

STORYBOOK

A Publication of Coastal Kids Home Care

Summer 2023

One Step at a Time

Will Ellie ever walk? This question worries Denise Consoli as she looks into her young daughter’s future. Ellie was born full-term. However, after a difficult labor at a birthing center, her newborn vital signs were very concerning due to complications from shoulder dystocia. She was immediately rushed to a local hospital and transferred by helicopter to Lucile Packard Children’s Hospital where she was treated for hypoxic-ischemic encephalopathy (HIE). The condition, which is caused by lack of oxygen to the brain, affects the central nervous system and can cause developmental delays. Among Denise’s biggest concerns is whether Ellie will rely on a wheelchair as she gets older.

Already 10 months old, Ellie has proven to be incredibly resilient. She spent her first long months in the hospital and suffered three seizures during that time. Initially she was also dependent on a nasogastric (NG) feeding tube for nutrition, and to be discharged she needed to meet her feeding goals. To her mom and dad’s delight, she finally did, and they could at last bring their precious daughter home.

At hospital discharge Denise was contacted by a nurse from Coastal Kids Home Care to discuss Ellie’s plan of care. Since that time, Ellie’s clinical team has become like an extended family. Once weekly nursing appointments combined with bi-weekly physical and occupational therapy offered Denise a lifeline in managing her daughter’s health and development. And what about the answer to that concerning question?

Denise is now hopeful that her daughter will one day walk. Patricia Krall, PT, PCS, C/NDT, Coastal Kids Home Care pediatric physical therapist, specializes in the treatment of kids like Ellie who have neuromotor disorders. Through her knowledge and compassionate approach, Trish put Denise’s mind at ease. Although her path will not



be easy, already Ellie is making great progress.

At each appointment, Denise works closely with Ellie’s therapists to set new goals and discuss next steps. It is truly a team effort, with Ellie in the lead. According to Denise, “So far she has met every single goal, she has done incredible work.” Ellie’s latest goal is to learn to crawl within the next few months. Up next? Only 10-month-old Ellie knows, but we are all excited to see.

Coastal Kids provides in-home medical care for kids and support for those who love them.

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“Just walk beside me and be my friend.” - Albert Camus



Letter from the Executive Director

Often, the experience of caring for a child with complex medical needs is described as a journey. For most families it has a sudden beginning, when a child receives an unexpected diagnosis, and from there the road is filled with unexpected turns and difficult obstacles. At Coastal Kids Home Care, our mission is *to meet the needs of medically fragile children at home*, that is, to accompany families on their child’s journey – wherever it takes them.

Our clinical teams fulfill this mission by meeting each child, and their family, where they are at. For our physical therapists, this involves offering toddlers, like Ernest and Ellie, the specific exercises, and tools they need to take their first independent steps. Other children, like Odinn, require the extra support of shift nursing and the family-centered services available through palliative care. And for the tiny twins Emir and Sael born to parents new to our country? Our team recognizes that sometimes it takes “all hands on deck” to ensure fragile infants have a strong foundation to begin life.

At Coastal Kids Home Care, we also know that the journey of serious-illness can result in the loss of a precious child. Our leadership of the Heal Together program is built upon our belief in the importance of escorting families in their next journey – that of grief. Over the past eighteen months Heal Together has brought healing and hope to thousands of individuals in our community.

This summer, take a moment to meet Ernest, Ellie, Odinn, and the unforgettable twins. As a friend to Coastal Kids, your support offers each of our pediatric patients a helping hand on their journey toward health, or access to the compassionate care they need to live well with medical complexity.

Thank you for walking alongside us today and every day. Your presence means the world to these exceptional kids.

