Valley Children's
HEALTHCARE

Cancer and Blood Disorders Center

2019 Annual Report

> “This last year, Craycroft, our inpatient cancer unit, hit a record of 510 days without a hospital-acquired central line-associated blood stream infection (CLABSI).”

David Christensen, MD, MHCM, FAAP, FACHE
Senior Vice President, Medical Affairs
and Chief Physician Executive

As the only pediatric healthcare network in Central California and a leading pediatric cancer and blood disorders center on the West Coast, Valley Children’s brings the best care closer to home for more than 1.3 million children. Having served as a pediatrician for more than 25 years, with the last 20 in healthcare administration, I can confidently and proudly say that Valley Children’s proves its place as one of the nation’s best children’s hospitals with consistent, real results.

Our Cancer and Blood Disorders Center continuously has patients enrolled in almost 100 clinical trials. This last year, Craycroft, our inpatient cancer unit, hit a record of 510 days without a hospital-acquired central line-associated blood stream infection (CLABSI). Our hemophilia treatment center has the highest number of enrollments in the region. These are all just examples of how our medical staff works endlessly to bring the best and most innovative care to our patients.

The stories and statistics in this report emphasize the important and life-changing work the oncology and hematology department has done this last year. In everything we do, we are driven by our mission: to provide high-quality, comprehensive healthcare services to children, regardless of their ability to pay, and to continuously improve the health and wellbeing of children.

Cover photo: Emoryi, age 1, is one of approximately 30 children in the U.S. born last year with Diamond Blackfan anemia.

Vinod Balasa, MD
Medical Director

Cancer and Blood Disorders Center

> “Our unwavering confidence in providing hope arises from our ability to provide innovative treatment options right here in the Central Valley.”

In the medical world, the term “zebra” is used to refer to a condition that is “rare”, or not commonly seen. While, in general, the term “rare” is often associated with something unusual, in the pediatric cancer and blood disorders world, we know that patients and parents associate a very different connotation when they hear the word “rare”. They usually interpret it as a condition that is unknown and unfamiliar to everybody, and this further increases their apprehension.

At Valley Children’s, we recognize the importance of providing parents reassurance and hope when it comes to treating their children. Our reassurance is based upon the experience our Cancer and Blood Disorders Center has in all diagnoses, both the antelopes and the zebras, the common and the rare. Our unwavering confidence in providing this hope arises from our ability to provide innovative treatment options right here in the Central Valley.

In 2019, our oncology practice enrolled children into 104 active studies. Beyond these studies, our department has worked tirelessly to bring cutting edge therapy and research to the Central Valley, helping our patients receive the best care closer to home.

For instance, we are only one of four hospitals in the United States participating in the International Rare Histiocytic Disorders Registry (IRHDR). Access to such resources has helped us treat all our pediatric patients, including those who have been diagnosed with disorders such as Langerhans Cell Histiocytosis (LCH), hemophagocytic lymphohistiocytosis (HLH), juvenile xanthogranuloma and Rosai-Dorfman disease.

Out of the 14 Hemophilia Treatment Centers across the Western Region, Valley Children’s had the highest number of enrollments in CDC research studies. In this last year, our hematology team has enrolled patients in eight research studies and treated patients for the most rare blood disorders, including deficiencies in factor VII (FVII), factor XI (FXI) and factor XIII (FXIII).

I invite you to read through the pages that follow to gain a deeper understanding of the work being done right here, in the heart of Central California. We are proud to specialize in the well versed to the complex in order to provide the best treatment options for every child in our 12-county footprint and beyond.

Partnering in Care

Valley Children's oncology and hematology team is committed to partnering with referring physicians to provide the best comprehensive pediatric family-centered care in the Central Valley. Our specialists are available to provide a new diagnosis, offer a second opinion, care for a relapsed patient or provide childhood cancer survivorship services.

Our pediatric oncology team sees all emergent referrals on the same day.

The hematology practice at Valley Children's provides consultations 24 hours a day and collaborates with other expert hematologists nationwide to offer the newest treatments for a wide spectrum of bleeding and clotting disorders.

Routine referrals are reviewed and scheduled within two weeks.

Meet The Team

Our trained team of pediatric cancer and blood disorder specialists work together in a multidisciplinary approach to ensure the most attentive care and comfort to our patients and their families.

Physicians

Vinod
Balasa, MD
Medical Director

Vonda
Crouse, MD

Karen
Fernandez, MD

John
Gates, MD

J. Daniel
Ozeran, MD, PhD

Latha
Rao, MD

Faisal
Razzaqi, MD

Bindu
Sathi, MD

David
Samuel, MBChB, MD

Wendy
Tcheng, MD

Ruetima
Titapiwatanakun, MD

Nurse Practitioners

Katie
Baker, NP

Kelly
Folmer, MSN, CPNP

Terea
Giannetta,
DNP, CPNP, FAANP

Therese
Hinz, MSN, PPCNP-BC

Malynda
Kemmer, NP

Service in Numbers

As the only pediatric oncology center and federally funded hemophilia treatment center between Los Angeles and the Bay Area, Valley Children's Cancer and Blood Disorders Center provides children and their families leading, expert care closer to home.

