

# Storybook



## ELYCE'S HOME IS WHERE HER HEART IS

Nine-month-old Santa Cruzan Elyce Forbes is in love with popcorn. "She'll eat a whole bag if I let her," says mom Noelle of the precocious babe whose cheery disposition belies her serious health challenges. "She is always happy and smiling, even after procedures that are painful or uncomfortable."



Born with Juvenile JXG, an extremely rare disorder that affects the blood and spleen, little Elyce has been fragile since day one. The baby was initially slated to receive six weeks of chemotherapy at Stanford Children's Hospital, administered through a plastic port inserted into her chest. "I kept thinking; I can't do this. The port will get pulled out. I'm going to give her an infection. My head was spinning," says Noelle.

But after several doses of chemo, Elyce's blood count dropped and further treatments were postponed until her condition stabilized. Overstressed and with another young child at home, Noelle was exhausted. "I can't tell you how many times we drove to the hospital and then just drove back due to her low blood count," says Noelle, "Too many times to think of."

Eventually, hospital staff referred the Forbes family to Coastal Kids so that the

toddler's weekly blood draws and dressing changes could take place at home. "Those first three months without help were awful," says Noelle. "It's so much better now with the help of our Coastal Kids' nurse."

"Mothers find comfort in having another set of eyes on their children," says Margy Mayfield, Executive Director for Coastal Kids. Noelle can phone Coastal Kids any time of the day or night and speak with an on-call nurse if Elyce's condition changes, or if there's a problem of any kind.

According to Lauren Bartley, the Forbes' home care nurse, a full assessment is performed every time she visits. Afterward, results and any concerns are reported to Elyce's team at Stanford Children's. "Elyce has rashes that need to be watched for changes, and she has a tendency to have bleeding issues," says Bartley. "Our home visits allow us to monitor her carefully, so small concerns don't turn into big emergencies."

These days, little Elyce can be found chasing her four-year-old brother Jace, whom she worships, or crawling into the kitchen in search of her favorite food. While the road ahead may be marked with obstacles seen and unseen, the Forbes family feels fortunate. "Even though she has been sick her entire life," says Noelle, "Elyce has the best personality. She has such heart."



Coastal Kids delivers the right kind of care, right when children need it most.

**COLORFUL LIKE A RAINBOW** Babies, young ones, teens...all unique. Count them up!

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**COASTAL KIDS HOME CARE**

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# THERE'S NO PLACE LIKE HOME

Letter from the Executive Director



If only we could click our heels...

Think of how families must feel, thrust into the world of hospitals, specialists, and tests when a baby is born prematurely, a seven-year-old is seriously injured, or a teenager is diagnosed with cancer.

Imagine being transported to a perilous, unfamiliar place, where complicated terms describe *your child*, countless documents with small print need your signature, and snap decisions must be made regardless of how exhausted or worried you are. Most parents want to grab their child and go *home*. Yet home can be frightening when a parent must administer treatment and medication, work with complex equipment and monitor symptoms on their own.

Now, imagine the relief when a caregiving family meets their home care nurse for the first time, realizing they are no longer alone as they relax and feel more confident, knowing they have medical experts on their team who make house calls and are available to address their concerns 24/7.

Our kids tell us, "There's no place like home." Home is where sick kids want to be and where, studies show, they feel better and heal faster. While they can't click their heels like in the movies, with your continued support, they can go home and be safe and comfortable while receiving the treatment they need.

This past year, through the generous support of our Board, volunteers, and community of new and old friends, Coastal Kids helped 696 children and supported 2,070 of their family members. Because of the financial and in-kind gifts we received, children awaited our nurses every day, snuggled in their own beds, surrounded by the love and warmth of family.

Thank you for your trust and faith in our mission.

Margy Mayfield, RN, BSN



**We honor our 2015 Board of Directors** who lovingly uphold the mission of Coastal Kids by giving countless hours of volunteer time to govern, support, and fundraise for our organization and the children and families we serve.

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Every one of our child patients is as unique and special as the colors of the rainbow. And in 2014, we saw 696 amazing kids. Our team of registered nurses, physical and occupational therapists, massage, music, and art therapists, and our remarkable social worker and counselor made 5,478 house calls. With every visit, a child's pain was eased, a caregiver's concerns supported, a life and spirit tended for one more day.

Nineteen children died during 2014 while on our service, and while we were deeply aggrieved by these losses, we were honored to be present with them and their families at the end of their lives.

- 4,334** nursing visits
- 305** physical and occupational therapy house calls
- 218** massages
- 315** art and music therapy play times
- 249** care coordination and anticipatory grief support sessions
- 57** bereavement appointments

# FACILITATING A CHILD'S LAST DAYS AT HOME

*Hospice Giving Foundation partners with Coastal Kids to bring quality in-home end-of-life care to terminal children.*

**IT SEEMS SO OBVIOUS:** Children should have access to quality, end-of-life care. Yet, it's a topic that's almost impossible to broach.