Kind Regards,

Margy Mayfield, RN, BSN
Executive Director, Coastal Kids Home Care

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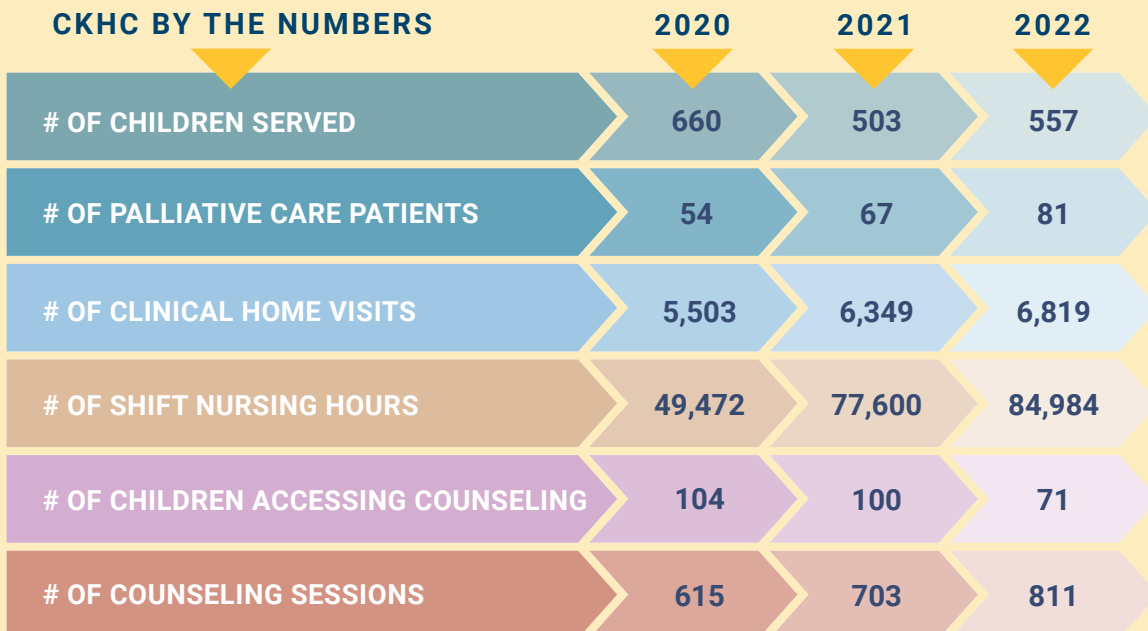
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Paving a New Path for Odinn

Six-year-old Odinn Eastes loves Elmo. He even had the chance to travel to Sesame Place in southern California last year to meet his favorite characters. That trip was a highlight on his families' long journey toward understanding their son's complex health issues. When Odinn was just a few months old, his mom Kathryn began noticing differences in his development compared to her two older boys. He frequently struggled with respiratory issues and had been admitted to Lucile Packard Children's Hospital numerous times.

After several genetic tests all his doctors could determine was that something was affecting Odinn. Yet, he did not fit easily into any diagnosis. Thus, all they could do was treat his symptoms and wait for science to catch up. That is until last year when they sent new lab genetic orders to Germany. They reran Odinn's blood work and compared the skin sample taken from him to confirm a diagnosis. At last, his parents had an answer. Odinn was diagnosed with a rare genetic disorder called CACNA2D1 which causes developmental delays, movement difficulties and greater vulnerability to respiratory and other infections.

For the first 4 years of his life, Odinn's family walked the difficult road of medical complexity alone. However, in 2022 after another long hospital stay, Kathryn told doctors she was ready to have help. Previously, she had refused, "I felt like I had to do it on



my own. I was not ready to have someone in my house and trust them to take care of Odinn." However, at long last Kathryn and her husband could feel burnout approaching. With the encouragement of a close friend who utilizes Coastal Kids, Kathryn learned more about her options.

This time when Odinn was released from the hospital, he went home to 8 hours of shift care with their new Coastal Kids Home Care nurses Amber and Nashia. Having trusted nurses to care for Odinn has helped tremendously by providing Kathryn and her husband a break to sleep, take care of the house, and work. According to Kathryn, "It is nice to have help at home and not feel like I have to do everything alone." Amber and Nashia have

become like family, even joining them on vacations to help provide care for Odinn.

Soon after accessing shift care, Kathryn learned that due to Odinn's diagnosis he also qualified for more comprehensive palliative care services. For Odinn this means frequent visits with music therapist, Daniel Le. Hearing Daniel sing his favorite songs from Sesame Street or Disney always brings a smile to his face. He also delights in watching his big brothers play video games. Despite being nonverbal, Odinn's laughter resonates throughout the entire house. Although their journey of medical complexity is not over, Coastal Kids shift nursing and palliative care services have helped to pave an easier path for the Eastes family.

On the Map in Santa Clara County

Coastal Kids is excited to announce the opening of a **brand-new clinical hub in Santa Clara County**. Access to this new space is made possible by the generosity of Michael Van Every, CEO and Managing Partner of Republican Urban Properties, Essex Property Trust, Inc. and our community of supporters through the San Jose Mercury News Wish Book Campaign. This office space will serve as a convenient location for our Santa Clara County providers to chart clinical notes, conduct meetings, trainings, and access key medical supplies. **Our nurses and social workers are thrilled to finally be on the map in San Jose.** Thank you to our friends in Santa Clara County for bringing care home to kids who need us.



