

# STORYBOOK

A Publication of Coastal Kids Home Care

Winter 2024

## ◆ A Shared Point of View ◆

This spring, Coastal Kids Home Care launched a new family engagement program with the goal of creating a vital space for caregivers to connect with each other, share their experiences of navigating the health and education systems, and simply get away from the daily stresses of caregiving.

In May, we hosted a Mother's Day Celebration at our San Jose office. It was a night of deep connection, fun, and relaxation which provided a much-needed break for these incredible women. In October at our Fall Harvest event, families had the opportunity to join in pumpkin decorating and a costume contest alongside other Coastal Kids. Most recently, our family engagement program has launched Caregiver Support groups in both English and Spanish. These groups are facilitated by licensed therapists and offer both a supportive community and a break from routines. Our hope is that this program will ensure that those who care for medically fragile children will take a moment to care for themselves.

Coastal Kids Home Care looks forward to offering additional engagement activities in the future, as we recognize the immense value of peer support gatherings. Do you have an idea for another activity for moms, dads, siblings, or the whole family? Please reach out to Rachel Pedinoff at [rpedinoff@coastalkidshomecare.org](mailto:rpedinoff@coastalkidshomecare.org).



## The Hero of His Own Story



Palo Alto are a testament to the family's resilience. Despite undergoing numerous surgeries, with another scheduled next week, Jose, now 13, remains optimistic. He mentioned being scared to return to school after the accident, but with time and determination, he has adjusted and now looks forward to spending time with his circle of friends every day.

At home, Jose enjoys spending time with his parents and his 6-year-old sister. The family spends their evenings watching movies and playing board games together. Jose also enjoys video games and loves to play Fortnite on his PlayStation 4. While sibling disagreements occasionally arise, these moments are balanced by the joy and connection they share as a family.

Two years ago, Jose was a typical 11-year-old boy when his life changed forever. A tragic accident left him with a fractured spine, and he was paralyzed from the waist down. Now reliant on a wheelchair for mobility, Jose and his family faced immense challenges as they navigated their new reality, soon Jose was diagnosed with scoliosis as well, compounding his physical challenges.

The family was referred to the Enhanced Care Management (ECM) program by the Natividad Clinic. They were connected with Marlene, their new Care Manager, and soon the program became essential to Jose and his family, providing vital resources such as food, transportation assistance, and ongoing support. "Coastal Kids Home Care has been so supportive," Jose's mom shared, expressing heartfelt gratitude for Marlene's dedication and care.

Jose makes regular trips to Stanford Children's Hospital for specialized medical care. The long drives from Greenfield to

Jose's care is now being managed by the Coastal Kids Home Care's palliative care program. His dedicated nursing team, Dillian and Jennifer, provides care for his catheter and dressing changes, while Michelle's massages offer relief and relaxation. With the holidays around the corner, Jose is looking forward to recovering from his upcoming surgery and has a special holiday wish—an Xbox to expand his gaming adventures.

While the family hopes to one day travel again, their focus is currently on Jose's recovery and continued care. His story is one of strength, resilience, and the profound impact of a caring community. Jose is truly the hero of his own story and Coastal Kids Home Care is honored to provide compassionate support to Jose's family as they navigate this journey together.

## ◆ Our Mission ◆

Coastal Kids Home Care meets the unique needs of medically fragile children in the comfort of their homes. Our clinical staff offers in-home nursing, specialized therapies, social services for children, and counseling for the whole family.



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# Rewriting the Future with Elijah

**A**t just 36 weeks pregnant, Shalray George was rushed into an emergency C-section due to preeclampsia. Her baby boy, Elijah, was born weighing just 4 pounds. From the start, it was clear Elijah faced unique challenges. His small size and difficulty meeting milestones led to months of specialized care in the NICU. At the suggestion of a caring RN student, genetic testing revealed

Elijah's diagnosis: Phelan-McDermid Syndrome, a rare condition requiring lifelong round-the-clock care.

Elijah's diagnosis was a turning point for the family. Shalray, who had just completed graduate school, found herself unable to work due to the demands of his care and the needs of their two older children. The family faced a grieving process, adjusting to a new reality. Yet, their journey has been one of perseverance, love, and unexpected blessings.

Today Elijah is a remarkable 14-year-old who has overcome challenges with great courage. Living with a rare syndrome, he navigates hearing impairments, partial blindness, hormone imbalances, hypotonia (weak muscle tone), and nonverbal autism. Over the years, he has undergone ten surgeries including the placement of a

g-tube to support his nutritional needs. Despite these obstacles, Elijah has infectious laughter and a sweet, affectionate soul. He loves music, BabyFirst TV's Harry the Bunny, and spending time in the water.

In 2024, the family was introduced to Coastal Kids Home Care through the new Enhanced Care Management (ECM) program. Elijah's high level of need led his Care Manager, Calli, to transition him to Coastal Kids comprehensive palliative care program. Six months later, Shalray credits Coastal Kids with being a lifeline. Their Shift RN, Nashia, has become like family, offering excellent care each day. Elijah also benefits from music therapy sessions with Daniel and soothing massages from Michelle, both of which bring him immense joy.

For Elijah's family, time together is precious. They cherish family hikes, beach days, and



life on their small homestead, where they sell eggs, honey, and vinegar at the local farmer's market. Shalray reflects on their journey with gratitude, saying, "I was terrified when we first got his diagnosis, but Elijah has been a blessing. He's enriched our lives in ways we never imagined." Through resilience, community support, faith and love, Elijah and his family continue to embrace life to the fullest, celebrating every small victory. Coastal Kids is honored to be a part of their story.

## License to Explore



For children with developmental delays, the simple act of moving independently is a milestone that can seem unattainable. Through a remarkable new Coastal Kids Home Care program called GoBabyGo, the dream of movement is becoming a reality. GoBabyGo is a unique initiative in which physical therapists work alongside families to modify mechanical cars, transforming them into accessible vehicles for toddlers with disabilities. The cars are equipped with customized

features like adaptive switches, seats, and safety harnesses that allow children with varying physical abilities to control their movement for the first time. For many kids, the moment they push a button or turn a wheel and begin to move on their own is nothing short of magical.

Since launching the program this spring, Coastal Kids Home Care has provided 13 children with GoBabyGo vehicles. Once in the driver's seat, children with mobility disabilities are given a means to move and a chance to play, explore, and socialize more easily. Instead of being pushed in strollers or carried, these devices give children a sense of control over their own journey. Each vehicle is adapted to the child's unique needs, ensuring a personalized experience. For children like Ellie (pictured above) mobility challenges are no longer an obstacle to exploring the outdoors alongside their loved ones, fostering a sense of togetherness and independence. For more information on GoBabyGo please email pkrall@coastalkidshomecare.org.

## *In 2024, your donation supported these vital programs.*

Nurses and therapists traveled more than 188,000 miles to provide in-home medical care to 556 children.

Counselors provided 2232 clinic-based or telehealth sessions for 158 children and youth with mild to moderate mental health needs.

Families caring for children with medical complexity received over 73,500 hours of shift and respite nursing.

Comprehensive palliative care services were available to 133 children with life-limiting illness and 14 families received compassionate end-of-life services for their child.

This year our clinicians distributed holiday gifts valued at nearly \$70,000 benefitting more than 480 families caring for medically fragile children in our community.

## **DONATE TODAY!**

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

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