

# Storybook



## JASON'S BIG GIFT



Margy Mayfield, RN  
Executive Director

"Over a nursing career that has spanned three decades, I have learned that it is the small, almost unnoticeable details, that have the greatest impact on the wellbeing of children and families. These little things, a light-hearted joke during a difficult procedure or a wordless hug when emotions become too much, are the art of nursing. At Coastal Kids it is always our goal to provide exceptional medical care. We monitor vital signs, conduct blood draws and administer medications – yet as pediatric nurses we know it is the "caring" in medical care that makes the biggest difference for our young patients."

### OUR MISSION

Coastal Kids Home Care improves the quality of life for children healing from injury or short-term illness, coping with chronic conditions or developmental delays, and those facing the end-of-life. Our staff provides in-home nursing, specialized therapies, social services and bereavement counseling to support the whole family.



**COASTAL KIDS  
HOME CARE**

ph: 1.800.214 (KIDZ) 5439  
www.coastalkidshomecare.org



At fifteen months old, Jason De Jesus-Rosale has already led his parents on a very windy road. Born in August of 2016 at Salinas Valley Memorial Hospital, he was transferred to Stanford Children's Hospital and later UCSF Benioff Children's hospital where specialists discovered the cause of his dangerously low-blood sugar level - Congenital Hyperinsulinism. This extremely rare condition is caused by the overproduction of insulin. His UCSF surgeons conducted radical surgery to remove 98% of his pancreas and place a gastrostomy tube to help manage his condition.

After an exhausting four months in a neonatal intensive care, the De Jesus-Rosale family brought Jason home to Greenfield in January. Initially nervous about caring for their delicate baby alone, they were relieved to have the support of nurses from Coastal Kids to help monitor his blood sugar and keep his weight in check.

Fast forward six months and Jason's health was stable, his bubbly personality was beginning to shine though, but his mom was concerned about his development. Unlike typical one-year-olds, Jason was not beginning to walk or even crawl. Since he was attached to a continuous dextrose pump, his mobility was limited and his parents found it easiest to transport their growing toddler in a stroller. Following up on mom's concerns, Coastal Kids Physical Therapist, Trish Krall, assessed Jason's developmental needs and created a plan of care.

With Trish as their guide, Jason's parents began simple exercises to facilitate more movement. To give the toddler increased freedom, his mom put his pump in a tiny backpack and encouraged him to play with favorite toys and books. In no time, the determined little guy began to show signs of progress. Today, just two months later Jason is proudly crawling and beginning to pull-to-stand. His parents expect his first steps any day now – a big gift for the whole family.



#### COUNTING OUR BLESSINGS:

This year, we have already provided **4500** home nursing and therapy visits to

**492** kids. Whether it is our first visit to a medically-fragile infant or a weekly blood draw for a child with leukemia – we treat every patient as our number one priority.



#### A LIGHT IN THE DARKNESS:

Caring for children at the end-of-life is the hardest work we do. Each child we serve is so special. In 2017,

our team offered medical and comfort care for 7 children at the end-of-life and supported 51 family members through their grief. We will hold them all in our hearts forever.



## BACK ON THE FIELD

"I know that you are in pain because your loved one died, but their kidney is alive in me and I will take very good care of it." These words spilled forth from Diego Ruiz in a recent visit with his Coastal Kids social worker, Ruth Emerson. He was grateful to be writing a letter to the family who had saved his life. One year earlier he had been desolate, tired of feeling sick and frustrated that he could not work to support his family or even spend time with friends.

At seventeen, Diego was diagnosed with a rare kidney disease. He became dependent on a complex medication regime and strict diet to survive. His Spanish speaking parents, busy with work and their other two children, struggled to understand the requirements for their sons care and worried about his future. Diego moved in with his aging grandparents, to help care for them, and do what he could to ease the families' stress. Diego tried to follow the guidelines his doctors set forth, but keeping up felt impossible. Less than eighteen months later he was in end-stage renal failure and tethered to his dialysis machine for up to eleven hours each day. Then in October 2016 he was admitted to the Palliative Care Program and Coastal Kids nurse Robin began weekly visits to his home.

With someone to help him maneuver his complicated illness, Diego began to follow through on his care plan. Robin responded to his questions, reminded him of upcoming doctors' appointments and talked him through his anger and guilt. In less than six months, Diego qualified for the kidney transplant wait-list, and two months after that he received the life-giving call.

Diego's transplant went well, and today his medicine regime is much simpler. He is losing weight and has more energy – and time. He recently found a new job and plans to enroll in college in January. He is most excited, however, to be back on the soccer field. Diego is playing in two local leagues and coaching his eight-year-old brother's team. The future is wide open once again.



## SILVER LININGS

One afternoon this summer, we received a surprise phone call from the mom of a memorable little Coastal Kid – Matthew Pierce. Aimee Grijalva-Pierce was reaching out to let us know that the local pediatric cancer research foundation that she was leading, Key for a Cure, would be donating much-needed medical equipment and supplies (pictured below) to Coastal Kids Home Care following their autumn gala. The story of the Pierce family is one that exemplifies silver linings.



Their son Matthew was diagnosed with acute lymphoblastic leukemia at age two months, and would spend the next two years of his life battling cancer and coping with the detrimental side-effects of his treatment. Following Matthew's death, his family has shared their story through blogs, newspaper articles and Facebook postings, and devoted incredible time and resources to raising funds for pediatric cancer research. Mindful of their own difficult journey, the Pierce family also supports local families caring for seriously-ill children. We are humbled to receive this generous gift from the Key for a Cure foundation on behalf of precious baby Matthew. Thank you from the bottom of our hearts.



## GOING ABOVE AND BEYOND A SPECIAL THANK YOU TO THESE SUPERLATIVE PARTNERS AND VOLUNTEERS:

Angel Warriors for Kids | Allure Salon | Annie Berlin  
Capital Insurance Group | Hospice Giving Foundation  
Dr. Lewis Cantor | Kevin Flanders | Justin Caniglia  
Living Breath Foundation | Naturipe Berry Growers  
Beth Miller | Wendy Neale | Partnership for Children  
Rio Grill | Salinas Valley Memorial Healthcare System  
Sylvia and Richard Prader | Andy and Steffanie Smith  
The Storey Family | Key for a Cure

Join us in bringing home nursing and therapy to sick kids in our community.

Make a gift today!

[www.coastalkidshomecare.org](http://www.coastalkidshomecare.org)