FY2019

Patient Visits

11,531

Hematology - 4,998
Oncology - 6,533

Unique Visits

3,448

Hematology - 2,148
Oncology - 1,300

144

Newly Diagnosed Oncology Cases

Blastomas	12
Ganglioneuroblastoma	
Nephroblastoma (Wilms)	
Neuroblastoma	
Pleuropulmonary Blastoma (PPB)	
Retinoblastoma	
Brain / CNS	33
Carcinomas	12
Thyroid	
Other Carcinomas	
Adenocarcinoma	
Adrenal Cortical Carcinoma	
Genitourinary (Genital Organs)	2
Langerhans Cell Histiocytosis (LCH)	7
Leukemia	46
Lymphomas	16
Extra-Nodal	
Sarcomas	14
Soft Tissue	
Alveolar Rhabdomyosarcoma	
Alveolar Soft Part Sarcoma	
Embryonal Rhabdomyosarcoma	
Embryonal Sarcoma	
Ewing Sarcoma	
Malignant Rhabdoid Tumor	
Myxoid Liposarcoma	
Rhabdomyosarcoma, NOS	
Sarcoma, NOS	
Bone	
Ewing Sarcoma	
Myxoid Chondrosarcoma	
Osteosarcoma	
Round Cell Sarcoma	
Other	2
Melanoma In-Situ	
Solid Pseudopapillary Tumor	

> On average, Valley Children's five-year survival rate is 85%, on par with national outcomes

Providing Hope Through Innovation and Research

Valley Children's oncology and hematology practice works to provide innovative treatments to every child that walks through our hospital's doors. In order to provide the maximum benefit to our patients, Valley Children's Cancer and Blood Disorders Center participates in a number of clinical trials and research protocols.

"We have the goal to bring the best options to where patients have their home support system and community. We want them to stay in their local area," explains Padma Desai, manager of research at Valley Children's. "This goal in mind is what drives us to continuously bring studies to the Central Valley."

It was this goal that guided the research team to establish the mission statement, "to give hope to families by meeting disease challenges through advancing knowledge and providing ethical, innovative treatment options close to home," and they're doing just that. At the end of FY19, Valley Children's hematology practice was enrolled in eight active studies and oncology practice was enrolled in 104 active studies.

As a member of the Children's Oncology Group (COG), Valley Children's also works to expand research efforts both here in the Central Valley, as well as greater medical knowledge worldwide.

"We participate in numerous partnerships and registries, both statewide and nationally," says Valley Children's Clinical Research Coordinator Rosanna Spicer. "Beyond that, we have a lot of investigator-initiated studies, so our doctors are able to carry out their own studies on topics and treatments they are very passionate about that will help care for future patients."

This tireless work by both the research team and the rest of the oncology and hematology staff does not go unnoticed. The research team takes pride in their "near perfect audit" that took place earlier this year by COG. Additionally, in 2018, the oncology research team's poster presentation received national recognition for the second year in a row. Their poster, "An Audit a Day Keeps the Errors Away", was recognized in a three-way tie for first place and selected to be presented at the COG Annual Meeting.

"Our hospital is very passionate about the best treatment for all of our patients, from the variety

> “Our mission is to give families hope by providing innovative treatment close to home.”

of available trials to patient interaction,” says Padma. “Our patients have the opportunity to see their specialist at our main hospital campus, but also at our specialty care centers closer to where they live, easing the burden of travel and the financial aspects that come with it. We do whatever it takes to make sure our patients receive the best.”

At the end of FY19

Valley Children’s hematology practice was enrolled in eight active studies and oncology practice was enrolled in 104 active studies.

In 2018, Valley Children’s Hospital had

142

new enrollments for therapeutic and non-therapeutic COG studies.

Among COG institutions worldwide, Valley Children’s ranked in the

94th percentile

for number of therapeutic and total enrollments.

Children’s Oncology Group: The Children’s Oncology Group (COG), a National Cancer Institute supported clinical trials group, is the world’s largest organization devoted exclusively to childhood and adolescent cancer research.
*Information for FY19 not yet available.

Bringing Radiation Therapy to Pediatric Patients in the Central Valley

Valley Children's knows that when cancer strikes the smallest patients, precision and targeted treatments are important to minimize negative side effects overtime. For these cases, Valley Children's oncology team recognizes the importance of having access to radiation therapy.

Targeted, high-energy X-rays allow enough radiation to get into the body to kill the cancer, while still keeping other cells as healthy as possible. In order to best make this happen, radiation therapy treatments are usually given multiple days in a row, helping to reduce side effects and giving healthy cells time to recover. Unfortunately, when treatments are given over a long span of time, that means months away from home, family and work. For children, this can mean time away from school and the specialists they're familiar with, making the treatment even more uncomfortable and terrifying than it already might be.

In 2016, Valley Children's established a partnership with cCare Cancer Center, working to expand the services and treatment options for patients while expediting care, appointments and information between physicians.

In the past, patients might have had to travel out of the area for this specific care option. This partnership with the California Cancer Associates for Research & Excellence (cCare) means treatments can happen 15 minutes down the road, allowing patients to remain closer to home and still be seen by their Valley Children's specialist.

Dr. Gopi Solaiappan, radiation oncology physicist, explains when patients come to cCARE after Radiation Oncologist consults, an in-depth process is followed with Valley Children's oncology team in order to create an accurate and personalized treatment plan based on the Radiation Oncologist prescription, catering to the small size of the pediatric patients and their tumors.

"The approved plan goes through multiple quality assurance tests before it goes to the machine for treatment," says Dr. Solaiappan. "Before the treatment, block verification simulation is done to verify the plan parameters transferred correctly and mechanical constraints of the machine are ready for treatment. Once the plan passes all the tests and verification, the treatment will be executed with greater

cCare high-quality serves Valley Children's older hematology patients, seeing adults older than 21.

