

# STORYBOOK

A Publication of Coastal Kids Home Care

Spring 2022

## "Slow and steady wins the race"

For many expecting moms, the 20-week check up is an exciting time. Getting to see your baby (sometimes for the first time) and perhaps even learning whether it will be a little boy or girl are the usual expectations. However, for Iliana Lopez, her 20-week appointment was anything but normal. The 2020 COVID-19 pandemic was underway, and Iliana answered questions about her family's medical history alone since her partner was not allowed in the appointment.

Unsure of why she was being asked so many questions, she soon learned that doctors had discovered a heart defect. After a referral to Stanford for a follow-up ultrasound, it was confirmed that her baby had Hypoplastic Left Heart Syndrome (HLHS), a congenital heart defect that occurs when part of the heart does not develop correctly as it should during the first 8 weeks of pregnancy. "I remember going back to my car and just crying because I didn't understand why any of this was happening," Iliana recalls. "I just knew we had a tough road ahead of us."

Her prediction proved true. The next 17 weeks included weekly check-ups and revealed that Iliana's baby would need heart surgery within days of birth. In September, Emma was born at five pounds and with declining blood pressure. She was rushed to the NICU and at just three days old, she had open-heart surgery. Emma's road to recovery was complicated by a brain bleed, and later a weak airway which required extended intubation. Finally after seven weeks in the hospital, Emma was finally ready to go home in November.

"I was so nervous to bring her home because she was high risk and everything was new to me," Iliana recalls. "But as we were being discharged, we were told an agency called Coastal Kids Home Care would be providing an in-home nurse to support us. I remember still being nervous but feeling a sense of relief because it made me feel better knowing I wasn't going to do this alone."

Coastal Kids nurses visited Emma each week, offering reassurance to Iliana who anxiously cared for her fragile daughter while they awaited her next surgery. After being rescheduled five times due to pandemic restrictions, at last, in March 2021, doctors were able to perform Emma's next surgery. Although the procedure seemed to go well and Emma was home within a week, her mom soon noticed that



Emma's head was getting bigger. Doctors soon discovered that Emma had fluid in her brain and scheduled another surgery. In May 2021, tiny Emma went in for her third surgery and extended hospital stay.

"Each time we have gone home from the hospital it feels so scary," Iliana explains. "But then I feel a comfort in my heart knowing that Coastal Kids will be there again. We have been in and out of the hospital but each time our nurses would go out of their way to text to see how Emma was doing. It makes you feel good to know that you come home to a team that cares for your daughter and that if you need something they will be there—nurses, office staff, whoever."

Now 18 months old, Emma is medically stable and developing a sweet personality. She will need future surgeries, but for now she is just enjoying being a little girl who loves to dance with her dad and go for walks with her mom. Although Emma's journey has been long, her slow and steady progress is a win for her doting parents.

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

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

*"No act of kindness, no matter how small, is wasted" - Aesop*



### Letter from the Executive Director

Over the past two years, our world has experienced loss, isolation, and division on a scale beyond that of recent memory. For some, the pandemic stole away loved ones too soon, for all of us, life – and our future – was forever altered. Through it all, I have drawn inspiration from the dedication of teachers, police officers, nurses and social workers and the kindness of children, friends, and neighbors.

At Coastal Kids Home Care our team is proud to have continued serving more than 500 of our community's most fragile children without interruption and easing the incredible burden on their families. In the spring of 2022, as we are at the dawn of a further reopening of our world, our team is grateful to partner with generous donors, especially Hospice Giving Foundation, to bring care to more community members through Heal Together.

This compassionate initiative is designed to offer healing through a range of bereavement services that meet the needs of children, adults, those coping with complex grief or simply in need of connection to other individuals dealing with loss. Heal Together brings bereavement care to all corners of our community, so that we can go forward together.

This hope-filled spring we reflect on the timeless morals of Aesop and are honored to share stories that reflect bravery, patience, perseverance and of course kindness in this issue of Storybook. We welcome you to take a moment to relax, enjoy... and be inspired.

