Numbers

180

Newly Diagnosed Oncology Cases

Blastomas	21
Ganglioneuroblastoma	1
Hepatoblastoma	3
Nephroblastoma (Wilms) Neuroblastoma	8 7
Retinoblastoma	2
Retinoplastoma	2
Brain / CNS	42
Carcinomas	12
Thyroid	9
Other Carcinomas:	
Adenocarcinoma	1
Nasopharyngeal Carcinoma	1
Renal Cell Carcinoma	1
Genitourinary (Genital Organs)	8
Langerhans Cell Histiocytosis (LCH)	3
Leukemia	55
Lymphomas	10
Hodgkin's Lymphoma	4
C-11-11-11-11-11-11-11-11-11-11-11-11-11	25
Sarcomas	25
Soft Tissue:	4.4
Sarcoma, NOS	11
Ewing's Sarcoma	6 1
Rhabdomyosarcoma	1
Bone:	
Ewing Sarcoma	1
Osteosarcoma	6

FY2022

Patient Visits

13,923

Hematology - 5,977 Oncology - 7,946

Unique Patients

4,020

Hematology - 2,587 Oncology - 1,453

Access to Care

Beyond providing the best care, Valley Children's ensures timely treatment 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, urgent referrals are seen within 24-48 hours and our access to care average for fiscal year 2022 is as follows:

Hematology



Referral to
Appointment:

28 days



Median Days to Schedule:

4 days

Oncology



Referral to Appointment: 15 days



Median Days to Schedule:

2 days

TOP HOSPITAL 2022

Quality and Patient Safety

Valley Children's has again been named a Top Children's Hospital by The Leapfrog Group for exceptional achievements in patient safety and quality of care. The Leapfrog Top Children's Hospital recognition, awarded to only 5% of the nation's hospitals, is one of the most competitive awards American hospitals can receive. This is the third time in four years Valley Children's has received this award.



Research: Investigative Work to Transform and Save Lives

Discover, detect, prevent and treat. For these reasons, the investigative work of our research teams remains fundamental to the care provided at Valley Children's Cancer and Blood Disorders Center. In order to provide state-of-the-art care for our patients, our Center is a member of the Children's Oncology Group (COG) and a participant of industry-sponsored clinical trials which allow us to offer our patients access to dozens of innovative protocols for treating childhood cancer. And through enhanced therapies and supportive care, Valley Children's cancer patient cure rates average 85%.

"Our department strives to give hope to families by meeting disease challenges through advancing knowledge and providing ethical, innovative treatment options closer to home", said Padma Desai, Valley Children's research manager. "We collaborate with some of the best subspecialists in genetics, maternal-fetal medicine, neurology, pulmonology, cardiology, surgery and more to provide access to the latest and novel, cutting-edge treatments

through innovative clinical trial participation opportunities for kids in the Central Valley."

In 2022, Valley Children's was one of the top enrolling sites for the Centers for Disease Control and Prevention (CDC) Community Counts Hemophilia Project in the Western States, Region IX with 179 participants for the performance period ending in September 2022. Valley Children's has also received membership by invitation to several reputable regional and national consortia including the Pacific Sickle Cell Research Consortium (PSCRC) and the American Society of Hematology (ASH) Research Collaborative.

"By providing eligible patients with the opportunity to participate in the latest clinical trials, we are increasing their odds of survival while paving the way for others," added Desai. "Beyond the work, it is truly the commitment of our patients who are trailblazing the way in our fight against cancer and blood disorders."



Hematology Data Compliance Score: Oncology Quarterly
Data Compliancy Score:
(as of Sept. 30 2022)

100%



Valley Children's is among the

TOP **10-20**%

enrolling site for several COG pediatric oncology protocols

Valley Children's cancer patient cure rates average



Meet The Team

Research Manager

Padma Desai

Oncology Research

Linda Grigsby Winter Olmos Maram Kiran Adriana Lopez Christine Edwards Kelsey Mello

Hematology Research

Sarah Saravia Brenda Lopez Claudia Nayares

A Legacy Carried On

A Children's Oncology Group (COG) principal investigator (PI) oversees the implementation of clinical trials, ensuring compliance with institutional review board (IRB) regulations, researches education for staff and manages timely and accurate reporting of data. Audits are routinely conducted by COG every three years and since 1987, these have been led by Dr. Vonda Crouse, Valley Children's oncologist.