Through this partnership, adults with bleeding and blood disorders are able to be seen at Valley Children's, the facility, nurses and staff they are most comfortable with.

For our youngest children who require sedation/anesthesia during their radiation therapy, our experienced Valley Children's pediatric anesthesiologists provide these expert services on-site at cCare.

accuracy with the help of cutting-edge machines with onboard imaging."

These treatments are delivered with state-of-the-art technology and within 1-millimeter of the designated area. In addition to cutting-edge equipment, cCare and Valley Children's work closely to ensure high quality care and communication.

"Every week, cCare physicians come to Valley Children's and run a combined clinic with our oncologists," explains Dr. Vinod Balasa, Medical Director of Valley Children's Cancer and Blood Disorders Center. "This is invaluable in providing the most efficient and appropriate care to the affected children. In addition to having a face-to-face consultation with the family, physicians from both locations are able to discuss and formulate the best treatment options. This is extremely beneficial to the patient experience because when a child is diagnosed with cancer and we determine their need for services at cCare, they can meet the specialists who will be working with them at cCare at Valley Children's Hospital, where they're comfortable and familiar. Further, they see the patient in follow-up after their radiation therapy in concert with the oncologist at Valley Children's, thereby diagnosing and appropriately treating any potential complications in a timely manner."

While for a child this process can be undoubtedly intimidating, Valley Children's and cCare have created a working relationship to make each patient's experience as smooth and comfortable as possible. By collaborating two teams of experts to ensure the most effective treatment plans, we are confident that every child is being given the best care closer to home.

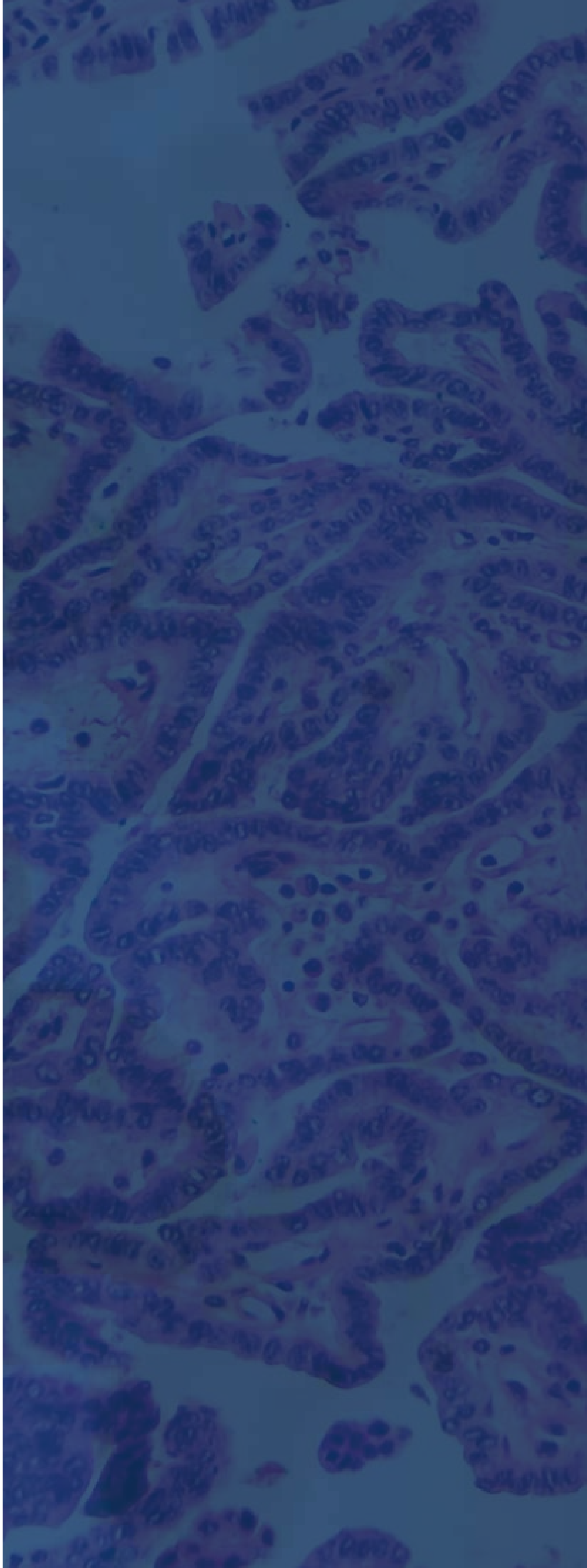
Safety guidelines, such as a block set, are part of each patient's plan, not only to triple check the preparedness of the team prior to a child's treatment, but also to provide some comfort to the pediatric patient who might be uneasy with what's ahead.

Through cutting-edge technology, cancerous tumors can be treated within 1mm of accuracy, providing the maximum radiation to a tumor while minimizing the potential dose of radiation that the surrounding areas are exposed to.

Histiocytosis Program

Due to the large area of the Central Valley that Valley Children's Cancer and Blood Disorders Center serves, rarer conditions that affect children such as the histiocytic disorders are seen. Of the histiocytic disorders, Langerhans cell histiocytosis is the most common, but the non-Langerhans cell histiocytosis are even rarer, affecting around one in a million children. Because of the rarity of these conditions, accurate diagnosis is difficult and the best treatment for these conditions are often unknown. The international community of doctors who treat histiocytic diseases in conjunction with the Histiocyte Society, created the International Rare Histiocytic Disorders Registry (IRHDR), which aims to make accurate diagnosis of the rare histiocytic disorders and to collect patient information to help improve treatment recommendations for these diseases.