"People expect to care for adults with life-threatening or terminal illnesses. While they are deeply saddened and sometimes afraid, they aren't surprised," says Siobhan Greene, Executive Director of the Hospice Giving Foundation. "But when a child has a terminal diagnosis, that's too hard, too painful to imagine. Still, at the common sense level, pediatric end-of-life care is something in which we must invest."

Time and again, the Hospice Giving Foundation has provided essential funding that has enabled Coastal Kids Home Care to bring palliative and compassionate end-of-life care into the homes of children living in Monterey County. In fact, since 2005, Coastal Kids has fulfilled the wishes of 88 families who wanted to bring their child home from the hospital for their final months. This is noteworthy, as Coastal Kids is the only resource in Monterey County that has the specialized skills, pediatric trained staff, and willingness to care for terminal children at home.

Greene understands the deep value of the services Coastal Kids provides. "The depth of medical services that critically ill children need is not available in our community at the hospital level," says Greene. "This creates hardships and a unique set of challenges for families. Going to appointments far away, dealing

with treatments, the constant worry—these challenges take their toll. Providing resources so they can be supported is tremendously important."

While public health insurance marginally covers the cost of care, additional financial support is vital to make Coastal Kids' services available to dying children and their families, especially those who are low-income and struggling to make ends meet. As a valued partner, the Hospice Giving Foundation underwrites thousands of home visits for Monterey County kids each year, ensuring that children have access to the same type of quality end-of-life care that adults do.

"The end of life affects us all," says Greene. "By bringing attention to end-of-life care, we intend to help people be supported through the process, whether it is a father, grandmother, or child who is dying."

From making art or music together, to giving a fragile child a comforting massage...from adjusting pain medicine, to coping with the practical and emotional matters of preparing for the end of a young person's life...there is so much that families of terminally ill children may not be equipped to deal with alone. With the help of the Hospice Giving Foundation, Coastal Kids is available to effectively and compassionately address the final needs of dying children and their families at this most difficult and tender time in their lives.



## OUR MISSION



*Coastal Kids Home Care works to improve the quality of life for children healing from injury or short-term illness, living with chronic serious conditions, developmental problems, or those facing the end of life.*

*Our professional staff is dedicated to the provision of in-home pediatric medical care, therapies to ensure comfort, and social services to assist the entire family. Services are available to any medically fragile child living in Monterey, San Benito, Santa Cruz, and Santa Clara Counties.*



## HOME AGAIN AND FEELING RIGHT

*Though they are small, their diagnoses are big and their needs are great. For these two local kids needing critical care, as well as for their busy families, home turned out to be the best place to heal.*



**KARINA REYES** is a spunky four-year-old living with Dermatomyositis, a big word for such a tiny tike. Plagued with skin rashes and joint pain, Karina's body works hard to combat the autoimmune disorder that causes constant inflammation.

Specialists at Stanford Children's Hospital prescribed weekly injections of a chemotherapy agent for Karina, and the treatment is helping. Gloria Reyes, Karina's mom was eight months pregnant when Karina was diagnosed, and therefore unable to provide the injections her daughter needed.

Coastal Kids was contacted and nursing staff immediately began providing weekly shots for Karina at home, so that Gloria and her new baby Daniel would not be exposed to the chemotherapy medication. While Daniel is now ten months old, he continues to breastfeed, so Coastal Kids' nurses still play a vital role in the family's health and life.

"Being the mother of three young children, and having one that has so many medical appointments is hard," says Gloria. "Having nurses come to our home, answer my questions and provide the treatment is very reassuring."

Eventually Gloria will have to provide the injections Karina needs herself. But Jenovie Valdez, their home care nurse, won't rush her. "I'll teach her slowly and support her through the process," says Valdez. "Right now, the plan is to let mom breastfeed her son while I come weekly to keep Karina pain free."

While Karina will be on some kind of medication her entire life, right now, with the assistance of Coastal Kids, the family can focus on treating their daughter's condition and easing her pain day by day. And that is so important because a pain-free Karina is a happy Karina...out running and playing with all the neighborhood kids.



"I won't be able to keep him alive feeding him like this," said Norma Chavez, of her seven-month-old son, **ANTHONY**.

Born with a seizure disorder that made it difficult for him to breast or bottle feed, baby Anthony endured a lengthy two-month hospitalization only to be sent home with a gastrostomy tube inserted in his stomach. The equipment makes it possible for Anthony to receive the nourishment he needs for his healthy growth and development.