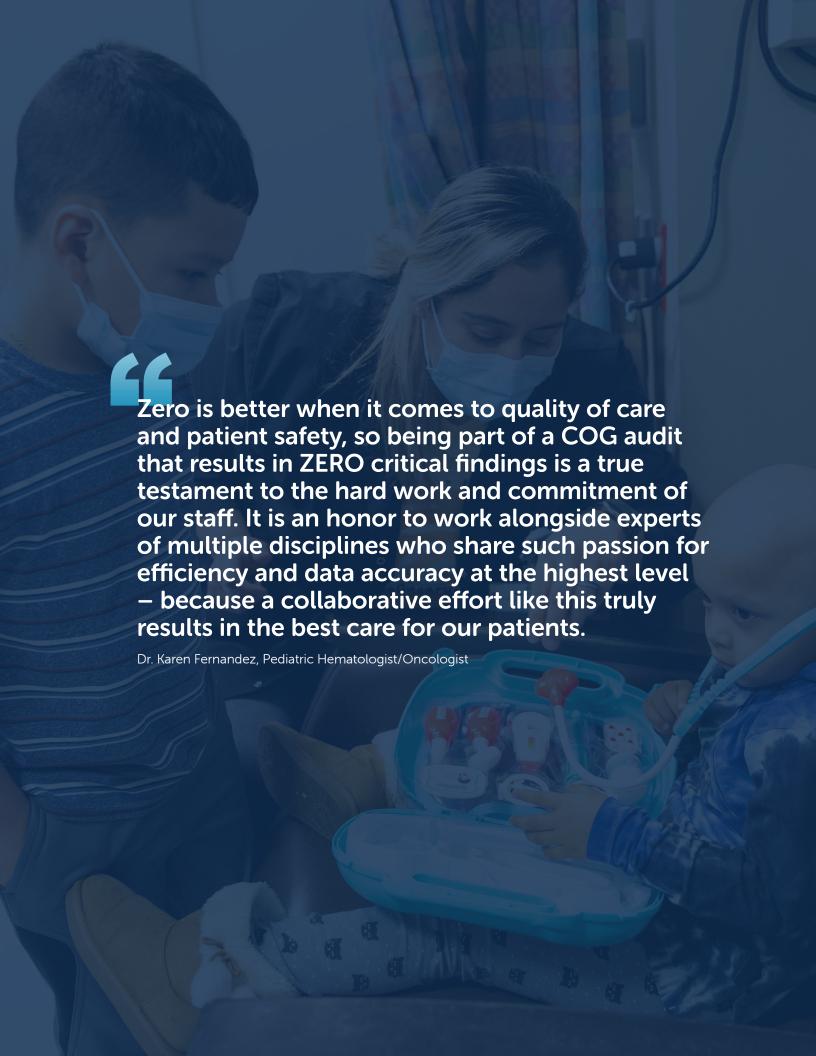
"It has been a great privilege to see firsthand how cutting edge advances of pediatric cancer has helped our community in the Central Valley," said Crouse. "I am grateful to Dr. Karen Fernandez for graciously accepting the role of PI. She will do a tremendous job that will continue to benefit our team at large."

Over a period spanning more than three decades, Dr. Crouse led 11 successful audits as the principal investigator for COG at Valley Children's.

"Being the COG principal investigator for Valley Children's Hospital is exciting and intimidating at the same time," said Dr. Fernandez. "I am thankful for the legacy of Dr. Crouse maintaining COG accreditation for more than 30 years, and I am also honored for the opportunity to represent our institution, and serve as the principal investigator. I hope to increase accruals of therapeutic and non-therapeutic studies, as well as to integrate digital technology into our operations."







Children's Oncology Group (COG) Audit: Reliable Care Others Can Count On

Quality and patient safety are central to everything we do at Valley Children's, which is just the case when it comes to accurate and timely documentation if an adverse event (AE) occurs. Such diligent systems are an essential component for safely conducting clinical trials and providing quality data for all professionals who are part of a greater care team.

COG accreditation is given to institutions that meet stringent criteria for providing high quality of care throughout various on-site disciplines and sub-specialties. Being one of the 150 worldwide COG member institutions is an affirmation of the high quality multidisciplinary approach to pediatric cancer in the Central Valley.