Valley Children's is one of four hospitals in the United States participating in the IRHDR. Since joining this registry in 2016, five patients with extremely rare diagnoses have been enrolled and include the diagnosis of Rosai-Dorfman disease and juvenile xanthogranuloma.



Only 1 in every 200,000

children in the United States are affected by Langerhans cell histiocytosis (LCH).

Each year, Valley Children's diagnoses and treats

5 to 10

children with LCH.

Valley Children's is only

1 of 4

hospitals in the United States participating in the **International Rare Histiocytic Disorders Registry (IRHDR).**

Over the last five years, Valley Children's has diagnosed

10

children with hemophagocytic lymphohistiocytosis

1

child with juvenile xanthogranuloma

3

children with Rosai-Dorfman

Valley Children’s Hematology:
Confident in the Uncommon

In a world where families expect to envision their child climbing trees and learning to ride a bike, being told, “your child has a rare bleeding disorder” can raise a lot of questions and concerns. Not only does the family have to develop an understanding of new concepts such as clotting factors or platelets, but it also requires specialists comfortable with diagnoses that, on average, only add up to approximately 3 to 5% of all coagulation disorders.

With the rarity of certain bleeding disorders, such as deficiency of factor VII (FVII) or factor XIII (FXIII), it can be hard for a parent to find nearby specialists who are not only familiar, but comfortable with these diagnoses. Valley Children’s hematology team cares for patients diagnosed with everything from the better-known bleeding disorders, such as hemophilia and von Willebrand disease, to the rarest. In fact, in FY19, Valley Children’s treated 28 patients with rare bleeding and blood disorders enrolled in American Thrombosis and Hemostasis Network (ATHN) studies.

In FY19, Valley Children’s treated

6 patients diagnosed with factor XI deficiency

19 patients diagnosed with factor VII deficiency

Out of the 14 Hemophilia Treatment Centers across the Western Region, Valley Children’s had the **highest** number of enrollments

Factor XIII deficiency occurs in **1 per every 5 million** births

In FY19, Valley Children’s treated **3 patients** diagnosed with factor XIII deficiency

The hematology department enrolled patients in **8 research studies** in FY19

Treating Generations of Rare: Diamond-Blackfan Anemia

"She's the family comedian – she can turn your frown upside down so fast," says Victoria James about her 1-year-old daughter, Emoryi.

With her high spirits and positive attitude, one might not even know that Emoryi has a rare blood disorder. Emoryi received the diagnosis of Diamond-Blackfan anemia at just weeks old. This diagnosis means that Emoryi's body doesn't produce enough red blood cells, as many of the blood cells she does produce die before they develop, leading to necessary specialty care and frequent blood transfusions.

However, Emoryi's mother Victoria is no stranger to this diagnosis and treatment routine, as she was also diagnosed with Diamond-Blackfan anemia at just 6 months old and treated at Valley Children's.

"It feels good knowing the nurses I grew up with are still here," says Victoria. "It's amazing how well these doctors know what they're doing and it's a comfort to know this team is here 24/7 for you, whether you have questions or not."

Terea Giannetta, hematology nurse practitioner, treated Victoria as a pediatric patient and knows the concern parents might have when it comes to a rare blood disorder.

"Genetics are much better now than when Victoria was a patient," says Terea. "So we did some genetic studies on Emoryi here at our genetics center, and then received approval to do the study on Victoria. We discovered they both carry a genetic mutation that has been known to cause Diamond-Blackfan anemia."

Terea goes on to explain that while gene identification is still very new, the hematology and genetics teams at Valley Children's recognized the importance of it in the case of Emoryi and Victoria. While it is typically very hard to identify such a rare disorder in newborns, identifying the gene helped confirm Emoryi's diagnosis.

"Because this diagnosis is so rare, if it isn't recognized, it can be life threatening," adds Terea. "If the patient doesn't get transfused correctly as an infant, it can damage their physical and mental growth and inhibit their longevity. It's so important these patients are seen at a qualified center where people educate the parents and even other providers. Because Diamond-Blackfan anemia is so rare, patients can have great providers who have never had experience with this disorder."

This expert care is also the highest of priorities for Emoryi's father, Kenneth Williams, Jr. After receiving Emoryi's diagnosis, her parents knew instantly that at Valley Children's, they would receive not only the best care, but also have the most compassionate staff who would welcome them to each appointment with smiles.

"I have to admit, I've never liked hospitals," Kenneth shared. "But after working with Valley Children's, it changed my whole perspective. After coming here, even the first time, each and every doctor and nurse changed my perspective of how a doctor is supposed to act. They treat me with nothing but kindness."

Victoria explained why she is more than happy to come back every month to Valley Children's: "When it comes to my daughter's wellbeing and livelihood, especially when it comes to such a rare disorder, there's no other option in my mind."

Diamond Blackfan anemia affects approximately

5 to 7 people

per million live births each year

This means each year, there are approximately

30

children born with Diamond Blackfan anemia

4

In FY19, Valley Children’s treated **four** patients with Diamond Blackfan anemia

Project Baby Bear

Last year, Valley Children's became one of only six hospitals to participate in a groundbreaking, state-funded pilot program called Project Baby Bear. This program provides rapid Whole Genome Sequencing (rWGS) to critically ill newborns in select cities throughout California. As part of a broader project funded by the State of California, Project Baby Bear aims to use rWGS to help improve the treatment of infants and children with undiagnosed illnesses who are under the care of Medi-Cal.