Sincerely,

Margy Mayfield, RN, BSN

Executive Director, Coastal Kids Home Care

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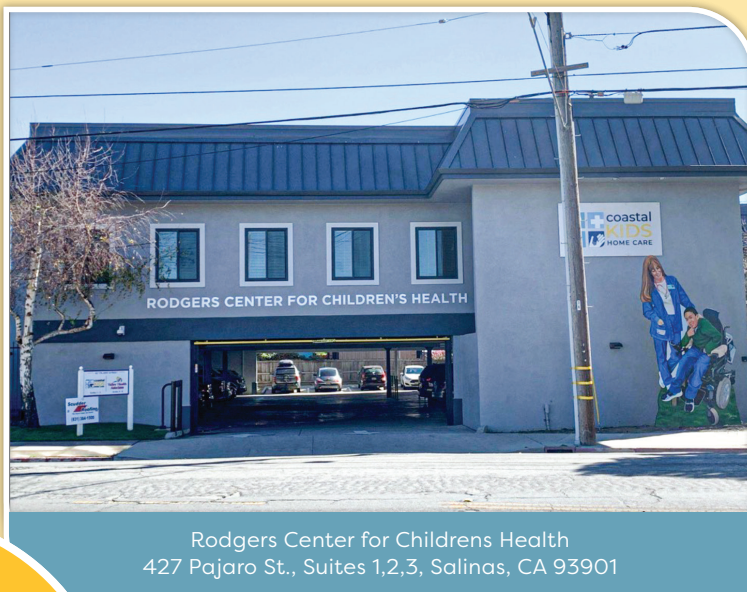
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## "We should never lose a grand opportunity"



Rodgers Center for Children's Health  
427 Pajaro St., Suites 1,2,3, Salinas, CA 93901

This spring, Coastal Kids Home Care is grateful to at last celebrate the grand opening of the Rodgers Center for Children's Health, the new home for our administrative and clinical offices near downtown Salinas.

After one year of renovations and a second navigating through pandemic uncertainty, Co-Founder and Executive Director, Margy Mayfield, is thrilled to finally get to celebrate with the community of supporters that helped make the building a reality.

"We have been dying to open our doors to show off all the hard work that was made possible by our donors," says Mayfield. "But we wanted a celebration in which we could feel safe and relaxed. We are so happy we waited."

Please join us on **May 19, 2022** for our Grand Opening

Open House for Friends and Families: 10:00 - 12:00

Ribbon Cutting and Donor Appreciation: 2:00 - 5:00



## "The hero is brave in deeds as well as words"

Ten-year-old Collin Jackowski has a bright smile and a sweet disposition. His brother, Ryan, ten years his senior, treasures Collin. In fact, when the pandemic hit, Ryan left his studies at San Francisco State University to become full-time caregiver for his little brother, who was diagnosed with cerebral palsy with spastic quadriplegia at birth and requires round-the-clock support. The Jackowski family lost Collin's twin, Valerie, at just three-days-old and their journey with Collin's medical care has been long and arduous.

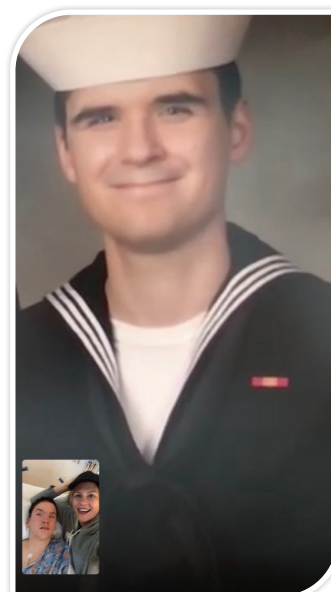
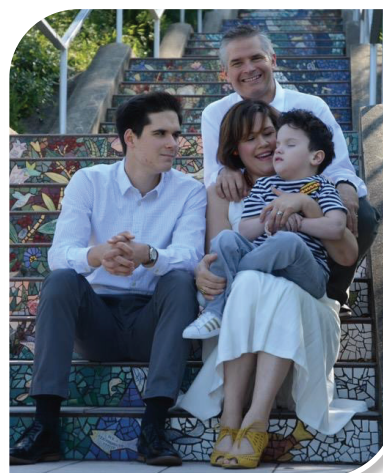
When they moved to California from the Midwest when Collin was an underweight two-year-old, his parents Julie and Matthew expected to find robust support. Instead they became overwhelmed by a fragmented healthcare system that did not have an easy fit for their complex son. Without care coordination, Julie became the expert, navigating pediatric specialists, insurance providers and the education system largely on her own. Despite needing help, the Jackowskis waited years to have access to in-home nursing. In fact, Julie describes most of her experience with Collin's care as "being in a holding pen" while you wait for services.