During Valley Children's COG audit, it was noticed that comprehensive adverse events (AE) source documentation detailing an event, grading and study attribution was sporadic. And, although all patient AEs were reported accurately, external AE log documentation was inconsistent. As a result, Valley Children's worked with all care team professionals to standardize real-time AE reporting in the electronic medical record system – Epic – and eliminated the need to update external AE logs entirely.

"Continuous improvements were implemented around leveraging Epic for improved real time research documentation around informed consenting, eligibility confirmation, risk stratification and adverse event notification in order to utilize Epic tools and research task features," explained Padma Desai, Valley Children's research manager. "These tools were developed and deployed in collaboration with oncology clinical team members and Epic build partners, as well."

The transition to digital reporting of adverse events in EPIC allowed everyone who is part of a patient's care team to access data in real time. If an adverse event did occur, notifications were instant and timely which resulted in improved workflow efficiency, data entry accuracy and overall patient safety outcomes. Findings from this improved process were shared at the COG fall meeting with rest of the member institutions.

"Using AE reporting within a patient's electronic medical record ensured efficient and synchronous clinical workflows with minimal delays in communication of AEs that can affect patient safety and research status," said Fernandez.

Additionally, the COG audit indicated that no critical or major deficiencies were identified, minor findings resulted in corrective and preventive actions (CAPA) which were accepted by COG.

"In my view, a successful audit is a loud statement of the quality of cancer clinical care provided at Valley Children's, not only from the oncologists, but also from the front office staff, nursing, case manages, navigators, pharmacy, laboratory, pathology, surgery, radiology, radiation oncology and psychology teams," added Dr. Fernandez. "Our clinical research associates do all the heavy lifting to ensure that all the clinical data involving research is accurately and timely reported back to COG, and together, it is a true team effort."



ATHN10: Genetic Testing for Rare Coagulation Disorders

The Rare Coagulation Disorders Project is a multicenter effort in collaboration with the American Thrombosis and Hemostasis Network (ATHN) to offer free genetic testing for individuals with bleeding or clotting disorders who choose to participate. Genetic results will contribute to the ATHN dataset – a safe and secure, national database that will help providers and researchers gain a better understanding of rare bleeding and clotting conditions in order to advance treatment and enhance the lives of patients.

"Through the end of 2022, Valley Children's had 18 patients enrolled in this study. Once enrolled, a patient's blood sample is tested per the ATHN10 genetic panel which consists of 29 genes that may have a direct relationship to rare bleeding and clotting disorders," explained Dr. Balasa. "These genetic results facilitate further patient treatment management, including additional genetic counseling, as appropriate."

The study also validates the ATHN10 genetic panel for reliable genetic diagnostic testing for rare coagulation disorders.

The ATHN dataset is foundational to improving our research and knowledge of bleeding disorders, especially those of the rarest kind. The impact of this work has the potential to transform care plans and profoundly enhance the lives of our patients.

Dr. Vinod Balasa, Valley Children's Cancer and Blood Disorder Center Medical Director and Rare Coagulation Disorders Project Principal Investigator

Meet Kobe

A decade ago, he was just 2 weeks old and experienced abnormal bleeding which was quickly noticed by a pediatrician. Further blood work led to the rare diagnosis of hypofibrinogenemia. Kobe's rare disorder is associated with easy bruising and can lead to excessive bleeding with any injury, and invasive or surgical procedures.

Hypofibrinogenemia is a rare bleeding disorder caused by one's inability to make enough of the blood clotting protein, fibrinogen. As a result, the body cannot form a strong and firm blood clot to stop bleeding. It is critical to be aware of this condition in order to institute preventive measures prior to high-risk procedures or surgeries, and also to administer appropriate therapy when bleeding occurs. Kids with this condition are advised to avoid certain medications which can interfere with clotting and are also provided with education regarding activities and sports that are suitable for them to participate in. Any minor injury that may be of minimal concern in normal individuals may lead to life-threatening complications in the affected children.

These are precautions that Kobe's mom, Leticia, does not take lightly in order to prevent severe injury.

"Over the last decade, I have had to make sure that Kobe isn't living in the fast lane which can be difficult sometimes, especially with a young and active boy," said Leticia. "We did have to limit Kobe's extracurricular participation in contact sports like football and soccer because the injury he can potentially sustain is not worth the risk. Although, he does everything else other children his age can do - we just do it with extra caution to ensure his safety."