"Our partnership with the Project Baby Bear initiative significantly shortens the path to a diagnosis that will enable physicians to better treat their patients," says Valley Children's Hospital NICU Medical Director Dr. Mario Rojas. "At the same time, it lightens the burden of uncertainty for parents whose child is suffering from a rare disease."

Medi-Cal does not currently cover rWGS testing. During this trial though, testing is available for free to participating Medi-Cal families. Test results are usually returned within three to five days from the lab located at Rady Children's Genomic Institute in San Diego. Once a diagnosis is identified, the goal is to have potential treatment and medication options available for patients.

These answers provide valuable information for new parents who potentially might have children impacted by a rare blood disease or even a predetermined cancer.

"Whole genome sequencing provides genetic information of our entire genetic code, consisting of approximately 20,000-25,000 genes," explains Lead Genetic Counselor Jason Carmichael. "The patient's clinical information along with parental samples can help guide the interpretation of the genetic information obtained from this test, which potentially can lead to diagnosing a child with a genetic condition. Finding a genetic diagnosis can help change management for the child, and provide information to parents regarding their reproductive risks for future pregnancies."

> “Parents have the option to request incidental findings of approximately 59 disorders, including genes associated with a predisposition to cancer.”

When consenting for whole genome sequencing, parents have the option to request incidental findings of approximately 59 disorders, or the ACMG 59, that are identified in individual patients based off whole genome sequencing results, including genes associated with a predisposition to cancer and cardiovascular disease. This means parents have the opportunity to be informed of the chances of future health conditions and can potentially take action to either prevent or guide management of health issues at an earlier stage.

As an additional resource for patients seen at Valley Children’s Cancer and Blood Disorders Center, the genetics practice provides genetics counseling for all, working with patients and families who are diagnosed with more common conditions to those who have a very rare diagnosis.

“When a patient comes in with a diagnosis that has been determined genetically, we meet with the family to discuss the natural history and the underlying genetic cause,” explains Jason. “We also are able to provide information to the parents on the likelihood of another child being born with the same diagnosis, and, if needed, offer testing on the parents or even the extended family members in order to provide the family with more insight into who might carry the gene change in the family and associated reproductive risks.”

Jason continues, “Our genetics department strives to always stay up to date with genetic testing technologies and being part of Project Baby Bear brings another valuable resource to our underserved patients in the Central Valley.”

Childhood Cancer Survivorship Program

The Valley Children's Childhood Cancer Survivorship Program, as part of the Cancer and Blood Disorders Center, works with childhood cancer patients who are cancer-free at least three years from completion of treatment. The program provides a comprehensive evaluation of the survivor's health, academic and social development and provides patient education about their diagnosis, treatment, potential late effects and health maintenance.

Since the program's inception in 2009, hundreds of childhood cancer survivors have benefited on a multitude of levels, physically, mentally and socially.

In FY19, in the Valley Children's Childhood Cancer Survivorship Program, there were:

762 **Attended Visits**

267 **Transitional Visits**

(off therapy between 12-36 months)

56 **New Survivorship Visits**

(first survivorship visit, about 36 months off therapy)

429 **Survivorship Follow Up Visits**

(majority were annual visits)

Surfing for Hope

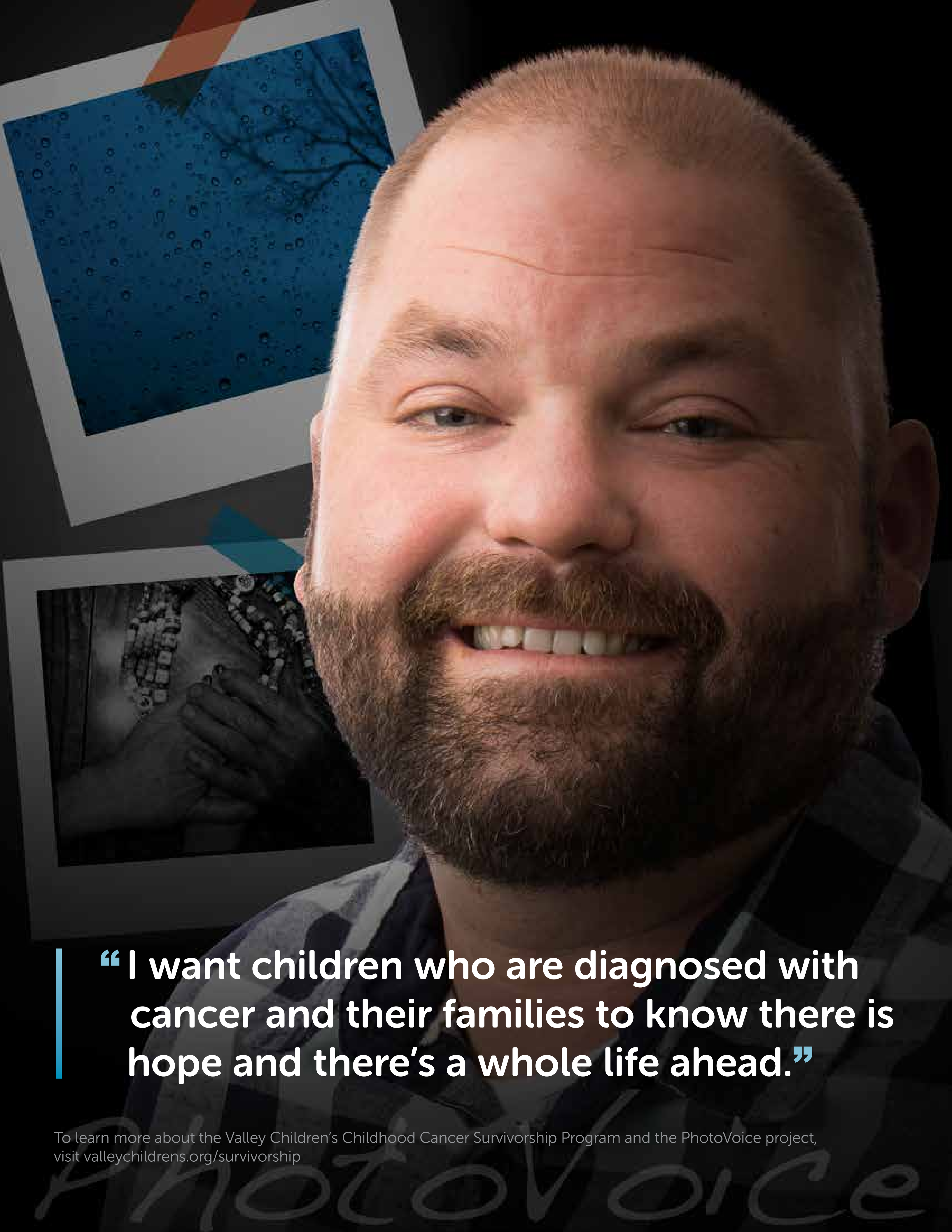
Surfing for Hope is a non-profit organization created to help ease the difficulty of cancer through the healing powers of the ocean. In FY19, 10 survivors experienced the therapy of riding waves in Pismo Beach, providing an experience where the survivors felt empowered and were able to network with other survivors.