Making His Own Way

Victoria and Ernest Sr. have faced and overcome more obstacles than most parents. At her twenty-week ultrasound, Victoria was excited to see her baby for the first time. However, a few minutes into the appointment she sensed something was wrong. Her fears were realized when doctors referred her to Stanford for further examination. Multiple tests and ultrasounds later, her baby was diagnosed with Agenesis of Corpus Callosum (ACC), a complex brain disorder that can cause significant developmental delays. According to Victoria, before Ernest Junior was even born, "We were told crawling, walking and talking would be severe challenges for him or completely non-existent."



could, and then as soon as Johnna came into our lives, he started growing leaps and bounds." Victoria was referred to Coastal Kids by San Andreas Regional Center (SARC) and she is so grateful that she found Johnna, "I couldn't see my son being where he is today without her and without Coastal Kids."

At two-and-a-half, Ernest is now a big brother to eight-month-old Johnny who also has ACC. According to Victoria, "We never anticipated both of our children being born with the same brain disorder. In the beginning we were like, 'why us' and 'what caused this' and it took us time

to acknowledge that there was nothing we could have done to change the outcome." Victoria and her fiancé now go on to say, "They are perfect just the way they are, we have agreed that no matter what life throws at us we are going to tackle it as a family."

For a mom and dad, this news was devastating. They learned that ACC was a wide spectrum and there was no way to know his future. Even so, they did their best to understand his diagnosis and look forward to his arrival. When Ernest Junior was born, they realized that no one can ever be fully prepared to care for a child with medical complexity. Those first months were harrowing and at six months old he received a second diagnosis of Cerebral Palsy. This new information made crawling and walking seem even less attainable.

Although both boys are diagnosed with ACC, they illustrate the broad spectrum of development. Johnny is already pulling to stand and crawling, while his big brother remains more reserved. Ernest Junior did just receive a new gait trainer which will assist him in taking his first steps. For the moment the whole family is focused on the goal of having both boys walk down the aisle at their parents' October wedding on the beach. Johnna is super excited to join them as a guest as they embark on this next stage of their family's journey.

Fortunately, Ernest met Coastal Kids physical therapist Johnna Miller when he was twenty months old and they clicked. According to Victoria, "We were doing the best we

Expanding Access to Bilingual Counseling

Coastal Kids is happy to announce the expansion of our mild to moderate counseling program. Joining our counseling team is Licensed Marriage and Family Therapist, Enrique Morales. As a bilingual therapist with over 10 years of experience working with children and adults, Enrique brings valuable expertise and background working with Spanish speaking families dealing with trauma and loss. He has also stepped up to fulfill a critical need for counselors in southern Monterey County where he serves patients one day a week. Enrique joins our other full-time therapist Nefertari Rossell, LMFT and a team of part-time therapists, who continue to meet the needs of the community by providing counseling services to children ages 5-21 in Monterey County. **Does your child need counseling? Call 800-214-5439 today for more information.**



Heal Together – A Journey Through Grief

Following the devastating impacts of COVID-19, Hospice Giving Foundation established Heal Together, a community-wide initiative to respond to grief and loss. Led by Coastal Kids Home Care, Heal Together educated our community in the language of grief and provided opportunities to accompany individuals through their unique journey.

Heal Together gathered more than 54 providers to bring their talents and expertise to grieving individuals. For some, one-on-one counseling or bereavement groups offered a path to follow. Others benefited from the healing touch of massage or cranial sacral therapy. Child life and music therapy were available to children and teens, while cooking and art classes benefitted older adults.

The program has reached all corners of our community and responded to the needs of individuals from different cultural backgrounds. Partnership with promotores de salud brought information on grief to hard-hit Spanish speaking communities, and outreach by therapeutic musicians has led to calming experiences for lonely residents of skilled nursing facilities.



Over the last eighteen months, Heal Together has accompanied 3,630 Monterey County residents on their grief journey. An additional 237,000 have accessed information on coping with loss and grief. **For more information visit www.heal-together.org or follow us on social media @healtogether831.**

“I’m forever grateful to Heal Together for the counseling services I am able to receive through them. I have access to a wonderful therapist who is guiding me and giving me tools to cope with the loss of my sister.”

- V.C., Individual Counseling Client



11 # of rapid grief responses

54 # of engaged mental health and wellness providers

106 # of community partners

646 # of intakes completed

724 # of individuals placed in bereavement care

827 # calls to the Heal Together Hub

1,850 # of counseling sessions

2,367 # of individuals participating in wellness and expressive activities

All Hands On Deck



When Coastal Kids Home Care nurse Monique Flores ventures into the home of a new home care patient, she never knows what she will encounter. Her experience in early June meeting the Vasquez twins, Emir and Sael, was more unexpected than most. After arriving at a small house in Salinas she was led to a back bedroom. What she found was a mother recovering from c-section and two premature twin boys, all lying on the floor. The only other items in the room were a few blankets and trash bags filled with the families' belongings. Monique took in the image in front of her, carefully examined the babies, and sat down with their parents to learn more.