Their situation began to change when they heard of Coastal Kids Home Care and reached out to learn more. "I received respectful and meaningful conversations immediately after contacting Coastal Kids," stated Julie. "In all of our previous experiences with medical agencies I felt like our family was caught in an unfeeling business model. I never experienced this with Coastal Kids. They immediately wanted to know about Collin, his condition and needs, and they were very honest about what they could provide in the short and long run."

According to Julie, "I felt a trusting relationship immediately."

This sense of trust was important to the Jackowski family. Recently, big brother Ryan decided to take a bold new step. He enlisted in the United States Navy. Upon leaving for training, Ryan expressed concerns for his little brother's care. However, he was relieved to hear that while he was away, Coastal Kids had stepped in to provide the day-to-day care Collin needed through shift nursing with Heather Trail, RN. When Ryan called home from bootcamp he told his mom, "I am so happy that you have support for Collin and that Heather and the Coastal Kids team are here for you."

Julie and Matthew agree wholeheartedly. Julie believes that Coastal Kids services truly add value to their son's life. In addition to nursing, Collin qualifies for expressive therapies through the palliative care program. Collin delights in music therapy, and massage brings relief to his uncontrolled dystonia. "Collin is developing his own relationships with his caregivers and they are making his world better," explained Julie, "We do not take one day for granted with [Collin] and we want our care experience to complement his dad and I's efforts to make our son's world as wonderful as we can. Coastal Kids has done that and I am blown away by the whole organization."



## "Lead by example"



In August 2020, Valeta and T.J. Rodgers stepped up as lead sponsors of our first annual Cruisin' for Coastal Kids Home Care. This newly styled event brought a parade of classic cars and other unique vehicles directly to the homes of children living with illness and disability in Santa Clara County. At that event Margy Mayfield met Valeta and T.J. Rodgers. Margy shared her vision for continuing to grow Coastal Kids services to meet the needs of medically fragile children. That

same day, T.J. stunned our Coastal Kids team by pledging a generous \$300,000 toward the purchase and renovation of a new building. In turn, we were grateful to name our new building the **Rodgers Center for Children's Health**, in honor of T.J. and Valeta. Again, in 2021 the Rodgers sponsored our event and they continue to lead by their generous example, investing in compassionate in-home medical care for children for years to come.

## "Misfortune tests the sincerity of friends"



Our community is grieving. More than seven hundred mothers, fathers, sons and daughters in Monterey County were lost to COVID-19. Countless individuals are living with the complex emotions around losing their loved ones suddenly and too soon. In 2021, Hospice Giving Foundation developed Heal Together, an initiative designed to meet the needs of these grieving individuals and help our entire community regain a sense of healing and hope.

In turn, Coastal Kids Home Care was awarded a grant of \$1.18M toward leading this critical community response to grief. Heal Together consists of three core objectives:

**Expand and develop grief literate mental health providers in our community.** An April training by the nationally recognized experts from the Dougy Center offers a greater depth of knowledge to licensed providers and other individuals who encounter grief in their work including healthcare workers, teachers, school counselors, pastors and peer counselors. By engaging local universities Heal Together also seeks to expand internships for social workers and therapists to better meet the high demands of these critical professions.

**Educate our community in the language of grief.** Through broad public awareness campaigns, Heal Together aims to break down stigmas around grief and bereavement, encouraging people to reach out for help for themselves and their loved ones. Partnerships with the **Center for Community Advocacy, Harmony At Home** and **Alliance on Aging**

offer inroads into the low-income and farmworker communities, access to schools and opportunities to reach older adults. Outreach to hospitals, skilled nursing facilities and other frontline workers are also priorities of Heal Together.