Childhood Cancer Survivorship Conference

Valley Children's Childhood Cancer Survivorship Program, in partnership with the Leukemia and Lymphoma Society, hosted the annual Childhood Cancer Survivorship Conference. This conference comprehensively addresses everything from transitions after high school and applying to colleges and jobs to celebrating survivors and hearing from some of our own survivors. In FY19, 120 people attended this conference.

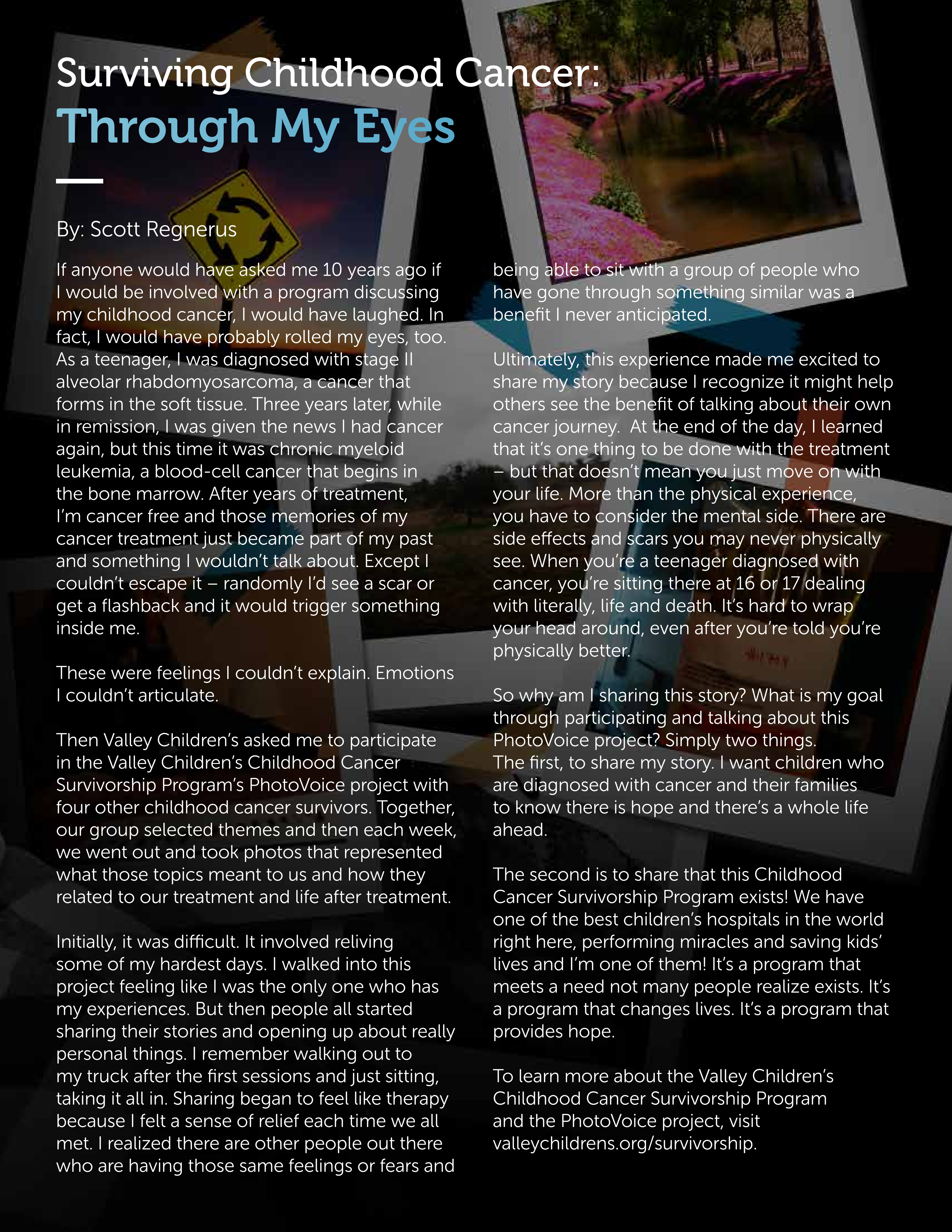
PhotoVoice: Through the Eyes of Our Survivors