As they talked for some time, the parents shared that they had traveled from Mexico to California in search of a better life for their newborns. Mom was only able to access prenatal care late in her pregnancy and was not aware that she was carrying twins until she arrived in Salinas. The boys' father was working in the fields, but once the babies were born, he had to stop momentarily to help care for his growing family. As soon as Monique left, she called her husband to let him know there was a family in need of their help. She stated, "I was not going to be able to sleep if I didn't get this family some necessities." Monique bought a travel bed for the

babies, clothes, diapers, and wipes and dropped off the items that same night along with some cash for groceries.

The next morning, Monique reached out to Monica, the Office Manager at Coastal Kids Home Care, to see if she knew of any resources for the family. Monica immediately realized that this was an "all hands on deck" situation and sent out an email to the whole staff. The response was swift. Office staff, nurses, family members and donors all stepped up to contribute. Together, team Coastal Kids donated two cribs, a bed for the family, diapers, wipes, a bassinet, blankets, clothes, and gift cards for food and other essentials. According to Monique, the parents who had moved so far to find a new life for their children, were overwhelmed with gratitude. And best of all? The identical twin boys are thriving.

Monique may not know what to expect when she walks into a new patient's home. However, she is confident that her compassionate colleagues are always just a phone call away. Since this time, clinical staff have identified additional families in need of necessities and more individuals have offered to help. Coastal Kids Home Care is truly ready to fulfill our mission to "meet the unique needs of medically fragile children in the comfort of home," even if that means going above and beyond... together.

A Heartfelt Thank You

Compassionate in-home care for children with illness and disability relies on the generosity of our community. Thank you to our 2022 donors.

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To see more 2022 donors visit
www.coastalkidshomecare.org/donors

TOUCH-A-TRUCK

On the Road to San Jose

History Park San Jose hosted our very first Touch-A-Truck San Jose on April 15, 2023. This event combined the beloved Cruisin' for Coastal Kids parade with the fun of Touch-A-Truck. Along with over 20 working trucks, it featured 50 classic cars in a parade with special guest Sharkie! The San Jose Sharks and Barracuda Street Team joined in the festivities and brought an inflatable slapshot booth that both children and adults loved. Other highlights included performances by individuals with differing abilities and fun activity booths coordinated by 10 local nonprofits serving children with special needs. The best part of all? Coastal Kids Home Care welcomed 12 of our own patients and their families to participate in all of the fun and enjoy a relaxing break in our Very Important Patient (VIP) section where they had front row seats to the parade.

We are excited to announce Touch-A-Truck will return April 20, 2024!



Going the Distance in Salinas

On August 27, 2023, Coastal Kids Home Care will host our **9th Annual Touch-A-Truck Salinas**. An event that started with two dozen trucks has grown to an annual autumn tradition for our community. This year in addition to more than 40 vehicles, the event will feature 5 food vendors, 5 activity booths led by nonprofit partners and 9 guests on the main stage for entertainment. If you arrive on time, you will be treated to a special highlight as a CalStar helicopter will be landing at the event too! Tickets are just \$5 per person and online sales have already begun. Join us on **August 27 from 12 - 4** at the Salinas Rodeo Grounds and get ready to climb, learn and explore! Visit www.coastalkidshomecare.org to learn more about this can't miss event for kids and kids at heart.

Tickets are on sale at www.coastalkidshomecare.org





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Join Our Community of Care

Share – Are you the parent or guardian of a Coastal Kid who would like to share their story with us? We'd love to hear from you! Reach out via Facebook, Instagram or email Lizette Carbajal at lcarbajal@coastalkidshomecare.org

Participate – Bring out a truck or become a sponsor at this year's 9th Annual Touch-A-Truck. Join us on August 27, 2023, for a day of fun. For more information, email Lizette Carbajal at lcarbajal@coastalkidshomecare.org

Contribute – Bring care home to children with illness and disability through contributing to Coastal Kids. Become a monthly donor at www.coastalkidshomecare.org or return the enclosed envelope and guarantee excellent care for kids year-round.

Promote – Is there someone in your life who has shown bravery, patience, perseverance or kindness in the past? We have a shirt for that! Buy Coastal Kids merchandise at www.bonfire.com/coastalkidshomecare and let the world know that you value quality care for kids.



www.coastalkidshomecare.org