**Connect individuals to appropriate grief and bereavement care.** The Heal Together Hub at Coastal Kids Home Care is designed to be a clearinghouse of information and resources. When an individual reaches out via the bilingual intake line or website they are immediately connected to a trained bereavement coordinator who assesses their needs and facilitates a connection with one-on-one counseling, a bereavement group or a community activity that will best meet their needs. For emergent situations, Heal Together offers licensed providers who are available to speak in schools, workplaces or other congregate settings.

The past two years have brought great misfortune to our community, and the world. Fortunately our friends at **Hospice Giving Foundation** had the foresight to envision a sincere response to the needs of individuals coping with grief and loss. And according to their President and CEO, Siobhan Greene, "[Coastal Kids] had the grit to make this work." Our team is proud to lead Heal Together and sincerely believe this initiative is poised to become a model of grief response that will extend well beyond the boundaries of our community.

For more information visit [www.heal-together.org](http://www.heal-together.org)



# "Faithful service should long be remembered"



This past February, the community of Salinas grieved the terrible loss of Officer Jorge Alvarado Jr. who was killed in the line of duty. While the whole community was affected by the loss, the 911 dispatch team who worked so closely with the police department, struggled to cope with his traumatic death. Recognizing her team’s need, Leslie reached out to Heal Together for support the morning after the incident. Less than 24 hours later, the dispatchers received a visit from Basil, a therapy dog, and his owner Jennifer.

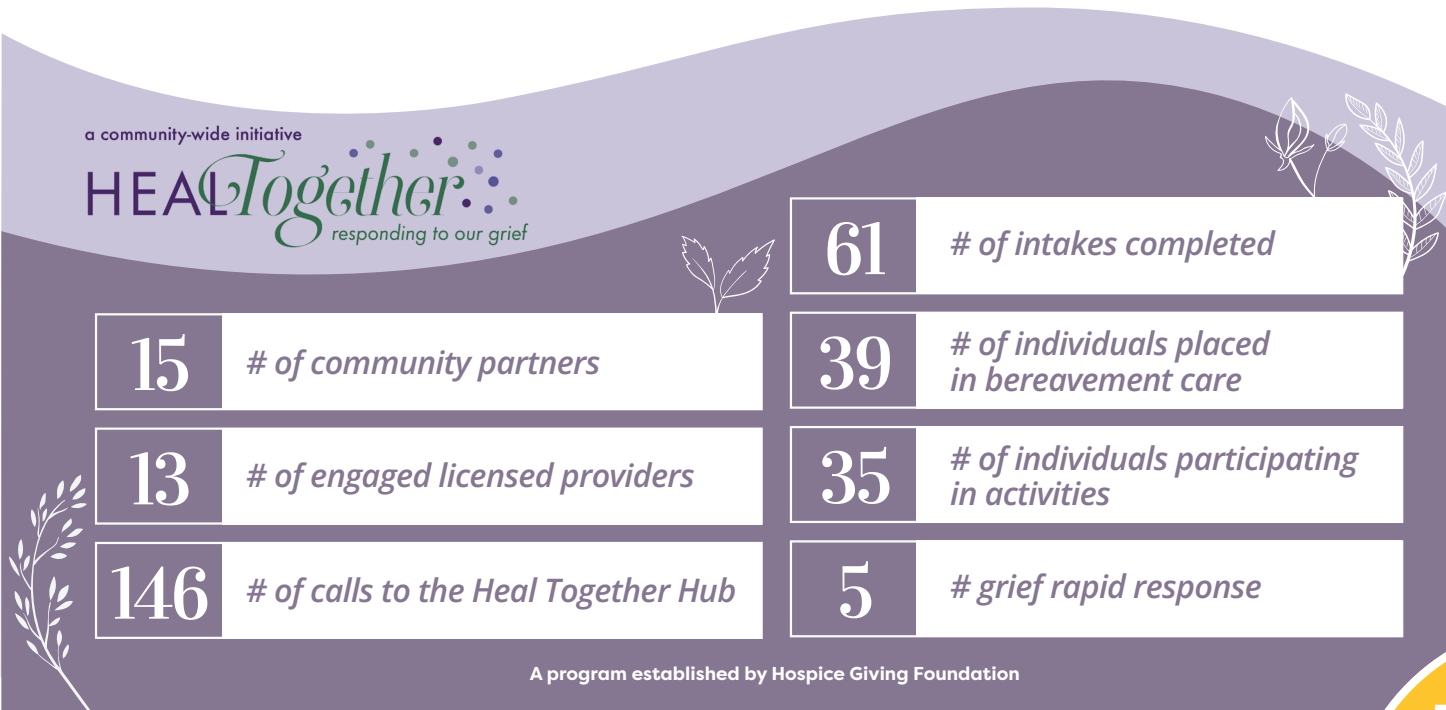
Dogs are widely recognized for providing comfort and companionship, certified therapy dogs, however, are professionals. They undergo extensive training and utilize