Norma felt uncomfortable and distraught caring for her son at home, especially given the pump that was meant to feed him during the night. "I was afraid to sleep because I was afraid Anthony would choke on the formula and I wouldn't hear him," said Norma.

But on the day they returned from the hospital, nurse Ellen Buckingham was there to greet them. She quickly assessed the family's situation and worked with Norma to devise a new plan: instead of using the pump, Norma would feed Anthony via his tube every three hours during the night. Norma was comforted and she found the schedule manageable. With Buckingham's help, Norma also learned to manage her baby's bathing, clean his tube, monitor the tube's wear, and even how to replace it in the event of an emergency. "I have learned a lot from my nurse and she is a very nice person to help me," says Norma.

Even after six months at home, Norma maintains her every-three-hour nightly vigil with Anthony. She is one of Freedom's busiest moms with the baby, as well as a seven, nine, twelve, fifteen, and eighteen-year-old to look after. As for Anthony, he's gained three and a half pounds since leaving the hospital. He is a burly boy with a big loving family.



# NICKIE IS A WARRIOR

On December 4, 2013, 23-year-old Nichelle “Nickie” Ellis was placed into a deep sleep, anesthetized as a team of surgeons from the University of California at San Francisco Medical Center (UCSF) removed a lemon-sized tumor from her brain.

“That summer I started having headaches,” says the Fresno State graduate. “They only lasted a second or two, but they were so bad, I’d be bent over in pain.” A neurologist ordered an MRI, and a few days later, Nickie received a call. “He gave us the news. He didn’t think it was cancerous, but it was very emotional.”

Unfortunately Nickie’s tumor was a malignant pediatric cancer. Doctors prepared her for the worst possible outcomes from her surgery. “They said I might not be able to talk when I woke up, or wiggle my fingers and toes. They said I might not recognize my family,” says Nickie. “I was prepared to spend three days in the ICU, and be in the hospital for a week. But that morning, in the prep room, I was gung ho. I thought, let’s do this! Let’s get it over with. I wasn’t nervous.”

The six-hour intricate surgery succeeded beyond expectation. “When I woke up, my Mom was sitting at the end of the bed. I said, ‘Hi Mom. Can you get me some water?’” Within 48 hours, Nickie was discharged from the hospital, and was on her way home to Gilroy to begin the arduous journey of rehabilitation.

Coastal Kids’ nurses visited Nickie at home, drew her blood and provided treatments to ensure hydration after chemotherapy. Physical therapist Claudia Roth and occupational therapist Judy Marshall worked with Nickie to combat the debilitating muscle weakness that followed her surgery and chemo treatments.

“At one point, I lost so much weight, I had to get a feeding tube. Then I got shingles and had to be in isolation for ten days in the hospital,” says Nickie. “When I got out, I had Foot Drop, a severe neuropathy in my ankles. My feet were just limp. When I met Judy, I was in a wheelchair.”



Marshall commented, “We worked on upper body strength, as well as core strengthening exercises and activities. Balance was a huge issue for Nickie, so we included vestibular rehab and that meant working on everyday activities such as baking while standing. We used therapeutic tools such as visualization, deep breathing, and guided imagery techniques.”

While Nickie’s clinical teams worked to address her physical and cognitive challenges, a remarkable connection helped rally the good wishes Nickie needed to keep going.

A sports agent friend of Marshalls represented Fresno State alum Derek Carr, now an NFL quarterback for the Raiders. “Derek was a year behind me at Fresno State,” says Nickie. “He sent me an autographed photo, posted my story on Instagram and Facebook. More than 2,000 people commented. The amount of support that came through... all the posts and kind words; it was totally awesome.”

Nickie gains strength every day. She spends her time at the gym running and participating in activities that bring her joy. When asked what she was most thankful for, she said, “My health team at UCSF, Coastal Kids Home Care, all the love and support from friends and family. I wouldn’t be alive today without all that love and support.”

As warriors go, Nickie is a remarkable inspiration. “Faith, hope, and love are the three virtues that got me through, along with a smile and a positive attitude,” she says, sporting a broad grin. “I’m cancer free!”





# BIG BLESSINGS



Coastal Kids' **Circle of Giving** gratefully acknowledges the donors and philanthropic foundations that provided financial gifts and sponsorships in support of in-home nursing and therapies for medically fragile children during 2014.

## **Circle of Compassion (\$100,000+)**

Hospice Giving Foundation

## **Circle of Healing (\$50,000+)**

Rudy E. Futer Fund for Human and Humane Needs at the  
Community Foundation for Monterey County

## **Circle of Grace (\$25,000+)**

Joseph and Vera Long Foundation  
Taylor Fresh Foods, Inc.