The Childhood Cancer Survivorship Program hosted their first ever photo project, PhotoVoice: Through the Eyes of Our Survivors. This project took five survivors and provided them with the opportunity to share their story through a series of group-selected photo topics. This project was aimed to empower the survivors while educating the general community on the effects of childhood cancer.



> “I want children who are diagnosed with cancer and their families to know there is hope and there’s a whole life ahead.”

To learn more about the Valley Children’s Childhood Cancer Survivorship Program and the PhotoVoice project, visit valleychildrens.org/survivorship



Surviving Childhood Cancer: Through My Eyes

By: Scott Regnerus

If anyone would have asked me 10 years ago if I would be involved with a program discussing my childhood cancer, I would have laughed. In fact, I would have probably rolled my eyes, too. As a teenager, I was diagnosed with stage II alveolar rhabdomyosarcoma, a cancer that forms in the soft tissue. Three years later, while in remission, I was given the news I had cancer again, but this time it was chronic myeloid leukemia, a blood-cell cancer that begins in the bone marrow. After years of treatment, I'm cancer free and those memories of my cancer treatment just became part of my past and something I wouldn't talk about. Except I couldn't escape it – randomly I'd see a scar or get a flashback and it would trigger something inside me.

These were feelings I couldn't explain. Emotions I couldn't articulate.

Then Valley Children's asked me to participate in the Valley Children's Childhood Cancer Survivorship Program's PhotoVoice project with four other childhood cancer survivors. Together, our group selected themes and then each week, we went out and took photos that represented what those topics meant to us and how they related to our treatment and life after treatment.

Initially, it was difficult. It involved reliving some of my hardest days. I walked into this project feeling like I was the only one who has my experiences. But then people all started sharing their stories and opening up about really personal things. I remember walking out to my truck after the first sessions and just sitting, taking it all in. Sharing began to feel like therapy because I felt a sense of relief each time we all met. I realized there are other people out there who are having those same feelings or fears and being able to sit with a group of people who have gone through something similar was a benefit I never anticipated.

Ultimately, this experience made me excited to share my story because I recognize it might help others see the benefit of talking about their own cancer journey. At the end of the day, I learned that it's one thing to be done with the treatment – but that doesn't mean you just move on with your life. More than the physical experience, you have to consider the mental side. There are side effects and scars you may never physically see. When you're a teenager diagnosed with cancer, you're sitting there at 16 or 17 dealing with literally, life and death. It's hard to wrap your head around, even after you're told you're physically better.

So why am I sharing this story? What is my goal through participating and talking about this PhotoVoice project? Simply two things.
The first, to share my story. I want children who are diagnosed with cancer and their families to know there is hope and there's a whole life ahead.

The second is to share that this Childhood Cancer Survivorship Program exists! We have one of the best children's hospitals in the world right here, performing miracles and saving kids' lives and I'm one of them! It's a program that meets a need not many people realize exists. It's a program that changes lives. It's a program that provides hope.

To learn more about the Valley Children's Childhood Cancer Survivorship Program and the PhotoVoice project, visit valleychildrens.org/survivorship.

Valley Children's Staff in Regional and National Organizations

All of Valley Children's pediatric oncologists are members of the Children's Oncology Group (COG). Many staff members also participate in organizations and are in leadership roles regionally, nationally and internationally, which are highlighted below.

Vinod Balasa, MD

- Executive Coordinating Committee, Western States Region IX Hemophilia Network

Vonda Crouse, MD

- Institutional Principal Investigator at Valley Children's Hospital for COG

Karen Fernandez, MD

- Children's Oncology Group (COG) Adolescent Young Adult – Responsible investigator (AYA RI)
- American Society of Pediatric Hematology Oncology (ASPHO) - Vascular anomalies special interest group Education committee
- International Society of Paediatric Oncology (SIOP)- Pediatric Oncology International Network for Training and Education (POINTE) Expert
- Central American Association of Pediatric Hematology/Oncology (AHOPCA)
- Health Volunteer Overseas (HVO)
- International Pediatric Specialists Alliance for the Children of Vietnam (IPSAC-VN)
- Consortium of iNvestigators of Vascular AnomalieS: CaNVAS – Member

Faisal Razzaqi, MD

- Member of COG Acute Myeloid Leukemia (AML) steering committee
- Responsible Investigator for COG Cancer Control Studies
- National Chair for Hematology/Oncology/BMT subgroup, Improving Pediatric Sepsis Outcomes (IPSO) collaborative, Children's Hospital Association

Bindu Sathi, MD

- Leadership Role in the Steering Committee of Pacific Sickle Cell Research Collaborative
- Site Principal Investigator for Pacific Sickle Cell Research Collaborative
- Member of Heartland Sickle Cell Disease Consortium
- Member of Pacific Sickle Cell Regional Collaborative
- Visiting consultant for Malabar Institute of Medical Science Cancer Center
- American Society of Hematology Grassroots network member