intuition and patience to reach into the hearts and minds of individuals of all ages. In fact, therapy dogs can have a profound impact on people’s emotional well-being by helping to relieve stress by providing affection, attention, and a calming presence.

Basil visited the evening shift of emergency dispatchers, connecting directly with the individuals who had been working during the tragic loss of Officer Alvarado. According to Jennifer, Basil visited every team member, all were interested in petting him, and many wanted photos too. “Overall I think Basil was a nice distraction to help get the dispatchers’ minds off of what had happened.”

Noemi Zavala (pictured) is one of the 911 dispatchers affected by the shooting and is also a long-time friend of Coastal Kids Home Care. In 2009, when her toddler was diagnosed with cancer, she was grateful to receive a referral to Coastal Kids Home Care for home nursing visits. Her daughter, Lyla, is now over 10 years in remission and thriving. Noemi and Lyla have stayed in touch with Coastal Kids over the years.

According to Noemi, “It’s been rough at our dispatch center these past couple days as we are all affected by the passing of Officer Alvarado; it is such a terrible tragedy. It was a nice surprise, though, to have Basil visit us but an even bigger surprise to know that Coastal Kids is in charge of Heal Together.”



# "The memory of a good deed lives"



Daphne Reyes was born preterm and as a micro-preemie has faced an incredible uphill battle in her little life. She has chronic respiratory failure and depends on a tracheostomy and ventilator to breathe. Since coming home from the hospital, Daphne and her parents have been supported by Coastal Kids Home Care's pediatric palliative care team. Daphne receives regular nursing, physical therapy, massage and music therapy and her parents receive social work support. In fact, a conversation with one of their social workers this past fall, revealed that amid all of Daphne's complications her parents, Joel and Areli, had not had time to plan a wedding.

Coastal Kids Home Care Director of Palliative Care offered to officiate at a small ceremony and the wedding planning began. On Saturday, February 19, Joel and Areli were married at the new Rodgers Center for Children's Health in Salinas.

Daphne, of course, was the flower girl. Her Physical Therapist worked with her during the days leading up the wedding and practiced how to drop petals as she walked down the aisle. Daphne's Music Therapist played music for the wedding and reception, and Coastal Kids Home Care staff and volunteers stepped in to coordinate all of the details including flowers, decorations, food and photography. The team was also thrilled to offer a surprise honeymoon gift for Joel, Areli and Daphne to none other than-Disneyland! We are so honored to provide critical in-home services to children like Daphne, and thrilled to help her family create memories that will last a lifetime. According to Director of Palliative Care Ruth Shapiro, "In the end this felt more like a gift to us."

For more on the NBC Bay Area Coverage of this remarkable story visit, [www.coastalkidshomecare.org/press](http://www.coastalkidshomecare.org/press).

CKHC BY THE NUMBERS	2018	2019	2020	2021
# OF CHILDREN SERVED	608	603	660	503
# OF PATIENTS ON PALLIATIVE CARE PROGRAM	9	9	54	67
# OF CLINICAL HOME VISITS	3,860	4,452	5,503	6,349
# OF SHIFT NURSING HOURS	11,568	28,832	49,472	77,600
# OF MENTAL HEALTH COUNSELING CLIENTS	58	60	104	100
# OF MENTAL HEALTH COUNSELING SESSIONS	419	520	703	615

# With Sincere Appreciation for Our Donors

Compassionate in-home care for children with illness and disability relies on the generosity of our community. Thank you to our 2021 donors:

**Circle of Change (\$500,000+)**

Hospice Giving Foundation

**Circle of Gratitude (\$100,000+)**

Central California Alliance for Health  
Harden Foundation

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Papillon Center for Loss and Transition  
Monterey Peninsula Foundation  
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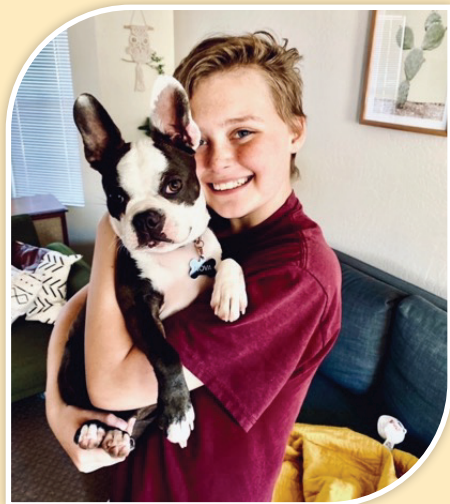
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A special note of gratitude to our friends at Broadway Bingo for their contributions.

To see more 2021 donors visit [www.coastalkidshomecare.org/donors](http://www.coastalkidshomecare.org/donors)

## "Whatever you do, do with all your might"



Nevaeh is a 15-year-old girl with a passion for her adorable pup Nova. In May of 2020 in the early days of the pandemic she was diagnosed with Acute Lymphoblastic Leukemia. About a year later, she was referred to Coastal Kids Home Care when she started maintenance. This meant less trips to Stanford since Coastal Kids nurses could travel directly to her home for her weekly chemotherapy treatment.

According to nurse Bri, "Each week, Nev greets staff with a smile and Nova greets us with a lick!" When the going gets tough, Nevaeh bravely breathes through nausea while Bri infuses the chemo as slowly as possible. Nevaeh is patiently counting down to the end of chemo treatment, which is predicted to be in January 2023. However, Bri says that you wouldn't be able to guess this girl is fighting cancer by her sweet personality and tenacious approach to life. "It's never easy seeing a child go through something so difficult but seeing her every week is a highlight for me as I continue to learn more about her and her wonderful family."

Nevaeh's mom, Leah, is grateful for Bri and the whole Coastal Kids team, "In addition to making our lives a little easier by not having to drive to Stanford every week, our Coastal Kids nurses have also gone above and beyond," Leah says. "Nurse Robin has come on a Saturday to make sure we could take a vacation

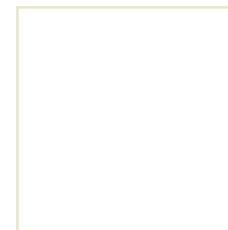
and nurse Bri has really connected with Nevaeh and allowed her to be a regular teenager. We are so thankful to have a village to support us."

Recently, Nevaeh has experienced fewer side effects from the chemo. She is gaining some strength back, and even began playing sports again. Due to her treatment, Nevaeh experienced avascular necrosis (AVN)-the death of bone tissue due to a loss of blood supply-in both her knees and hips and was told she would never be able to run again. However, in December of 2021, doctors reviewed her case and cleared her to play again. Since then, she has played a water polo season and recently finished basketball too. Through it all she has maintained a 4.0, has started a class at Cabrillo College this spring, recently gotten her driver's permit, and started her first job. This dynamic teenager is fighting cancer with all of her might, and wowing all those who know her (Nova included.)





427 Pajaro Street, Suite 1  
Salinas, CA 93901



## Join Our Community of Care

**Share** – Are you the parent or grandparent 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 Cassie Jimenez at [cwaggy@coastalkidshomecare.org](mailto:cwaggy@coastalkidshomecare.org)

**Participate** – Bring out a truck or become a sponsor for this year's 7th Annual Touch-A-Truck. Join us on September 11, 2022 for a day of fun. For more information, email Yadira at [ychave@coastalkidshomecare.org](mailto:ychave@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](http://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 year? We have a shirt for that! Buy Coastal Kids merchandise at [www.bonfire.com/coastalkidshomecare](http://www.bonfire.com/coastalkidshomecare) and let the world know that you value quality care for kids.



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