## **Circle of Courage (\$10,000+)**

Caroline's Non-Profit Thrift Shop  
Children's Miracle Network  
Community Foundation Santa Cruz County  
Driscoll's Charitable Fund at the Community Foundation  
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Harden Foundation  
Monterey Peninsula Foundation  
Nancy Buck Ransom Foundation  
Palo Alto Foundation Medical Group Community Health  
Care Endowment Fund  
Rite Aid Foundation  
Wallis Foundation

## **Circle of Promise (\$5,000+)**

Markie Foundation  
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## **Circle of Joy (\$1,000+)**

Alpha Xi Sorority  
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Sigma Alpha of Omega Nu Santa Cruz  
Andrew and Steffanie Smith  
Town 'N Country Realty  
The Upjohn California Fund  
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Yellow Brick Road Benefit Shop



## **WE LOVE EMERALD CITIES**

In an effort to conserve paper and preserve our precious environment, Coastal Kids has limited the number of 2014 donors listed in our *Storybook* newsletter. However, *we love and thank you all*, and every single one of our supporters is acknowledged on our website at [www.CoastalKidsHomeCare.org/supporters](http://www.CoastalKidsHomeCare.org/supporters). Thanks for helping us to maintain our forests and keep our world green.



## TOUCH-A-TRUCK EARNS \$13,555 AND LOTS OF SMILES



Coastal Kids 2014 Touch-A-Truck event was a resounding success! More than 20 vehicle operators shared their rigs and more than 500 kids and kids-at-heart came out to enjoy a fun filled day of exploring trucks, tractors, fire engines, trolleys, and more! We thank the generous sponsors who made our event possible, especially, Rabobank and

the House family. \$13,555 was raised to help bring medical care to chronically ill children in our local communities.

If you had a grand time last year, or if you are bummed you didn't make it, don't worry. Our 2015 Touch-A-Truck promises to be a hair-raising, big wheel rolling good time too!

Is there a good witch or wizard out there? Then please help us fulfill our wishes for 2015!



**Have a Heart.** Each one of our child patients has a medical need, whether it is a dressing change, a lab test, an injection, a medication, or myriad other procedures prescribed by doctors. With 5,500 home visits planned for this year, we could use a bit of magic. **\$100 in fairy dust sends a nurse scurrying to half a dozen kids. \$500 in glitter rallies a small army of loving clinicians. \$1,000 or more is a miracle we'll never forget.**



**Be Brave.** Art therapy helps our kids to cope, to tell their stories, to express what they can't say out loud about chronic illness. **A donation of \$50 brings us closer to our goal of \$2,000.** Help us to purchase luscious paints in many colors and oversized pads of paper...so our courageous kids can express all those big feelings.



**Just Think.** 7,000 square miles of distance to cover. Seventeen cars burning more than 80,000 gallons of fuel, traveling 150,000 miles from home-to-home across four counties. That reaches \$45,000 a year in cost. These are the facts. **\$25 equals five home visits, \$50 funds 10 cross-county treks, \$200 fuels our Clinic on Wheels with joy!**



**Villagers Needed.** It takes a village to care for a sick child. Please volunteer to help Coastal Kids. Are you a tech geek? Or a filmmaker, attorney, retailer, homemaker...whatever skills you have, in whatever way you think you can help, we can use your time, energy, and smarts!



**It's downright easy to make a gift!** Go to [coastalkidshomecare.org](http://coastalkidshomecare.org) and select "Donate" OR make a check payable to Coastal Kids Home Care and insert it in the enclosed envelope.



## COASTAL KIDS HOME CARE

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## Stories in the Making

### **"All You Need Is Love"** (June 2015)

John Lennon wrote the words and immortalized the song. But this coming June, you can make them count. Pledge your dollars to quality home care for medically fragile children. Our friend-to-friend virtual campaign will ping into your email, your phone mail, and nudge your Facebook page. Send the love, and your contribution, with just one click.

### **"Touch-A-Truck"** (September 13, 2015)

Join us for the second annual frisk a fender, paw a dashboard, and climb a fire engine event at the Salinas Rodeo grounds. There'll be lots of different vehicles to explore. It's going to be a blast for the kiddies, and a rare good time for parents, foodies, and friends who just want to have fun.

### **Entre Nous Society, "An Autumn Affair"** (November 2015)

Coastal Kids' great friends and supporters, the Entre Nous Society, is hosting a noontime feast at the fabulous Corral de Tierra Country Club. Indulge your culinary guru and help the beautiful ladies of Entre Nous help us. All proceeds benefit Clinic on Wheels programs for 2015.

Don't forget to join us on [Facebook](#).  
Send us your email address via our [website contact page](#). You'll be the first to get the skinny on upcoming events.



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