At 10 years old, a follow-up appointment at Valley Children's led to the option to participate in the Rare Coagulation Disorders Project.

"Until this testing, we believed Kobe's condition was something that he simply developed - we know more now than we have ever known before," explained Leticia. "When it comes to your child's health, knowledge is power, so I am grateful for the opportunity to participate in a study that supports a national effort to help other kids like Kobe."

"Hemophilia treatment centers from all over the country and ATHN are committed to improving the quality of life for people with bleeding and clotting disorders – patients like Kobe who participate in this study will help us do just that," added Dr. Balasa.

Bleeding Disorder Surveillance: A National Collaboration to Improve Detection

Valley Children's was one out of 13 regional hemophilia treatment centers (HTC) in the Western Region to participate in the Centers for Disease Control and Prevention (CDC) Community Counts hemophilia project. This study was established to monitor the health and safety of patients with bleeding disorders, provide free inhibitor testing to patients with hemophilia A and B and to enhance the HTC national database by conducting site-specific research.

"The community benefits of this study will be transformational to the knowledge we have about bleeding disorders and the care we can provide to patients for generations to come," said Dr. Vinod Balasa, Valley Children's Cancer and Blood Disorders Center medical director and principal investigator of this study. "Through data collection, we can identify opportunities to prevent potential complications and improve overall care for patients while shaping best practices across the country."

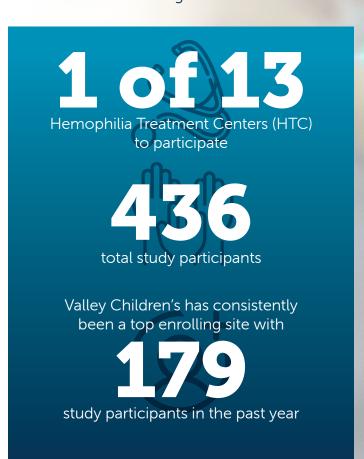
Centralized inhibitor testing for either screening or confirmatory measures is provided to participating patients free of charge. In addition to being very helpful in the patient's clinical management, the information gathered through this testing will enhance the CDC's national database in order to establish national estimates of new and existing inhibitor cases, identify inhibitor trends over time and potential outbreaks, as well as determining any factors that might influence how inhibitors develop.

"Through a network of experts frequently assessing and contributing to the HTC database, we are afforded the opportunity to explore different topics and trends specific to our region and patient population," added Dr. Balasa.

Since the Community Counts project serves as a national data source for bleeding disorder-specific measures at the federal level, critical information on the occurrence, distribution and complications of bleeding disorders can help change and improve best public health practices at the local, regional and national levels.

"Data and research is how we ensure consequential changes and advances in the care we provide to our patients. This study helps us do that," added Dr. Balasa.

This project continues to provide an avenue to obtain reassuring results for the patients and families from a reputed lab in regards to development of inhibitors and infection exposure in a very high-risk population of individuals with bleeding disorders.





Gabby's Story: Neurofibromatosis of the Rarest Kind

There are two forms of neurofibromatosis (NF) - NF1 and NF2 and both involve changes in proteins that are tumor suppressors. When the protein is abnormal, it is like having a light switch stuck "on," forcing the nerve cells to grow out of control.

The rarer of the two is NF2, which is a genetic abnormality in the Merlin protein. When this protein is abnormal, tumors grow along nerves, skin lesions may appear and eye problems may develop. Tumors are typically located around the nerves that help with hearing (vestibular schwannomas), spinal nerves or tumors from the meninges (tissue surrounding the brain and nerves). Patients with NF2 need to be followed by a team of doctors experienced with NF and should have routine surveillance and imaging starting around 10 years of age to monitor for tumors that can be aggressive and life threatening.

Signs of NF2 can often be overlooked when they present in childhood, especially for children who do not have a known family history of NF2 ... and this was just the case for Gabby.

At 16 years old, Gabby was an active teenager who spent much of her free time with her family and loved playing and crafting with her toddler niece and cousins. One morning at school drop-off, Gabby's mom noticed her dragging her left leg as she was walking from the car. Gabby shared that she felt severe tingling and numbness on her entire left side which was very alarming. That day, school drop-off turned into a pit stop on the way to a local hospital, which later resulted in a transfer to Valley Children's. Gabby was diagnosed with NF2 – she had tumors of the rarest kind around her spine and nerves involved with hearing. Her weakness

was caused by the development of a cervical meningioma that if left untreated, would have left her paralyzed from the neck down, in need of a ventilator to breath, and would likely have taken her life.