David Samuel, MBChB, MD

- Institutional principal Investigator for UCSF Study: "RadART-PRO, A Prospective Multi-Institutional Study to Assess the Risk of Radiation Induced Vasculopathy and Stroke in Children with Cancer who Received Radiation Therapy to the Neck and Brain"
- Valley Children's Hospital, Site Principal Investigator, Clinical outcomes of pediatric Primitive Neuroectodermal tumors and Medulloblastomas with correlation, radiologic and treatment-associated parameters
- Valley Children's Hospital, Site Principal Investigator, NACHO (North America Consortium for Histiocytic Disorders)
  - Site PI, NACHO-LCH IV (International Collaborative Treatment Protocol for Children and Adolescents with LANGERHANS CELL HISTIOCYTOSIS) 6th June 2018

- Site PI, NACHO-Bio (A translational biology platform to advance understanding of pathogensis and improve outcomes for patients with histiocytic disorder) 5th September 2018
- Co-Investigator, Children's Oncology Group, since Jan 2010

Terea Gianetta DNP, CPNP, FAANP

- Liaison to AANP National Program Committee for the National Association of Pediatric Nurse Practitioners (NAPNAP)
- American Association of Nurse Practitioners (AANP) Fellow
- Member of the Thalassemia Alliance for the western region

Ruthloren Martinez, RN, BSN

- Hemophilia Coordinating Committee (Nursing), Western States Region IX Hemophilia Network
- Chapter Secretary, California Central Valley Oncology Nursing Society (CCVONS)
- ANCC-Board Certified Hemostasis Nursing

Alistair Robertson, MSW

- Member of the Association of Pediatric Oncology Social Workers (APOSW)
- Served on the Board of Directors of APOSW 2012-2017
- 2016 APOSW Social Worker of the Year Award
- Pre-Institute Seminar Speaker at 2019 APOSW Conference

Laura Andrews, RN-BC, BSN

- Member of Association of Pediatric Hematology/Oncology Nurses (APHON)

Publications

Sathi BK, Khurana M, Gruner B. Recurrent metastatic high-grade osteosarcoma: Disease stabilization and successful pregnancy outcome following aggressive multimodality treatment. *Indian Journal of Medical and Paediatric Oncology*. 2018;39(4):530. doi:10.4103/ijmpo.ijmpo_83_17.

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Chelle P, Yeung C, MacLeod S, Croteau S, Lissick J, **Balasa V**, et al. Development and Validation of a Population Pharmacokinetic Model for rAHG-FL-PEG (Adynovate): A Report on behalf of the WAPPS-hemo Investigators ad hoc Subgroups. Poster Presentation at the 27th International Society of Thrombosis and Hemostasis Congress and 65th Annual Scientific and Standardization Committee Meeting, Melbourne, Australia, July 2019

Karen S. Fernández, Melissa Mavers, Ruetima Titapiwatanakun, Katherine Baker, Christine Chang-Halpenny, Brian Pugmire, Wendy Tcheng, Rajni Agarwal. Feasibility of Brentuximab Vedotin as Consolidation Therapy After Autologous Stem-Cell Transplantation in Children and Adolescents (< 18 years) with Early Relapse Hodgkin Lymphoma. Presented at the American Society of Clinical Oncology (ASCO) Annual Meeting. Chicago IL. May 31 – June 4, 2019. J Clin Oncol 37, 2019 (Suppl; abstr e19012)

Katherine Baker, William Koole, Douglas Tamura, J. Daniel Ozeran, **Karen S. Fernández**. High Dose Acetaminophen With N-Acetylcysteine Rescue for Unresectable Hepatoblastoma. American Society of Pediatric Hematology/Oncology (ASPHO) Annual Meeting. New Orleans, LA. May 1 -4, 2019. Poster# 280. Pediatr Blood Cancer. 2019; S130 DOI 10.1002/pbc.27713

Caroline Chinchilla, Yvette Zavala, Ruetima Titapiwatanakun, Katherine Baker, Wendy Tcheng, **Karen S. Fernández**. Hodgkin Lymphoma in Children Under 5 years of Age in Central California. American Society of Pediatric Hematology/Oncology (ASPHO) Annual Meeting. New Orleans, LA. May 1 - 4, 2019. Poster#101. Pediatr Blood Cancer. 2019; S60 DOI 10.1002/pbc.27713

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Caroline Chinchilla, Steve Hardee, Laide Jinadu, Brian Pugmire, **Karen S. Fernández.** Rossai-Dorfaman-Destombes Disease as a First Manifestation of Systemic Lupus Erythematosus. Presented at the American Academy of Pediatrics (AAP) Annual National Conference and Exhibition. Section on Pediatric Trainees. New Orleans, LA. October 25-29, 2019. Abstract ID: 672243. – competitive presentation- abstract selected among 500 submission to be in the 10 abstracts from residents.

Bindu Kanathezhath Sathi, Yilin Yoshida, Micheal Weaver, Lila Nolan, Barbara Gruner, Cara Hirner, Carlos Schmiedt, **Vinod Balasa**, Talissa Altes, Carlos Leiva- Salinas. Unusually high prevalence of Silent Stroke and Cerebral Vasculopathy in Hemoglobin SC Disease. (Accepted, American Society of Hematology Annual Meeting, 2019, Abstract#2276, https://ash.confex.com/ash/2019/webprogram/Paper122975.html).

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