

STORYBOOK

A Publication of Coastal Kids Home Care

Winter 2021

* Of Color & Light *

Art is a natural language for children. For kids coping with illness and disability, art provides a way to explore their feelings. For this reason, Art Therapy has long been one of the most sought-after services for children on our Pediatric Palliative Care program. After Coastal Kids Home Care moved into our new building in Salinas, we saw an opportunity to share the experiences of our pediatric patients with the whole community -- through a partnership with the Arts Council for Monterey County. Paul Richmond, a talented local artist, painted a farm scene in our Physical Therapy room and later designed a twenty-foot mural for our garden area. Paul completed both projects with the help of Arts4MC teaching artist, Brenda Saglio. Together, they painted, danced, and brought brightness to our new home. Each child portrayed in the mural is representative of a Coastal Kids patient, Paul and Brenda creatively named each of them to highlight their unique meaning.

Joaquin, the little artist, offers an example of a kid who looks typical on the outside, but may be struggling on the inside. He asks us to be kind. Although **Brady** is wheelchair bound, he does not let his disability hold him back. He inspires us to make the best of every situation. **Elton** is our "rocket man", a child who requires the miracle of medical technology to survive, thrive and rocket to his future. He offers us gratitude for what is possible. Sweet **Joy**, our bubble blower, represents the kids who have made an impact on this world, even if here for only a short time. She shows us that even fleeting beauty has value. **Esperanza**, the gardener, is a reminder that with hope – and tender care – a way forward can be found in even the darkest of situations. Come see them in person at 427 Pajaro Street, Salinas, CA 93901.

Clockwise from bottom left--Joaquin, Brady, Elton, Joy, Esperanza



Shining a Light on Marcos



As a one-year-old, Marcos Sanchez Mireles seemed off balance, would frequently fall and refused to use his right hand. His mom, Rosa, checked in with his pediatrician who made a referral to Coastal Kids Home Care for Physical Therapy. When Director of Rehabilitation Services, Trish Krall, evaluated Marcos she felt that the toddler may have something more critical, and referred him to a neurologist. Soon he was diagnosed with a brachial plexus injury which can cause pain, weakness and numbness in the arm and hand. "When I evaluate kids, I am always looking out for issues outside my scope of practice. I want to make sure that we understand what could be causing the symptoms we are seeing," says Trish Krall, PT, DPT, PCS, C/NDT.

"Having the diagnosis from the neurologist meant that we could safely continue treatment."

Today, in addition to Physical Therapy, Marcos also receives Occupational Therapy from Lisa Alexander, OT. While Trish is working on balance, jumping, running, and climbing; Lisa is focused on fine motor skills like vision, grasping and shoulder position during reaching. On occasion, Trish and Lisa team up to see Marcos so that each of them can see what the other is working on. "It is so great to see what progress kids can make when we all work together as a team," says Trish. "Mom is awesome with recommendations. When Lisa or I come back for his next appointment, Marcos is already doing better because mom is so good at following through."

Marcos will be two years old this December and he has improved tremendously. Today, he is running, climbing up and down ladders, and using both hands to play with balls, cars, and Mr. Potato Head. His parents, Rosa and Eddie, are thrilled to see his progress, "It was so frustrating wondering why our son couldn't hit his milestones," says Rosa. "But even after just a week with Coastal Kids [Marcos] was starting to make huge progress and now he is finally starting to look like a normal kid. Coastal Kids is such a welcoming environment, and we are just so grateful to Trish, Lisa, and everyone at Coastal Kids Home Care."

* Our Mission *

Meeting the unique needs of medically fragile children in the comfort of their home.



1.800.214 (KIDZ) 5439
coastalkidshomecare.org

A Bright Light in this World

When Claire Watson was only five months old, she was diagnosed with Mucopolysaccharidosis type II (also known as I-cell disease), a progressively debilitating disorder with profound medical and developmental impacts. At the time, her parents, Susi and Matt, were told that she would only live to be two years old. However, her second, third and fourth birthdays came and went, and Claire thrived. Growing to only 3 ½ feet tall, her small size, unique appearance, and sparkling personality meant she made a big impact on whoever she met.

Claire defied all expectations and reached her thirteenth birthday this spring. Her mom reflected, "I am so proud of [Claire]. She is resilient. She has made me compassionate and has taught me to smile and laugh a lot. We know that she won't live to see her 20th birthday, but she has taught me to not live life with 'What ifs.'" Along their journey, after hours of discussion, Susi and Matt made the deliberate choice not to ask their precious daughter to undergo any more painful procedures. Instead, they opted to celebrate her life and encouraged her to share her light with the world.

Enter Coastal Kids Home Care. A fortunate encounter at a Shark's Hockey game in 2019, led Susi to reach out to learn more about the pediatric home health services available to Claire. "I was shocked to hear that there was an agency providing support for children like Claire," says Susi. "We had been offered some services by adult agencies, but I would rather be with an agency that is designed for kids. It feels like home because they know children and understand what parents go through."

Soon, the Watson's learned that Claire qualified for the Pediatric Palliative Care and Shift Nursing programs through Coastal Kids. With 40 hours a week of LVN shift nursing, Claire could have a familiar nurse care for her at home and join her in school. She soon charmed Ann Do, LVN and a special friendship formed between the quiet nurse and boisterous Claire. The Palliative Care program offered wraparound services for the whole family. Claire found her inner rockstar in Music Therapy with Daniel Le and her parents and siblings connected with Ruth Emerson for counseling.

Sadly, this past September 2021, Claire passed away. When her light went out, the world lost an extraordinary presence. She is missed by many, especially her Coastal Kids Home Care team. Fortunately, a beautiful portrait of Claire in our new office space reminds us of her bright spirit every day. Her parents generously asked their family and friends to donate to Coastal Kids in Claire's memory too. The Watsons remain connected to Ruth, according to Susi, "I had healed some during the time we were working with Coastal Kids because I was able to reflect on how life might look after she passed" says Susi. "The team prepared her brothers and sister to understand that something could happen. Our family is doing fine, but we have our moments. During those moments we talk about Claire and share memories." Even though she is gone, Claire continues to light up the lives of all those that she touched.



Light in the Darkness

Grief can feel like all-consuming darkness, and facing another day may feel impossible. Connecting to others coping with loss can offer a tentative light along the path to the future. Already this year, 250 individuals have found this light in bereavement groups, a legacy of Papillon Center for Loss and Transition.

Now under the umbrella of Coastal Kids Home Care, these groups are tailored to individuals of different experiences and offered both online and in-person. According to one participant who lost his wife to cancer, "Grief doesn't travel in a straight line. This group has helped me to navigate this crazy crooked road to put me on better footing, after my wife passed away...by talking to people who have been where I've been and where I am going." Thank you to Papillon staff, volunteers and donors for entrusting Coastal Kids Home Care to carry the torch of bereavement care forward for our community.

Counting the Stars. In 2021 your support means...

Nurses and therapists traveled more than 100,000 miles to provide in-home medical care to 520 children.

Counselors provided 725 clinic-based or telehealth sessions for 68 individuals with anxiety and other mild to moderate mental health needs.

Families caring for children with medical complexity received over 70,000 hours of shift and respite nursing.

Comprehensive pediatric palliative care services were available to 54 children with life-limiting illness and 9 patients received compassionate end-of-life care at home.

More than 250 individuals coping with grief and loss experienced connection and healing through participating in 79 bereavement sessions.

DONATE TODAY!

www.coastalkidshomecare.org

Mailing Address:
1172 South Main Street, #125 Salinas, CA 93901