"There are limited treatment options for patients like Gabby, but we were able to perform a neurosurgical resection and will follow her closely for recurrence and the possible need for radiation therapy," explained Valley Children's Cancer and Blood Disorders Neuro-oncologist, Dr. Audrey Green-Murphy. "While Gabby had some difficulty post-op due to the size of the tumor resection and the need of a ventriculoperitoneal shunt, she has healed and is thriving."

Gabby's care team includes a neurologist, neurosurgeon and oncologist. Together, they will follow her symptoms, monitor for any changes in her hearing, watch for tumor growth and most importantly, help her continue to heal physically, emotionally and spiritually.

"After Gabby's second surgery, we got a glimpse of her old self again," said Alexandria, Gabby's sister. "And today, she is happy, healthy and back to being active with the family again. We prayed for a miracle, and I really believe that our prayers were answered in the form of what is Gabby's care team at Valley Children's. They saved her life."



1 in 25,000

is born with neurofibromatosis type 2 (NF2)

50%

of people with NF2 inherit the mutation, while the remaining have a spontaneous mutation in the NF2 gene

††††† ††††† ††††† 15 people

are born with NF2 each day; that is a new NF2 patient every 90 minutes



More Than Surviving: Living Cancer Free and Thriving

Just 50 years ago, a fraction of children diagnosed with cancer lived to see their next birthday. Today, kids with cancer have a remarkable 85% survival rate. As childhood cancer survivors grow into adulthood, we continue to learn more about the potential physical, emotional and other long-term side effects of their cancer treatments.

There are approximately 1,500 members in The Fresno Truck Center Childhood Cancer Survivorship Program that is led by Dr. John Gates, Valley Children's pediatric hematologist/oncologist and program director. Through various events and activities hosted throughout the year, members and their families are able to connect with other survivors to create a safe community with shared understanding and empathy.

"The intention is to give survivors a chance to relate to something outside of their own life which is why participants get so much out of regular events," explained Dr. Gates. "Members are able to connect with other survivors who have an unspoken acceptance and understanding of their cancer experience that their friends and family don't exactly share in the same way. There is a sense of growth that comes of pushing yourself out of your comfort zone a little, sometimes to the point of inspiration."

Last year, the program awarded \$13,000 in scholarships to 13 survivors headed to college or vocational training. The program also hosted an annual conference for more than 30 survivors in partnership with the Leukemia and Lymphoma Society (LLS). Additionally, nearly 100 survivors attended a virtual holiday paint party held in collaboration with the Merced County Arts Council and sponsored by the Pediatric Brain Tumor Foundation, a special tailgate at Fresno State, and a special Light the Night hosted in partnership with LLS.

"In addition to the emotional benefit to help our survivors stay connected, get involved and give back, we are excited to continue to provide medical evaluation, education, psychosocial support and services to improve the quality of life of individuals surviving childhood cancer to live healthy lives, both physically and emotionally," said Alistair Robertson, Valley Children's pediatric oncology social worker.

The Fresno Truck Center Childhood Cancer Survivorship Program is the only one of its kind in the region, working with cancer-free patients from Valley Children's and other facilities who are three years from completion of treatment by providing education, support and health maintenance.





Together, we will improve the quality of care available to cancer survivors and make a positive impact in the lives of hundreds of survivors of pediatric cancer and their families.

Doug Howard, The Fresno Truck Center President

Local Family Business Donates \$2 Million for Valley Children's Childhood Cancer Survivors

The Fresno Truck Center is the Freightliner and Western Star commercial truck dealership owned and operated by the Howard family for more than 90 years. For more than 50 years, The Fresno Truck Center and Howard Family customarily purchased equipment each year needed by our clinical teams on behalf of their loyal customers.

This year's transformational investment will ensure long-term funding for our Survivorship program. Dr. Vinod Balasa, medical director of Valley Children's Cancer and Blood Disorders Center said, "this program caters to a huge unmet need among these individuals. The support provided by Fresno Truck Center is extremely valuable and very much appreciated."

The transformational gift of \$2 million will support the Childhood Cancer Survivorship Program Endowment. In recognition of this gift, the program is now "The Fresno Truck Center Childhood Cancer Survivorship Program."

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